

LIVING WITH SCHIZOPHRENIA

A phenomenological study of people with schizophrenia living in the community

Volume 1

Joanne HARRISON BSc

submitted for the degree of Doctor of Philosophy

Division of Nursing

University of Bradford.

2008

ABSTRACT

Joanne Harrison

Title: Living with schizophrenia: a phenomenological study of people with schizophrenia living in the community.

Key words: Phenomenology, schizophrenia, disempowerment, users' views, nursing, carer burden

Research question: How do you people with schizophrenia and their carers live with a diagnosis of schizophrenia?

Research aim: To gain a greater understanding of the meaning and experience of schizophrenia. The objective of this phenomenological study was to explore the lived experience of schizophrenia.

Sample: Self-selected sample of 35 participants (22 people with schizophrenia and 13 carers) recruited from the local community. .

Data collection: 33 unstructured audiotaped interviews conducted in participants' own homes. In addition some participants completed diaries. Interviews were conducted in two stages: in stage one 10 participants were interviewed, transcripts were analysed and probes were fine tuned and in stage two these probes were used in the remaining interviews.

Data analysis: Verbatim transcripts were analysed using the coding paradigm proposed by Strauss (1987), in conjunction with Burnard's (1991) 14 stage model of analysis. Inductive coding was used and respondent validation was completed.

Findings: Stress was described as a major cause of schizophrenia. Some participants with schizophrenia described moving on in their lives, a factor associated with having a positive self-concept. Other participants with schizophrenia reported feeling stopped in their lives, which was associated with acceptance of the diagnosis, and having a negative self-concept. The most severe problems they reported were social and psychological. Male and female participants with schizophrenia were treated differently. Some participants with schizophrenia sought support while others chose isolation. Mental health nursing care was reported as coercive and disempowering.

Carers described conflict within families, carer burden, and stress. Those who had been caregiving for longer appeared to have adapted and now experienced less stress and burden than others. Younger carers and carers who have been caregiving for a shorter time and were less willing to accept the caregiving role, reported more burden and stress.

Conclusions: These findings suggest that a positive self-concept may be necessary to move on after the diagnosis of schizophrenia. The inability to move on may be a result of a negative self-concept or disempowering care. There was no partnership and no shared understanding of schizophrenia, or of care, between these participants with schizophrenia and nurses, or between these participants with schizophrenia and their carers, or between carers and nurses. Many of the participants' self-identified needs were not met. A new attitude displaying reluctance about a caregiving role may be emerging.

CONTENTS

	Page
ACKNOWLEDGEMENTS	
INTRODUCTION	5
CHAPTER ONE: THE SOCIAL CONSTRUCTION OF SCHIZOPHRENIA: MEDICALISATION, COMPLICITY AND COMPLIANCE	22
CHAPTER TWO: PARTNERSHIP AND EMPOWERMENT	59
CHAPTER THREE: FAMILY DYNAMICS: EXPRESSED EMOTION	113
CHAPTER FOUR: CARER BURDEN	147
CHAPTER FIVE: PEOPLE WITH SCHIZOPHRENIA'S VIEWS OF MENTAL HEALTH NURSING	180
CHAPTER SIX: METHODOLOGY	212
CHAPTER SEVEN: RESEARCH METHOD	238
CHAPTER EIGHT: FINDINGS	284
CHAPTER NINE: DISCUSSION AND CONCLUSIONS	419
REFERENCES	516
APPENDICES	545
1. Interview schedule	546
2. Search strategy supplementary questions	548
3. Research methodology used in literature	549
4. Non research based literature	550
5. Web sites	551
6. Information form for participants	552
7. Consent form	544

CONTENTS

	Page
8. Biographical details form	555
9. Essence of interviews	556
10. Biographical details: people with schizophrenia	567
11. Biographical details of carers	572
12. A summary of carers' biographical details	575
13. Composite picture of <i>passivity</i> group	576
14. Composite picture of <i>questioning</i> group	577
15-16 Composite picture of <i>seek support</i> group	578
17-18 Composite picture of <i>choose isolation</i> group	579
19-22 Composite picture of <i>stopped</i> group	580
23-26 Composite picture of <i>moved on</i> group	582
27 Major differences between <i>moved on</i> and <i>stopped</i> group	584
28 Links/flowchart of themes and concepts	585

ACKNOWLEDGEMENTS

I am grateful to my academic supervisors, Professor Neil Small and Professor Robert Newell who supported me in the writing of this thesis. I wish to thank all the participants - voice hearers and carers - who spoke to me of their experiences.

LIVING WITH SCHIZOPHRENIA: A PHENOMENOLOGICAL STUDY OF PEOPLE WITH SCHIZOPHRENIA LIVING IN THE COMMUNITY

INTRODUCTION

In this study the aim is to explore the lived experience of schizophrenia as reported by 22 participants with schizophrenia and 13 carers. This study adopts the phenomenological approach to research. Phenomenology is appropriate because it captures experience as it is lived, revealing the nature of the phenomenon as perceived by the person (Doona 1995). This study describes - in theoretical terms, in the literature review and in practical terms in the findings - key issues such as: medicalisation, disempowerment; conflict and stress in families; carer burden; people with schizophrenia's experience of mental health nursing interventions and of returning to their community. Unstructured interviews are used to enable participants to raise issues which are important to them. By this means, participants in the study could clarify feelings and meanings which they attached to events and experiences.

The contrasting views of nursing care and interventions, and the need for common ground between health professionals and service users, are now discussed. According to Jablensky et al (1992), schizophrenia is a major psychotic disorder affecting one percent of the population. It is well researched, yet effective interventions, including nursing care seem to elude health professionals. Within the literature there are conflicting views of nursing interventions. The current concept of nursing is that it is a benevolent intervention and aims to deliver person-centred care with the emphasis on collaboration (DoH 1994a, National Institute for Clinical Excellence 2002). This, however, is often not supported in empirical research when people with schizophrenia's views are sought.

There appears to be a reluctance to accept the views of people with schizophrenia. According to Shields (1985) there is a historically accepted view that the perceptions of the mentally ill are invalidated because they are mentally ill.

A clearer understanding by health professionals of their relationships with people with schizophrenia, which are currently negatively influenced by people with schizophrenia's perceptions of their own disempowerment, may lead to improved relationships and collaboration. Understanding the experience of people with schizophrenia and carers could enable mental health nurses to target areas of care and deliver meaningful support to both groups and alleviate stress and burden.

Summary of method

In this study there were 22 participants with a diagnosis of schizophrenia living in the community (13 men and 9 women, age range 23-57 years, mean age 44 years) and 13 carers (6 men and 7 women, age range 40-75 years, mean age 52 years). Interviews in this study were conducted for one hour in the participants' own homes in Bradford or in the School of Health Studies, University of Bradford. The research proposal was approved by the ethics committee of the School of Health Studies, University of Bradford. Interviewee anonymity was assured by allocating unique identifying numbers. Data were pooled to prevent particular responses being attributed to interviewees. Confidentiality was assured by storing biographical details separately from the findings.

The purpose of the study was to explore the lived experience of schizophrenia, and its meaning for participants. Recruitment was by advertisement in a local newspaper. Each unstructured interview was conducted using a brief interview schedule. Silverman (2000) asserted that when findings reflected the phenomenon and personal meaning of

the phenomenon was explored, internal validity was achieved (Silverman 2000). It may be the case that internal validity was achieved in this study according to this criterion. Silverman (2000) has also argued that when contrary cases are highlighted within the findings, external validity is strengthened (Silverman 2000).

It may be the case that' as the research sample in this study was a small self-selected convenience sample, it was not representative and inferences could not be made about wider populations of people with schizophrenia and carers (Silverman 2000). Silverman (2000) and May (2001) argued that where findings cannot be replicated, reliability is weak. It may be the case that because full interview transcripts were available and QSRNUD*IST 4 (Qualitative Solutions and Research Pty Ltd 1997) was used to analyse and code data, reliability was strengthened (Silverman 2000). It was likely that interviewer bias occurred when using probing or supplementary questions to further explore issues, and therefore there may have been limited objectivity in this study (Silverman 2000).

Procedures are now discussed in this subsection. Each one hour interview was preceded by giving participants an information sheet, with details of the proposed research, a consent form, to be read and signed, and a form to record biographical information. In each interview, a brief interview schedule was used (Appendix 1). A copy of this was given to each participant to read prior to the interview.

Stage one in this study involved interviewing 10 people with schizophrenia, using QSRNUD*IST 4 to generate transcripts and categories and themes, and returning the transcripts and list of themes and categories to them, to confirm accuracy. Emerging themes from these first interviews assisted the researcher in stage two. Stage two

involved interviewing 12 participants with schizophrenia and 13 carers, and returning the transcripts to confirm accuracy. Notebooks and stamped addressed envelopes were given to participants, and three were completed and returned.

An inductive coding scheme was used. Coding was undertaken both manually and by using QSRNUD*IST 4. Data were initially coded, using the coding paradigm proposed by Strauss (1987), with the focus on conditions, interactions, strategies and consequences (Appendix 1). This was followed by open coding, which is unrestricted coding, proposed by Strauss (1996). This involved reading each transcript and coding for emerging themes, line by line. Axial coding (intense analysis of one theme or category at a time) was then used (Glaser and Strauss 1968). Each theme and category was summarised. Further phenomenological analysis was completed, using Burnard's (1991) framework of analysis. Minority themes, dichotomies, differences and commonalities were identified, and a summary of the lived experience of schizophrenia was completed.

Overview of Thesis

In Chapter One the social construction of mental illness is explored. Medicalisation of people and their complicity and compliance in the medicalisation process are examined. The Foucauldian perspective is critiqued. In Chapter Two, partnership and empowerment are explored. The lack of partnership and empowerment is discussed and the views of health professional and service user authors are explored. Chapter Three examines high expressed emotion. The validity of the concept of high expressed emotion is critically examined and the causes and origins explored. In Chapter Four, carer burden is discussed and the concept of carer burden is analysed. The causes,

nature and consequences of carer burden are examined. Chapter Five examines the views of users of mental health services. Their views on nursing care are discussed. The work of service user authors and health professional authors are examined. In Chapter Six, phenomenology, a methodology, is discussed. The rationale for this approach to research and its strengths and weaknesses are discussed. The philosophical basis of phenomenology, with discussion of ontology and epistemology, is examined. In Chapter Seven, the method of unstructured interviews is discussed. The rationale for this method and reliability, validity, objectivity, bias, and ethical issues are discussed. Data collection and data analysis are described. Burnard's (1991) model of data analysis is used. In Chapter Eight the findings are described and analysed using the coding paradigm proposed by Strauss (1987) and open and axial coding proposed by Glaser and Strauss (1968). QSRNUD*IST 4, a computer assisted data analysis programme, was used. Findings are related to the views of participants with schizophrenia and carers. In Chapter Nine, findings are analysed and supporting information and literature from web sites are examined. Findings are discussed and related to the literature. The implications of the findings and their significance are examined. Findings are summarised and problems with the findings are described, conclusions are stated and proposals are offered for a way forward.

Literature Search Strategies

A literature search and review was conducted between March 1999 and March 2000 and updated in July 2004.

Rationale for literature search and review

According to Hek and Blunden (2000), looking at many studies minimises the risk of bias and error and engaging in a meta-analysis results in a synthesis of results into a single finding. Meta-analysis can change a literature review from a subjective narrative into an objective study. However a limitation of any literature review and meta-analysis is that studies which are not well designed can be included. Some key principles of a systematic review of literature were acknowledged by Hek and Blunden (2000). These included criticising descriptive and uncritical literature, a point also made by the NHS Centre for Reviews and Dissemination (2001).

Some of these principles are described here. A range of methodologies was used to explore the practice and consequences of nursing because this gives a consistent picture and develops a complete and comprehensive understanding of the phenomenon. It increases the validity and reliability of the findings and may establish generalisability, although this may not be the researcher's aim. The strengths and weaknesses in primary research were identified to avoid drawing false, inaccurate and simplistic conclusions. The process of the search was followed by critical appraisal and evaluation of the literature. A key principle was systematic, explicit, thorough, rigorous review. A detailed description of the search strategy was given with criteria for including a piece of work which was based on the research topic. Explicit criteria were necessary for assessing the validity of each work to ensure transparency of methodology. A comprehensive list of published and unpublished studies should be offered, although in this search strategy, no unpublished works featured because they were not available. There was balance between high recall, amount of literature found, and high precision, finding material relevant to the research topic (Hek and Blunden 2000).

The NHS Centre for Reviews and Dissemination (2001) guidelines highlighted three stages in carrying out a systematic review: planning, reviewing and disseminating. Planning involves three phases: identifying the need for a review, preparation of the proposal for a review and development of a review protocol. Conducting the review involves the following: identification of research, selection of studies, study quality assessment, data extraction and monitoring progress, and data synthesis. Reporting and dissemination involves writing and disseminating the report and recommendations, and getting evidence into practice.

In these guidelines it was recommended that studies be selected in an unbiased way with the focus on selection criteria that flowed directly from the review questions. The researcher should sift through the citations found by the search, looking at full reports of potentially relevant citations, assessing those and then identifying studies which best fit the inclusion criteria. In phase 5 (Conducting the Review), experimental studies (e.g. random controlled trials) are considered the highest level of evidence, and expert opinion, based on pathophysiology, bench research, or consensus, is considered to be the lowest level of evidence. In this research, the weaker evidence, according to these guidelines, yielded a great deal of interesting and important data relating to the research topic. These were controlled observational studies, cohort studies, case control studies and observational studies without a control group.

These guidelines (NHS Centre for Research and Dissemination 2001 box 8. 4, stage 111, phase 8 p.10), maintained that these level 2, 3 and 4 studies were poor quality studies with poor efficiency because evaluations were carried out without “sensible sensitivity analysis.” To guarantee accuracy in the level 2 and 3 studies, namely, controlled observational studies, cohort studies and case control studies, the following

criteria were required: narrow population spectrum, differential use of reference standard, not blind and case control study design. To guarantee accuracy in level 4 studies, (e.g. observational studies without control groups) three or more of these criteria were considered to be required.

These guidelines offered a hierarchy of study design and quality criteria for assessment of observational studies. Expert opinion with little critical appraisal was the weakest level of evidence at level 5. There were examples of quality criteria for assessment of qualitative research, and there was a description of a hierarchy of economic evidence (NHS Centre for Research Dissemination 2001 tables 5.11, 5.13).

The Research Topic

Initially, the research question was: ‘What is the lived experience of schizophrenia?’ This was later changed to: ‘How do people live their lives with a diagnosis of schizophrenia?’

Rationale for key word selection

These key words were linked to emerging themes, ideas which emerged from discussions with my academic supervisor and the research topic.

Key words

Initially the search commenced with the following key words and phrases:

schizophrenia, living with schizophrenia,

experience of care, users' views on care,
social construction of schizophrenia, structuration theory, agency,
power and powerlessness, empowerment, types of power,
nursing, mental health nursing, roles of nurses, cultural bias and effect on nurses,
family dynamics and power, users' views, carers' views,
phenomenology and schizophrenia,
care, caring and people with schizophrenia, Benner Peplau, nursing theorists,
advocacy and care and schizophrenia, advocacy and mental health nursing,
care, control and therapeutic interventions,
carers' experiences,
child carers,

Example of key word search

An example of the keyword search using Cinahl and Medline is given here.

1. schizophrenia
2. social construction of schizophrenia
3. causes and contributing factors of schizophrenia
4. schizophrenia and families
5. schizophrenia and users' views
6. schizophrenia and users' experience
7. 4 and 5
8. 5 and 6
9. 2 and 6
10. mental health nursing and schizophrenia
11. 10 and 6

12. 10 and 4
13. 10 and 2
14. power
15. power and people with schizophrenia
16. power and carers
17. child carers
18. mental health nursing and advocacy
19. care and people with schizophrenia

In this subsection, literature and research sources are stated and the process of identifying themes is described. Initially, computerised data bases Assia, Cinahl, Medline, and the Cochrane Library were accessed. This led to a broad book and journal search of schizophrenia. This was later changed to a narrow focused search on each specific related key word, theme and supplementary question. Regular service user publications by MIND and the National Schizophrenia Fellowship, now called Rethink, were accessed manually. Some literature was obtained from the British Library and through interlibrary loans. The main themes were identified and emerged naturally from the reading and discussion with my academic supervisor (for example, power, role boundaries and nurses' roles). When reading about the social construction of mental illness and schizophrenia and the works of Foucault, other themes were clearly linked to this, for example power, power relations, identity, roles of nurses, societally assigned roles of people with mental illness. These themes highlighted concepts and practices which underpin and reinforce the social construction of schizophrenia and create conditions and social boundaries for people with schizophrenia to live in. These themes were linked to care and treatment models and how people lived on a daily basis with

schizophrenia. Supplementary questions, which emerged as a result of the researcher's reflections and informed the search process, were listed (Appendix 2).

Themes were identified by discussion with supervisors, literature review and consideration of the gaps in my knowledge. They were stored in a file as follows:

Main finding: over protective care and conflict in family

Theme: family dynamics

Author: Kalia, A., Rago, N., Gamble, C.,

Study: A Clinical study of schizophrenia family work

Journal/book: British Journal of Nursing (1995) p.9, pp.504-506, pp.523-525

Publisher

Narrow focused selection	How many References	Relevant
ASSIA	300	24
CINAHL	2800	250
COCHRANE LIBRARY	100	20
MEDLINE	1000	20
TOTAL	4200	314

Choice of Literature

Many of the works found were not relevant, in that they did not fit or were not linked to the research question, although Hek and Blunden (2000 p.51) have highlighted the subjectivity of a decision made to exclude and include literature based on perceived 'fit'. Many were old, pre 1990, and thus were potentially out of date for the current

study, or were not in English, and some were not obtainable. The intention was to keep the literature as current as possible with the exception of seminal works by key authors who have discussed and analysed main themes and theories relevant to this study.

The exclusion criteria were as follows: works that were not relevant to the research question, and if relevant to the research question were older than 1980, or were in a foreign language. Inclusion criteria were as follows: works that were relevant to the research question, dated from 1980 and were in English.

Methodology used in the literature

The methodology was varied with 114 works based on quantitative research methodology, 60 works based on qualitative methodology and five based on mixed methodology (Appendix 3 and Appendix 4).

Web sites

Ninety web sites were found and these offered information to people with schizophrenia, health professionals and relatives/carers (Appendix 5). They contained chat rooms, support groups and discussion areas. There was extensive information on symptoms, causes and treatment and communicating with one's psychiatrist. They contained resource links and details of organisations (e.g. the National Alliance of the Mentally Ill). They offered descriptions of schizophrenia, clarification and a glossary of terms. There were online resources for schizophrenia and other mental health information. They offered information for relatives to help them understand schizophrenia, and there were recommendations for literature and advice on how to find

a support group. There was access to resources for coping with schizophrenia, news, support services, literature, conferences and courses, information on symptoms, seeking help, treatment, family support and research.

Peat (2001) asserted that there were benefits to people with schizophrenia and others in accessing web sites. A wider audience could be reached by web sites and the information was current. There was no exclusion, as there often was in paper based forms of communication, and the person accessing the site could remain anonymous. Learning was facilitated and stigma and ignorance could be reduced (Peat 2001). The web sites considered most important, and which were recommended by the National Schizophrenia Fellowship, are the following:

The Mental Health Foundation: www.mentalhealth.org.uk

MIND Mental Health Charity: www.mind.org.

NSF: www.nsf.org.uk

NSF Young Peoples' Mental Health: www.at-ease.nsf.org.uk

Depression Alliance: www.depressionalliance.org.uk

Mad Pride: www.madpride.net

U.K. Mental Health Resource Centre: www.info-exchange.org.uk

Mentality: www.mentality.org.uk

Young Minds Mental Health Charity: www.youngminds.org.uk

Mental Health Training and Employment: www.Kaleidoscopensf.co.uk

In the search strategy two of these were explored in detail:

www.info-exchange.org.uk

The United Kingdom Mental Health Resource Centre (UKMHRC) (2003a) *Mental Health On Line Community page* was accessed but this did not seem central to the research question. On returning to the main page, the home page was then accessed which led me onto UKMHRC (2003b) *The Mental Journal*, UKMHRC (2003c) *Users and professional views and* UKMHRC (2003d) *Users' views*.

<http://www.info-exchange.org.uk/libry/mag/index.htm#USER>

This website gave details of the on line mental health community (e.g. geographical area of origin, gender and age group). This also gave the following information: key senior staff involved in delivery of care nationally and regionally, a summary of the National Service Framework and key themes for service development. Information on Primary Care Trusts and Primary Care Groups was available here and, most central to the research topic, articles written by people with schizophrenia and by health professionals expressing their views.

www.nsf.org.uk

This National Schizophrenia Fellowship (NSF) web site was central to the research question and offered further pages on schizophrenia, diagnosis and prognosis, living with schizophrenia, treatment, care and aftercare, employment, money benefits, legal rights and other organisations. It also offered the following: NSF (2003a) *Information*, NSF (2003b) *What you need to know about schizophrenia*, NSF (2003c) *News and views*, NSF (2003d) *Our latest news and your latest views*, NSF (2003e) *Looking for help and* NSF (2003f) *How to access services*. These last two sites, and NSF (2003g) *Living with schizophrenia* were accessed and were central to the research topic.

The following search trail was followed:

Living with schizophrenia

Talking about schizophrenia

What is someone with schizophrenia going through?

Helping someone to accept their diagnosis

Self-management

Is schizophrenia hereditary?

Living with schizophrenia

Dealing with unusual thoughts and behaviours

Coping in a crisis

These pages are for relatives/carers.

News and views

This offered other pages: NSF (2003h) *Press releases*, NSF (2003i) *Briefing notes*, NSF(2003j) *Your voice*, NSF(2003k) *Campaigning for change*, NSF(2003l) *Employment bulletin board*, NSF (2003m) *National Schizophrenia Fellowship policies*, NSF (2003n) *National Schizophrenia Fellowship responses to consultation documents*.

The following search trail was followed:

NSF (2003o) *News and views*, *Bulletin board* (17 pages long) a chat line where people exchange views, problems and life experiences. This was central to the research question and supported many of the themes in the empirical data and in the literature review (Appendices 3 and 4).

The types of literature used are now summarised.

Literature by type

Books 149

Journals 165

Total 314

Professional reports of users' views 86 out of 314

User reports of own views 42 out of 314

Anyone reporting users' views 128 out of 314

Professionals reporting carers' views 10 out of 314

Carers reporting carers' views 2 out of 314

Professionals reporting own views, engaging in a literature review or an overview of the topic/theme 173 out of 314

Research based 179 out of 314

44 different journals were used and those which were used most frequently were:

British Journal of Nursing 6

Mental Health Nursing 5

Journal of Psychiatric and Mental Health Nursing 9

Journal of Mental Health 6

Journal of Clinical Nursing 5

British Journal of Psychiatry 9

Mental Health Practice 5

Journal of Advanced Nursing 9

Psychiatric Care 8

Nursing Times 21

OpenMind 18

Limitations and conclusions

This subsection outlines the limitations of the literature used in this study and the conclusion. The period searched for books and research papers was from 1980 to 2005. Qualitative and quantitative research papers were accessed, The period searched for Policy Documents (e.g. DoH reports) was from 1994 to 2005. The web sites were dated 2003. User journals which were relevant to the research question were accessed for dates 1999 to 2005. All were in English. Many works which might have shed light on aspects of this study, because of subjectivity in the selection process, were in all likelihood rejected. High recall was achieved and high precision was achieved through examination of the literature and books, some of which were written by carers. The web sites were extremely useful and supported many of the key themes which had emerged from the previous literature search and empirical data.

CHAPTER ONE:
**THE SOCIAL CONSTRUCTION OF MENTAL ILLNESS: MEDICALISATION,
COMPLICITY AND COMPLIANCE**

The value of medicalisation of mental distress and illness is a contested issue in the literature. It has been argued that this medicalisation is actually anti-therapeutic for people with mental health problems, particularly severe and enduring mental ill health such as schizophrenia. Accordingly, an investigation of the debates around medicalisation is relevant to an examination of the experiences of people with schizophrenia and their relatives and carers. In this chapter, the concept of medicalisation is examined and the work and concepts of Foucault are critiqued. There is discussion of key positions on the causes and origins of schizophrenia.

These themes have been explored using key seminal works. Rose (1994) highlights how medical truth is created. This work offers various interpretations of Foucault's medical gaze or *regard medical*. Osborne (1994) proposes that Foucault's original concept of the gaze was observation of an individual with no dialogue. Others offer different interpretations of the gaze. Armstrong (1994) interprets the gaze as surveillance by authority. Rose (1994) contends that the gaze is something that individuals are subjected to, but they also turn the gaze on themselves and self-monitor. In this first section, I will summarise and critique Foucault's approach to disciplinary power via an examination of this idea of the gaze and his use of panoptic power. Fox (1993) supports Armstrong's interpretation of the gaze and also offers two perspectives of panopticism or panoptic power. Firstly, panopticism subjects individuals to the discipline of power and secondly, people accept the discipline of power and the shaping of their subjectivity and aspirations. The nature of biopolitics and biopower is clarified with the emphasis

on control of the social body in Foucault (1980:1995: 1996). The opposing views of Porter (1987) and Foucault (1980,1995,1996) are presented. Porter (1987) maintains that institutionalisation has the goal of curing and restoring the insane to society, while Foucault proposes that institutionalisation was a deliberate policy of segregation and social exclusion.

In presenting the theme of medicalisation the views of Freire (1970), Illich (1975), and Bunton (1997) are considered. All these authors propose that individuals willingly comply with medicalisation, a position which is contrary to Foucault's early position on medicalisation but is in alignment with his later position on self-formation. Dinges (1994) disputes the concept of medicalisation as a one sided process in which individuals are coerced and offers an alternative concept of medical socialisation.

The theme of docile bodies is discussed and the views of Bury (1986), Nicolson and McLaughlin (1987), Rabinow (1991), Fox (1993), Foucault (1980) *Power/Knowledge*, Foucault (1995) and Johnson (1997) are offered. Two positions are offered: firstly, oppressive medicine creates docile bodies, a position held by Bury (1986), Rabinow (1991), Fox (1993), and Foucault (1980, 1995), and secondly, individuals are complicit in medicalisation and there are no docile bodies or oppression, a view held by Johnson (1997) and Nicolson and McLaughlin (1987).

Lupton's (1997) analysis of the Foucauldian perspective of power highlights the inconsistencies in Foucault's position, a key inconsistency being the two opposing position of control of the social body and self-formation. Falzon (1998), Rabinow (1991), Lupton (1997), and Fox (1993) contend that self-formation is exercised by

individuals and there is no coercion. Rose (1999) clarifies the role Governmentality plays in shaping the conduct of individuals and he believes that there is no coercion.

Bury (1986) and Nicolson and McLaughlin (1987) offer contrasting views on social constructionism and the value of medical knowledge. Bury (1986) proposes that relativism is the flaw in the argument for social constructionism and that medical knowledge should not be represented as an apparatus of power or control. Nicolson and McLaughlin (1987) are supportive of social constructionism, and believe that knowledge changes, but this does not undermine the social constructionist approach. Medical knowledge is connected to reality, which changes.

Dinges (1994) shows that within Foucault's perspective on medicalisation there is a paradox. Dinges (1994) points out the impossibility of proving or falsifying Foucault's ideas on the basis of empirical knowledge and agrees with the position that Bury (1986) adopts about relativism.

I will discuss the current perspective on social exclusion. Social exclusion is discussed in Office of the Deputy Prime Minister (2004), Laurance (2002), DoH (1998), DoH (1999), and The Sainsbury Centre for Mental Health (1998). These reports propose that social exclusion currently appears to be social and economic, and not the original institutional exclusion proposed by Foucault (1995, 1996, 1980). Current evidence of social and economic exclusion is offered by Bonner et al (2002).

In this section I will discuss positions on causes and origins of schizophrenia. Bentall (2003) traces current understandings of mental illness and believes they are flawed. He suggests that hallucinations and delusions may be part of human variation. Van Os et al

(2000), in a prospective study, came to the same conclusion. Roberts (1991), in a clinical study, concluded that successful deluded people can have positivistic meanings and purpose in life. Romme and Escher (1994), in their empirical research, concluded that people who hear voices may adapt and cope well with the experience, and this conclusion was supported by Leudar and Thomas's (2000) clinical study.

In this section I will discuss the association between trauma and the development of schizophrenia. The theme of trauma preceding psychosis is explored. Goodman et al (1997) concluded that trauma precedes psychosis and supports Bentall (2003) in this conclusion.

1.1 The Technologies of Truth

Rose (1994) discusses Foucault's concept of technologies of truth, examining the conditions under which the link between medicine and contemporary reality is formed. People are created and defined as ill through differentiation, which is created by apparatuses for managing people whose behaviours are problematised. With differentiation comes segregation (e.g. asylums where people are exposed to medical scrutiny).

Rose (1994 p. 59) writes of truth "machines", which create interpretations of mental ill health based on positivistic knowledge. The term "truth machine" is a metaphor and describes "assemblages of parts", one of which is the asylum. Asylums are part of the social apparatuses which produced accepted medical knowledge and truths. "Truth machines" involve social apparatuses which create knowledge of human individuality and document and describe people in medical terms (e.g. mentally ill). According to this

conceptualisation, hospitals became curing machines at the same time as the increasing hospitalisation of the poor and mentally ill in the eighteenth century (Rose 1994 p.59).

Positivistic knowledge was a concept developed in the Age of Reason (1657-1800). Positivistic knowledge claims to be rational and scientific and involves observable proven facts (e.g. psychiatric categories and diagnoses with consistent signs and symptoms). Positivistic knowledge created certainties and truths about insanity. This took the form of medical truth and created distinctions between normality and abnormality. Medicine is connected to other practices (e.g. the law and religion) and together these authorities create normality and identity and differentiate abnormality (e.g. the insane). Through differentiation and categorization, medicine manages the conduct of those deemed to be insane. The insane are admitted to asylums, scrutinized, and their conduct is documented. They are managed or acted upon by psychiatry with the goal of producing self-regulating people (Rose 1994). Prior to the Age of Reason, such knowledge was not accepted as truth. Truth is created within a cultural and historical context, specifically one of increasing urbanization and industrialization. People who are not perceived as useful citizens are perceived as a problem and as a sickness in the social body. Associated with this positivistic knowledge is the expertise of psychiatrists, who produced medical regimes with the goal of managing or transforming the insane.

According to Rose (1994), an epistemology is created, illnesses are normalised and new classifications of disease and mental illness emerge. Categories are empirically identified using the clinical gaze, and divergence from the norm is identified. This is a philosophical, conceptual and practical standpoint by which truth can be explained, predicted and calculated.

The clinical gaze has been interpreted differently by different authors. Osborne (1994 p. 34) proposes that Foucault's original concept of the gaze was the *regard medical*, and the observation without dialogue of a disease in an individual. The clinician works with the patient, sees and records what is empirically present. Armstrong (1994) interprets the gaze as surveillance by medical experts, to which individuals were subjected, and which has sinister connotations and involves medical domination, but Osborne (1994) suggests that this is not the original concept of the gaze. Rose (1994) proposes the gaze is part of "the practical technologies of health in which people are required to disclose their problems and transform themselves." Individuals are both subjected to the gaze and engaged in self-monitoring as a consequence. This is in alignment with Foucault's later concepts of self-formation, self-regulation and techniques of the self. Nettleton (1994) maintains that the gaze creates knowledge. Something (e.g. a person responding to hallucinations) is observed and the observation becomes part of knowledge and discourse.

The gaze has a function, goals and outcomes. The conduct of patients in asylums is recorded in detail and classification systems and criteria to describe insanity are created. The goal of medical scrutiny is to promote health. Using the gaze, medicine divides sickness from health. The risk of illness and disease is calculated and curative measures are used to combat illness and disease. Dealing with sickness and health becomes a business, and professions emerge to administer this business with their knowledge and expertise (e.g. medicine and nursing). Practical technologies are created to produce health (e.g. the asylum, promotion of self-health). Health regulation is the desired outcome and the health of the social body is deemed to be important. Therefore, the practice of applying the gaze to the sick is perceived to be necessary and rational. People are made visible and transparent to the gaze of medical experts. Medical

expertise makes possible the political goal of good health and promotes the aspiration of this goal in the population. Medical expertise shapes individuals' aspirations, desires and acceptance of responsibility to be healthy. The gaze is first focused on individuals' bodies, than later on minds, and social spaces. The gaze becomes accepted as truth (e.g. evidence of insanity); therefore, empirical knowledge of the body, mind and social life is created and developed by the gaze, through examination by experts (Fox 1993, Nettleton 1994).

Phenomena are perceived as symptoms and pathology is focused on, whilst medicine becomes a social science which manages the population according to the goals of generation of wealth, good order and public tranquillity. All life is problematized and regulated, and doctors are perceived as experts who could improve the social body's health. In conclusion, medical knowledge is accepted as truth. The position of doctors as experts supports the opposing concepts of insanity and sanity. Truth machines (the social apparatuses which create knowledge, document and describe people) categorise people in medical terms. The focus on madness emerges from acceptance of positivistic knowledge, implying acceptance of the presence or absence of normal mental functioning.

1.2 Creation of disease and objectification of people

Fox (1993) asserts that panoptic power has made objects of the mentally ill. He makes reference to Bentham's Panopticon, a physical circular structure in which prisoners were placed, where they could be observed but were unable to see their fellow prisoners. According to Shearing and Stenning (1996), Bentham's Panopticon is a punishment designed to create compliance (Shearing and Stenning 1996). Fox (1993)

offers two statements about Panoptic power. Firstly, through the Panoptic power people are subjected to the medical gaze and the discipline of medical power. Secondly, people accept this and engage in self-discipline and self-regulation. The first position is that the person being observed (e.g. the patient) within the Panopticon is subject to surveillance by an observer. The observed is alone within the cell and relates to the observer as an individual. Panoptic power is an exercise of power through these relations (Fox 1993). When this practice is applied to the insane, patients can be subjected to the medical gaze and disciplinary power, observed and classified. This means that the observer observes, and the observed accepts this observation. The subjectivity of the observed is shaped by this exercise of power and they self-regulate their conduct. This is part of Governmentality, which means practices of acting on the action of others, and will be discussed in more detail in the section on self-formation.

1.3 The Foucauldian perspective of biopolitics and biopower

According to Foucault (1980,1995,1996) biopolitics (where medical technology interfaces with politics to define people) was linked to biopower (the power held and exercised by the medical profession) and emerged at the same time as the Panopticon and the clinical gaze. Biopower and biopolitics led to population regulation and treatments for nonconforming individuals who were perceived as deviant. Biopolitics created a common knowledge between patients and health professionals, facilitated population participation, and created shared norms through participation. However, biopower and biopolitics were associated with power/knowledge, which maintained and supported medical power, authority, and acceptance of medical expertise in society. Biopower linked individuals to the social body, which was to be controlled (Foucault 1980,1995,1996). Fox (1993) is in agreement with this view, stating that biopower

involves prohibition and the clinical gaze, and invalidates the patient's own views. Insight involves acceptance of, and agreement with, a diagnosis.

1.4 A Critique of Foucault

The views of Porter (1987), Nicolson and McLaughlin (1987), Bury (1986), and Dinges (1994) and Lupton (1997) are explored. Empirical research by Bonner et al (2002) on the theme of social exclusion is examined.

1.4.1 Institutionalisation

This section examines the contrasting views of Porter (1987) and Foucault (1980,1995,1996) about institutionalisation. Foucault argued that prior to the Age of Reason madness stated its own truths and engaged in dialogue with reason. Porter (1987), describes this view of madness as romantic primitivism, but he makes the point that after 1800 the mentally ill were increasingly institutionalised and segregated, with the goal of promoting a rational society. Foucault called the institutionalisation of the mentally ill the 'great confinement' and in his view it was deliberate policy. Porter (1987) proposes that the new faith in therapy maintained segregation because it was believed that the mentally ill could be cured by these tactics and restored to society. He argues that civil policy, the law and the strong perception of people in society that the mentally ill are different from those with normal reason, are the factors which lead to segregation of the mentally ill. Likewise, psychiatry is given permission and power to segregate the mentally ill. Foucault expressed fears that those who did not conform were likely to be incarcerated indefinitely in asylums. Porter agrees with Foucault that the consequences are institutionalisation and segregation, but disagrees with Foucault

about the intentions of society at the time. Foucault believes that power relations are the driving force, with deliberate exclusion and control of the mentally ill as its intention. Porter asserts that the institutionalisation and segregation are not repressive and punitive, but done with the rationale of curing the mentally ill.

In this section social exclusion is further explored. The Office of the Deputy Prime Minister (2004) and the work of the Social Exclusion Unit highlight and attempt to address factors which relate to the exclusion of the mentally ill (e.g. exclusion from employment). Laurance (2002) in his work also discusses exclusion from employment and the opportunities employment offers for social inclusion, integration and meaningful activities.

Bonner et al (2002) suggested that institutional exclusion, which Foucault discusses, has been replaced by social and economic exclusion. They conducted empirical research to evaluate the effectiveness of primary care-based mental health team registers to reduce social exclusion in people with severe and enduring mental illness. The sampling frame was 274 people in six general practices and from these, 128 participants were randomly selected, and from these, the final sample was selected: 40 people (21 females and 19 males) with severe and enduring mental illness, who were receiving care from six general practices. Interviews which involved questionnaires were used - specifically the Camberwell Assessment of Need (CAN) (Brown and Rutter 1966, Phelan et al 1995), and the Life Fulfilment Scale (LFS) (Baker et al 1994). The CAN asked participants about need in the following domains: accommodation, looking after the home, daytime activities, self-care, social contact, intimate relationships and sexual relationships. The LFS focused on the following: housing, use of spare time, work satisfaction and

security, social life, family, close friendships and relationships with spouse/partner. There was an initial base line assessment and a 12 month follow-up assessment.

The baseline assessment and follow-up assessment revealed the following findings. When level of need was assessed, more than half the participants expressed need in the domains of psychological distress, day time activity and physical health. When overall needs were assessed, using the CAN questionnaire, the mean number of domains in which participants believed they had a need was seven out of a possible 22. Their unmet needs were psychological distress, day time activities, physical health and the company of others. When participant's quality of life was assessed using the LFS, health, happiness with self and close friends received low ratings. The pattern of unmet need did not change and need was related to psychological distress, day time activities, physical health and quality of life issues (specifically: health, having close friends, and being happy with oneself), and all of these factors received a low rating, indicating social exclusion.

This study suggests that primary care-based mental-health registers do not reduce social exclusion, local mental health services are not adequate, and that the policies are not effective (for example the DoH (1999), the review Sainsbury Centre for Mental Health (1998) and (DoH 1998)). Bonner et al (2002) suggest that setting up registers may not ensure proactive interventions. A register is simply a monitoring tool. More human resources are necessary to produce proactive interventions.

Bonner et al (2002) suggest that the participants may have been low functioning individuals or may have had high expectations, and it may not necessarily be the ineffectiveness of services which has led to these findings, but there is no empirical

evidence to support this position. It may also be the case that the focus on safety takes precedence over reducing social exclusion and promoting engagement with people with severe mental illness.

These authors state that CAN has face validity. Both of the data collection tools are valid and reliable, according to the authors. There was random sampling, which means that the sample is likely to be representative of the wider population, and the findings can be generalised. It is always possible that there was sample bias because of the presence of a common characteristic in the random sample, and this would reduce reliability. Replicability is likely to be strong because the data collection method is clearly stated. Questionnaires were used and because these were conducted face-to-face in an interview situation, potential interviewer bias exists. However, a feature of questionnaires is standardized questions, in which no probes are used, and therefore reliability and validity are likely to be strong. Statistical probability was stated as $P=0.05$ and it is unlikely that the findings emerged by chance.

Therefore Bonner et al (2002) provide evidence to support the view that social exclusion still exists, although the nature of the exclusion is different from Foucault's views and time, and takes the form of social and economic exclusion.

1.4.2 Medicalisation

The views of Freire (1970), Illich (1975), Bilton et al (1996), and Bunton (1997) regarding medicalisation and docile bodies are discussed here. There is debate over the view that medicalisation occurs with society's consent. Freire (1970 p. 68) discusses the concepts of "praxis" and transforming responses. Peoples' actions and reflections

are “praxis”. Action and reflection transform reality and the world and are a creative transforming activity in which people engage. As a result of this, expert systems are created (e.g. medicine). This is an idea similar to the concept of Structuration Theory proposed by Giddens and described by him in Giddens (1989/2001). Illich (1975) disputes Structuration Theory, and proposes that medicine is given the power to define reality and deviancy. Bilton et al (1996) argue that people are actively complicit in society in creating structures and resources (e.g. mental health systems and services). Giddens (1989/2001) proposes that Structuration Theory and human agency exist, and asserts that social relations and power structures emerge from these. Within Structuration Theory, all people, including people with mental illness, learn to play specific roles and conform to the rules of society. People are social actors who create power and power structures, and so are complicit with the medicalisation process. Bunton (1997) explores the interrelationship between the state and medical expertise and the medical gaze, and concludes that society approved of medicalisation and medical power as a response to perceived social problems. Medicine has based theories on Cartesian dualism and scientific positivism, and under the influence of medicine, nursing has done the same. This is manifested in the creation of dichotomies (e.g. sick-well, functional-dysfunctional) and psychiatric and nursing diagnostic categories. This theme was addressed earlier by Illich (1975), who asserts that power is willingly given. In conclusion, Freire (1970), Illich (1975), Bilton et al (1996) and Bunton (1997) appear to support the view that people willingly comply with medicalisation.

The works of Bury (1986), Nicolson and McLaughlin (1987), Rabinow (1991), Fox (1993), Foucault (1980,1995,1996) and Johnson (1997) discuss the concept of docile bodies. According to Nicolson and McLaughlin (1987), Foucault denounces medicine as oppressive, and states that medicine creates docile bodies. However Nicolson and

McLaughlin (1987) propose that patients' complicity is genuine, and that medical interventions and medicalisation lead to improvements in mental health.

Johnson (1997) and Giddens (1989/2001) deny the docility of populations, and Johnson (1997) asserts that people negotiate power with health professionals. Giddens proposes that the mentally ill are subject to external processes and social agency, but they are not docile bodies because they do not submit to society's will, and this is why society excludes them by social processes.

Other authors dispute this view and propose that compulsion of mentally ill people is successful (Armstrong 1994, Bury 1986, Rabinow 1991, Fox 1993, Foucault 1980,1995,1996). Armstrong (1994), a supporter of the Foucauldian view that medicalisation exists and involves coercion, asserts that diseases are created by medicine and patients are objectified and are perceived as less important than the disease. In consequence, social relations between doctor and patient have changed. Prior to the Age of Reason, the doctor delivered bedside medicine whilst the patient had control over the doctor-patient interaction and defined the nature of the illness. In objectification, patients lost their individual identity. New knowledge was created and this created new ways of perceiving the body and human identity (e.g. sick or well, mad or sane).

Bury (1986) and Rabinow (1991) assert that medical power creates docile bodies which can be used to serve society. Fox (1993) proposes that surveillance medicine facilitates the medical gaze on whole populations, promoting conformity and facilitating population regulation. According to Foucault (1980, 1995,1996), biopolitics encompasses both repressive and constructive approaches to mental illness. The former

demands conformity and compulsory admission into hospital and the latter involves participation and common shared knowledge about mental illness and normality. It also involves uncritical acceptance of the knowledge and defining labels, leading to negative self-labelling, compliance with treatment and insight, therefore in this way people become docile bodies (Foucault 1980, 1995, 1996).

Complicity and negotiation are considered by Johnson (1997), who disagrees with Foucault's perspective on medicalisation. Johnson (1997) emphasises negotiation between patients and health professionals and the giving of power to medicine based on trust and faith. He asserts that society gives medicine and psychiatry power, that doctors are just a link in a set of power relations and that power passes through doctors with everyone's consent. He points out that we all live under a medical regime and for those with schizophrenia it is more strict. Lupton (1997) also makes this last point. The Foucauldian view that medicine and psychiatry keep good order, promote health and productivity, may be too simplistic. Foucault's view denies the possibility that doctors and patients negotiate power. While medicine creates a body of knowledge and expertise and uses it to exercise power over the populations, individuals negotiate power by manipulating, conforming and behaving in a way which receives a positive social evaluation. Foucault assumes the reality of medical power, but society invests sovereign and disciplinary power in medicine, which may be used positively (e.g. surveillance of morbidity and mortality rates) (Johnson 1997).

1.4.3 Lupton's Views on the Foucauldian perspective of power

Lupton (1997) proposes that the medicalisation critique includes the following ideas: dependency has been encouraged and social inequality has been ignored as a social

problem, and this has been inappropriately treated as disease. This has been harmful to traditionally disempowered social groups (e.g. the working class). To be medicalised is perceived as undesirable by Foucault.

Lupton (1997) asserts that Foucault's position on power contains apparent inconsistencies. The first inconsistency is that in the Foucauldian perspective, power is repressive, yet it is also acknowledged to be productive, producing knowledge of health, discourse and pleasure. Another inconsistency is that in the medical encounter and through disciplinary power, people are guided to experience and understand their bodies. Medical power persuades people that certain ways of thinking are right, and coercion is not required, and therefore medical power creates the patient and the illness. Doctors are only part of the wider system of power relations. Everyone invests in power and we all live under a medical regime.

Lupton (1997) discusses the complicity and collusion of lay people in accepting medical practices. She proposes that Foucault has a simplistic perception of western medicine which denies the real improvement in patients' health status. There is an over-emphasis on doctors' power over patients and of patients being victims of power. She asserts that patients willingly participate in and collude in medical dominance and people place a positive value on recovery from illness. She maintains that the Foucauldian perspective acknowledges, to a small degree, that power cannot be taken from doctors, and that everyone invests in the strategy of power that is transmitted through all social groups.

1.4.4 Resistance to medicalisation

An inconsistency which Lupton (1997) reports is that in medical encounters patients accept advice and willingly engage in a relationship like that of a parent/child, because this offers emotional comfort. When Foucault proposed the concept of self-formation, he examined resistance by people to strategies of power. Foucault identified subjugated knowledge, which he believed was hidden under expert and dominant knowledge. People comply with and collude with medicine, but also choose to challenge medical power because they have their own subjugated knowledge. People are rational, autonomous individuals who are consciously aware of what they are doing. This becomes evident in the doctor-patient relationship when the patient challenges the doctor, rejects advice and negotiates power. Lupton believes that Foucault's original argument is deterministic, in that Foucault maintains that human agency is subjugated, no resistance is permitted, and people are docile bodies trapped in the clinical gaze. The inconsistency appears later when Foucault asserts that people may choose to resist power via a process of self-formation.

Mutual dependence is proposed as a reality by Lupton (1997), who asserts that in the Foucauldian view of medicalisation, mutual dependence between doctors and patients is denied. Foucault, in his views on self-formation and practices of self, asserted that patients were rational actors. Lupton disagrees with this view, asserting that patients are not always rational in the medical encounter. Lay people both invest in medical power and attack it and this is part of mutual dependence. She concludes that in medical encounters, people accept advice from doctors.

1.4.5 Lupton's analysis of the orthodox medicalisation critique

Lupton (1997) discusses the orthodox medicalisation critique and the paradox contained within this critique. She proposes that Foucault himself finds paradoxes in the orthodox medicalisation critique. On the one hand, medicine is ineffective and is often iatrogenic, and on the other hand, medicine has become powerful, and social life and problems are medicalised. In Foucault's orthodox critique of medicalisation, it is proposed that people should take control from doctors and acquire their own medical knowledge. It is also acknowledged that this leads to another form of medicalisation, preventative medicine, self-care and an intense individualistic focus on one's own health status. Therefore, the clinical gaze increases, with people examining their own health and emotional states.

1.4.6 Summary of Lupton (1997)

- Firstly, an inconsistency is that people are docile bodies, but they also resist medicalisation
- Secondly, power is perceived as both repressive and productive.
- Thirdly, medical power exists, and utilizes coercion but doctors are only part of a wider system of power relations, which everyone accepts and invests in, and coercion is not required.
- Fourthly, people comply and collude with medicalisation yet resist it in the medical encounter.
- Fifthly, people understand their bodies through the guidance of medicine yet have their own subjugated knowledge, which comes to the fore when patients reject medical advice.

- Sixthly, people are docile bodies and victims of medicalisation, yet in the concept of self-formation and practices of self, they are viewed as rational actors. According to Lupton (1997) they are not always rational, displaying dependency on the doctor and ambivalence about this. Mutual dependency exists between patients and doctors, an issue which Foucault did not acknowledge.

1.4.7 Self-formation

Falzon (1998), Rabinow (1991), Lupton (1997), Fox (1993) and Rose (1999) discuss self-formation. Falzon (1998 p.64) defines self-formation as “self-forming activity” within practices of the self. People regulate themselves and act on themselves, and form and shape themselves, to achieve a certain state of perfection. Rabinow (1991) discusses Foucault’s ideas of self-formation, asserting that it is accepted by society that people are capable of self-formation, (e.g. transforming oneself, developing insight, displaying self-control, and so preventing insanity). However, as Rabinow argues, this is not expected of the lower classes, who are perceived to be prone to biological determinism, loss of self-control and insanity. The lower classes are subjected to identification and social control more than any other group in society.

Lupton (1997) highlights an apparent inconsistency in Foucault’s views on self-formation, specifically the conflicting views of creation of docile bodies and self-formation. Lupton maintains that Foucault proposed self-formation after he proposed, and then de-emphasised, the idea of the technology of domination and power. Later in his life, Foucault maintained that individuals were capable of individual domination, could change themselves and so were not docile bodies.

Fox (1993) is critical of Foucault's perspective on medicalisation and docile bodies. Fox supports the concept of self-formation, supporting the view that medical oppression may not exist. There is a strong argument that people engage in self-formation, and Foucault later asserted that people use technologies of self. Technologies of self means behaving rationally and regulating one's actions, effecting, by one's own means or with the help of others, a certain number of operations on one's body, thoughts, and conduct, to transform oneself in order to attain a certain level of happiness, purity, wisdom, and perfection. It means self-care, a key element of which is self knowledge and identity. Within the medical model, self-care and examination of thoughts and how these relate to reality and rules are important, with people becoming their own doctor or censor (Foucault 1988). Technologies of self may prevent domination by technologies of domination.

Rabinow (1991) uses the terms lower classes and professional classes as he perceives the situation of domination of the lower classes by the professional classes. There is a potential weakness of his view that the lower classes cannot engage in self-formation and must be controlled. Without the willing compliance of clients from this group, the mental health services are unlikely to be able to exert any control of the population with mental illness, indicating self-formation by this group.

Rose (1999) adopts the view that there is no coercion involved, but the conduct of individuals is shaped. He believes that the following interpretation of Foucault's ideas is simplistic: people are dominated by a hierarchy of power, the state has all the power, professionals and their knowledge serve the state, individuals' subjectivity exists independently of power, and the effects of power on individuals' subjectivity can be evaluated.

Rose (1999) proposes that all knowledge, including psychological knowledge, is historically and culturally situated, related to cultural assumptions, and receives tacit support from the population. Psychological knowledge, which is produced by organisations and people, shapes people's subjectivity and conduct. Language, power and truth are connected. Populations accept the language of psychology given to them by psychologists, and they accept what are presented as empirical truths about mental health problems. The state does not drive this acceptance but does influence it. Medical authorities are created and accepted by populations.

Rose (1999 p. XX1) develops Foucault's hypothesis on Governmentality, which, for Rose is the "conduct of conduct, a programme of strategies and techniques for acting on the actions of others." It is the "ensemble formed by institutions, procedures, analyses, and reflections and tactics that allow the exercise of power over people" (Rose 1999 p.5). In Governmentality the human resources of society are supervised and maximised. There are a variety of connected authorities and within these lie the psychological sciences which influence how individuals are governed. These psychological sciences promote active autonomy, freedom, self-regulation and self-realization. He believes there is a cost to this (specifically a loss of mutuality and commitment to others), and individuals learn to evaluate their lives in terms of achievement, self-improvement or failure to achieve. Within Governmentality, subjectivity is focused on. Governments use psychological assessments and techniques to access and understand individuals' subjectivity (their subjective experiences). Subjectivity is "ontological: habits, emotions and will; epistemological: what is known through observation, testing and confession; ethical: the kind of self people should seek to be, autonomous self; and technical: what people must do to themselves, to improve themselves, to be autonomous" (Rose 1999 p. X11). People are shaped and are

expected to accept that they are part of a group (e.g. workers in employment, patients in hospital). Goals which will lead to self-fulfilment are encouraged.

Authorities are interested in individuals' subjectivity and intersubjectivity (shared experiences) because knowing the subjectivity of individuals allows authorities to manage human resources more effectively. Through organisations, the government acts on the conduct of populations. Health professionals are authorised to seek out people's subjectivity and offer therapy if an individual is perceived as failing to be an autonomous, self-regulating person. A consequence of knowing people's subjectivity is that new professional knowledge (e.g. psychology) is created and accepted. All mental life can be mapped, coded and recorded without coercion. Experts (e.g. psychologists) can act on the wishes of the population because their subjectivity is known. People are offered positive images which they are shaped to desire (e.g. the image of a self-fulfilled person) and are shaped to engage in technologies of the self, which involves self-examination and self-regulation. In psychotherapy, self- management and self-government are promoted and people willingly submit themselves to the gaze of the experts (Rose 1999). It may be that prior to this focus on the self, people knew they were individuals, but the focus on the self created a culture around this idea.

Modern liberal democracy has created people who learn to govern themselves in schools, hospitals and work places. The goal behind this is social and mental hygiene, and if an individual seems unable to achieve self-regulation, the psychotherapies help them to achieve this. The psychotherapies, through assessment, engage in judgment of normality and deviancy.

A range of psychotherapies which are part of the disciplinary apparatuses in society shape individuals. Individuals learn practices of the self which involve moral codes and what is ethically significant; ethical scenarios and apparatuses where moral codes are dispensed (e.g. court rooms); and techniques of the self which are self- examination and self-transformation and which can be achieve through a range of psychotherapies. The goal is to be free and autonomous (Rose 1999).

Psychotherapy has the goal of self-understanding. Client centred therapy helps a person to direct their life and be fully functioning. Primal therapy helps a person to be what they want to become. Transactional analysis promotes self-control, self-direction, self-transformation, self-awareness and autonomy.

The main assumption in behavioural therapy is that all behaviour is a learned reflex and can be changed. The therapeutic goals are self-management and improved mental hygiene. Behavioural therapy competes with other therapies to shape and liberate individuals. People learn new coping skills, which make them free and autonomous. Self-doubt and self-scrutiny are always present and success equates to happiness and fulfilment and self-management.

There are apparatuses and encounters involved in shaping individuals (e.g. doctors, hospitals). Rose (1999) maintains that life events and problems associated with them (e.g. bereavement and associated stress, failure to adjust) are colonized and pathologized by medicine. Individuals learn to evaluate their failure to adjust and accept self-responsibility. Reactions to life events are viewed as a failure to cope and, potentially, as a mental health problem. Social conduct is pathologized and an individual's inability to interact with others may be viewed as a problem and a cause of

further social problems. In psychotherapy, individuals are encouraged to address this problem.

The psychotherapies do not operate in isolation from political logic and thinking and promotion of self-government. They influence each other and create a way of conducting a life. They promote self-responsibility, self-transformation and openness to the judgment of others. Therefore, psychotherapy, in conjunction with social and political processes, creates an autonomous self, which is a decision making individual who can direct his/her own life, accept self-responsibility and achieve personal fulfilment and self-regulation. An individual's life and identity are tied to these ideas. Psychotherapy, in conjunction with science and ethics, now governs individuals and their subjectivity. Norms of truth and health are created without coercion. Individuals choose the goals of autonomy, happiness and fulfilment, which are also social, institutional and political goals. Most individuals have limited direct contact with the expertise that shapes them into being self-regulating individuals. They simply conform and succeed in this goal.

However, Rose (1999) highlights a paradox. There are limits and boundaries to autonomy and some conduct is not tolerated, for example, conduct which limits the freedom of others, (e.g. paedophilia) and excessive conduct (e.g. alcoholism). "Reasonable exercise of free will" is tolerated (Rose 1999 p. 266). The public person and the private person with secrets are compared and if there are discrepancies, the person is judged to be flawed or failed. Public conduct is perceived as indicative of an inner problem. Therefore, in this way there is a standardization of individuals' identities, lives and conduct, which are shaped and influenced with the consent of the population. Therefore, individuals are autonomous within limits, self-regulate,

willingly confess, and self-transform their inner self and public conduct. Free will does not exceed accepted boundaries and no coercion is required (Rose 1999).

Dinges (1994) discusses a paradox within the Foucauldian perspective on medicalisation.

He proposes that Foucault's theories are impossible to falsify on the basis of empirical findings, a point made earlier by Bury (1986). Foucault's work is incompatible with empiricism, and Foucault's idea that madness and reason can be reunited is impossible to prove or falsify. Medical enlightenment does not lead to self-reliance. Instead people become more sensitive to issues of health and disease, and increasing discourse on new symptoms and illness leads to more reliance on medicine. Dinges makes the point that medicalisation is represented by Foucault as a one-sided process in which doctors act and people receive care, but if we replace the idea of medicalisation with medical socialisation, it is possible to see the human agency of the population. They are agents in their own right; the interaction between official medicine and lay healers exists historically, and people choose from amongst these medical services.

It is possible that medicalisation is not a one-sided process for most people. However for some individuals who are diagnosed with a mental health problem, and disagree with this evaluation of themselves, it may be perceived as a one-sided process of medicalisation and coercion.

1.4.8 Critique of the Foucauldian perspective by Bury (1986) and Nicolson and McLaughlin (1987).

Bury is critical of Social Constructionism, while Nicolson and McLaughlin (1987) are more supportive. Contrasting views of the value of medical knowledge are discussed here.

Bury (1986), in a debate about Social Constructionism's strengths and weaknesses, considers that Foucault destroys all constructions without offering anything new. Foucault proposes that the production of medical knowledge is compromised, because it is part of the growth of social organisation and power. Within Social Constructionism, all forms of knowledge are part of discourse. Social constructionism claims to be a form of critical enquiry. It challenges the neutrality of science and rationality in medical thought and practice, and does not accept the concept of a neutral scientific discovery. It challenges the taken for granted, individualistic levels of explanation by connecting ill health and social structure. In social constructionism, "social practices replace rationality, social contexts are the foundations of knowledge, and power struggles replace progress in accounting for change" (Bury 1986 p.151).

According to Bury (1986), social constructionism has serious flaws, and he is critical of the Foucauldian analysis of mental health care. By representing medical knowledge as power, controlled by the interests of powerful groups, the caring responses of medicine to the suffering of people are denied. He proposes that, if the criteria of truth and rationality are the products of particular times and social situations, there can be no grounds for preferring one belief over another. This is the problem of relativism. For Bury (1986 p. 151) the premises of Social Constructionism are in doubt because of the

relativistic nature of the approach: it insists that “ scientific and medical categories are relative only to a given time, place and social configuration”. Social Constructionism itself must also be relative to these factors. According to Bury (1986), Foucault dispenses with categories, believing that medical knowledge is simply an interpretation of reality. Bury (1986) casts doubt on the Foucauldian view that the development of modern medicine can be portrayed without reference to changing demographic and mortality patterns, and he questions whether it can be treated as an interpretation of reality. Categories are not fabrications and play an organising role in society, and reality is stable and is a precondition of all social life. Even if a category is value laden and not neutral, it remains a legitimate category (e.g. insanity, because insanity involves behaviours and incapacities which are an unacceptable disability in society).

Bury (1986) has further criticisms. Medicalisation and medical power are exaggerated by social constructionism. People can resist medicalisation and Foucault’s emphasis on, and analysis of, power ignore human agency. He makes no comment about self-formation. He asserts that Foucault undermines his own position by adopting the stance that he does not have access to a privileged version of reality, and for him the truth value of Foucault’s arguments is not addressed or proved.

In reply to Bury (1986), Nicolson and McLaughlin (1987) express the view that medical knowledge is linked to the real world and changes when it encounters reality. Nicolson and McLaughlin (1987) assert that medical knowledge is not socially constructed or neutral. It changes when it encounters reality and is discarded when it is not useful. Bury (1986) asserts that a flaw of Social Constructionism is that if all knowledge is socially caused, then the beliefs of Social Constructionism are also socially caused and cannot be real or relied upon because this knowledge is not stable.

Nicolson and McLaughlin (1987) maintain that this is inaccurate, because, in their view, knowledge serves a purpose and this is how knowledge is assessed. Good knowledge is knowledge which is fruitful in practice and how that knowledge arose is irrelevant. Knowledge should not be devalued because the basis of belief in the knowledge is contextual and cultural. Reality leads to creation of knowledge, and knowledge is subject to feedback correction. According to Nicolson and McLaughlin (1987), knowledge is both socially constructed and realist, and the dualisms or dichotomies of truth or falsehood are not good explanations of knowledge in society. Sayer (1984) terms this “dualisms” and Silverman (1993) terms this “polar opposites”. Any belief is a product of a specific time and place and should not be devalued because of this, and, therefore, relativism is acceptable. The potential flaw in this argument is that Nicolson and McLaughlin (1987) appear to support both realism and relativism. It could be argued that they should decide if reality does or does not exist.

1.5 The views of Bentall (2003): Psychosis, human variation or illness? A criticism of the madness-sanity dichotomy

In this section I will examine key positions on the causes and origins of mental illness. Bentall (2003) questions the positivistic knowledge of mental illness. He proposes that hallucinations and delusions may be part of human variation and he questions both the scientific attribution of mental illness and the reality of the dichotomy between mental illness and sanity. He proposes that positive adaptation to hearing voices occurs, and that the presence of internal voices does not always indicate psychosis, although he acknowledges the difficulty in distinguishing between delusions, as identified by the Schneider's First Rank Symptoms model (Schneider 1959), and unusual beliefs. This argument may weaken the case for the objective fact of psychosis as illness, and may support the points made earlier by Rose, who reports the description of people in medical terms, and the creation and definition of people as mentally ill through differentiation (Rose 1994).

Bentall (2003) discusses the positive perception of hallucinations: the voices are sometimes perceived as pleasant and as real people in the lives of the experiencer, possibly reducing the feelings of isolation which may be a consequence of schizophrenia. He proposes that people adapt to having such experiences. He makes three statements:

- Firstly, those who accept the voices cope better.
- Secondly, those who perceive the voices to be positive are more likely to accept the voices.
- Thirdly, those who feel stronger than the voices are likely to accept the voices, cope better, and may not seek help.

The flaw in his argument is that he states that only those who perceive their voices as positive and feel stronger than them, accept the voices and so cope better with the voices. Should the voices be critical and negative, and the voice hearer accepts them, it is unlikely the voice hearer would cope better and adjust. He does not discuss this latter scenario. Therefore better coping appears to depend on what type of voices one has.

Bentall (2003) highlights the theme of differentiation of the mentally ill. He concludes that the origins of this lie in faith in the Kraepelinian paradigm and the current Diagnostic Statistical Manual IV (DSMIV) (American Psychiatric Association 1994) classification system, which identify people with schizophrenia as being disordered. In the UK the position is that the International Classification of Disease 10 (ICD10) (World Health Organisation 1992a, Goldberg et al 2000) is promoted as a classification system by the National Service Framework (DoH 2000). As a diagnostic criteria the ICD10 is narrower than the DSMIV, and people who would receive a diagnosis of schizophrenia under the DSMIV would not receive this diagnosis under the ICD10 (Bentall 2003). Bentall (2003) believes that these classification systems are flawed and arbitrary, and have their cultural roots in an industrialised and scientific economy. A person who has a psychotic symptom, might not experience a behavioural breakdown, can participate and function in social life, and can have a valued role in society. Bentall is critical of the Jablensky et al (1992) study, which found that there was a uniformly distributed liability to schizophrenia, and suggested that people experienced psychotic symptoms with no distress and did not seek help. Variability in the actual incidence of schizophrenia was ignored.

There is a broad definition of schizophrenia used by the USA and Soviet Union and a narrow definition used by other countries. Therefore the accurate identification of a person with schizophrenia becomes problematic.

In this section I will examine positions on schizophrenia, examining key studies. These will point out that some people who have a diagnosis of schizophrenia do not perceive themselves as ill and have a positive experience.

1.6 The views of Roberts (1991): Successful deluded people with positive meanings and purpose in life

In a study of perceived meaning in life, Roberts (1991) conducted semi-structured interviews, and used three rating scales:

- the Purpose In Life Test (PILT) (a self-rating scale), (Crumbaugh and Maholick 1964).
- a Life Regard Index form (LRI), (a self-rating scale which assessed the relative contribution of their system of meanings and the degree of life satisfaction) (Beck and Beck 1972, Battisata and Almond 1973).
- the Beck Depression Inventory (BDI).

The PILT self-rating scale, designed to quantify perceived meaning and purpose in life, had previously been shown to be reliable. However one flaw was that it was considered to be biased towards a white, western, middle class, protestant world view. The sample was a group of chronically deluded people (n=17) (the P group). The findings were compared with three other groups: C1, a group of people who were previously deluded and were now in remission (n=17), C2, a group of psychiatric rehabilitation nurses

(n=16), and C3, a group of Anglican Ordinands (n=33). The PILT and the LRI were used to compare the strength of perceived meaning in life. The findings were that the chronically deluded people perceived their lives to have very positive meaning and purpose, a process which seemed to occur as their delusional systems and hallucinations became more elaborate. The P group had low levels of depression and suicidal inclination, in contrast to the C1 group who were in remission and objectively mentally well, but who had high levels of depression and suicidal inclination. The P group had a comparable score with C3, yet the C3 group had a superior quality of life when viewed objectively. Therefore psychosis appears to create its own positive benefits, and delusional formation may be viewed as a positive adaptation, rather than illness. The P group may have reconstructed their reality, and in their perspectival world they were protected against depression. Roberts (1991) proposed that successful deluded people may exist, who are not in contact with services.

1.7 The views of van Os et al (2000): A continuum of hallucinations and delusions

Van Os et al (2000), in a prospective study, interviewed a large sample (n=7706) of men and women over three years. This was a multi-stage, stratified, random sample of people living in the community, and the sample represented the Dutch population in terms of gender, marital status and urbanisation. The Composite International Diagnostic Interview (CIDI) was used, which led to Diagnostic Statistical Manual-III-R diagnoses (DSM-III-R) (American Psychiatric Association 1987). There was high inter-rater reliability and high test-retest reliability. The ratings of Clinical Psychosis and Plausible Symptoms were checked by a psychiatrist; therefore, potential misinterpretations of participants' answers by lay interviewers, was reduced. Findings suggested that hallucinations and delusions existed on a continuum and may apply to

the general population. There were flaws in this study. There was an under representation of individuals aged 18-24 years old. This is highly significant as this is a key age group for the first onset of schizophrenia. There was also a heavy reliance on the identification of positive symptoms of schizophrenia (hallucinations and delusions) rather than the negative symptoms. These findings therefore do not prove conclusively that the self-reported psychotic experiences measured in this study account for all the experiences in schizophrenia, as suggested by Van Os et al (2000).

1.8 The views of Romme and Escher (1994) Adaptation to voices

Romme and Escher (1994) shared Bentall's (2003) belief that adaptation to voices occurs. Romme and Escher's research used questionnaires with a self-selected sample of 173

voice hearers. Some respondents reported feeling able to cope with, and manage, their voices (n=58). Of these 58 voice hearers, many (n=39) reported feeling stronger than their voices, and many (n=54) reported being able to ignore their voices. This coping group of 58 voice hearers also engaged in selective listening, setting limits on their voices, and experienced more positive voices. One voice hearer reported coping better with voices by accepting voices as a part of oneself, rather than denying the voices. Those who reported not coping (n=115) felt weaker than their voices and experienced more negative and commanding voices. Ignoring voices, selective listening and dialogue were reported as successful strategies. These were associated with coping and were part of the "Phase of organisation", the second phase of a process which voice hearers appeared to go through (Romme and Escher 1994 p.19). In the third and final phase "Phase of stabilisation", the voice hearers were able to choose to accept or reject what the voices told them and adjust to the voices (Romme and Escher 1994 p.22).

Greater self-esteem was a consequence of accepting voices, according to Romme and Escher (1994).

1.9 The views of Leudar and Thomas (2000): coping with voices

Leudar and Thomas (2000), in a clinical case study, reported coping mechanisms used by people who hear voices. One cognitive technique was paying attention, reflecting on the content of the voices and accepting their guidance. This minimised distress. Leudar and Thomas provide the example of an individual who had a dialogue with a voice, which advised her and made her feel calm and reassured. As a result of this dialogue, the individual's self-esteem, self-confidence and social functioning increased.

The original foucauldian ideas and subsequent classification systems failed to acknowledge factors in a person's life which might lead to mental illness. In his criticism of the DSMIV classification system, Bentall (2003) suggests that an experience of a traumatic event, specifically abuse, after which victims of trauma show symptoms of long-term physiological arousal, may lead to mental illness.

Bentall (2003) explores the role of trauma in the development of psychosis and concludes that trauma (e.g. sexual or physical abuse) appears to precede psychosis. He cites Goodman et al (1997) to support this theory.

1.10 The views of Goodman et al (1997)

Goodman et al (1997), in an overview of research (13 studies) on the association between abuse and the development of schizophrenia, found that there was evidence of

physical and sexual abuse during childhood in people who later developed schizophrenia. However, these authors highlighted methodological problems in data collection. There were difficulties in assessing abuse histories in severely mentally ill women because hallucinations and delusions affected memory. Victimization history had not been assessed using adequate instruments or procedures. Over-reporting may have occurred because of potential secondary gain. Under-reporting may have occurred because of respondents' shame, guilt or fear. In past studies the impact of childhood abuse and adult abuse had not been clearly differentiated. These authors highlighted other explanations for the association between abuse and the onset of schizophrenia. They proposed that abuse survivors may have been misdiagnosed as having schizophrenia, when a diagnosis of post traumatic stress disorder may have been more appropriate. Goodman et al (1997) proposed that trauma may have affected the course of schizophrenia through other routes (e.g. substance misuse). They noted that in two studies (Beck and Van der Kolk 1987, Craine et al 1988) there was an association between childhood sexual abuse and problematic use of drugs in women. This association between early trauma and problematic substance use is still unclear, and either of these factors independently, or a combination of these factors may have led to the onset of schizophrenia.

It is suggested in this review that early trauma in women who developed schizophrenia may have interfered with the development of good interpersonal relationships and social adjustment, which are believed to be potential predictors of an outcome of schizophrenia. However this is not a clear finding, and, therefore, the association between abuse and the onset of schizophrenia remains unclear.

1.11 Summary

Some authors propose that all mental illness is socially constructed. Scientific positivism

has influenced theories of insanity and the creation of new medical knowledge, which has led to differentiation, categorisation, and exclusion of the mentally ill. Empirical evidence shows current social and economic exclusion of the mentally ill. There are paradoxes within the Foucauldian orthodox medicalisation critique. Oppressive medicalisation, in which people become docile bodies, is proposed by some authors, while others suggest that compliance, collusion, self-formation, self-regulation and negotiation with medicine are frequent behaviours by people. However, an individual's conduct, aspirations and the self an individual strives to be are shaped by a range of authorities and organisations through Governmentality. Key studies explored positions on schizophrenia, which dispute the earlier position, in which patients were identified as mentally ill using specific criteria. Some authors propose that the presence of delusions and hallucinations is part of normal human variation and that mental illness classification systems are flawed. It is reported that people appear to make a positive adaptation to hallucinations; however, there is a flaw in this theory (Bentall 2003). Some people with delusions and hallucinations are reported to perceive their lives very positively. Delusions and hallucinations may be viewed as a positive protective adaptation. Hallucinations and delusions may exist on a continuum and may apply to the general population.

Most individuals in society appear to self-regulate and accept medical knowledge and expertise willingly. It could be argued that self-regulation is a form of partnership with medical expertise. A recent and growing minority movement is emerging in which

individuals who have a psychiatric diagnosis do not accept medical expertise. However, it could be argued that they self-regulate and self-manage their condition or experiences (e.g. schizophrenia and hallucinations) through self-help groups.

In the following chapter an exploration of individuals' experiences, specifically in relation to the themes of partnership and empowerment, is presented.

CHAPTER TWO: PARTNERSHIP AND EMPOWERMENT

The main purpose of this chapter is to examine and review the background literature concerned with partnership and empowerment. Partnership is implicit in self-formation, and in any complicity between patients and health professionals because of the shaping of individual's subjectivity, which is part of Governmentality, as discussed in Chapter One. The contrasting views of health professionals and service users on partnership and empowerment are highlighted. Empirical research is examined and conflicting evidence offered on the following: that partnership exists, that there is lack of partnership and that there are potential barriers to partnership. Additionally, a number of themes are examined: self-determination, factors involved in service user empowerment and the disempowerment of mental health nurses. The theme of self-empowerment is explored in empirical research which concluded that self-empowerment is possible. The contrary positions of empowerment and lack of empowerment of service users are explored. Finally a brief exploration of the negotiation of power by service users is offered. This chapter incorporates the views of users of mental health services and compares these views with the views of mental health nurses on the issues of partnership and empowerment within mental health nursing. Shields (1985) proposes that there is a commonly held view that the very nature of mental illness invalidates the views and perceptions of this group. However, user groups and current legislation assert that the views of users of mental health services are important.

The following Department of Health reports promote partnership between mental health service users and health professionals: (DoH 1990), (DoH 1994a), (DoH 1997a), (DoH 1997b), (DoH 2000) and (NICE 2002). Seminal works by a range of health

professional authors maintain that nurses work in partnership with service users: Benner (1994), Barker (1999), Clinton and Nelson (1999).

Rose (1994, 1999), and Fox (1993) in their discussion of coercion, Governmentality, the clinical gaze and self-formation all maintain that individuals work with health professionals, accepting their knowledge and practices.

The conclusions of empirical research, which sought service users' views on the issue of partnership, are examined. Johansson and Lundman (2002), in their study, concluded that clients participated in decision-making. Simpson and House (2002) explored partnership, sought service user' views and concluded that there is partnership. Kai and Crosland (2001) explored partnership, sought service users views and came to the same conclusion. Crowe, O'Malley and Gordon (2001) sought users' views and supported the conclusion that there is partnership between nurses and service users.

Some authors explored partnership and maintained the position that there was no partnership between service users and health professionals. Morrall (1998a), in his study and Devane et al (1998), in their study, both concluded that nurses did not engage in partnership with service users. Hickey and Kipping (1998) maintain the same position. Barker (1999) agrees but suggests and explains the concept of alliance between service users and health professionals.

Some authors explore self-determination. Jones and Tallis (1994), in their work discuss self-determination and their position is that it can occur after partnership has been achieved. Cutliffe (1997), in his study, concluded that self-determination is separate

from partnership. Hickey and Kipping (1998) believe that self-empowerment is possible.

Empirical research by McCann (2004), which explored self-determination, concluded that self-determination was possible and essential, and Valimaki (1998), in his study concluded that there were levels of self-determination.

Potential barriers to partnership are examined by a range of authors. Hickey and Kipping (1998) identify barriers to partnership. Barker (1999), Barker and Davidson (1998), in their overview, Keyzer (1988), in his chapter, Rodwell (1996), in his paper, Campbell and Lindow (1997), in their work, and Hickey and Kipping (1998), and Nocon and Qureshi (1996), in their papers all explore barriers to partnership. These authors believe that factors attributable to the characteristics of professionalism in health prevent partnership, and empirical research by Beresford and Branfield (2006) came to the same conclusion.

Mind (1992), in their report, Campbell and Lindow (1997), Coleman (1997), in his work, and Coleman and Smith (2005), in a later work, all clarify the nature of empowerment and emphasise the importance of human agency in service users.

The factors involved in being empowered are examined in the following works: Nocon and Qureshi (1996), Hickey and Kipping (1998), Rodwell 1996), Morrall (1998b), Campbell and Lindow (1997), Barker (1999), Moorey (1998). Empirical research (Morrall (1998a), Collins and Williams (1999), and Bertram and Stickley (2005)) identifies factors involved in empowerment of service users. Nocon and Qureshi (1996), Hickey and Kipping (1998) and Williams and Collins (1999) emphasise the

importance of human agency and maintain that self-empowerment is essential. Nocon and Qureshi (1996) and Hickey and Kipping (1998) introduce the concept of service users as citizens and clarify the citizen-consumer model. Rodwell (1996) discusses the nature of empowerment, whether it is a process or a product and the implications of this. Rodwell (1996), Nocon and Qureshi (1996), and Barker (1999) clarify the concept of enablement. Moorey (1998), Bertram and Stickley (2005) and Morrall (1998b) highlight the lack of empowerment. Nocon and Qureshi (1996), Rodwell (1996), Morrall (1998b), Moorey (1998), Hickey and Kipping (1998), Barker (1999) and Bertam and Stickley (2005) all hold the view that there are health professional barriers to service user empowerment. Collins and Williams (1999) explained how empowerment can be achieved.

Patel and Fatimilihen (1999), in their chapter, hold the view that there are oppressive practices and organizational factors within the mental health system which disempower service users. Ryan (1999) explores empowerment and explains why service users' empowerment is limited, emphasising the focus on risk management by mental health nurses. Barker (1999) holds the view that there is inequality between service users and health professionals, even where partnership is possible. He explores how mental health nurses may disempower service users. Chadwick (1997), in his study, explored how redefining psychoses can lead to feelings of empowerment.

Some authors support the position that mental health nurses empower service users: Benner (1984), Rogers et al (1993). Pieranunzi (1997) concluded that empowerment occurs, and Pitt and Kilbride (2006), in their study provide evidence to support this position.

A range of authors explain service user disempowerment by focusing on the disempowerment of nurses. Rodwell (1996), Campbell and Lindow (1997), Morrall (1998a) (empirical research), Moran (1992), in his paper, and Ryles (1999), in his analysis, all hold the view that nurses are disempowered. This view is supported by empirical research by Pontin and Webb (1995).

Negotiated power is explored in the following works: Hugman (1991), in his overview, Johnson (1997), in his overview, and Rose (1994, 1999), in his analysis of Governmentality and coercion. Rose (1994, 1999) holds the position that individuals accept medical goals and, although individuals are shaped through Governmentality, they still have power.

2.1 The importance of partnership

In this section I will now discuss why partnership is important, and the legislation and policies which support partnership between service users and health professionals. Current legislation highlights partnership with, and involvement of, users of services (DoH 1994a, Duffy 1997, DoH 1997a, DoH 1997b, DoH 2000, National Institute for Clinical Excellence 2002). The DoH (1994) affirms the importance of service users having choices. Client-centred care and needs-led nursing services are promoted. Participation and partnership extends to planning and decision making (DoH 1994). Duffy (1997), a nurse author who reports nurses' views on partnership in a brief overview of this theme, proposes that Home Treatment and the Care Programme Approach (DoH 1990) are good examples of initiatives which enhance partnership (Duffy 1997). The DoH (1997b) highlights the importance of equal participation and involvement of users, perceiving this to be a valid goal to which mental health nurses

are committed (DoH 1997b). The National Institute for Clinical Excellence (2002) emphasises partnership and addresses treatment and services for people with schizophrenia. The evidence underpinning these guidelines consists of randomised controlled trials, the strongest level of evidence, clinical studies other than randomised controlled trials, a weaker level of evidence, and expert committee reports and opinions, which are the weakest level of evidence according to the National Health Service Executive (1996).

These National Institute for Clinical Excellence guidelines propose that partnership involves building a “supportive and empathetic relationship with users and carers”, and involves giving clear information to users and promoting recovery (National Institute for Clinical Excellence 2002 p.6). Treatment and care should be delivered in an atmosphere of hope and optimism. Joint decision-making between the person with schizophrenia and the clinician, in the choice of medication, is proposed.

2.2 Partnership exists: the views of health professionals and authors, and empirical evidence

I will now explore literature and research which supports the position that partnership occurs between service users and health professionals. Benner (1994) asserts that nurses deliver engaged care which involves acceptance of the client and their behaviour, and partnership between nurse and client. Peplau (1994), who proposes nursing theory with no empirical evidence, asserts that nurses are change agents who work with clients to overcome their difficulties outside hospital, an activity which requires partnership. Barker and Jackson (1997) support Peplau’s ideas about nurses’ role as change agents. However like Peplau (1994), Barker and Jackson (1997) offer no research to support

this view. Barker (1999), in a later work, again with no empirical evidence, asserts that nursing is a craft, and craft work involves a contractual relationship involving partnership.

Westwood (1997), a nurse author, asserts that, in mental health nursing, partnership exists between nurses and people with schizophrenia, and people with schizophrenia are encouraged to define their own goals. Mental health nurses attempt to address these goals and other areas of personal development and growth (Westwood 1997). However no empirical research evidence is offered for these views.

Clinton and Nelson (1999) maintain that working with people with mental health problems in the community means facilitating an equal relationship with them and developing partnerships. However this is the authors' own view, and there is no empirical research evidence to support this view, although other works lend credence to this view (e.g. Rose 1999). Tomson (2002) maintains that promotion of the patient centred consultation, with emphasis on acknowledging equal status of client and nurse, leads to partnership. The client is to be perceived as an expert in their own experience and health professionals are to be perceived as experts in areas of specialist knowledge and skills. According to Tomson (2002), the move from provider controlled care to client centred care leads to the construction of better care, with caring making sense to the client. Once again, there is no empirical research evidence for this view.

Rose (1994, 1999) contends that individuals and society accept the monitoring of illness and the promotion of health within the social processes which exist within Governmentality. Medical authorities are given legitimacy by society to shape and transform individuals, and self-regulation is accepted and practiced by individuals. This

shaping is achieved through a range of psychological therapies which individuals accept. Individuals subject themselves to the gaze of the experts who practice and deliver psychotherapies (e.g. client-centred therapy) with the desired goal of achieving good health, happiness and fulfilment. This is part of Foucault's original concepts of self-formation and technologies of the self and explains how and why individuals choose to manage themselves. Self-management is central to being a modern self, which involves autonomy and self-monitoring (Rose 1994, 1999). However, without partnership between individuals with mental health problems and health professionals, this is unlikely to occur.

Fox (1993), who discusses the Foucauldian perspective on coercion and resistance, maintains that both patients and health professionals create, accept and give legitimacy to medical knowledge and norms of health in their interactions. The organization of health and related practices (e.g. a ward round or appointment with a therapist) offer patients opportunities to interact with health professionals. Patients accept and comply with these practices, which, according to this author, are patient-centred and meet a need. Trust between patients and health professionals exists. What power exists is benign and is derived from the health professional's expertise, which is accepted by the patient. Fox's position is that patients accept health professionals' care practices and therefore there is partnership. There are shared meanings and understandings of health, even though these have been shaped. However, he acknowledges the argument against this position, which is that resistance of medical power and discourse does exist and that health care must be organized and patients' subjectivity must be shaped. Resistance may occur when there is an expectation of a reciprocal interaction between patient and health professional, but the patient perceives that reciprocity is not genuine. Compliance may be replaced by resistance in the form of demands and complaints (Fox 1993) (this has been discussed in more detail in Chapter One).

There is empirical research to support the position that partnership exists. Johansson and Lundman (2002), in a phenomenological study using unstructured interviews with five clients in a mental health facility, concluded that there were opportunities to participate in decision-making about one's own care and there was flexibility of care. The sample was too small ensure reliability and interviewer bias may have occurred (this is discussed in more detail in Chapter Five).

Simpson and House (2002) conducted a systematic review which consisted of 12 studies (5 randomised controlled trials, 5 clinical controlled trials, 2 studies which used interviews). The research question was 'does involvement of ex or current users in the delivery or evaluation of mental health services improve outcomes for service users?' Many of the findings were qualitative findings, whilst those from the quantitative studies were derived from service users' evaluations, which were sought using rating scales, thus involving an element of subjectivity and lack of precision. The researchers concluded that partnership exists and that when service users are involved in the delivery and evaluation of mental health services, patient outcomes are improved and service providers respond to the active participation of service users. The positive outcomes for service users were stated as: more face to face contact with service users and staff, improved quality of life, improved social functioning, fewer life problems, longer periods between hospital admissions, fewer hospital admissions and shorter hospital stays. It may be that ex-service users involved in providing care and interviewing are sensitive to the important issues in the lives of current service users because of shared experiences and empathy. This empathy may in turn lead to more tolerance by these ex-service users, compared with health professionals, towards behaviours which are a result of symptoms of mental illness. Current service user satisfaction with services was not increased as a result of ex-service user involvement,

but satisfaction levels appeared to depend on who interviewed the current service user. The satisfaction level was lower when ex-service users interviewed current service users, and was higher when health professionals interviewed them suggesting potential interviewer bias in these interviews and in the emerging findings (Simpson and House 2002).

Kai and Crosland (2001) used grounded theory and individual unstructured interviews in a primary care setting, specifically four General Practice surgeries, to explore how 32 service users with enduring mental health problems experienced health care. Twenty-one group interviews with health professionals were also conducted. The data were analysed using grounded theory methods: reality was explored, categories were generated, abductive reasoning was used (a cyclical process: data collection, hypothesis formation, more data collection) and thematic content analysis was carried out. A main finding was that partnership was reported. These authors reported other findings: there was a positive therapeutic relationship between participants who were also service users and health professionals and these participants valued the empathy and listening skills which health professionals displayed. There were some potential flaws in the research methodology. Firstly two interviews were discounted because these service user participants did not believe they had a mental health problem, which may have led to bias in the findings. Secondly, the themes from the service user interviews were validated using 21 group interviews with health professionals, not the original service user participants, and these flaws weaken reliability in the findings.

Crowe, O'Malley and Gordon (2001) conducted a consumer satisfaction study, using 131 semi-structured individual interviews with mental health care service consumers. The aim was to evaluate whether the mental health services were meeting the needs of

consumers in the community. Data analysis involved thematic content analysis, and responses to questions were coded under themes and categories. The percentage of consumers who made a specific response was recorded (e.g. 69% reported that nurses gave sufficient information about illness). These authors concluded that partnership existed between these consumers and mental health nurses, and these consumers valued community mental health nursing care. These consumers valued the nurse's role in monitoring mental state and responding, and they trusted nurses. This might suggest dependency and lack of equality in the nurse-consumer relationship. Lack of partnership was not reported, but the findings include the issue of nurses considering the power within their nursing roles and there was a perceived power imbalance in the nurse-consumer relationship, which may appear to be a contradiction, unless partnership can exist without equality between two parties. These authors do not analyse this but do suggest that consumers should become more active in their care. These authors maintained that the rigour in this study could be assessed using the Guba and Lincoln (1989) criteria. Consumers of mental health nursing care were involved in the construction of the interview schedule, which increased credibility. Transferability was guaranteed because the findings were similar to those of other studies, although this research was context specific, which may have weakened transferability. Dependability was ensured because one researcher had the role of ensuring that all interviews were conducted in the same way. There may have been bias as a result of the overrepresentation of female participants (79 females, 59 males) (Crowe et al 2001). Qualitative findings were treated in a quantitative way because the percentage of consumers who made a specific response was recorded. It could be argued that the strength of numbers of responses does not belong in qualitative research and percentages were irrelevant, considering the research aim, data collection and analysis methods.

2.3 Health professionals reporting lack of partnership

I will now discuss literature and research which disputes the previous position and contends that there is no partnership between service users and health professionals. Morrall (1998a) conducted a mixed qualitative and quantitative longitudinal study and a multiple case study with the aim of evaluating Community Psychiatric Nurses' (CPNs) clinical autonomy. A main finding was that CPNs have autonomy by default. That is medicine gives them some autonomy but it is not legitimate autonomy, and in reality CPNs engage in surveillance of people with mental health problems and do not engage in partnership. The sample was 10 CPNs and the data was collected using a diary-interview schedule, audio-taped structured interviews, audiotaped focused or unstructured interviews, field or participant observation (150 hours). Data analysis involved thematic analysis, and quantitative data from the interview schedule was analysed using the Statistical Package for the Social Sciences (SPSS). Field notes were read and coded. Coding from the standardised interviews, focused interviews and field notes were compared.

Face validity was present because peer and expert scrutiny were sought for this research project, specifically for a fit between the research aims and the methodological procedures. Internal validity was present because within-method triangulation (one method was used consistently over different occasions with the same subjects) and between-method triangulation were present. Content validity (the representativeness of the items measuring the construct) and construct validity (how well the underlying theoretical constructs are measured) were present. Convergent validity was present and was gained by examining accounts from CPNs and managers and using researcher observation. Discrimination validity was present and was gained by including

discriminating questions relating to perception of autonomy in the interview schedules. Ecological validity was present because there was a match between the everyday world of the participants and the research techniques, and a high level of ecological validity was achieved in the standardised interviews, because it was a longitudinal study. Internal reliability was present because interview transcriptions were made available and two colleagues examined and commented on the original data. External validity was present because the researcher's roles, the underlying ideas, units of analysis, data collection and analysis methods were all clearly stated and four case studies were re-tested by the original researcher.

Potential flaws were that there was only one researcher, and the research design changed during the data collection as a result of methodological reflexivity. There was limited external validity as the sample was not representative. A potential flaw in the data collection methods was that the researcher became attached to some participants and there may have been potential reactivity, which may have influenced participants and researcher bias (Morrall 1998a).

Devane et al (1998), highlighted that even with training, nurses had poor collaboration and partnership skills and there was no negotiation of mutually agreed goals with clients. It was suggested that these nurses did not have the following skills: a negotiating style of communication, interpersonal skills and giving feedback to service users. These nurses had not received any training in these aspects of collaboration or partnership. They had received training in hierarchical settings, and therefore these skills were not developed.

These claims were based on a controlled study, using rating scales involving 34 nurses (control group n=17, group receiving training for family work and Cognitive Behavioural Therapy n=17), There were three independent raters who rated the taped clinical sessions blindly and inter-rater reliability was reported as good. A potential weakness was the small sample size, and there was an over-representation of nurses on the Thorn Psychosocial Interventions course, which means that the views of this specific group of nurses are likewise over-represented in this study.

Bracken and Thomas (1999), who discuss users' views, highlight the lack of partnership and equality in mental health nursing. They maintain that, in in-patient services, medicalisation of distress promotes dependency, a finding which Hickey and Kipping (1998) agree with. Surveillance, containment and monitoring of symptoms also exist within these services. Community services are intrusive and alienate people with schizophrenia, and may be perceived as a surveillance mechanism according to Bracken and Thomas (1999). There is however, no reference to empirical research in this work, in relation to these views.

2.4 Self-determination, partnership or alliance for service users

I will now examine literature and research which explores self-determination, partnership and alliance for service users. Self-determination appears to be the ideal goal for a service user and it goes beyond partnership and alliance, placing service users in a stronger position. Some authors propose that self-determination for service users is more appropriate than partnership. Jones and Tallis (1994) maintain that when working with individuals with schizophrenia, nurses must help service users to achieve

autonomy, which means choosing for oneself. This choice comes from self-determination, which can be achieved through partnership (Jones and Tallis 1994).

Cutcliffe (1997) supports the goal of self-determination as opposed to the goal of empowerment or partnership. According to this author, self determination involves deciding what to do and what to be. Self-determination may be achieved by service users if nurses are proactive and question, critique and balance organisational needs and clients' needs by negotiation (Cutcliffe 1997). A potential organisational need is over-caution in risk assessment, which may not permit community leave for clients. This situation may be a result of a culture of control, legislation and avoidance of litigation.

According to Hickey and Kipping (1998), self-determination may be achieved if health services are fully user controlled. Self-determination, where the service user makes all the decisions, is within the Democratization approach and this involves a redistribution of power, although there are potential barriers to this (see 2.5). Both Cutcliffe (1997) and Hickey and Kipping (1998) link self-determination to autonomy and choice. However, there is no reference in this literature to empirical research findings.

McCann (2004) used grounded theory, non-participant observations and 44 unstructured, face-to-face, 60-90 minute interviews, with an aide-memoire to explore the processes used by nurses to promote client self-determination. The sample was young adult clients with schizophrenia (n=9) and community mental health nurses (n=24) from three mental health centres. Data analysis involved coding of transcribed data, axial and selective coding. The main findings were that nurses must educate clients about their illness and well-being and foster self-control, and these were essential to the promotion of self-determination. A reciprocal relationship between nurses and clients was essential to achieve this goal.

McCann (2004) highlights the need for a participatory approach, rather than an expert led approach, with the emphasis on partnership between nurses, families and clients. Fostering self-control in clients means helping them to make decisions and take control in care and in their recovery. Two key categories were highlighted: changing the balance, which means nurses have to give up the expert role and give responsibility to clients, and enabling control, which means consulting clients and involving clients in decision-making.

The deficit model of education is inappropriate because within this there is the assumption that people with schizophrenia do not know enough about schizophrenia. This model of education produces certain nurse behaviours, (e.g. blaming) which focus on clients' illness behaviour and ignores wider social issues which contribute to illness behaviour. It is individualistic and individuals are held responsible for their illness behaviour. The collaborative interactional model is more effective because the client's beliefs and experiences are focused on. Some control is necessary because without this individuals cannot achieve well-being. However this does imply, at least initially, that there will be an unequal relationship between client and nurse. The assumption in the promotion of self-determination is that individuals choose "wellness-focused behaviour" (McCann 2004 p.18). It is a transitional process with nurses giving up control over time. The client becomes more enabled and the balance changes. The term alliance is emphasised rather than partnership because McCann acknowledges the reality of the power imbalance between nurses and clients. He concludes that some self-determination can be achieved but the level of self determination achieved by each client will differ because each client is an individual and there are limits to self-determination. Therefore nurses must be supported in delivering the collaborative interactional model of education and nurses must consider whether their relationships

with clients foster self-control. Promotion of self-determination is one phase in the care relationship and an alliance is necessary to support it.

McCann (2004) used the Lincoln and Guba (1985) criteria to assess rigour: credibility, dependability, transferability, and confirmability. Transferability and credibility were present because there was purposive sampling (participants had a known characteristic). There was reflection and acknowledgment of the researcher's presuppositions. Findings were verified but details of how this was done were not given. It may be assumed that strategies and operational techniques stated in the Lincoln and Guba (1985) model to assess trustworthiness of research were used. Researcher bias was reduced, a daily reflective diary was produced and there was clear identification of a theoretical perspective. However the results were limited to the study context and setting, therefore findings are not generalizable, although generalizability is not essential in qualitative research (see Chapter Six).

Valimaki (1998) explored what self-determination meant to participants with long term mental health problems. A convenience sample was drawn from a larger sample of 183 participants, a purposive sample, as they all had a long-term mental health problem. The convenience sample was 72 (39% of the original sample of 183) participants, both in-patients and out-patients. The drop-out rate was 50 percent of 183 participants. Of these 72 participants, only 52 presented any views (72% of the convenience sample of 72 participants). Most (82%) of the convenience sample of 72 had a diagnosis of schizophrenia. Data was collected using an initial pilot study with 12 participants, using a structured schedule and open-ended questions, and later unstructured interviews and was analysed using thematic content analysis.

The emerging themes were four levels of self-determination. The first level was intrapersonal aspects of self-determination. In the first level, intrapersonal self-determination, self-determination meant deciding for themselves, taking care of themselves, having freedom and the power to refuse. The theme of human agency is apparent in this finding. Interpersonal aspects of self-determination were described. Within this the second level was shared self-determination, which meant sharing self-determination with nurses, and being valued by nurses. The third level was limited self-determination, which meant that the client had limited rights, especially if the client was unwell. The fourth level was no self-determination, which meant that clients were coerced. Clients' movements between these levels depended on how ill they were, nursing staff actions and where the client was receiving treatment and the specific environment.

Many of this small sample of participants reported that they had autonomy and self-determination, but also included the right to interact with nurses, implying some partnership. They perceived that nurses had an advocacy role, which supported client self-determination, and a degree of dependency should not be perceived as a reason to avoid helping a client work towards self-determination. Client-nurse dialogue and interaction were part of the client's journey towards self-determination. Valimaki was not certain about the influence of the mental health problem on the participants' ability to think. These participants had their own views and understandings on self-determination and this study concluded that there are opportunities within mental health nursing to support the goal of self-determination in their clients (Valimaki 1998). It may be that a client's mental health problem compromises their ability to achieve full self-determination, but all clients have the right to work towards this goal with the support of mental health nurses.

This study had flaws. Sample bias was possible for several reasons. The drop out rate was high. Some participants were excluded as a result of the researcher's evaluation of their mental state. The researcher's subjectivity cannot be excluded in this decision, which was made on an evaluation of severity of symptoms. She believed their responses were odd. Therefore the sample may have been unrepresentative. Of the 52 final participants who offered their views, some had never heard of the concept of self-determination before, a situation which may have weakened validity. If the term has many different meaning to different participants, how can we be sure they are discussing the same idea? Reliability is likely to be weak because of the sample problems.

Barker (1999) believes that there is no real partnership because if the service user disagrees with the health professionals, the service user loses the right to choose what will happen to him/her. Barker (1999) believes that alliance is a shared understanding in decisions about care. Alliance might be a better concept because it involves groups who have different agendas and different positions of power and who can work together to achieve an agreed goal. An alliance between service users and nurses can only occur after roles have been negotiated and clarified. Barker believes that within nursing there is the potential for supporting service users to achieve decision making in life. Despite being influenced by organizational needs, nurses can adopt the advocacy role and support the needs of service users. He raises two important issues. Firstly, nurses have to negotiate between organizational needs and service user needs and secondly, nursing philosophies may be different from those of other disciplines, and while this may lead to conflict, it may also lead to an improved service for service users. Diversity can make a team stronger (Barker 1999). However Barker (1999) offers no empirical evidence.

Jones and Tallis (1994), Cutcliffe (1997) and Hickey and Kipping (1998) draw the conclusion that it may be that self-determination is a more appropriate goal for service users. McCann (2004) examined the concept of self-determination, and Valimaki (1998) explored the levels of self-determination that service users could achieve and concluded that not all service users can achieve full self-determination. Barker (1999) explored the concept of alliance, which acknowledges the power imbalance in the health professional-service user relationship. It could be argued that a person under the influence of a severe mental health problem has limited self-determination, because their inner experiences are controlling or constraining them and they are not free to choose their own actions. It may be that some initial external control and active treatment are necessary to help a person with a severe mental health problem achieve self-determination.

2.5 Potential barriers to partnership

I will now discuss potential barriers to partnership. The views of Hickey and Kipping (1998), Barker and Davidson (1998), Barker (1999), Tomson (2002), Keyzer (1988), Rodwell (1996), Campbell and Lindow (1997), Nocon and Qureshi (1996) and Rose (1994, 1999) are offered here. Empirical research by Beresford and Branfield (2006) supported these authors in their view that there are potential barriers to partnership.

Hickey and Kipping (1998) highlight several factors that lead to constraints in partnership.

- Firstly, some service users do not want to take part in decision-making. A similar idea is proposed by Barker and Davidson (1998), who suggest that some

people with mental health problems do not want any responsibility for themselves, or for their treatment or recovery.

- Secondly, organizational culture is a barrier. Staff at all levels of an organization may not be committed to user involvement in decision making. The organization may have insufficient staff and staff cannot involve users if they have no time. User involvement may not be accepted as a core value. Health professionals may be disempowered and so cannot empower service users, a point also made by other authors (Keyzer 1988, Rodwell 1996. Campbell and Lindow 1997, Morrall 1998a). Health professionals may not feel valued and may fear criticism, with the result that they may not speak up on behalf of service users. Financial resources may not be available to provide services for service users (Hickey and Kipping 1998). It may be that organizational culture restricts choice by stating what areas of care delivery service users will have choice in, a point made by Nocon and Qureshi (1996) (see section 2.6.2). This aspect of organizational culture is closely related to professional culture.
- Thirdly, lack of commitment of health professionals may prevent empowerment of service users by preventing allocation of resources. Allocation of resources is a prerequisite for empowerment of users.
- Fourthly, they highlight the issue of low staffing levels. This means that staff cannot spend time with users, and therefore cannot empower them.
- Fifthly, professional culture, in which expert power exists, contrary to what Tomson (2002) asserts, and in which there is a focus on illness, prevents partnership. The assumption is that clients cannot hold a valid opinion. Within this professional culture, professionals create dependence on them, which prevents service users from dealing with their own health problems.

- Sixthly, professional socialisation may lead to professionals holding assumptions about service users' inability to hold a valid opinion, and this may lead to nurses restricting partnership.
- Seventhly, wider society also determines attitudes to people with mental health problems. Negative stereotypes (e.g. sad, incoherent, pathetic people), lack of understanding and fear of this group, exist in society. These factors create a wish to control people with mental health problems and this control inhibits their involvement in decision making and partnership.

Beresford and Branfield (2006) conducted a case study, and used a series of focus groups involving an unspecified number of service users with the goal of seeking their views on the concept of quality outcomes and on outcomes in their lives. (For discussion of focus groups, see Bertram and Stickley (2005) in section 2.6.2). This was a national three year project undertaken by the '*Shaping Our Lives*' organization, a national user controlled organization, in which service users of all kinds are involved and focus on common factors. Three main themes emerged: inequality of power, status and resources. These authors concluded that there were barriers to service user networking at individual and collective levels. At the individual level there were mobility problems and the effort of active involvement. At the collective level the barriers were reported as: lack of funding, inequality with bigger organizations and charities, dependence on a few committed activists, few local user-controlled organizations, and under provision for ethnic minority group involvement. Health professional factors also emerged in these findings. Health professionals engaged in tokenism and did not permit service users to engage as equals. Service providers did not permit easy access by service users with different access needs (e.g. ramps) and therefore service users could not contribute as equals. Health and social care

organizations did not accept service user knowledge. There was a concern that if the service users' views diverged from those of the service provider, funding could be withdrawn.

There was a need to challenge the barriers which marginalised service users' knowledge. More commitment to change and focus on diversity and service user networking and knowledge development was perceived as necessary. More effective partnership could be achieved by not marginalising service users and by enabling service user engagement on equal terms with health professionals.

Therefore, in conclusion, lack of partnership may be the result of behaviours by service users or health professionals or the impact of social values. However the weight of the evidence in this brief literature review suggests that the health professionals may make major contributions to barriers to partnership formation between service users and health professionals. Rose (1994, 1999) holds the position that there is partnership and maintains that people who receive health care accept the health care and expertise of health professionals and comply and collude with the knowledge and practices of health professionals. Individuals accept Governmentality, social norms and the goal of good health. Their views and expectations are shaped by social processes, but within this shaping there is no coercion and there is partnership because individuals willingly self-transform (see Chapter One for a more detailed discussion).

2.6 Empowerment

This section addresses the views of service user authors on disempowerment and on factors involved in becoming empowered. It goes on to consider the existence of service user empowerment according to health professional authors who report service

users views. The United Kingdom Code of Conduct (UKCC) (1996) and Nursing and Midwifery Council (NMC) (2002) make it clear that mental health nurses must promote clients' autonomy, independence and empowerment. Many user authors however, maintain that there is no user empowerment.

2.6.1 The views of user authors: lack of empowerment

Views expressed by MIND (National Association for Mental Health) (1992) are discussed here. MIND (1992), in a report on stress in women, which presents no empirical research evidence, asserts that part of disempowerment is lack of choice (e.g. lack of choice in treatments or about how their day will be planned in hospital).

Campbell (1997) writes of his own experience. He asserts that there is little power sharing or empowerment and that this is intentional. In a similar work with Lindow, Campbell offers an explanation for this lack of user empowerment. Campbell and Lindow (1997) offer three points of view: firstly, nurses do not want to empower service users; secondly, nurses are disempowered and cannot empower service users; and thirdly, service users are reluctant to be involved and involvement is a necessary prerequisite for empowerment. They propose that empowerment means a wish to assist people in controlling their own lives. They contend that society continues to view all people with mental health problems as unable to make a rational choice or informed decisions. They maintain that commitment to supporting users' decisions is judged to be risky by health professionals. In their view, society perceives the role of mental health services to be that of maintaining public safety, and so containing the mentally ill is an action which denies choice and reduces the influence of service users and partnership. They suggest a range of ways in which nurses can empower service users,

(e.g. involve them at all levels of planning, give full information). These authors raise the issue of trying to empower a client in a “situation of compulsion” (e.g. if the client is on a Mental Health Act 1983 section) (Campbell and Lindow 1997 p. 11). A desirable goal is to reduce the effects of compulsion by focusing on informed consent, not using threats, and by acknowledging that the nurses’ role has limitations.

Coleman (1997), a user author who expresses his own views, asserts that there is a power imbalance and that users like him are disempowered. He maintains that once a person is in the mental health system, it is difficult for them to reclaim personal power. He believes that interventions in hospital prevent recovery because they prevent the development of good self esteem, self confidence and self acceptance. Coleman (1999) in a further similar work, asserts that reclaiming power by the individual is a prerequisite to recovery. In this work, he is critical of the concept of empowerment as used by health professionals, asserting that only the language has changed, and that the empowering approach has failed. He asserts that the empowering approach is merely part of the political correctness of the mental health system. The failure of empowerment to become a reality for users is because the nature of power has not been understood. He believes that power cannot be given, but that it can only be taken, and users of mental health services must reclaim power, while mental health professionals must give up their power.

Coleman and Smith (2005), who express their own views, assert that voice hearers should retain control of practitioners’ practices and their own voice hearing experiences. In this work they offer voice hearers advice on a range of actions that are intended to help them reclaim their lives. In their view, it is necessary for voice hearers to have control over their voices. In this way voice hearers can cease to be victims and

empower themselves. Their position is that voice hearers must redefine themselves as well people who have unusual experiences. This involves focusing on and analysing the voices and analysing the power of and relationship with the voices. There is emphasis on the importance of having a support network, organising their experiences, developing an action plan and setting goals. Voice hearers must choose to do this for themselves and empower themselves.

2.6.2 Factors involved in becoming empowered: user authors and health professional authors

In this section I will examine factors which appear to be essential for empowerment. Houghton (1982), a user author, discusses control of one's life and self managed care, which involves being freed from medication, creating one's own routine, self discipline, living at a slower pace, and in a calm atmosphere. It involves creating a new life for oneself and providing one's own structure for everyday living. Houghton states the importance of setting achievable, reasonable goals and achieving them. He highlights the harm created by goals and deadlines imposed by others and by stressful routines.

Beale and Lambric (1995), health professional authors, link personal empowerment to the concept of recovery and assert that those who achieve personal empowerment make a better recovery.

Ralph and Lambert (1996), health professional authors, discuss empowerment and highlight the combination of internal and external factors involved in empowerment. They highlight the internal strengths which must be combined with interconnectedness

with others to provide the self-help, advocacy and caring about what happens to oneself and others. Moreover they assert that empowerment comes with self-managed care.

Williams and Collins (1999) used grounded theory and a semi-structured life history interview involving 15 participants who were service users with a diagnosis of schizophrenia. Thematic analysis was carried out and data was coded. The research aim was to explore how these service users defined themselves in relation to their illness. The main finding was that service users valued self-empowerment. Self-empowerment involves redefining illness, regaining self-efficacy, pursuing personal goals, acknowledging the discrepancies between the ideal and real self, acknowledging the differences between self and illness, coping with relapse and being connected to an accepting social group. In this way, they maintained personal power, had a positive self image, social connections and support. These authors concluded that nursing needs to change to a focus on hope and recovery, and promote service users' active roles in their own recovery. These service users reported that they could empower themselves, and that nurses could work with them to achieve this goal. However sample bias may have existed as most participants were men (13 men and 2 women) and this may have weakened reliability, but there were two researchers, which may have strengthened reliability.

Some authors believe that certain factors are involved in becoming empowered. Nocon and Qureshi (1996), who report their own views, believe that empowerment is linked to the consumerist approach, although within consumerism there may be a wide range of practices, from the customer relations model, in which the goal is to give the customer what they want, to the citizen-consumer model, in which the service user takes part in policy making. They contend that service users can define and decide outcomes of care.

They highlight the discrepancy between two sets of concepts and potential consequences. Firstly, there is the historical perception of service users as unfortunate victims, and this may lead to health professionals devaluing service users and their ability to participate in decision making and defining health and care outcomes. Secondly, the most recent set of concepts being applied to service users, specifically enablement, empowerment and self-determination, may lead to health professionals believing that their expertise and power are under threat. Health professionals may not perceive service users as citizen-consumers. Empowerment involves choice, but even if choice is offered, there may be disagreement about what service users should have choice in (e.g. choice of staff, choice of decor), the implication being that choice of staff may be more empowering. Throughout this work, these authors emphasise that empowerment involves choice, and personal control of one's own life and care. In their "ladder of empowerment", they link full autonomy to empowerment and state that service users have the authority to make decisions (Nocon and Qureshi 1996 p. 50). This is the highest level of empowerment and would be genuine empowerment.

They propose that exit empowerment is real empowerment. Exit empowerment is the power to leave the current services because of dissatisfaction and access alternative services. Exit empowerment is a feature of the democratic or market approach in which people are consumers and can influence services. However exit empowerment may not be realistic as there may be no alternative services. Within the democratic approach, service users have voice empowerment, which means the power to influence a service provider (Nocon and Qureshi 1996).

Hickey and Kipping (1998) support the views of Nocon and Qureshi (1996) in their discussion of the theme of empowerment. They connect the Democratization approach

to the concept of citizenship. A citizen decides what services will be comprised of, while a consumer accepts existing ideology and evaluates the service. A citizen has more active agency than a consumer. In their “participation continuum”, while consumerism empowers people, it fails to facilitate partnership, user control of services or give decision-making power to service users (Hickey and Kipping 1998 p. 85).

Rodwell (1996) maintains that people with schizophrenia must be in an empowering situation to be empowered. According to Rodwell (1996 p. 306) empowerment means “to invest legally or formally with power, to authorize, to impart power, to enable”. Rodwell (1996 p.306) favours the terms “enabling” and “imparting power to others”, and empowerment being the result of empowering. Empowerment and control are dichotomies which exist in the delivery of health care. Empowerment could be perceived as part of caring and the service user is a consumer of care. Control could also be perceived as part of caring, an idea which Benner (1994) supports when she discusses the need for monitoring and prevention of harm. Rodwell (1996) believes that there is a dilemma in giving up professional power, and enabling and empowering service users. A service user may be legally judged to be in need of care and control and mental health professionals are not permitted to abdicate responsibility for this care and control if the service user is sectioned under the Mental Health Act (DoH and Welsh Office 1983). Enabling within empowerment relates to enabling service users to identify and acknowledge strengths, abilities and personal power, and enabling leads to power sharing.

Rodwell (1996) maintains that empowerment may be a process and a product. If empowerment is a process it involves providing service users with chances and resources they need to change their situation or world. If it is a product, this product

could be used to develop capacity and authority to take charge of one's own life and an "energizing experience that mobilizes resources and enables change in creative ways" (Rodwell 1996 p.308). An empowered person has direction in life. Rodwell contends that empowerment leads to positive self-esteem in those who are empowered. This author also believes that for empowerment to exist power must be transferred to service users and this does not occur. A reason for this is that nurses are disempowered and as a consequence nurses, as a professional group, lack positive self-esteem, self-worth and fail to recognise the worth of service users. Rodwell (1996) agrees with Keyzer (1988), Morrall (1998a) and Campbell and Lindow (1998) on the issue of disempowered nurses.

Barker (1999) discusses empowerment and believes that when we try to achieve empowerment we mean enablement. According to this author, enablement means "providing conditions under which the person is able to do (freely) something that they previously appeared unable or unwilling to do" (Barker 1999 p. 111). Enablement is a developmental nursing activity. However if we mean that by empowerment, we allow a person to do something, key questions are: why were they not allowed to do it before and who prevented them from doing something? Barker's (1999) position is that within professionalism, health professionals disempower clients.

Morrall (1998b) who presents his own views, maintains that there is a discrepancy between the reality and rhetoric of empowerment for service users and there is no empowerment. In the rhetoric, service users are no longer passive customers but are active consumers, but he maintains that there is only token empowerment of and participation in decision making by consumers. This author suggests that it is not in health professionals' interests to give up power. Empowering situations are not created or offered to service users, a view also maintained by Rodwell (1996). Social conditions

(e.g. poverty and homelessness) also continue to disempower service users, and because these situations cannot be altered by the service user, empowerment is not possible, even if it is offered. Mental health services create inequality because they control treatment options and availability, and some treatments (e.g. psychotherapy) promote the assumption that the individual service users should take responsibility for their situation, whilst, in reality, some service users cannot do this.

Moorey (1998), who presents his own views, discusses power and professionalism. With professionalism comes expert status which involves knowledge and skills, a situation which creates inequality between client and health professional and dependency in service users. Moorey (1998 pp. 46-47) discusses the “diagnostic relationship”, in which the health professional identifies the problem, its cause and delivers the solution to the client. This relationship makes the health professional’s power legitimate and disempowers the service user.

Bertram and Stickley (2005) conducted a study which discussed mental health services and the roles of nurses. The aim of this study was to examine staff attitudes toward social inclusion. One objective was to explore mental health professionals’ views on how service users may view services and staff, with specific focus on attitudes and practices which prevent social inclusion. Data collection was by two semi-structured focus groups (5 people in each group) and the researcher moderated each group. A predevised aide-memoire was used, with open-ended prompts. The purposive sample was 10 nursing staff (5 qualified and 5 unqualified). Data analysis was by open coding then axial coding, in which an independent colleague analysed the data, created sub categories and discussed these with the original researcher, and the final subcategory list was refined. The last type of coding was selective coding.

The main finding was that staff attitudes prevent practices to promote empowerment and social inclusion. The care or control dilemma was apparent with the service user's right to autonomy being sacrificed to promote public safety, control, and surveillance by mental health nurses. Exploration of choice and involvement of service users in decision-making were not encouraged by these participants because they believed that conformity was important and they perceived service users to be incapable. They acknowledged that they contained the mentally ill.

Professional barriers to empowerment and social inclusion were highlighted; for example, these health professionals believed that they had a professional responsibility for their client group, which was interpreted by Bertam and Stickley (2005) as paternalism, although this may be their own subjective view. An alternative interpretation, for example, might have been taking one's duty of care seriously. However, it may be that nurses' attitudes and practices disempower service users.

Focus groups were effective because the researcher did not miss subtle information which may be missed in interviews or in observation. There was a focus on a theme which the participants thought was important and the researcher could probe. Participants were perceived as experts and so were likely to feel valued. However they were assumed to be experts on the views of other service users, which they may not have known. Other potential weaknesses were that the researcher may not have gained access to minority views, because it may have been suppressed by more dominant participants and because of group conformity, which often occurs in focus groups. Inarticulate individuals may not have participated fully. The research objective was context specific, so the researcher could not assume that participants fully understood

the phenomena (service users' view on staff practices and attitudes, with emphasis on social inclusion) in a wider sense.

The researcher claimed to be a non-participant observer, but had previously been involved with this team and was also the moderator of these focus groups and had an insider role. Thus, there may have been researcher influence. The researcher believed that she was "metaphorically invisible" (Bertram and Stickley 2005 p. 393) and there were no researcher influences on the participant's responses, but it could be argued that the researcher could not be sure of this. This was small scale study and the findings may not be generalizable.

2.6.3 Empowerment: User views reported by health professional authors

In this section I will explore service users' views on empowerment, as reported by health professional authors. Chadwick (1997) is a health professional author who is also an ex-user of mental health services. He reported user views and asserted that mental health services were disempowering. This was an ethnographic study involving 33 case studies and conversations over 10 years with 33 people with a diagnosis of schizophrenia. The cognitive structures of the sample population was explored. He questioned the validity of evidence based psychiatry. This was a convenience sample and reliability may have been weak, although it was a longitudinal study, therefore reliability may have been strengthened. The views of this small population could not be considered representative of all people with schizophrenia and replicability could not be guaranteed, but this study dealt with themes in depth and the views expressed were supported by other authors. A potential weakness was researcher bias and Chadwick's own views may have been imposed on this work. There was no opportunity to collect

expansive data and place it in a background context. Chadwick (1997) asserted that people with schizophrenia feel marginalized. He highlighted the trend of psychosis being perceived as an attractive state by these respondents and asserted that by adopting this positive view of psychosis, people with schizophrenia could escape negative feelings and achieve the feeling of power.

Patel and Fatimilehin (1999) report user views which were supported by research carried out by Rogers et al (1997). Patel and Fatimilehin (1999) assert that people did not feel empowered by mental health services. The mental health system is eurocentric and ethnic minority clients are placed at the bottom of a hierarchy. Western models of health and treatment are imposed on ethnic minority service users and this is inappropriate. There is a focus on deficit models of health and clients' deficiencies, which are perceived to be predetermined, related to ethnicity, and explain a service user's mental health problem. Oppressive practices lead to a feeling of disempowerment: fear of being compulsorily detained, higher medication levels than white service users, and there is no clear communication between service users and providers.

They maintain that self esteem, self efficacy and self control are necessary factors of empowerment. A collaborative approach and partnership are also necessary. According to these authors, the collaborative approach must be led by client needs, as defined by clients. Empowerment involves clients making choices about services, which meet their needs (Patel and Fatimilehin 1999).

In the Rogers et al (1997) study, a consumer constructed scale was used to measure empowerment among users of mental health services. Empowerment was positively

related to quality of life and inversely related to using mental health services (Rogers et al 1997).

Barker (1999) provides a collection of papers and an overview of mental health nursing. He asserts that for patients there is only powerlessness and inequality, and that nurses do not empower people. All therapy is intrusion, in his opinion, and people change when they are ready to change and they decide how and when. He asserts that the real power people with schizophrenia have is the power of individual action, decision-making and the power to refuse. When they do not change, this is their choice, but mental health nurses interpret their choice as a sign of illness.

In his view, current care infantilizes people and creates dependency. Nurses use the power they have to return a client to a life they had, even if this life was a source of distress, and this life fits into a set of social norms accepted by nurses. Nurses do not challenge the social norms and instead focus on illness and maintain the client in a disempowered state. Nurses deliver care to clients, and do not work with clients. Their relationship is characterised by inequality, with the nurse being the expert and the client being subordinate. In this situation collaboration may be discussed, but compliance is what is really happening. There is no empowerment because of the inequality and because the client's participation is being controlled by the nurse. Diagnosing illness and offering solutions does not empower clients. He asserts that nurses should promote wellness, and this means working with clients, joint decision-making and helping them to work towards their own development. However it may be the case that some clients do not want to engage in this type of work or want to take responsibility for their own health. Other authors raise this issue (Campbell and Lindow 1997, Hickey and Kipping 1998, Barker and Davidson 1998).

Barker raises the issue of nurses valuing and empowering clients and asks why nurses have to create value and empowerment in the interactions because clients come with their own value and power (Barker 1999).

Ryan (1999), a health professional author who reports user views, emphasises lack of choice and empowerment, with the only real choice permitted to users being whether they accept or reject treatment. He is therefore in agreement with Barker (1999). Ryan (1999) asserts that choice is overridden in the name of risk management, a similar point to that made earlier by Campbell and Lindow (1997).

2.7 Empowerment exists

In this section I will explore literature and research which adopts the position that service user empowerment occurs. Some health professional authors maintain that mental health nurses do empower users. Benner (1984) asserts that nurses have autonomy and empower people and Rogers et al (1993), in an overview of mental health nursing, highlight positive views expressed by users who reported that they felt empowered and were treated as equals.

Pieranunzi (1997), in a phenomenological study involving semi-structured interviews with ten nurses, offered a view of caring from the nurses' point of view. This method achieved an understanding of the experience of the nurses. According to this author, these nurses believed that power was dynamic, both nurses and patients had power, and power was created by people in the care situation. There was power in the therapeutic use of self and in the mutuality which was created. Power was linked to knowing, and

expert nurses believed they knew that connecting to people led to satisfaction for both nurses and patients. There was an emphasis in this study on nurses knowing reality.

This work did not acknowledge different ideas of reality which depend on different personal situations. Interpretation was stressed in this study, and the findings were the interpretations of these ten nurses, and were not generalisable because of the small sample. This method was empirical, detailed, individualistic, subjective, anti-inferential and atheoretical. There may have been lack of control and one could not rule out alternative explanations for the findings.

Pitt and Kilbride (2006), in a phenomenological study which used unstructured interviews, explored service users' perspective on recovery from psychosis. The sample was seven service users, (5 men and 2 women). Phenomenological analysis, specifically thematic analysis, was completed and the insider perspective was gained. The main finding was that empowerment was reported. Recovery is a process in which empowerment is a necessary first step and these participants reported that mental health nurses had empowered them in their journey to recovery. Empowerment contributes to the rebuilding of the self, taking control, rebuilding self-esteem and connecting with other service users. Rebuilding the self and empowerment were perceived to be precursors to the following: rebuilding their lives, which involves active participation in life and rebuilding social support, and developing hope for a better future, which includes social inclusion. Good practice (e.g. listening and acceptance) by mental health nurses was reported by these service users.

2.8 Disempowered nurses

I will now explore one potential reason for disempowerment of service users, that of nurses being disempowered and therefore being unable to empower others. Disempowerment of nurses may contribute to disempowerment of service users. However there is no empirical research to support this view. Freire (1970), an educationalist who focuses on oppressed groups in different social situations, discusses oppressed, disempowered groups. His views may be relevant to the situation of people with schizophrenia and mental health nurses. He proposes that people internalise their oppressors' values and working patterns (Freire 1970). It may be the case that nurses have internalised the previous oppressive working methods of psychiatry. Defining service users' views as invalid, and promoting the assumptions that nurses have expert knowledge and service users do not have expert knowledge may occur in nursing, leading to disempowerment for the service user, with nurses being perceived as an oppressor group by service users. It may be that nurses, however, have their own oppressor group and have been disempowered by medicine.

Keyzer's (1988) work is an analysis of the roles of nurses and the factors which have shaped these roles. This author maintains that nurses are disempowered by medicine. He disagrees with the views of Benner (1984), asserting that team membership, specifically membership of teams with clear role boundaries, limits nurses' autonomy and professional power and disempowers nurses (Keyzer 1988).

Pontin and Webb (1995) assert that nurses themselves must be empowered to facilitate an approach which allows patients to be empowered, and that nurse empowerment does not occur. Rodwell (1996) believes that for empowerment to exist, power must be transferred to the service user, and that nurses are disempowered. The consequence of

this is that nursing as a profession, lacks self-esteem, self-worth and does not recognise the worth of service users, and therefore cannot empower service users.

Campbell and Lindow (1997), user authors, support the view that nurses are disempowered. These authors acknowledge that it is difficult to encourage people to take power if one is not certain of one's own role and value. Nurses say that they are powerless and express uncertainty about their senior managers' commitment to user involvement. Moreover, nurses appear to worry about lack of support from colleagues, or opposition from colleagues if they try to initiate change.

Morrall (1998a) agreed with Keyzer (1988) in asserting that nurses are disempowered because of the power of medicine. Morrall (1998a) concluded that nursing is a mediated profession, which means medicine has traditionally controlled the knowledge base and roles of nurses, and access to clients is controlled by doctors. The level of nursing autonomy is influenced by medicine, and medicine facilitates the power and roles of nurses. The extended role of the nurse is only possible with the permission of medicine. As a mediated profession, nursing does not define its work processes or outcomes and is therefore not professionally autonomous in the same way as medicine. Therefore for Morrall (1998a), nurses are not in a position to empower patients because they have limited power themselves.

Moran (1992), a user author, offers no empirical evidence, but expresses the view that nurses are disempowered, a situation which leads to client disempowerment. He proposes that nurses have unsupportive managers, a situation which keeps nurses disempowered.

Ryles (1999), in a literature review which analyses the concept of empowerment and tries to explain why nurses fail to empower service users, maintains that nurses are disempowered and are in a similar position to those deemed to be mentally ill. For nurses to empower others, they need to give up power, and a prerequisite to this is a desire to compromise and co-operate. Collective support and action are needed to facilitate compromise and co-operation and these are not present. It is left to individuals to decide to give up power, compromise and co-operate. Influences are present which prevent individual nurses from doing this (e.g. beliefs, values and professional socialization). Nurses learn that participation with service users involves controlling them. They are trapped in a system of disciplinary power, a Foucauldian concept, in which career development is hierarchical and competitive. They are subject to a gaze in the same way as a mental health service user. Discourse defines nurses and they are not permitted to leave the category into which they have been placed by others (e.g. caring, self-sacrificing). Nurses do not control their own discourse. They have not been able to challenge the status quo and their knowledge is subjugated knowledge. Nurses are low in the hierarchy and are marginalised.

Simultaneously nurses are engaged in professional territorial expansion and are trying to empower themselves by adopting the same practices as medicine, which this author believes is the disciplinary elite group in the health services. Ryles (1999) does not state specifically which practices nurses adopt. He is discussing a theme similar to that discussed by Keyzer (1998) and Freire (1970), - the adoption of similar practice to medicine to empower themselves and the nursing profession, and, in doing so, disempowering service users. Nurses attempt to persuade service users that the empowerment of nurses will benefit service users. They are an oppressed group, in the same way as service users are. Nurses should recognise and acknowledge this and create

a partnership with service users, with the goal of empowering them. Collective active is needed in nursing to achieve this and to challenge the current structure and hierarchy in the mental health system. First nurses must understand how power works in organizations, according to Ryles (1999).

Moore and McCulloch (1999), health professionals who present their own views, agree with Campbell and Lindow (1997) and Moran (1992), and assert that nurses do not have the structure, freedom, autonomy or support from their managers to engage in empowerment. Ryles (1999) maintains that nurses are disempowered and there is empirical evidence from Morrall (1998a) to support this position.

2.9 Nurses could empower people

I will now explore the position that nurses could empower people, if they chose to. Barker (1999) offers a new focus of nursing which would allow nurses to empower people. He asserts that the client could be helped to gain a new perspective on health, illness, disability and to develop an awareness of their own power and abilities. According to this author, this would be the proper focus of nursing and it reflects both Peplau's (1994) and Gournay's (1995) views of nursing and what it should be (Peplau 1994, Gournay 1995, Barker 1999). According to Barker (1999), nurses could provide the necessary conditions for promotion of growth and development, and facilitate empowerment. However there is no research evidence for these views of nursing. In conclusion, these authors maintain that nurses could empower service users if they chose to, and, if nursing focused on service user empowerment, growth and development of service users may be promoted.

2.10 Negotiated power

I will now explore literature which suggests that negotiated power between service users and health professionals is possible. Hugman (1991) and Johnson (1997) propose that people can negotiate power. It may be that people with schizophrenia can negotiate power in the same way as health professionals. These authors maintain that power is socially structured. There are social agendas and issues, and conflicts exist between service users and health professionals. Resistance is possible because service users can refuse to comply with treatment. However most service users do comply because facilitation of care and treatment is perceived as part of health professionals' normal role. In their relationship with service users, health professionals may not accept that they exercise power. It may be that no overt power is needed because of their authority which is "a form of influence which can be exercised outside of power relations", which is accepted by the service user (Hugman 1991 p. 34). Within authority there is a genuine consensus of interests, but there may be unequal power relations in communication between service users and health professionals (e.g. when a health professional asks a service user to comply with treatment). The health professional's goal is a professional or clinical goal, not equality within the relationship. The service user's interests may be supported but the health professional's interests are dominant and dominance is achieved through communication which is dominated and controlled by the health professional. Despite this Hugman (1991) believes that service users have the power to challenge professional power by not complying, and self help groups help service users to negotiate power with health professionals.

Johnson (1997) is in agreement with Hugman (1991) and maintains that people can negotiate power. If "living power" exists and power is socially constructed by the

social judgement of people, as Johnson (1997 p.180) asserts, the work of user organisations could socially reconstruct and negotiate power through communication and dialogue with health professionals. He asserts that people construct power through dialogue and social relations. Power is not the same concept as force. When people agree on a goal, power is being exercised through language. One process in “living power” is client negotiation for a service to meet a need, while the health professional gains prestige and acknowledgment of expertise (Johnson 1997 p.180). Occupational authority is negotiated and is derived from the social judgments of other people.

Service users use strategies to gain power in the care situation – specifically, negotiation and non-compliance. Service users negotiate care and treatment in a socially acceptable manner (e.g. not being continually disruptive and not becoming unpopular). Negotiating is perceived as an acceptable way of exercising power and maintaining some control over one’s care. Non-compliance, which can disempower the health professional by ignoring their professional goals, followed by negotiation, is a frequent strategy used by service users. However, Johnson (1997) acknowledges that the service user is in a weaker position than the health professional because the service user has less negotiating or bargaining power.

Rose (1994, 1999) asserts that individuals engage in self-transformation, under medical expertise, and they accept the medical goals and social norms of health. Individuals and their conduct are shaped through Governmentality and social processes and there is no coercion involved (see Chapter One, section 1.4.7). Rose (1999) maintains that individuals engage in techniques of the self, specifically, self-scrutiny, self-formation and self-management. People are citizens with active agency, and government and its workers enable, and do not coerce. An individual’s subjective experiences are shaped

but not coerced and an individual is free to choose an attitude to health. Individuals create and shape authorities, which in turn shape power and people. The relationship between the psychotherapeutic approaches and political power creates the autonomous self, who is free to choose, and is likely to self-scrutinize and self-control. Psychotherapy helps individuals achieve this and be free active citizens (Rose 1999).

An implication of service users' faith in professional expertise is that they may not try to empower themselves because they believe that health professionals know best. Self belief and the internal locus of control are prerequisites for empowerment. Service users may lack self belief and accept the external locus of control.

2.11 Discussion of themes

Some authors believe that nurses can be change agents (Peplau 1994, Barker and Jackson 1997), and so empower service users, and there is some empirical evidence to support this (Williams and Collins 1999). Other authors maintain that nurses are disempowered and cannot empower service users (Keyzer 1988, Rodwell 1996, Campbell and Lindow 1997, Morrall 1998a, Moran 1992, Ryles 1999, Moore and McCulloch 1999). The structures and systems in which nurses work disempower them. It also may be due to a lack of confidence, because nurses have been oppressed by medicine, according to Rodwell (1996). They may feel a collective lack of self-worth and self-esteem, which prevents them from seeing the worth of service users. It may be the case that nurses have no control over the situation in which they work, and that nurses are made to compel service users to comply with treatment, an issue raised by Campbell and Lindow (1997). Historically nursing has been a mediated profession and access to clients and nursing roles and boundaries have been controlled by medicine

(Keyzer 1988), and nurses have no or limited professional autonomy (Morrall 1998a). The training of nurses may lead to their disempowerment. Devane et al (1998) concluded that the nurse participants had received their professional training in hierarchical settings, and nurses are low in the hierarchy, and nurses did not develop the skills needed to negotiate or collaborate. It may be that nurses' roles are defined by others (Keyzer 1988) and that the surveillance role is emphasised (Bracken and Thomas 1999, Morrall 1998a). Practical factors may disempower nurses (e.g. low staffing levels) and may prevent nurses from engaging in therapeutic work with service users. The desire to empower service users may be stifled because of fear of criticism, or a perception or a reality of lack of support from other nurses, other colleagues and managers, for this goal (Hickey and Kipping 1998). Keyzer (1988) and Freire (1970) discuss the professional territorial expansion of nurses, which seems to imply that they have some power. Nurses copy the oppressive practices of medicine, their oppressor group. It may be that nurses who engage in territorial expansion understand the nature of power in organizations and achieve empowerment for themselves. In theory, they could be empowered to become change agents and empower service users, but the overwhelming evidence is that they do not, and power sharing appears to be incongruent with territorial expansion.

Rodwell (1996) uses the term enablement, which involves helping service users to identify their strengths, abilities and personal power and he perceives enablement to be part of empowerment. Enablement is a developmental activity (Barker 1999). Nurses could choose to create situations for service users, in which service users could engage in new activities and learn new skills. It may be that health professionals do not choose to provide such opportunities or are not permitted to because of the emphasis on overcautious risk management, or fear of service users not coping or coming to harm.

With developmental activities, one can never be sure of the outcome. The health professional and the service user may have different intended outcomes. It may be the case that the limited power base of the nursing profession creates a reluctance to give up any power.

The power to diagnose a problem, to identify its cause and to offer solutions may empower the health professional and disempower the service user. Power which is associated with knowledge and expertise, which Foucault (1980) terms Power/knowledge does not involve enabling service users. Service users may be shaped to expect such a relationship with health professionals and therefore do not question it. Rose (1999) believes that health professionals offer an enabling relationship, even though service users are influenced to accept professional knowledge and expertise.

Some service users may not want to be enabled or empowered and are content to be a patient, receiving care and treatment. This may occur through a process of culturalization where the service user adopts the patient role, which is essentially a passive role, and service users may have no interest in being a citizen-consumer of mental health services (Campbell and Lindow 1997, Hickey and Kipping 1998, Barker 1999, Barker and Davidson 1998).

The issue of empowerment or self-empowerment is important. Some authors hold the position that empowerment of service users occurs and involves the following factors: power sharing between service users and health professionals, full involvement in care decisions, equality of service users and choice of services, although it could be argued that choice in one area (e.g. of key worker) is more important than choice in another (e.g. meal times) and service providers may control how much choice is offered.

Empowerment involves being a citizen-consumer, and deciding and defining care outcomes and exercising human agency (Nocon and Qureshi 1996). If empowerment is a process (Rodwell 1996), it offers service users opportunities and resources to change their situation, but some service users may be reluctant to use these opportunities and resources because it involves taking some control over one's own life situation. If empowerment is a product, the end product is a service user who has taken charge of and has direction in life, but this requires human agency as well as the developmental practices of nurses (Barker 1999). Self-empowerment is better than empowerment but involves the service user choosing to work towards their own recovery and redefining themselves and their experiences (Coleman 1997 and Coleman and Smith 2005, Williams and Collins 1999). Service users who perceive themselves as victims cannot empower themselves.

Some authors believe that the citizen-consumer model would help service users achieve empowerment and partnership but there is an interesting discussion about what the terms consumer and citizen-consumer mean. Nocon and Qureshi (1996) discuss service users as citizen-consumers, while Hickey and Kipping (1998) discuss citizens, a different role from that of consumers. If service users are perceived as consumers of mental health care, this implies that there is choice and partnership, because consumers make choices. Nocon and Qureshi (1996) assert that empowerment is linked to the consumerist approach, and consumerism includes both the customer relations model and the citizen -consumer model. In the customer relations model the goal is to give the customer what they want and in the citizen-consumer model the goal is to involve the service user in policy making, service users can define and decide care outcomes and have authority to make these decisions. In the citizen-consumer model the service user is more empowered than in the customer relations model and may achieve self-

determination. Hickey and Kipping (1998) assert that consumerism fails to facilitate partnership because service users do not have the power to make decisions or control services, however consumerism empowers service users, in their view. However it is difficult to envisage how empowerment can exist without partnership. Being a customer appears to be different from being a consumer, which also appears to be different from being a citizen-consumer and it seems there are levels of empowerment, depending on which role the service user adopts, or which model is in place.

Being a citizen involves deciding what services will be available and using active agency while a consumer accepts and evaluates the services which are provided (Hickey and Kipping 1998). Whether health professionals choose to empower service users may depend on how they perceive service users, as citizens with active agency or as consumers. It may be that only citizens may achieve full self-determination.

Chadwick (1997) and Williams and Collins (1999) concluded and Coleman (1999), Coleman and Smith (2005) assert that people with psychoses, may redefine their experiences and themselves and achieve a feeling of empowerment. If service users are socially excluded and have few material resources, it may be the case that redefining oneself is not enough, when there are many wider social inequalities which are outside the service user's control. Health professionals may give the illusion of empowerment in the care situation, which is at odds with the service user's wider social and economic situation. It is difficult to perceive how a person can be empowered if they are socially excluded.

The concept of self-determination is discussed by a range of authors (Jones and Tallis 1994, Cutliffe 1997, Hickey and Kipping 1998, McCann 2004, empirical research, and Valimaki 1998, empirical research). Self determination appears to be a step beyond

empowerment and self-empowerment because it involves service users achieving autonomy, although it could be argued that everyone's autonomy is limited by the needs and concerns of others, and the need to live in society. Hickey and Kipping (1998) propose that service users could achieve self-determination if they fully controlled the health services, power was redistributed and the Democratization approach was used. What this view may not take into account is the poor judgment displayed by and mental distress experienced by some service users. It is unlikely that other citizens and service users would accept the poor judgment and decision making of vulnerable and distressed service users. It may be that, as McCann (2004) and Valimaki (1998) concluded, there are only limited opportunities for self-determination for some service users because of their mental health needs. Some control by mental health professionals may be necessary, and it could be argued that the service user is only free to achieve self-determination when free of the influences and constraints of the mental health problem. This is similar to an idea proposed by Benner (1994) who discusses the need for monitoring and prevention of harm within caring.

It appears that partnership can exist without empowerment if both health professionals and service users accept this arrangement. Crowe et al (2001) concluded that there was partnership between health professionals and service users, but there was a power imbalance. It is interesting that in this study, the health professionals perceived the services users as consumers and wanted them to be more active. These service users did not feel empowered and these findings also suggest some dependency in these service users. For example, it was reported that service users valued nurses' monitoring of mental state and responses by nurses, indicating that they may not self-monitor their own mental state. Kai and Crossland (2001), in their empirical work, also concluded that partnership without empowerment can occur. Hugman (1991) asserts that within

health professionals' authority there is often a consensus of interest but no empowerment or equality. The health professional's goal is a professional or clinical goal, not equality with the service user. The health professional controls the interaction and communication; therefore the health professional's interests are dominant, a point also made by Barker (1999).

However, the Department of Health (1994a) states that partnership involves decision-making by service users. The DoH (1990) states that the Care Programme Approach includes partnership, but Ritchie and North (1995), in an evaluation study which reported users' views, disagreed with this point and reported that there was no partnership, and that users felt coerced. A range of authors believe that where there is partnership, and also features of empowerment (e.g. service users defining their own goals, equality with health professionals, participation in decisions about care) (Westwood 1997, Clinton and Nelson 1999, Tomson 2002, Johansson and Lundman 2002, Simpson and House 2002).

There is a view that service users negotiate power with health professionals, individually and through support groups. When power is negotiated, this reciprocity and mutual dependency may benefit both groups, a view also stated by Lupton (1997). The health professional gains prestige and their authority and expertise are validated. The service user gains the desired care and treatment. The power and authority of health professionals depends on service users' social judgment; therefore, it is in the health professional's interests to negotiate power. It is suggested that the service user is negotiating from a position of weakness (Johnson 1997). It may be that service users negotiate from a position of power and health professionals' need service users' support and approval. Rose (1994, 1999) maintain that, although individuals are shaped through

Governmentality, individuals have power and choices and shape power and authority (an idea similar to Giddens' Structuration Theory (2001)). When a service user chooses to accept the practices of health professionals without negotiation, this may be a deliberate decision, made without coercion. It could be argued that health professionals do not permit negotiation of power because health professionals control the interactions and communications between service users and health professionals (Hugman 1991) and possibly the resources and funding (Beresford and Branfield 2006).

It may be the case that collaboration is really compliance, but there may or may not be coercion and control involved in this process. Hugman (1991) and Johnson (1997) assert that most service users comply because they perceive facilitation of care and treatment to be a normal part of health professionals' work. They could resist but they do not. They have been shaped to accept the care situation (Rose 1994, 1999, Fox 1993). It may be that service users perceive that they are complying under coercion, whilst health professionals believe this situation to be collaboration, even though the health professional has the power to diagnose and this in itself disempowers the service user (Barker 1999, Moorey 1998). McCann (2004) concluded that the presence of initial inequality and control over the service user was necessary to help the service user to achieve well-being. Some service users may not move beyond a situation of health professional control and limited rights because of their mental health problem (Valimaki 1998).

Therefore, there are conflicting views on the issue of whether nurses can be change agents and empower service users. Nurses at the individual level may be in a position to enable and empower service users, but the system nurses work in constrains them. Moreover, it may be that not all service users want to be enabled or empowered.

Empowerment is an ongoing process and there is some power sharing in mental health care but it is partial and inconsistent. Self-empowerment is better than being empowered and is an end result of a process which nurses could initiate. Self-empowerment requires active agency by service users. How service users are perceived by health professionals (e.g. as citizens or consumers) will influence the behaviours of both groups and the outcome for service users.

Redefining oneself and one's experiences is a necessary first step to self-empowerment, but may not be enough to achieve self-empowerment, if the wider social inequalities remain outside of the control of service users. Some self-determination could be achieved by some service users if power was redistributed, although not all service users can achieve full self-determination because of their mental health problems. It is possible to have partnership without empowerment and equality but many authors find that where this is partnership there are also features of empowerment. Service users can negotiate power but some choose not to and some health professionals do not facilitate negotiation. Where health professionals perceive collaboration, service users may perceive compliance under coercion. Compliance may occur under coercion or willingly, but there is no collaboration if there is a power imbalance.

2.12 Summary

Mental health legislation emphasises partnership. According to various nurse authors, partnership is part of nursing, and some nurse authors maintain that service user empowerment occurs, although there is limited empirical evidence for this position. There is conflicting evidence on whether there is partnership between health professionals and service users, but the weight of evidence supports the view that there

is lack of partnership. Self-determination as an alternative goal is proposed by some authors. There is some empirical evidence that self-determination can be achieved by some service users. The concept of an alliance, which acknowledges the power imbalance between health professionals and service users, is suggested. Practical barriers to partnership are outlined (e.g. reluctance of service users to take responsibility, organisational culture, lack of commitment by health professionals, low staffing levels, professional culture and negative attitudes of wider society), and health professional and organizational factors appear to be dominant. Professional and government legislation promotes empowerment of clients but many authors report that empowerment does not occur in reality, although a few studies report that empowerment occurs. User authors assert that mental health nurses do not empower people and some health professionals also support this perception. Rogers et al (1993), health professionals reporting users' views, offer evidence of empowerment of users by nurses and this is supported by empirical research. .

Nurses believe that they empower people with mental health problems but other health professionals dispute this, and explain this situation by asserting that nurses themselves are not empowered. It is suggested that nurses could empower people if the focus of nursing was changed. It may be the case that if the citizen-consumer model of health care was a reality and service users were perceived as citizens, with control and choice, they could achieve empowerment. It is proposed that service users may negotiate power and although service users are influenced and shaped to accept the expertise of health professionals, they engage in negotiation with health professionals.

Self-determination may be a more valid goal. However, there are potential barriers to promoting self-determination. Current legislation has given mental health nurses power,

but not autonomy. Emphasis on risk assessment and management may lead to overcaution in nurses' interactions with mental health service users. Nurses are compelled to engage in risk assessment, which may result in compulsion for clients. This may reduce trust between nurses and clients and prevent successful therapeutic relationships and empowerment.

There is a strong view that there is limited partnership between service users and health professionals, and it is likely that the same lack of partnership exists between service users and family carers. Family carers may exhibit high expressed emotion in their interactions with their relative with a mental health problem. High expressed emotion is explored in the following chapter.

CHAPTER THREE:

FAMILY DYNAMICS: EXPRESSED EMOTION

In the previous chapter the lack of partnership between service users and health professionals was explored. The lack of partnership between service users with schizophrenia and their relatives at home may occur and lead to many difficulties for both parties.

Key works have been used to explore high expressed emotion. Family dynamics are explored in the works of Laing and Esterson (1964), Hirsch and Leff (1975), and Weschler (1977). Birchwood and Tarrier (1994) and Atkinson and Coia (1995) define and explore the concept of high expressed emotion (HEE) in these overviews. How HEE is measured is examined in empirical research by Vaughn and Leff (1976), and Leff et al (1982).

The origins of HEE are explored in the empirical research by Leff et al (1982), Brown et al (1962), Leff et al (1987), and Paley et al (2000). These origins are also explored in overviews of schizophrenia by Croydon-Smith (1982), Leff and Vaughn (1985) and Barrowclough and Tarrier (1997). Croydon-Smith (1982) holds the position that family responses lead to HEE, while Brown et al (1962) Leff et al (1982) and Leff et al (1987) support the theory of high face-to face-contact. Barrowclough and Tarrier (1997) identify overprotection by families as a causative factor. Paley et al (2000) examined Bowlby's (1977) attachment theory and believe that attachment theory explains HEE. Empirical research by Diamond and Doane (1994) also supports this position.

A range of authors adopt the position that relapse is a result of HEE. Empirical research by Brown et al (1962), and a replication study by Brown et al (1972) came to this conclusion. Vaughn and Leff (1976), Leff and Vaughn (1981) concurred with this finding. Leff et al (1982), Tarrier et al (1988), and a follow up study by Tarrier et al (1989) came to a similar conclusion. Leff et al (1987), and Kuipers and Raune (2000) supported this conclusion and Van Os et al (2001) concluded that HEE was associated with relapse. Gamble (1995), and Tredget (1999), in an overview of 15 studies, also support this view.

Others dispute this view: MacMillan et al (1986) in a follow up study, in which the findings were inconclusive, Birchwood and Tarrier (1994), who discussed the Salford Intervention Project, and Atkinson and Coia (1995).

Leff and Vaughn (1981), Gamble (1995), Birchwood and Tarrier (1994), and Barrowclough and Tarrier (1997) adopt the position that HEE is an objective concept, while Hughes et al (1996), Meuser et al (1992) and Croydon-Smith (1982) dispute this, suggesting that HEE is not a stable factor.

Birchwood and Tarrier (1994) adopt the view that focusing on HEE does not address the needs of families. Meuser et al (1992) concluded that HEE was a negative label and did not address families' needs. A study by Van Os et al (2001) supported this view, concluding that HEE in a family indicates a desire to care.

Low expressed emotion (LEE) is discussed and explored by a range of authors. Croydon-Smith (1982), Birchwood and Tarrier (1994), when discussing the

Birmingham Intervention Project, and Hughes et al (1996) adopt the position that LEE is not beneficial to the person with schizophrenia.

3.1 High expressed emotion

This chapter reviews the concept of HEE, an interactionist concept wherein patients and family members affect each other. Additionally, a number of themes are explored: the origins of HEE, relapse as a result of HEE, the reality of HEE and an analysis of the concept of HEE.

Family conflict and destructive family dynamics are identified prior to relapse in people with schizophrenia (Laing and Esterson 1964, Hirsch and Leff 1975, Weschler 1977). Many studies, since the 1970s, have examined the concept of HEE, which is proposed to explain relapse in schizophrenia. According to these accounts, the following situation develops. The patient with schizophrenia exhibits symptoms of schizophrenia. The relative becomes distressed, anxious, critical, over-involved and hostile towards the patient. The relative is not flexible in their interactions with the patient and all interactions between the patient and relative are characterised by conflict. The relative's behaviour is characterised by coercion (with the goals of reinstating desirable behaviours and damage limitation), and over-involvement (with the goal of preventing further harm to the patient). In such a situation HEE now exists in the relationship. The patient develops a physiological response to HEE which involved increased sympathetic nervous system arousal with increased electro-dermal activity and heart rate. The HEE of the relative creates a stressful environment for the patient to live in. Long-term physiological arousal leads to increasing disturbances of perception, attention and thinking in the patient. The patient has difficulty in processing information, which can

lead to a prodromal state in which the positive symptoms of schizophrenia are more evident, and relapse comes shortly afterwards (Barrowclough and Tarrier 1997).

Hughes, Hailwood, Abbati-Yeoman and Budd (1996) report that as many as 60 percent of long-term schizophrenia sufferers live with significant others. Health professionals must therefore be concerned about the phenomenon of high expressed emotion in families.

Birchwood and Tarrier (1994 p. 54), in an overview of schizophrenia, define expressed emotion as a “measure of verbal report and tone of voice”. They state that:

“the concept of expressed emotion is a well established distal measure of interpersonal stress and has been operationalised in terms of hostility, over-involvement and the number of critical remarks during the course of a factual interview with a carer about the patient” (Birchwood and Tarrier 1994 p.34).

Atkinson and Coia (1995), in an overview of schizophrenia, conclude that expressed emotion is comprised of three elements: critical comments, hostility and emotional over-involvement, and that emotional over-involvement is itself comprised of overprotectiveness and intrusion.

These elements are assessed and measured by using the Camberwell Family Interview (CFI), a semi structured interview devised by Vaughn and Leff (1976), who reported that it was a valid and reliable instrument (see section 3.2). Leff et al (1982) also concluded that validity, objectivity and inter-rater reliability were good in the CFI (see section 3.2). The CFI is usually carried out with relatives when clients' symptoms have

worsened or at time of discharge. Expressed emotion is perceived as a neutral operational measure of environmental stress which can be quantified. The CFI focuses on events leading up to the last admission, the symptoms of the client, the relatives' attitude to the symptoms and behaviours of the client, how the illness affects family relationships, with special emphasis on arguments, irritability and the quality of the relationship between the patient and the relative. The rating of expressed emotion consists of five dimensions: the frequency of critical comments, hostility measured on a four point rating scale, emotional over-involvement measured on a six point scale, warmth measured on a six point scale and the frequency of positive remarks (Atkinson and Coia 1995). The CFI was the first method of identifying and measuring expressed emotion.

There is some dispute about the validity and reliability of the CFI. There are potential weaknesses in all semi-structured interviews. The interviewer may probe beyond the standardised questions, and while this allows exploration of a theme, it also may lead to reduction of reliability, and the introduction of research bias and influence and potential subjectivity in the findings (May 2001). In the CFI the cut-off point for critical comments was changed leading to potential loss of reliability in the assessment of validity of the concept of HEE (Hughes et al 1996, Meuser et al 1992 and Atkinson and Coia 1995). Hughes et al (1996) and Meuser et al (1992) concluded that HEE and LEE were subjective concepts.

Leff et al (1982) measured HEE using the CFI. In this controlled trial of special interventions with families (experimental group n=12, control group n=12), they concluded that HEE led to relapse and family interventions led to reduced HEE. These

authors reported that validity and objectivity were indicated because an independent rater rated the expressed emotion blindly.

One theory which is proposed to explain the origins of HEE is Bowlby's (1977) attachment theory. Bowlby conceptualises the propensity of people to form affectional bonds with others, and relates this to emotional distress (e.g. anxiety and depression) in later life, which unwilling separation and loss can lead to. The main ideas he proposes are as follows:

1. Parental patterns contribute to emotional distress.
2. Current experiences with others are distorted by past experiences with parents.
3. Deviation or failure of development of attachment lead to psychiatric disturbance.
4. Anxious, ambivalent or insecure attachment styles lead to the child dealing poorly with stress or life difficulties in later life.

If parents are unresponsive to the child's care-seeking behaviour, or if their response is rejection or disparaging remarks, or threats to withdraw love, or to abandon the child, or if there is discontinuity of parenting (e.g. the child spends time in an institution), the child is likely to display features of anxiety attachment, and become anxious, insecure and over-dependent.

According to Bowlby's (1977) theory, during childhood, people develop an internal working model of self and others, which later influences adult relationships. Early attachment is associated with parenting in later life and these relatives are repeating their own attachment patterns which existed in childhood. If a relative has a perception of receiving low parental care and low over-protection, they are likely to display criticism and hostility to their offspring with schizophrenia. If a relative has a

perception of high parental care and high over-protection, they are likely to display emotional over-involvement.

This overview of principles, which derive from ethology, cognitive psychology, and control theory, “conforms to the criteria of scientific discipline” (Bowlby 1977 p.201). As empirical evidence is one of the criteria of a scientific discipline, Bowlby supports his statements through research evidence.

Bowlby (1979), in a series of lectures, discusses attachment theory, mental illness and poor parenting. In this work, he asserts that early childhood experiences lead to mental illness, and that some parents do not provide the child with a secure base. Separation occurs, which can lead to anxiety, insecurity, over-dependency, depression, phobia and personality disorder. At no point in this work does he state that such experiences lead to schizophrenia. In this work, Bowlby suggests that attachment theory is rejected by others, and even those who accept this theory are unsure what childhood experiences are relevant.

Bowlby (1979) acknowledges that many children grow up with such experiences and do not go on to develop a psychiatric disturbance but instead grow up to be secure, self-reliant, trusting, co-operative and helpful towards others. This potentially suggests that other additional factors may be operating when some children have such experiences and develop later psychiatric disturbances.

Bowlby’s attachment theory is supported by Diamond and Doane (1994). This study used two rating scales: a Parental Bonding Instrument (PBI) (Parker 1979), and a Five Minute Sample Speech (FMSS) (Gottschalk and Glesser 1968, Ainsworth et al 1978).

They used a two hour Intergenerational Family Attachment Bonding and Separation-Individuation Interview (IFABS-II) (Diamond 1986, Diamond 1987), with a series of 5-point Attachment Bonding and Separation Scales, which were assessed and rated blindly by an independent rater. Parental affective style (AS) was measured by the Kriesman Scale of Rejecting Attitudes, a 24 item questionnaire which measured reactivity and rejecting attitudes (Kreisman et al 1979). Affective style (AS) and EE are different but related concepts. In negative AS the parent displays personal criticism, guilt induction, and intrusiveness. The parent and offspring may be unaware of this behaviour. Negative AS is more related to the parents' interactions and relationship with their own parents, than to the actual behaviour of their offspring. The offspring internalises a negative attachment style, of which negative AS is an element. The convenience sample consisted of young adults and adolescents (n=49) and their families, who were receiving long term treatment. Parents of disturbed young people, who did not have a close relationship with their own parents, were more likely to have a negative affective style and be critical of and hostile to their children. The lack of emotional support from their parents in their own childhood may have meant they were unable to emotionally support their own children.

Potential flaws in this methodology were, a small convenience sample, which may not be representative of a wider population, and the findings may have limited generalisability. However, in the FMSS, the codes were standardised and reliable (e.g. presence of secure attachment) and there was good inter-rater reliability. In the FMSS, concurrent validity was confirmed by comparing the composite scores with the results from the IFABS-II attachment scales.

Bentall (2003) warns against blaming parents for adverse effects of parenting on children, and suggests that people with schizophrenia play their part in negative emotional interactions in the home. Unusual comments or behaviours by a person with schizophrenia lead to critical comments by parents, which in turn lead to further unusual behaviours. Bentall (2003) agrees with Bowlby's (1977, 1979) ideas of attachment relationships, and concludes that lack of secure attachment to a parental figure in childhood can lead to vulnerability to psychosis.

Paley et al (2000), in a study of expressed emotion in 55 relatives of long term stable community based people with schizophrenia, used the CFI and The Parental Bonding Instrument, to measure expressed emotion, and the Krawieka, Goldberg and Vaughan Symptom Scale (Krawieka et al 1977) to assess the symptoms of 33 people with schizophrenia. They concluded that the origins of HEE could be explained by Bowlby's (1977) attachment theory (Paley et al 2000). Bowlby (1977) and Paley et al (2000) propose that HEE stemmed from the relatives' own parental influences. Croydon-Smith (1982) and Bowers (1991) suggest that HEE may have its origins in family responses. Croydon-Smith (1982) in an overview of schizophrenia, asserts that HEE is a family response to being negatively judged by health professionals. He suggests internal causation, asserting that an adult with schizophrenia, living in the family home, has faulty protective filters. If the family are critical of this person, he or she is likely to experience over stimulation and excess social communication and to respond by increased social withdrawal (Croydon-Smith 1982). Bowers (1991) expresses the opinion that high expressed emotion is a response to apathy on the part of the person with schizophrenia. Birchwood and Tarrier (1994) maintain that lack of coping by families leads to HEE. They contend that its origins lie in families who have problems and coping deficits, which contribute to a stressful environment.

High levels of face-to-face contact between the person with schizophrenia and their family are thought by some authors to be the origins of HEE. This view of HEE is supported in Brown et al (1962), Leff et al (1982), Leff et al (1987) (see section 3.3), which are clinical studies, and in Croydon-Smith (1982), Leff and Vaughn (1985 pp.123-149), Barrowclough and Tarrier (1997), Bradshaw (1997) and Baguley and Baguley (1999), which offer overviews of schizophrenia.

Baguley and Baguley (1999) assert that communication between people with schizophrenia and carers may have a role in the amelioration of symptoms. This is part of the family maintenance model of schizophrenia in which family relationships affect the course of the illness. Family generated stress is associated with deterioration in the person with schizophrenia's mental state. Patients who live in families with high face-to-face contact are more likely to relapse than those who live in families with low face-to-face contact.

Barrowclough and Tarrier (1997) propose that extreme over-protectiveness is caused by hostile communications between health professionals and the family. The negative attitude of nurses lead to anxiety about the welfare of the person with schizophrenia. This, in turn leads to over protectiveness, which results in a reduction in the families' effective coping strategies. In conclusion, a combination of health professional-family interactions and family dynamics may be the origins of high expressed emotion according to these authors.

3.2 Relapse as a result of high expressed emotion

Brown et al (1962) tested two hypotheses: HEE at home would lead to relapse, and relapse would not occur if there was reduced contact with family members. They used a 5- point rating scale to measure mental state during a Psychiatric Interview which measured flatness of affect, other affects (e.g. suspiciousness, depression or hostility), speech disorder, delusions, and hallucinations. They used a Socially Embarrassing Behaviours Scale Interview, which measured social withdrawal, motor activity (under or over), deteriorated personal habits, bizarre behaviour and antisocial behaviour at the time of discharge and again at the end of the year or at readmission. These factors were rated as 1 if they were absent to 5 if they markedly present. Informants were interviewed twice, one week apart, by two different interviewers. Ten pilot interviews were completed, followed by further interviews. The sample was men with schizophrenia (n=128) and their female carers (n=128). A four point scale was used to measure emotional involvement of carers, and this was carried out at home. The specific factors measured were 1. uncontrolled emotion, 2. emotion frequently expressed, 3. no emotion expressed and 4. evidence of indifference or casualness. Pilot interviews were conducted prior to these interviews.

Fifty five percent of all the men showed a deterioration in behaviour (which was defined as worsening of symptoms). Of those in the high Emotional Involvement (EI) homes, 76 percent deteriorated, compared with 21 percent of those in the low EI homes. Men with moderate or severe disturbance, who were discharged to a high contact, high EI relative had a deterioration rate of 96 percent, compared to 50 percent for those similar patients discharged to a low contact relative. Both hypotheses were supported, but the second hypothesis was supported only for twenty three men who were rated as

moderately or severely disturbed and returned home to a high EI relative. There is no explanation for deterioration in those with no or minimal disturbance living with a low contact and low EI relative. It may, in such instances, that the person with schizophrenia had a very severe form of schizophrenia or may have experienced stressful life events.

It is possible that some of the elements measured in the Psychiatric Interview were subjective, for example, suspiciousness, depression or hostility. These elements were rated 1-5 and the highest rating for any element (e.g. 4 for delusions 2 for flatness) was taken as the final result, a decision which may have ignored variability in the symptoms, coping strategies by the person with schizophrenia and the reasons for suspiciousness or hostility. In the Socially Embarrassing Behaviour Scale, the data was collected from nurses who had worked with the patients with schizophrenia, and there may have subjectivity in the nurses' identification and measurement of these behaviours. There was a clear correlation between the presence of severe social embarrassing behaviours and deterioration in mental state and it may be the case that deteriorating mental state caused these behaviours. However it may be the case that the presence of socially embarrassing behaviours led to HEE in these nurses and others, and HEE contributed to the deteriorating mental state. There may have been other reasons for some of the elements, for example social withdrawal may have been a coping strategy, and this was not explored in this study. In the Emotional Involvement 4-point scale indifference and casualness is rated. This could be a family which is not coping. This element was measured in the homes of parents, a situation which may have led to loss of reliability, because these situations may have been dissimilar.

The sample was homogenous: male, European and English-speaking, and the carers were all female, wives and mothers, which potentially limited the representativeness of

the sample and the generalisability of the findings. There was reported general agreement between the two interviewers; however the level of inter-rater reliability was not stated. There may have been interviewer subjectivity in the assessment of relatives.

Patients returning to high EI homes were more likely to have a deterioration in their mental state. However this may not be a simple causal relationship. The patient may have had a very severe form of schizophrenia and the relatives' high EI may have been a response to the patient's past or current behaviours. Lack of consistency in behaviours of parents and patients may be an important issue. It may be the case that in individual relatives there was a variation in tolerance to a patient's behaviour and EI expressed. Some parents may have learned to ignore behaviours which previously distressed them. There may be some variation in the level of self-control by patients, and behaviours which could be perceived as disturbing by others may have been well controlled in some situations and with some people outside of the family. High EI could be independent of the behaviour of the patient, and could be a parental trait.

Brown et al (1972) replicated the Brown et al (1962) study, using the CFI, and focused on the influence of family life on the course of schizophrenia. The hypothesis was that HEE leads to relapse independently of other factors. Initially, semi-structured interviews were carried out to confirm the diagnosis of schizophrenia. Multiple interviews were carried out with patients (n=101) and key relatives (n=101) by a research team of five. The main family interview was conducted twice, with relatives at home, while the patient was in hospital. Interviews with patients and family members were conducted nine months after discharge, and compared with previous interviews. There was a joint patient and family member interview two weeks after discharge.

The family interview dealt with relatives' accounts of events at home prior to admission, and feelings about people and events. The following relatives' factors were measured: emotional responses rated by the number of critical comments, hostility (present or absent), dissatisfaction (a 4-point scale describing 8 areas of family life), warmth (a 6-point rating scale), and emotional over-involvement (EOI) (a 6-point rating scale). The relatives' expressed emotion (EE) was rated.

The following patient factors were measured: patients' behaviour before and at admission, work impairment, disturbed behaviour, social withdrawal, schizophrenic presentation and type of relapse. Factors which were explored were high contact in the home, and relatives' emotional responses (critical comments, dissatisfactions, hostility, warmth and EOI). HEE was associated with relapse independently of the following factors: high contact in the home, typical schizophrenic symptoms, paranoid schizophrenia, being under 45 years old, being male, acceptance of admission, no regular medication, severity of patients' disorder, work impairment, disturbed behaviour, and type of relative (e.g. parent or spouse). This replicated the main previous findings in the Brown et al (1962) study.

Potential flaws were heavy reliance on respondents' self-reporting and retrospective recall of behaviour and feelings, and lack of independent data. Scales were relative with comments divided into critical or positive. There was potential interviewer subjectivity because there was reliance on interviewers' judgement on tone of voice in the rating of emotional responses, specifically critical comments. The level of EE at the time of admission was assumed to be a consistent factor in the relatives' behaviour, but it might have been inconsistent, and a short-term response to their relatives' behaviours (see section 3.5). In this sample only 51 men were assessed as having definite

schizophrenia, with others only having some clinical features; therefore, validity may be weak.

Reliability and validity were present because the CFI was used and the sample was large. High inter-rater reliability was reported and there was a high level of agreement between parents in the rating of emotional responses. The respondents' statements could be clarified and expanded. Objective events and subjective feelings were differentiated. The focus was on the recent time period with the aim of increasing accuracy, and overcoming potential unreliability of retrospective accounts. It allowed analysis of unusual events.

These authors acknowledged that some HEE factors were easier to measure than others. Critical comments were the easiest factors to measure. Difficulties in measuring emotional over-involvement and hostility may have led to weak reliability. The simple causal model is not fully supported because patients and relatives affect each other.

Vaughn and Leff (1976) used the CFI to measure EE in families of patients with schizophrenia. They concluded that patients who returned home to high involvement homes (as judged by relatives' behaviours when interviewed with the patient) were more likely to relapse during the one year follow-up period.

Two main assumptions in this study may have been flawed: firstly, that relatives gave an accurate description of relationships in the home, although these were not observed, and secondly, that attitudes and behaviours in the interview situation accurately represented those at home. These authors reported that the CFI was useful in families that had only one member with a mental health problem. Moreover, the CFI had

predictive validity for relapse patterns in schizophrenia and the judgements made had predictive accuracy. It was a standardised tool which measured and quantified observed emotions such as warmth, hostility, emotional over-involvement, positive or critical remarks, and there was inter-rater reliability. Every major aspect of family life was covered.

Leff and Vaughn (1981), in a two year follow up study using the CFI, involving 25 patients with schizophrenia, concluded that HEE led to relapse (HEE group 62% relapse, low expressed emotion group (LEE) 20% relapse). Family interventions reduced relapse rates in patients with schizophrenia in HEE families, and maintenance medication did not protect those in HEE homes.

There were flaws that may have limited the generalisability of the findings. Four of the 11 patients in the HEE/maintenance medication group had discontinued their medication and this may have influenced their relapse. Of the four HEE/maintenance medication group who did not relapse, two had left home before the two year point and so had reduced contact with relatives; therefore other factors may have influenced their lack of relapse.

Leff and Vaughn (1981) examined the consistency of the attitude of the relative towards the patient over time and concluded that a negative attitude was consistent over time. However this finding does not shed light on cause and effect, specifically whether the patient with schizophrenia's behaviours lead to HEE in the relative or vice versa. These authors acknowledged that there were probably a number of factors which led to HEE. Another potential flaw is that there was self-selection for drug compliance. Those who accepted or did not accept maintenance therapy were self selected and this may have

had an influence on the finding that there was no relapse in patients from low or high EI homes in those patients who remained on maintenance therapy between the nine-month and two-year follow up period. The loss of the maintenance therapy effect was at the two-year follow up point and not before. Self-selection may have led to weak reliability, and this sub-sample was potentially unrepresentative, and the findings may thus not have been generalisable.

Using the CFI, Leff et al (1982) conducted a nine month controlled trial of social interventions. These were

- an educational programme.
- a relatives group for family members.
- family sessions where the sick relative attended.

The sample (n= 24 families) was randomly allocated to either an experimental group, which received the social interventions (n=12), or a control group, which received routine outpatient care (n=12).

These authors concluded that high levels of face-to-face contact led to relapse, and relatives' HEE played a causal role in schizophrenic relapse. Social interventions, combined with drug treatment, led to a reduced relapse rate (experimental group 9 percent relapse rate, compared to 50 percent in control group). There was a significant reduction in criticism in the experimental group over nine months, and face-to-face contact had fallen below 35 hours per week in the experimental group. These factors were absent in the control group.

The potential flaws in this study were that the therapeutic effects of medication could not be discounted as all patients continued taking medication. There was drop out in the social intervention group, and, therefore, the findings were not based on twelve families. Attendance was not consistent, therefore the social interventions may not be the only factors leading to lack of relapse. However, the assessment of EE was conducted independently by two raters, and where there was disagreement, a third rater rated EE blindly. There was strong inter-rater reliability when assigning families to a HEE or low expressed emotion (LEE) group.

The cause and effect of HEE is not completely clarified in the Leff et al (1982) study. These authors found that maternal over-protection and emotional over-involvement were present prior to the onset of schizophrenia, when the patient was a child. These two factors existed independently of the schizophrenia and were not altered by the social intervention. These mothers appeared reluctant to reduce these responses and to spend less time with the patient. Also, where this was found, the offspring were found to have multiple problems as children, a situation which may have created overprotective behaviour in their mothers.

MacMillan, Crow, Johnson and Johnstone (1986), in a two year follow up study of 82 relatives of 77 discharged patients with first episode schizophrenia, administered the CFI, with a view to examining the components of expressed emotion and clarifying predictors of relapse. The only component present often enough to be used was critical comments. Most of the patients did not live in HEE families or high face-to-face contact situations. There was a strong association between longer duration of illness prior to admission, after two years, and higher critical comments rating. However, these authors maintained that the causal link between HEE and relapse was not clear or

proved. Over-involvement was unusual and social contact was generally low in these relatives. Where there were high critical comments there was low social contact, the explanation given being that when the relative found the behaviours of the person with schizophrenia intolerable they reduced the face-to-face contact. These authors concluded that overall HEE was not a good predictor of relapse. The sample was too small to detect changes or show that components of HEE could predict relapse; therefore the findings were inconclusive.

They may have been a complex relationship between severity of schizophrenia, carer burden and carers' responses to burden. It may have been the case that critical comments were a response to long-term severe schizophrenia. High social contact may have been a factor which increased as the person developed chronic schizophrenia, or may have been a caring response, although these authors do not support these views. The sample may have been unrepresentative. The 77 patients were a small proportion (30.4%) of the original sample. There was drop out for the following reasons: no discharge from hospital and lack of co-operation; some interviews could not be carried out because some participants could not speak English.

In the *Salford Family Intervention Project*, Tarrier et al (1988) conducted a controlled trial of a behavioural intervention with families in the attempt to reduce relapse. There were three groups: the behavioural intervention group (n=25), the education only group (n=14), and the routine treatment group (n=15).

Behavioural interventions in HEE families led to lower relapse rates in patients with schizophrenia, over nine months. There was significant reduction in the expressed emotion and in hostility in the behavioural intervention families. This behavioural

intervention led to reduced relapse rates (12 percent, n=3), compared with routine treatment (53 percent, n=8), or short-term education programmes (43 percent, n=6). The results may have been skewed because at nine months there were fewer HEE relatives in the behavioural intervention group than in the other groups.

Of the three patients in the behavioural intervention group who relapsed, two had dropped out of treatment. Relatives did not co-operate and relatives' attendance was inconsistent. The third person relapsed after medication was reduced. This implies that there was limited internal motivation on the part of these carers and patients with schizophrenia to complete the behavioural intervention.

In a later two year follow up controlled study, Tarrrier et al (1989) found that both the relapse rates of the behavioural intervention group and the LEE group were 33 percent, compared to the 59 percent relapse rate in the non-intervention, HEE group. Readmission rates were used to indicate relapse.

Potential flaws were that readmission rates may be a weak indicator of relapse rates and there may be many potential reasons for readmission. However bias was minimal, as this was a blind assessment of records and notes, carried out by volunteers who were blind to the patients' treatment groups. Identified relapses were identified by the first author and confirmed by other authors in all cases.

The short education programme did not reduce relapse. The behavioural intervention may only have delayed relapse, but not prevented it, because the relapse rate was increased in the behavioural intervention group after nine months, in five of the eight participants (63% relapse rate). An alternative explanation is that the risk of relapse

was reduced while the intervention was being delivered and increased when the intervention finished. It may be the case that there is a need for continued interventions. It may also be the case that life events led to high physiological arousal levels, which in turn led to relapse. The behavioural intervention group had more life events than other groups. Perhaps in becoming more active, these participants were exposed to more life events, which increased the risk of relapse. Paradoxically, the behavioural intervention which was intended to reduce relapse may have contributed to increased risk of relapse. However, this was not proved conclusively in the study.

Leff, Wing and Ghosh (1987) in a one year follow up study of patients with schizophrenia in Chandigarh, used the CFI to explore the influence of relatives' EE on the course of schizophrenia. There was good inter-rater reliability using the CFI. In this study, there were 93 patients and their families who were from one rural and one urban area. Relapse was a consistent feature of those living with a HEE relative, as was lack of relapse with an LEE relative. These authors concluded that HEE and high face-to-face contact led to relapse. HEE families were more common in urban areas, and the urban participants' relapse rate was higher than rural participants (urban 19 percent, rural 9 percent). These authors suggested that other factors may have influenced relapse, specifically, living in an urban area, being male, single and having life events. A combination of life events and lack of maintenance medication may have contributed to relapse. Forty four participants in the study had life events and most of these lived in LEE homes. Life events appeared to play a causal role in the onset of schizophrenia for participants who were not on maintenance medication and were living in LEE homes.

Birchwood and Tarrier (1994), discussed the *Salford Family Intervention Project*, and, when relapse rates were measured in both HEE and LEE families, concluded that relapse rates were lower for HEE families at 9, 12 and 24 months. However, the difference was only present for up to eight years, when the relapse rates were similar for HEE families who received family interventions (67 percent) and LEE families who received routine care (69 percent). Therefore HEE was not shown to be a good predictor of relapse (Birchwood and Tarrier 1994). It may also be the case that LEE families become HEE families because of lack of meaningful support.

Gamble (1995) concludes that people with schizophrenia, who live with HEE relatives, have higher relapse rates, and that health professionals can help to reduce the level of expressed emotion in families.

Bradshaw (1997) asserts that many studies show that there are higher relapse rates in patients who live with HEE, and contends that the concept of HEE has a high level of reliability as an indicator of relapse in patients, a view supported by Paley et al (2000).

Tredget (1999), in an overview of family interventions, reports that seventeen predictive studies have been carried out exploring the relationship between expressed emotion in patients with schizophrenia and relapse in nine different countries. Fifteen of these studies show that HEE in families leads to relapse. Tredget, however, believes that HEE is not the only stressor or factor involved in relapse.

Stressors other than HEE are discussed by Barrowclough and Tarrier (1997). These authors propose that there are genetic, biological and environmental stressors. In the Threshold Model there may be chronic stress, caused by relatives' HEE and acute stress from life events. A combination of these may lead to relapse. Leff et al (1987) concluded that factors other than relatives' HEE may have led to relapse (e.g. being

single, being male, living in a city and the presence of particular life events). There may be social stressors which the patient may otherwise have coped with, but the long-term heightened physiological arousal is likely to lead to an increased reaction to the social stressor and in turn may increase the risk of relapse.

Kuipers and Raune (2000) conducted a first-onset study using social and demographic data collected from key carers (n=46) and patients (n=46). The Social Isolation Scale (SIS) (O'Connor and Brown 1984) and the CFI (Vaughn and Leff 1976) were used to measure isolation and EE. Coping styles were examined using COPE (a measurement of the frequency of coping styles), (Carver et al 1989, 1993). The Beck Depression Inventory (BDI) (Beck et al 1979) and the General Health Questionnaire (GHQ) (Goldberg and Hillier 1979) were used to measure depression.

Forty four percent of the key carers were rated as HEE. Other factors reported by carers were high levels of disengagement and subjective burden, avoidant coping and attribution of blame. HEE parents made more critical, intrusive, comments and suffered burden more severely than LEE parents, and this negative affective style was a predictor of relapse.

Van Os et al (2001) investigated HEE. Expressed emotion (EE) was measured using the Five Minute Speech Sample (FMSS) (Gottschalk and Glesser 1968, Ainsworth et al 1978), which these authors maintained is reliable. Criticism and emotional over-involvement (EOI) were rated. The World Health Organisation Life Chart from the Multi-Centre Study on the Course and Outcome of Schizophrenia by the World Health Organisation (1992b) was used. This measured three items about family involvement: family custodial care, monitoring of medications and involvement in treatment decisions, which were rated as, 'never', 'sometimes' or 'most of the time'. The sample

was 31 relatives of people with a diagnosis of schizophrenia or schizoaffective disorder. These authors concluded that HEE was linked to relapse, and was associated with family involvement.

These authors acknowledged that the Camberwell Family Interview (CFI) is more sensitive at identifying emotions, than the FMSS, which they used. There were few positive EE ratings, and these authors believed that sample bias may explain this, as most of these participants were parents, and EOI and criticism are parenting traits, in their view. The final conclusions were based on a small number of observations, which may have limited the reliability, and a larger study was proposed.

Bentall (2003), in a critical overview of mental illness, explores the reasons relationships may be so damaging to mental health. He concludes that living with HEE relatives increases the risk of a future episode of illness. Critical comments from relatives lead to negative beliefs being expressed and low self esteem, which may lead to positive symptoms of schizophrenia. He highlights stress vulnerability in people with schizophrenia and the presence of high expressed emotion relatives as factors which lead to relapse.

3.3 The reality of high expressed emotion

Leff and Vaughn (1981) asserted that HEE is a reality. Gamble (1995), in an overview of Thorn Nurse Training, concludes that people with schizophrenia are sensitive to stimulation and stress in their social environments and that HEE is an objective fact and

HEE is defined by the CFI (see section 3.1). Hughes et al (1996), in an overview of family interventions, conclude that expressed emotion is not a fixed stable factor but changes over time. They propose that the concept of HEE and LEE may be dubious.

Barrowclough and Tarrier (1997) propose that when the interactions of HEE relatives are observed, HEE behaviours can be identified. Relatives who are previously rated as over-involved are found to be intrusive using this method of observation. They assert that the home environment is the best predictor of relapse. This literature review strongly suggests that HEE is an objective reality.

3.4 Analysis of the idea of high expressed emotion

Croydon-Smith (1982) proposes that LEE may be a strategy and an LEE family may be burnt out, distancing themselves from the source of stress. He proposes that it cannot be assumed that families who display HEE do so consistently. It may be a short-term strategy in response to a stressful situation, but there is no empirical base for this view.

Meuser et al (1992), in an assessment of the educational needs of chronic psychiatric patients and their relatives, question the validity of the concept of HEE, proposing that it is negative labelling, pejorative and does not take seriously the families' concerns. They assert that families object to the term HEE, but there is no empirical base for this assertion.

Van Os et al (2001), in their empirical research, proposed that HEE might be a strong indicator of a caring family and yet these carers are labelled as HEE, which is a negative concept, implying that these carers cause harm to the their relative. These authors

acknowledged the association between HEE in carers and relapse in the person with schizophrenia, but suggested that HEE may be a response by carers to a person with schizophrenia who has frequent relapses, and HEE may not necessarily be the cause of the relapse.

Birchwood and Tarrier (1994) propose that EE is a binary concept, rather than a unitary concept, with HEE and LEE being clearly identifiable. They highlight a flaw in the concept of HEE in the *Birmingham Family Intervention Project*. They assert that simply looking at HEE does not allow health professionals to involve LEE families in need of help. In their view, LEE families have high needs, and they assert that HEE is too narrow a concept to allow examination of family need. These authors suggest that HEE exists, but focusing on it does not address the needs of families who have a relative with schizophrenia.

Atkinson and Coia (1995) cast doubt on the association between HEE and relapse, and the validity of the concept of HEE. According to these authors, a great amount of research between the mid 1960s and the mid 1980s seems to confirm the link between HEE in families and relapse rates, but later research shows this link to be less clear. These authors propose research journals favoured research with positive findings and research concentrating on first episode patients. They propose that the predictive power of EE is weak because of methodological issues in the research (e.g. changing the cut-off point for critical comments, low preadmission contact with families, the patient not living with the family after discharge and small samples). Criticism of studies that conclude that HEE is related to relapse has led to the present narrower definition of HEE. Atkinson and Coia (1995) believe that defining relapse is important and in their

work it is defined as exacerbation of symptoms rather than admission to hospital. They suggest that this improves prediction.

Hughes et al (1996) question the benefits of LEE, expressing the view that in LEE families the lack of family involvement may prevent a person with schizophrenia from improving their social functioning. Therefore LEE in a family may not be beneficial to a person with schizophrenia.

Barrowclough and Tarrier (1997) and Birchwood and Tarrier (1994) assert that EE is a dichotomous measure, with relatives being rated as either LEE or HEE depending on their scores. Barrowclough and Tarrier (1997) point out that rating scales were altered over time and relatives who scored six or more critical comments were rated as HEE. However in the past, those who had a score of seven or more were rated as HEE. The cut-off point for emotional over-involvement changed from 4 or above to 3 and above, as evidence of HEE. Barrowclough and Tarrier (1997) propose that only one element of EE needs to be scored highly enough in order to merit a HEE rating. They suggest that high levels of warmth, a positive factor, is often related to EOI and that EOI may not always be a negative factor. It is proposed that HEE is a negative label and that families object to the term (Meuser et al 1992, Barrowclough and Tarrier 1997). Economically disadvantaged families may express HEE in response to interactions with health professionals, because these families believe that they are being negatively judged. Health professionals may not share the same beliefs and values as these families, a situation which can lead to conflict. An LEE family may be an uninvolved family, which distances itself from their relative with schizophrenia (Croydon-Smith 1982, Hughes et al 1996, Barrowclough and Tarrier 1997). HEE may be a short-term

response and not a consistent response (Croydon-Smith 1982, Barrowclough and Tarrier 1997).

3.5 Discussion of themes

There may be methodological flaws in the CFI. The CFI may have weak validity because it is carried out in a contrived environment, and not in the family home. The assumption is that relatives will display the same behaviours consistently under observation and at home. This assumption may be flawed (Atkinson and Coia 1995, Barrowclough and Tarrier 1997)

The CFI is a semi-structured interview, in which the interviewer may probe beyond the standardised question, and this may lead to reduction of reliability, introduction of researcher bias and influence and potential subjectivity in the findings.

The CFI can measure the environmental stress crudely, but it cannot distinguish the patients' physiological responses to criticism or hostility in EOI. It is possible that the patient is responding to the presence of the HEE relative even when the relative is not displaying HEE responses at a specific time. Therefore it is difficult to separate out different parts of the relative-patient interaction and identify the patient response to each part of the interaction. When negative statements are made by relatives, an evasive reaction is common in patients; therefore non-verbal behaviour is part of the interaction. When examining non-verbal behaviour there may be retention of relatives' negative affective style (AS) (criticism, guilt induction and intrusiveness). Negative AS may be a non-specific stressor that may lead to relapse. When negative AS is present, the family's ability to cope with everyday stressful situations will be reduced. If the conversation is

not emotionally neutral the patients may display physiological arousal (e.g. raised heart rate) (Atkinson and Coia 1995).

Atkinson and Coia (1995), Hughes et al (1996) and Meuser et al (1992) maintain that HEE and LEE are subjective concepts. These authors dispute the validity of both concepts. The cut-off point for critical comments has been changed over time (Atkinson and Coia 1995).

At the point of hospitalisation, relatives are likely to be very upset and make critical responses and show over-involvement, as a caring response perhaps, or be hostile to the patient with schizophrenia. Another argument for the subjectivity of HEE is that in EE assessment only one dimension needs to be rated as high (e.g. six or more for critical comments, one or above for hostility, three or above for over-involvement) for the relative to be assessed as the HEE relative. This could mean that there is a different presentation in each relative and a potential variety of responses, suggesting weak reliability (Barrowclough and Tarrier 1997). However these authors acknowledge that there are common response patterns which lead to a classification of HEE: critical, or critical and over-involved, or critical and hostile. Hostility and criticism may exist prior to, and independently of, the patient's illness or behaviour (Atkinson and Coia 1995, Van Os et al 2001). Some authors believe that the CFI is a valid and reliable instrument and by implication that HEE is an objective fact (Vaughn and Leff 1976, Leff et al 1982). Inter-rater reliability has been reported when using the CFI (Leff et al 1982).

The behaviours that cause the relative to become upset or cause coping difficulties are identified in the critical comment assessment. In the assessment of EOI, distress responses are identified and the goal is to assess how the relatives' quality of life and

well-being are affected as the result of the illness. There is no subjective comment by the researcher on whether the relative's concerns are realistic or not. In assessment of EOI coping responses are identified but no value judgment is made about these responses (e.g. intrusive behaviours). The effects on the patient with schizophrenia and relative's well-being are focused on. These are objective factors (Barrowclough and TARRIER 1997).

Atkinson and Coia (1995) and Van Os et al (2001) support the view that the CFI has sufficient sensitivity to identify emotions. A range of authors support the view that the CFI has predictive validity, but it depends on how relapse is defined. All the studies in this literature review defined relapse as admission to hospital and support this position: Brown et al (1962), Brown et al (1972), Vaughn and Leff (1976), Leff and Vaughn (1981), Leff et al (1982), MacMillan et al (1986), TARRIER et al (1988, 1989), and Leff et al (1987). However, TARRIER et al (1989) suggest that admission may be weak indicator of relapse and that there may be other reasons for admission. Atkinson and Coia (1995) maintain that predictive ability of the CFI is increased if relapse is defined as exacerbation of symptoms, rather than admission into hospital.

The consistency of HEE and LEE is disputed. Brown et al (1972) found that one third of relatives were rated as HEE when the patient was admitted and as LEE later when the patient was in remission, indicating that HEE and LEE are not consistent responses. If they are not consistent, the reliability of the measures, specifically the CFI, must be in doubt. It may be the case that EE can only predict relapse at the critical point of admission into hospital. It may be the case that the categories need to be altered to explain this inconsistency. Perhaps some relatives are HEE consistently when the patient is being admitted and later when the patient is being discharged, which

Barrowclough and Tarrrier (1997) term high-high EE relatives. Perhaps some relatives are high-low EE relatives, which means being HEE at the point of admission and LEE when the patient is in remission (Barrowclough and Tarrrier 1997), and this view is supported by Birchwood and Tarrrier (1994). A LEE family may become a HEE family if it receives no support (Hughes et al 1996).

LEE may not be beneficial for people with schizophrenia. The LEE family may be uninvolved, leading to the onset of negative symptoms (e.g. loss of volition)(Hughes et al 1996). Brown et al (1962) measured EI and used a scale which identified indifference or casualness in relatives. Indifference may be a symptom of poor coping and the family may be distancing themselves from the person with schizophrenia. Croydon-Smith (1982) maintains that LEE is a family strategy and that an LEE family may have high needs, a view held by Birchwood and Tarrrier (1994). It may be the case that if we only focus on HEE, the needs of LEE families will not be met. A LEE relative may not be calm and coping, and while the relapse rate of LEE families is lower than in HEE families, the social functioning of the person with schizophrenia may be lower in LEE families (Birchwood and Tarrrier 1994).

Returning to an HEE family is reported to lead to relapse in the majority of these studies in this literature review, but the situation which leads to relapse may be more complex than this. Barrowclough and Tarrrier (1997) suggest that a combination of high face-to-face contact, no medication and a HEE relative leads to relapse. It is proposed that the patient experiences physiological responses or arousal (electrodermal activity and increased heart rate) in response to the high face-to-face contact and HEE responses. If there is sustained physiological arousal, this is likely to lead to positive symptoms of schizophrenia and relapse. There may be severe disturbances of

perception. The patient may be unable to process information, which can lead to a prodromal stage, in which the positive symptoms of schizophrenia are evident, and relapse comes shortly after. The stressful environment leads to increased physiological arousal, and the effect of all other stressors (e.g. social stressors) is increased. It is likely that the HEE relative is not flexible and both relative and patient are locked into interactions which are characterised by conflict. A HEE relative may make more attributions to illness-related events and may believe that the patient is responsible for, and can control their behaviours. A HEE relative may believe that illness events have negative consequences and try to understand the illness events. In LEE relatives, there seems to be less evidence of this behaviour. HEE relatives do two things: coercion, with the goal of restoring desirable behaviour, which is linked to beliefs about internal attribution, and damage limitation, which is linked to EOI, intrusion into the patient's life, and beliefs about external attribution (Barrowclough and Tarrier 1997).

It may be the case that a patient living with a hostile, over-involved relative will have low social functioning. However a low social functioning patient in the home could lead to the relative becoming hostile, critical, over-involved, with high face-to-face contact, in an effort to manage a difficult situation. In the Threshold model, HEE relatives may contribute chronic stress into the life of the patient in addition to acute stress caused by life events, and this combination may lead to relapse (Barrowclough and Tarrier 1997).

A finding which emerged from Family Intervention studies was that changing relatives HEE to LEE led to a reduction in relapse rates (Tarrier et al 1988, 1989, Leff and Vaughn 1981, Leff et al 1982). However it may be the case, as Barrowclough and Tarrier (1997) suggest, that an intervention in a family leads to clinical improvement in

the mental state of the patient, and this in turn leads to LEE in relatives. Barrowclough and Tarrier (1997) suggest that HEE may be a cause or a consequence of relapse because EE is interactional, with patients and relatives affecting each other.

Other stressors cannot be ruled out. Stressors may be biological, genetic or environmental. We must consider the individual, genetic vulnerability to stress. The biological factors of fight and flight, where the person with schizophrenia is permitted to do neither, may lead to acute and chronic stress. Family behaviours contribute to environmental stress and, in addition, social stress contributes to the general level of stress and potentially to relapse (Barrowclough and Tarrier 1997).

Empirical research supported the view that factors other than HEE can lead to relapse, suggesting that being male, being single, living in a city and experiencing life events can lead to relapse (Leff et al 1987). It could be argued that the starting point is the carer's perception of carer burden. HEE is related to high subjective carer burden and some carers cope less well, do not adjust, become fearful and anxious, and patients relapse (Atkinson and Coia 1995).

3.6 Summary

Differences in values and beliefs between poorer families and health professionals may lead to these families feeling that they are being negatively judged, a situation which contributes to expression of HEE. There are various explanations for HEE (e.g. high levels of face-to-face contact, offspring-parental relationship). HEE is a binary concept or dichotomous measure with LEE and HEE being easily identifiable, but past methodological flaws in research into EE, and changes in rating practices, cast doubt on

previous findings. There is some dispute about the validity and reliability of the CFI. HEE and LEE may be subjective concepts. Most of the literature and research supports the hypothesis that HEE leads to relapse, but, again, there are flaws in past research. It is possible that HEE is not expressed consistently by relatives. The simple causal model of HEE is not fully supported. Studies suggest that relatives and people with schizophrenia affect each other negatively. Some elements of schizophrenia may exist prior to the onset of schizophrenia and independently of the behaviours of the person with schizophrenia. Life events may contribute to the onset of schizophrenia. Genetic, biological and environmental stressor may contribute to the onset of schizophrenia. LEE may not be a positive situation for people with schizophrenia.

HEE is related to subjective carer burden. A carer who perceives that the caregiving situation is very demanding and stressful is likely to display HEE. Carer burden is examined in the next chapter.

CHAPTER FOUR:

CARER BURDEN

Introduction

This chapter focuses on the nature and types of burden carers report. The views of Thompson and Doll (1982), Creer, Sturt and Wykes (1982), Crotty and Kulys (1986), Namyslowska (1986), Perring et al (1990), Adams (1994), Wheeler (1994), Eakes (1995), Atkinson and Coia (1995), Greenberg, Greenley and Benedict (1994), Howe (1995), Provenchar (1996), Rimmerman et al (1999), Ward-Griffin and McKeever (2000) and Ferriter and Huband (2003) are examined. In addition, the issue of who becomes a caregiver is explored.

In discussing high levels of stress and distress in families, Tredget (1999) asserts that families often feel burdened by the serious persistent nature of the illness. This is important because 60 percent of first admissions return home (MacMillan et al 1986) whilst 60 percent of first episode patients with schizophrenia live with their families (McCarthy et al 1989). Moreover, 60 percent of long term schizophrenia sufferers live with significant others (Hughes et al 1996). Therefore carer burden is an important topic in examining the experiences of people with schizophrenia and their families.

Key seminal works have been used to explore various aspects of carer burden. Thompson and Doll (1982) and Provenchar (1996) offered empirical evidence that objective and subjective burden exist. A range of authors conclude that carers experience subjective burden: Adams (1994), Wheeler (1994), Eakes (1995) and Ferriter and Huband (2003). Creer et al (1982), Greenberg et al (1986), and Namyslowska (1986) disputed this position, and Crotty and Kulys (1986) reported

mixed and inconclusive findings, offering only partial support for the presence of carer burden.

Rimmerman et al (1999) offered insights into carer burden, and discussed the benefits to carers of partial disengagement from the offspring with schizophrenia.

Empirical work by Creer et al (1982) and Namyslowska (1986), and overviews of carers of people with schizophrenia concluded that adaptation to caregiving occurs, and Namyslowska (1986) disputed that disruption at home is caused by the person with schizophrenia. Measurement of carer burden is examined by Perring, Twigg and Atkin (1990) and Atkinson and Coia (1995), who adopt the position that there are flaws in measures used to assess carer burden.

Some authors investigated the mental health of carers (Perring et al 1990, Aldridge and Becker 1993, Ward-Griffin and McKeever 2000 and Ferriter and Huband 2003). Some authors discuss who becomes a carer and adopt the position that carer burden is not shared equally within the family (Platt 1985, Perring et al 1990), but Martin (1995) disputes this. A range of authors have noted that carers are more often female (Thompson and Doll 1982, Crotty And Kulys 1986, Aldridge and Becker 1993, Howe 1995).

4.1 Objective and subjective burden exist

In this section the evidence for the existence of carer burden will be evaluated. There is evidence that objective and subjective burden occurs in families who care for a mentally ill person. Objective burden means the caregiving tasks that the carer engages in, and

is assessed without considering carers' feelings about these. Subjective burden means the emotional responses to these tasks (e.g. depression).

Thompson and Doll (1982) used interviews and rating scales to measure subjective and objective burden in 125 carers. Subjective burden was measured using Freeman and Simmons' (1961) Index of Family Members Embarrassment, which contained five questions, and the Incomplete Sentence Blank test (ISB) (an example of a question is: My husband's behaviour...) with the carer completing the sentence (Rotter and Williams 1947). Reliability for the ISB was high (0.74), using Chronbach's Alpha. The ISB measures four dimensions: overload, feeling trapped, resentment and exclusion (which means disengagement from the patient and reluctance to keep the patient within the family). Objective burden was measured by five indicators: financial burden, role strains, interruptions in normal life, supervision, and problems with neighbours. These were measured by the presence and extent of these factors (e.g. 0 no burden, 1-2 moderate burden, 3-5 severe burden).

Most carers reported moderate subjective and objective burden. There was a weak association between severe subjective and objective burden, in that 27 percent of carers were rated as having severe objective burden, while only 15 percent reported severe subjective burden, suggesting that a carer could have severe objective burden but moderate or no subjective burden. Thompson and Doll (1982) propose that this indicates adaptive tolerance by carers. Severe subjective burden was related to the psychiatric condition of the ill relative.

Reliability was present in the Index of Family Members Embarrassment because the Chronbach's Alpha reliability score was high (0.86). The sample was random, which

potentially could have been representative, but was in fact a homogenous sample (white, female, social class 1V and V), limiting the representativeness of the sample and the generalisability of the findings. Bias might have been introduced into the sample and findings because clients identified carers to be interviewed, which suggests they had a good relationship with their carer, which, in turn, may have led to positive comments by the carers.

These authors introduced above link high expressed emotion (HEE) to carer burden. They concluded that critical comments and hostility, as assessed by Brown et al (1972) and Vaughn and Leff (1976) were a response to the care burden, and the care burden explained the anger and resentment in these carers.

Provenchar (1996), in a study of objective burden among 70 carers of people with schizophrenia, used a self report questionnaire to assess objective and subjective burden. Objective burden meant the observable negative consequences for individuals who care for people with schizophrenia (for example, restricted social life). Subjective burden meant the internal feelings generated by the care giving situations. An Objective Burden Questionnaire (Platt 1980:1983) administered, measuring negative consequences for family members at home. The negative consequences were measured using a three point scale of severity, with higher scores indicating greater objective burden.

However this was a convenience sample and there was a high level of homogeneity that limited the generalisability of the findings. The homogeneity prevented exploration of other variables and relationships (e.g. type of relationship between patient and primary caregiver, family income or age and gender of care giver and patient). The study

population, of 70 people, were 90 percent white, 90 percent parents, 80 percent female, 50 percent unemployed or retired and the mean age was 59 years. These were mainly white elderly mothers, and most of the ill relatives were single, unemployed males, with a mean age of 34 years (Provenchar 1996). The findings may not be perceived as truly objective as they were based on self reporting by the primary caregiver, who was likely to be influenced by subjective factors. The OBQ is a modified version of the Social Behavioural Assessment Schedule, a semi-structured interview (Platt et al 1980:1983) which was altered to become a self report questionnaire to measure negative consequences on family members. The OBQ was not validated to ensure that reported subjective burden was accurately reflected in objective burden.

The findings highlighted tense relationships, physical and emotional problems for carers, disturbance in work performance of carers and disruption in family life. Provenchar (1996) proposed that it could be inferred that these primary care givers gained some benefits from membership of self-help groups because restrictions and disruption to social life were not frequent and they managed their private lives well. The problem only existed when the ill person was present.

Subjective burden will now be discussed. Creer et al (1982), in interviews with 52 relatives of clients with mental health problems, examined the type of support given to patients and the burden on relatives. The assessment tools used were rating scales: an 18 item rating scale which identified the type of care given by relatives, and a subjective burden rating scale, which was a measure of satisfaction, resignation or dissatisfaction. The main findings were that relatives assisted clients with self-care, washing, dressing, managing money and taking medication. Socially difficult behaviours were identified: embarrassing behaviour in public, threats or violence, disturbances at night, and carers

believed that they could not leave their relative alone. Subjective burden was examined and overall 60 percent of relatives were content with their level of responsibilities, while 15 percent were dissatisfied and 25 percent were resigned. This suggests that subjective burden was not high in this sample. Carers appeared to adjust to the caregiving situation. What was perceived to be a burden by one, was not perceived as such by another. The more neutral term offered was support, rather than burden. Practical assistance and emotional support were the most frequently identified areas of desired help. The interviewers identified objectively that of the 50 relatives, 31 had one unmet need. The isolation of these relatives and their lack of a voice were reported in this study. Reliability was reported as strong because there was high inter-rater reliability in the assessment and there was high overall agreement between the interviewer and an independent observer. There was overall agreement of 97 percent in the rating of 18 support items, and agreement on the ratings of relatives' attitudes (satisfaction, resignation, dissatisfaction) was 90 percent. However, this was a small sample and findings may not be generalisable.

Other authors found evidence of subjective burden. Adams (1994), in an ethnographic study of six caregivers of chronically confused people, used interviews and collected daily diaries, to examine the emotional experiences of the caregivers. These carers reported feeling low, anxious and depressed. They experienced frustration, guilt, physical pain and tiredness, and feelings of loss. However, the study's generalisability is limited because of the small sample. This study sample were carers of elderly people with mental disorders and the findings are similar to those of carers of people diagnosed with chronic schizophrenia.

Wheeler (1994), in a qualitative study of impact of caregiving among four primary caregivers, used semi-structured interviews to explore their views at the point of diagnosis of schizophrenia. Content analysis was used to analyse data and this qualitative approach facilitated exploration of the way people live, experience and analyse life events. The semi-structured interviews may have led to interviewer bias. The relatives with schizophrenia were all young male adults and the term used in this study was 'impact' rather than 'burden'. The main limitation of this study was the small sample size, which limits generalisability. However in-depth information was gained in the four interviews, highlighting the severity of the impact of caregiving, and of schizophrenia, in all areas of these caregivers' lives.

These four caregivers reported trauma, distress, fear and uncertainty. Three out of the four reported relief once they were informed of the diagnosis of schizophrenia. They felt devastation, powerlessness, grief and loss; specifically loss of the son, who had changed so much. They felt anxious and fearful when their sons absconded and they worried about their sons' future. Some reported feeling that there was no hope, whilst others held onto hope, never giving it up. Some reported that old friends did not speak to them any more and actively avoided them. Their lives became disrupted and they became preoccupied with their sons' problems, which, according to Barrowclough and Tarrier (1997), is part of HEE. They had a restricted life and reported physical illness, anxiety and sleep problems. They became socially isolated because of the lack of support. This study painted a very negative picture of the impact of schizophrenia on a caregiver. The term 'burden' was not used but burden was clearly described. Trauma, distress, fear, uncertainty and family and life disruption were all negative themes. Relief on being informed of the diagnosis was the only positive theme.

Eakes (1995) reported caregiver burden, in an American study using a questionnaire and a follow up interview to explore the lived experience of ten parents of chronically mentally ill individuals. The main focus was on emotional burden and chronic sorrow. All these parents were between 54 years old and 75 years old and the mean age was 62 years. All the children were male and only four were diagnosed with schizophrenia. Their ages ranged from 27 to 46 years old. This study population was similar that that in the Provenchar (1996) study.

Eighty percent of the parents showed evidence of chronic sorrow. The chronic sorrow experience was described in detail. The main triggers were unending care giving responsibilities and poverty. The chronic sorrow experience appeared to be permanent, periodic and pervasive. All the findings pointed to permanent grief related feelings. Chronic sorrow was described as:

“a perception of sorrow or sadness over time in a situation that has no predictable end. The sadness or sorrow was cyclic or recurrent and was triggered either internally or externally and brought to mind the person’s disappointments, losses or fear. The sadness or sorrow was progressive, and could intensify even years after the initial sense of loss, disappointment or fear”

(Eakes 1995 p.78)

Anger, confusion and frustration were the most frequently described emotions. The unending care giving was the main trigger event for the grief related feelings. Eakes (1995) proposed that chronic sorrow was a normal response to a never ending loss situation which was a prolonged grieving process, not an illness. This work shed light on the long term emotional reactions and permanent emotional pain these parents suffered. This was a small convenience sample of ten, limiting its generalisability.

There was strong inter-rater reliability between the independent ratings of the researcher and a colleague. According to Eakes (1995), validity and reliability had already been established on the Burke/Nursing Consortium for Research on Chronic Sorrow (NCRCS) (caregiver version) assessment tool (Burke 1989, Eakes et al 1991). Burke (1989) is an unpublished doctoral dissertation in Boston University and this work could not be examined. In this assessment tool, some of the questions were open ended, so reliability may be limited as repeatable findings could not be ensured. Face validity is likely to be strong as all the questions focus on the carers' experiences.

In an overview of schizophrenia, using a series of 21 case studies, Howe (1995) highlighted family issues, emotional burden and interactions between caregivers and health professionals. Howe described the impact of a son with schizophrenia on families and highlighted family stress, fear and disruption. The term 'impact', rather than 'burden', was used when describing and discussing family consequences. Carers reported that they felt alone with overwhelming problems. They felt depressed and frustrated and had to deal with their son's anger, aggression and jealousy at home. Howe highlighted the severe emotional burden and strain on family members and the powerlessness that parents felt. Family breakdown, with isolated older mothers attempting to care for offspring with schizophrenia, and the concept of the state of victimhood as a consequence of family burden, for these caregivers was highlighted. In conclusion, in this study carers reported negative consequences of caregiving. However the sample was small, limiting the generalisability of the findings.

Ferriter and Huband (2003), in a series of interviews with 26 parents of 22 people with schizophrenia, used a degree of burden scale (Thompson and Doll 1982), a focused life story interview (Tagg 1985) and a three point scale on the views of helpfulness of

others (Lewis and Zeichner 1960), with the aim of ascertaining their experiences. This work had limitations and flaws. It used a random sample but all parents were white, so this sample was unlikely to be representative of all parents in this situation. The number given was 22 people with schizophrenia, but the parents of these individuals were interviewed and the reader had to work out the number of parents who were interviewed as this was not clearly stated. The term helpfulness was not defined and may have had different meanings to different people. There was a potential ethical issue, in that the study may have increased self-blame by parents because the pathological parenting theory was proposed to them. The focus on negative issues may have caused harm to these parents and bias in their responses. There was a focus on negative aspects of caregiving and there was no focus on the contribution made to family life.

These parents reported they suffered emotional distress, fear, stress, grief, confusion, guilt, self-blame and feeling trapped. They expressed loss (specifically, loss of what might have been). They could not cope with their children's' difficult behaviours (e.g. social withdrawal, verbal violence and reversed sleeping pattern) and they suffered financial hardship because they supported their offspring financially. They reported that health professionals were unhelpful and gave them no information about schizophrenia and did not reduce the burden. There were some positive findings, in that some parents did not feel blamed or neglected and this was associated with psychiatrists' and nurses' input. In conclusion, what emerged from this study was that parental perceptions of burden were different from professional perceptions of burden.

Some authors reported that carer burden occurs, but that if carers can disengage from their ill relatives, carer burden will be reduced. Rimmerman et al (1999), explored the impact of caregiving on carers in an Israeli study of 100 ageing mothers and their 100

dependent adult children, with psychiatric disability, who lived with them. They used four methods of data collection: a demographic questionnaire, a 38 item assessment 'Structure of Psychological Stress and Well Being in General Population' (Veit and Ware 1983) a Social Network List (Kazak 1988) and a questionnaire which was linked to an interview, exploring mothers' involvement in caregiving. The interviews were single interviews and it was not a longitudinal study, which may have limited its reliability. However, the multi-method approach and triangulation enhanced reliability. This Israeli study may not translate well into British society because of the cultural differences between the two.

Emotional and psychological impact were explored and the term 'burden' was not used. Mothers who had the greatest involvement with their dependent adult offspring, a social support network and whose children took part in a day treatment programme, had lower levels of psychological distress and higher levels of well-being than mothers who did not have these factors. Married, educated, mothers with no disability or chronic illness, had the highest scores of well-being, linked to maternal involvement, a good social support network, and attendance of the dependent adult child at the day treatment programme. Day treatment had a bigger positive impact than maternal involvement or social support network, perhaps because it allowed disengagement from the interdependence of the child, and mothers could separate themselves from their adult child for a while. Having co-terminous life boundaries with mentally ill offspring led to psychological distress. These authors supported Perring et al (1990), as they concluded that mothers who could balance their own needs and their children's needs could achieve well-being.

4.2 Carer burden is disputed

Some authors disputed or offered only partial support for the existence of carer burden. Crotty and Kulys (1986), used interviews, the Family Burden Scale (FBS) (a four part rating scale) (Schainblatt and Hatry 1980), and the Social Support Network Inventory (SSNI) (Flaherty et al 1983), to measure family burden in a sample of 56 people with a diagnosis of schizophrenia and their significant others (n=112). Interactional variables were measured (e.g. frequency of contact, type of support given by carers, type of support given to carers by clients). Interactional variables were coded on a five point scale (e.g. frequency of contact-1 once a year or less, 5 usually daily).

Reduced reported carer burden was associated with carers' perceptions of increased support. Sixty two percent of female carers and 40 percent of male carers did not perceive the client to be a burden. Sixty percent of female clients and 56 percent of male clients were not perceived to be a burden. Predictors of being perceived as a burden were outlined: not having a confidant, being female and young, having higher levels of education and living in a large household. Social support appeared to reduce the level of burden.

The FBS was reported to have good face validity and for this measurement tool the Chronbach's Alpha score was high (0.89), indicating reliability. The SSNI had a high test-retest reliability. The carers were identified by clients and the presence of good relations may have introduced bias into the sample findings. The carer sample may not have been representative of the wider community, although this sample had similar characteristics to the Thompson and Doll (1982) study sample which had an overrepresentation of female carers. Only burden experienced in the month prior to the

study and perceived by carers to be caused by the ill relative, was measured. This potentially relied on retrospective recall and subjective feelings, and ignored past perceived burden. This study may have offered only a snapshot, which may have been unrepresentative of carers' burden.

Crotty and Kulys (1986) reported mixed findings, with significant numbers of carers identifying that their relatives with schizophrenia were not a burden. There was increased burden if a person with schizophrenia lived in a large household with many members. However it may be the case that conflict is more likely in a large household. Increased burden occurred if the person with schizophrenia had no confidants. However it may be the case that family respondents did not have a good relationship with the person with schizophrenia, or client respondent, or acknowledge that the person with schizophrenia had a confidant, and these family members may have emphasised the client respondent's lack of connectedness with others, and may have over-emphasised the importance of family members. Subjectivity in the findings was possible. Family respondents who were not confidants of the client respondent reported that the client respondent had no confidants, while family confidants who perceived themselves as a confidant to the client respondent reported the opposite. What was reported was a subjective view based on perceptions, and on the closeness of the relationship between the client respondent and the family respondent. The family respondents who were confidants of the client respondents reported less severe burden than family respondents who were not confidants of client respondents. It may be the case that the close relationship between client respondents and family respondents allowed family respondents to take a positive view of the client respondent and develop empathy with them. A potential implication of this is that if a client has no outside confidant or social support, the family may perceive them as a burden. A family with

carer burden may not be able to effectively support a client with schizophrenia. The client may become stressed and relapse and this may lead to admission into hospital.

Namyslowska (1986) reported that the presence of a mentally ill family member does not necessarily lead to family disruption, that disruption exists in normal families and that relatives adapt to caregiving situations. In this controlled study, the sample was a research group, families with a member with schizophrenia (n=152), and a control group, normal families (n=1832). They used a standardised questionnaire (Markowska 1980 *The every day life of a Polish family*) to examine objective burden, and this tool examined all aspects of family life and compared findings from both groups. Subjective burden was examined using a detailed questionnaire. The use of the standardised questionnaire may have strengthened reliability.

There may be an explanation for these results. The illness and even individuality may have been perceived as less important than the proper functioning of the family system. There was pressure on the encouragement for the person with schizophrenia to continue to accept their family roles and responsibilities. There was no exclusion of the person with schizophrenia in these closed, autonomous, nuclear families. The person with schizophrenia remained in contact with all family members and there was genuine love and affection between the carer and the spouse with schizophrenia.

Greenberg et al (1994) used postal questionnaires, telephone and face-to-face interviews, in an American investigation of family respondents' views and the contribution that people with serious mental illness made to their families. The views of these clients (n=725), and their carers (n=725), were sought using the Client Questionnaire and the Family Questionnaire (Bumpass and Sweet 1989).

Clients with serious mental illness were reported to provide help to their families (e.g. companionship, housework, shopping and listening). These clients were not perceived to be a burden by their families. There were high levels of agreement between clients and family members.

Clients in this study may have had high functioning, as assessed by the Global Assessment of Functioning Scale Rating (GAF). Levels of functioning were indicated by the GAF, which is part of the Diagnostic and Statistical Manual-111-R (American Psychiatric Association 1987). They concluded that the higher functioning of the family based clients appeared to have a minimal effect on the client helpfulness rating. Internal consistency-reliability was reported as adequate for these measures. There was a high level of consistency between the Client Questionnaire and the Family Questionnaire. To assess reliability of these measures, Chronbach's Alpha was used. However, the sample was predominantly white, which potentially limited the representativeness of the sample and the generalisability of the findings.

How caregiving as perceived by the carer is likely to influence their reporting of burden. If caregiving is reported as a normal parental responsibility, it is likely that it will be perceived as a neutral or positive activity. If caregiving is perceived negatively and is done reluctantly, carer burden will be reported. It may be the case that if caregiving is redefined, there will be less severe burden reported, regardless of the actual caregiving tasks.

Atkinson and Coia (1995), in an overview of schizophrenia, discuss the impact of schizophrenia and caregiving on the family and examine the concept of, and perception of, burden. Like Wheeler (1994), these authors do not use the term burden but impact.

They suggest that the person with schizophrenia may not want to accept that they are a burden, and the family may be upset at the idea of a loved one being perceived as a burden by others. The care burden needs to be understood in the context of relatives having no ability to choose to withdraw their caregiving. They state that the use of the term 'burden' to describe the impact of caring is not only emotionally negative, but serves to limit the role of the carer. A more neutral term might be 'support', which may include the more positive side of caring. Elsewhere the term 'impact' is used, a statement also made by Perring et al (1990). Atkinson and Coia (1995) highlight the clear positive correlation between less caregiver burden and the following: redefining the stressful caregiving experience in a way that makes it more understandable and manageable, problem solving, the presence of spiritual support and the extended family supporting the carer.

How the person with schizophrenia's behaviour is perceived is related to, and affected by, the carer's own perception of stress and burden. What is burdensome to one is not burdensome to another, according to Atkinson and Coia (1995), and this view is reflected in the works of Creer et al (1982), Thompson and Doll (1982) and Perring et al (1990). In discussing the incidence of anxiety and depression in carers of people with mental health problems, Atkinson and Coia (1995) conclude that new carers are much more likely to experience emotional distress than carers who have been caregiving for some time.

4.3 How burden is measured

I will now discuss how burden is measured. If the measures are potentially flawed, the reliability and validity of the identified phenomena of carer burden is weakened.

Perring, Twigg and Atkin (1990) review research about family caregivers of people with mental illness which examines the impact of mental illness on the family. This work contained acknowledged limitations in that it did not focus on race, or on those caring for children, or on substance abusers.

According to Perring et al (1990), the burden of care issue is more complex than past research into this issue suggests. Much past research focuses on easily quantifiable features (for example financial and educational disruption), while caregivers are more concerned about issues which are difficult to measure (e.g. emotional distress). There are difficulties in trying to measure carer burden, especially subjective burden.

These authors find a link between caregiving and psychiatric illness in carers. However, interestingly, greater distress correlates with a shorter history of caring and there is a strong indication that families adapt to the new caregiving situation. An alternative explanation, offered by Perring et al (1990) for this finding, is that some families do not survive intact with a mentally ill member, and so are not present in this study population, and therefore the surviving adjusting family is not typical. Perring et al (1990) question the concept of caregiver burden and conclude that health professionals heavily influence the general acceptance of this concept. Issues of interpretation and meaning were not explored in the past because the dominant method of exploring carer burden has been quantitative (e.g. rating scales which focus on easily measured aspects of family life).

Atkinson and Coia (1995) discuss measurement of burden, asserting that there is no uniform criterion or measure of burden, and that burden is conceptualised by different authors in different ways, with the result that it is not possible to compare studies.

Burden is difficult to define or measure because there is a “fine line between acceptable normal duty and desire of relatives to care and the burden of care which they find unacceptable” (Atkinson and Coia 1995 p.94).

4.4 Carers’ Mental Health

In this section, studies which investigate poor mental health in carers will be explored. This is related to subjective burden (e.g. reported depression). In Ward-Griffin and McKeever (2000) the roles of carers are discussed in this ethnographic study of relationships between caregivers and nurses. Twenty three nurse-caregiver pairs were interviewed and field notes were collected and analysed. This work offered insights into the roles and needs of family caregivers of elderly relatives. The most common roles for caregivers were worker and patient. According to these authors, the stress within caregiving, and the simultaneous roles of worker and patient, created tension in the nurse-caregiver relationship. Chronic stress, caused by the daily problems, had the most negative effects on physical and mental wellbeing.

According to Aldridge and Becker (1993) child carers experience stress and depression. In this study, 15 young people were interviewed twice. Initial interviews were semi-structured and later interviews were structured, using a structured verbal questionnaire. This questionnaire was adapted from the National Association of Health Authorities and Trusts (NAHAT) (1991). Thematic content analysis was used to analyse data. Four respondents were adult carers who had been caregiving since childhood. Of this sample, 11 were aged between 3 and 18 years old and only 4 were from an ethnic minority group. The sample was accessed by contacting relevant health professionals, then contacting the young peoples’ parents for permission and consent by telephone. This

was a convenience sample, which may not have been representative of wider samples of young carers. A mediator was present at the point of contact with the ethnic minority parents and young people. This may have created a confidentiality issue. Three methodological issues were highlighted in this study. Firstly, shyness of the young people, who had not spoken of their experiences before, and the presence of a female interviewer with young males of Asian origin, which may have inhibited them. Secondly, to gain trust, the interviewers empathised with these young people, which may have reduced their impartiality and neutrality, and this may have influenced the interactions and created unintentional bias. Finally, words had to be changed to reflect young peoples' understanding (e.g. the word 'depressed' was changed to 'sad').

The semi-structured interviews, with the use of probes, may have led to reduced reliability and potential interviewer bias, but validity was likely to be high because all questions were focused on the participants' experiences. Reliability was likely to be increased when structured interviews were used.

In Ferriter and Huband (2003), parents reported they suffered emotional distress (e.g. fear, stress, grief, confusion, guilt, self blame and feeling trapped). They could not cope with difficult behaviours. There was evidence of protective parenting in these parents of offspring with schizophrenia, and this may have led to further difficulties and HEE (see Chapter Three).

4.5 Family disruption

In this section family disruption will be discussed. Namyslowska (1986) concluded that family disruption exists in every family and that it may not be the person with

schizophrenia who causes it. Family disruption is found in many studies, but most of these are not controlled studies. Namyslowka's (1986) is the exception.

Perring et al (1990) suggest that disruption in families is not caused by the person with schizophrenia. Instead, they assert that disruption in families is common, and, in consequence, many studies, in their view, are flawed, because they have no control groups, with the result that accurate measurement and evaluation of disruption is impossible.

According to Perring et al (1990), because past research focuses on easily quantifiable features (e.g. financial disruption), there are difficulties in trying to measure carer burden. Financial disruption may occur because the carer has to leave paid employment or because carers have to take time off to care for their ill relative. This is not necessarily the fault of the person with schizophrenia, but is likely to be a result of deficits in the support system for carers and for people with schizophrenia.

4.6 Who becomes the caregiver?

In this section who becomes the caregiver will be discussed. According to Platt (1985), there is a different level of impact on different family members. Perring et al (1990) agree with Platt (1985) and are critical of a trend in previous research to study families and burden, denying the reality of one main caregiver having the larger share of caregiving (Perring et al 1990). The idea that there is a different level of impact on family members was questioned by Martin (1995). She suggested that the focus should be on the whole family's needs, suggesting equality of burden within the family.

A range of studies highlighted the trend for carers to be female (Thompson and Doll 1982 and Crotty and Kulys 1986, Provenchar 1996). Aldridge and Becker (1993), in a series of case studies, asserted that child carers were likely to be female, and that there was family collusion in delegating care roles onto these female children. Howe (1995) proposed that caregivers were most likely to be women and mothers, specifically elderly mothers, delivering 24 hour a day care with no opportunity to lead a normal life. Jones et al (1995) agreed with this last point, maintaining that most caregivers were female and most clients being cared for were young males, a pattern they reported was repeated in most other studies.

4.7 Discussion of themes

The measurement of burden is perceived to be flawed because in past research, only factors which can be measured using quantitative research have been examined (Perring et al 1990 and Atkinson and Coia 1995). In this literature review, most of the studies included measures which analysed data in a quantitative way (Thompson and Doll 1982, Creer et al 1982, Crotty and Kulys 1986, Namyslowska 1986, Greenberg et al 1994, Eakes 1995, Provenchar 1996, Rimmerman et al 1999, Ferriter and Huband 2003). However qualitative methods and methodologies were also included. Interviews were used in Thompson and Doll (1982), Creer et al (1982), Crotty and Kulys (1986), Aldridge and Becker (1993), Adams (1994), Wheeler (1994), Greenberg et al (1994), Eakes (1994), Rimmerman et al (1999) and Ferriter and Huband (2003). Case studies were used in Howe (1995). There were flaws in these studies. There was potential bias in the sample (Thompson and Doll 1982), use of convenience and unrepresentative samples (Aldridge and Becker 1993, Provenchar 1996, Ferriter and Huband 2003) and limited generalisability in the findings (Adams 1994, Wheeler 1994, Howe 1995,

Provenchar 1995). There was potential interviewer bias, because of the use of semi-structured interviews (Aldridge and Becker 1993, Wheeler 1994, Provenchar 1996).

However strong reliability was present in studies which used rating scales and other measures which assessed data in a quantitative way. Thomson and Doll (1982) used rating scales, Index of family Embarrassment, and Incomplete Sentence Blank test, whilst Creer et al (1982) used an 18-item rating scale to assess burden. Crotty and Kulys (1986) used two rating scales and a Social Support Network Inventory. Aldridge and Becker (1993) used structured interviews and Greenberg et al (1994) used questionnaires. Eakes (1995) used a questionnaire and a care giver assessment tool (the NCRCS) (Burke 1989, Eakes et al 1991) on which reliability and validity had already been established). Rimmerman et al (1999) used a 38-item assessment tool and the Social Network List and questionnaires.

High inter-rater reliability was present in the following studies: Creer et al (1982), Eakes (1995), and high test-retest reliability was present in Crotty and Kulys (1986). Strong face validity was present in Eakes (1995) and Crotty and Kulys (1986), and validity was likely to be present in all studies which used interviews, questionnaires and case studies, because the focus was on the experiences of the carers and on carer burden.

In this literature review there was no uniform measure of carer burden, a point made by Perring et al (1990). Past studies have used a correlation between physical and psychiatric health as indicators of carer burden. As example of this is the Social Behaviour Assessment Schedule (SBAS) (Platt et al 1980:1983). The Objective Burden Questionnaire used in Provenchar (1996) is a modified version of the SBAS and identified symptoms of physical and psychiatric illness in carers. It could be argued

that there is a correlation between physical and psychiatric health indicators and carer burden, but the flaw in this argument is that carers are frequently older people and older people are more likely to have physical health problems. Despite the reliability and validity claimed by authors when assessing and measuring carer burden, it may have to be accepted that it is not a totally accurate science.

Carer burden was described in a range of works which used different terms. Some studies used the term 'burden' (Thompson and Doll 1982, Creer et al 1982, Crotty and Kulys 1986, Aldridge and Becker 1993, Eakes 1995, Provenchar 1996, Ferriter and Huband 2003). Other authors used the term 'impact', although the impact was consistently negative. Adams (1994) used the term 'emotional experiences' and he described a negative emotional experience. Coleman and Smith (2005) propose that if people with schizophrenia redefine themselves, they can develop a positive view of themselves and their experiences, and it may be the case that carers can engage in this process. A carer's negative perception of the caregiving situation may lead to an increased experience of burden (Adams 1994, Greenberg et al 1994). It may be the case that if carers redefine their situation, it becomes more manageable (Adams 1994, Greenberg et al 1994, Atkinson and Coia 1995). However this position ignores the loss and stress experienced by carers. The consequences for carers appear to be consistently negative and stressful, regardless of the term used.

The term 'burden' may be misleading. Carers may perceive their work with the person with schizophrenia as valuable family support. However this view places the focus on the patient who is to be supported, and the carer is viewed only in terms of their relationship to the patient. Carers' needs and rights may be ignored (Perring et al 1990).

Health professionals' perceptions of the caregiving situation may be different from those of carers. Carers may be trying to support their sick relative because they are concerned about him or her, and the health professional may consider the carer to be emotionally overinvolved or over-protective (Howe,1995, Ward-Griffin and McKeever 2000). This view, with the focus on HEE, may cast doubt on the reports and perceptions of the carers. It is possible that carers and health professionals have different perceptions and understandings of schizophrenia. Health professionals may know and perceive schizophrenia as an illness and a list of clinical features, yet not connect this knowledge and perception to the reality of carers, who experience subjective and objective burden (Howe 1995). Carers build up their own expertise on schizophrenia and its management, and this expertise may be ignored by health professionals. Health professionals may have different goals from those of the carers. Health professionals may not focus on the wellbeing of the carer or a reduction in the carer's burden. Through exhaustion and illness, carers become patients. Carers' needs for practical support are often not met and carers are advised to seek emotional support from carer support groups (Ward-Griffin and McKeever 2000). The ill and vulnerable are expected to support each other. Partnership between carers and health professionals could improve the situation for carers.

I will now discuss disruption in families. Disruption is proposed to include social and personal life, employment and financial aspects of life and the emotional impact of caregiving (Perring et al 1990). One position is that disruption may not be caused by the person with schizophrenia, and that disruption occurs in all families (Namyslowska 1986, Perring et al 1990). Family disruption was reported in the following studies: Thompson and Doll (1982), Creer et al (1982), Wheeler (1994), Adams (1994), Howe (1995), Eakes (1995), Provenchar (1996), Ferriter and Huband (2003). Family

disruption was also reported in Crotty and Kulys (1986) who did not fully support the position that carer burden occurred in families.

Certain aspects of disruption were reported: a restricted life (Crotty and Kulys 1986, Provenchar 1996), financial problems and the negative impact of disruption on family life (Crotty and Kulys 1986, Eakes 1995, Ferriter and Huband 2003). All the studies in this literature review supported the position that disruption was caused by the person with schizophrenia, with the exception of Namyslowska (1986). It may be the case that researchers and health professionals only pay attention to families where disruption is obvious. The most common manifestations of disruption in this literature review are in carers' social and personal life, with a restricted life being reported and the emotional burden of caregiving. Disruption may not be consistent. It may be a short-term problem because the person with schizophrenia and the family are in crisis.

There may be some benefit to carers if they partially disengage from the person with schizophrenia (Rimmerman et al 1999). Howe (1995) maintains that the lack of opportunities for carers to disengage from the person with schizophrenia is an important factor in family breakdown. Thompson and Doll (1982) identified carers' behaviour, specifically 'social withdrawal' and 'emotional withdrawal', behaviour which was similar to disengagement as described by Rimmerman et al (1999). However, Thompson and Doll (1982) coded 'social withdrawal' and 'emotional withdrawal' under 'exclusion of the patient', which appears to be a negative evaluation of this behaviour and may be a potentially subjective judgement by these researchers. The degree of withdrawal was not clarified by Thompson and Doll (1982). Rimmerman et al (1999), clarified their term to mean partial disengagement and viewed this as a positive coping strategy which helped carers find time for themselves. There may be a re- evaluation of

such behaviour between 1982 and 1999, with partial disengagement being accepted as a positive strategy and the presence of co-terminous life boundaries being perceived as harmful to carers. Most carers are female, and this re-evaluation of such behaviour may also be a re-evaluation of female behaviour, with less emphasis on females being based in the home.

I will now discuss adaptation by carers. Namyslowka (1986) discusses carer adaptation to caregiving. These carers lived in closed, autonomous, nuclear families who received no help from outside the family. The person with schizophrenia was actively included in all aspects of family life and was not excluded or marginalised. Sixty percent of the relatives in the Creer et al (1982) study reported being content with their level of caregiving responsibilities. This may indicate adaptation or lack of carer burden, but the overall picture is complex. Most of the relatives in this study had one unmet need and the most frequently reported unmet needs were 'practical assistance in supporting the relative', 'opportunity to discuss management of difficult behaviours', and 'emotional support for relatives'. It may appear that carers adapt, but this does not mean they do not need care and support, or even a break from caregiving. The isolation of these carers was noted and without support, and carers may lead a restricted life. In Wheeler (1994), adaptation was reported as a minority finding, with carers perceiving adaptation as a necessary strategy, but one that was accompanied by feelings of loss. Therefore adaptation should not be perceived by health professionals as a positive strategy without exploration of subjective burden.

In Eakes (1995) carers tried to adapt, unsuccessfully. The grieving process could be viewed as part of the healing process, and is associated with loss. The loss which accompanies adaptation is discussed by both Wheeler (1994), Adams (1994) and Eakes

(1995). It may be the case that chronic sorrow is the recurrence of the grieving process and may be a necessary stage before acceptance of the new situation occurs. Nurses may need to recognise a recurrence of grieving and offer support in a long-standing loss situation. Adams (1994) links adaptation and loss to HEE, because parents became preoccupied with their offspring's problems, and preoccupation is an element of HEE. Accepting that the person with schizophrenia will probably not achieve their former ambitions or potential may be one of the most difficult adaptations carers must make (Howe 1995).

It may be the case that a surviving family which adapts is not a typical family. The implications of this are that when conducting research on families with a member who has schizophrenia, we do not see the wider picture. The majority of families in carer burden research report carer burden, and a minority report that they cope with the situation. It is possible that many more families have not coped, have not survived intact and are not included in the research (Perring et al 1990).

How caregiving is perceived by carers may influence how it is reported. If it is perceived as a normal parenting responsibility, it may be viewed as neutral or positive, but if not, it is likely to be viewed as negative and as a burden (Provenchar 1996). Greenberg et al (1994) also reached this conclusion. The implication of this is that redefining the caregiving experience may reduce carer burden. Ferriter and Huband (2003) discussed carers' tendency to blame themselves. There may be positive aspects to self-blame, specifically behavioural self blame (as opposed to characterological self blame, which is in the carer's character). These carers, who are parents, created a behavioural hypothesis, which included an underlying assumption that they could have some control over events, and could plan for dealing with recurrence of traumatic

events. This perception of control and planning could be viewed as an adaptation, and carers who do this may adapt better than carers who blame others or fate. These parents may have needed to find a reason why their children developed schizophrenia, and self-attributed fault may have met this need (Ferriter and Huband 2003). However it could be argued that self-blame may lead to depression, in which case it would not be a positive strategy.

Therefore there are a range of strategies which carers may use to adapt to a caregiving situation. Carers may disengage from the person with schizophrenia, or adopt the opposite strategy, which includes involving the person with schizophrenia on all aspects of family life and being a self contained family unit, but this may lead to all family members leading a restricted life. Carers may work through a grieving process. They may focus on their relative with schizophrenia's needs, but this may be viewed as HEE. They may use cognitive strategies, focusing on the positive aspects of their lives, and redefine the situation. They may engage in self-blaming and plan responses to recurring traumatic events. Adaptation occurs in some families, but not without a cost, and families who appear to adapt still require support.

I will discuss the issue of family breakdown and the question of whether a surviving family with a schizophrenic member is a typical family. Some authors adopt the position that a family cannot survive intact when caring for a person with a chronic mental health problem (Thompson and Doll 1982, Perring et al 1990). The social and emotional cost of caregiving may be too great. All families with a relative with schizophrenia should be viewed as vulnerable (Thompson and Doll 1982). It could be argued that some carers and families are more vulnerable than others, because of genetic vulnerability to stress. In such a family, patients are vulnerable, because they are ill,

and carers may become ill and therefore vulnerable, and the result is that the vulnerable are caring for the vulnerable. There is evidence that carers become patients. In Ward-Griffin and McKeever (2000) one of the carer roles identified was that of patient. Other roles were worker under the supervision of the health professionals. The chronic stress, isolation, and despair experienced by carers were highlighted by Ward-Griffin and McKeever (2000). It may be the case that carers and people with schizophrenia place each other under stress, and this may create severe carer burden, and relapse in people with schizophrenia.

Family breakdown may be the result of excessive and unreasonable demands made by the person with schizophrenia. This may create fear and compliance in the carer in the short term, but is likely to lead to family breakdown. Lack of early diagnosis and interventions may lead to family breakdown. The reluctance of health professionals to label young people with the diagnosis of schizophrenia may leave a family having to deal with problems without support. Health professionals' denial of problems, because they have not witnessed these problems, may lead to severe carer distress. Behaviours may occur in the family home but do not occur in the presence of health professionals, because the person with schizophrenia may be able to exercise some limited control, for a short time, over his/her behaviours. The carer may be informed that he/she is making a fuss over nothing or may even be informed that they are causing the behaviours. Blaming by health professionals, in addition to carer burden may lead to family breakdown.

It may be the case that families decide that the person with schizophrenia has to leave for the family to survive (Howe 1995), a conclusion which would not be supported by the Namyslowska (1986) study, which places family unit survival as a priority, but includes the patient in all aspects of family roles and life. If all the family problems were attributed to the person with schizophrenia, it is likely they would be helped to

leave this family. Whatever the cause, no-one benefits when family breakdown occurs. Family breakdown leads to an unsupported person with schizophrenia with schizophrenia or an unsupported isolated carer. Early diagnosis, treatment and family support could prevent family breakdown.

Carers used various strategies to negotiate the mental health system in order to gain support, and to cope with the caregiving experience. To gain support they asked for support to deal with daily practical problems (Creer et al 1982, Howe 1995, Ferriter and Huband 2003) and sought help from carer organisations (Howe 1995).

To cope with caregiver experiences, they used cognitive strategies, focusing on the positive aspects of their lives (Eakes 1995). Families turned in on themselves, which was reported as a positive strategy in Namyslowska (1986), who disputed the reality of carer burden, and was reported less positively in Howe (1995), who reported carer burden. Carers tried to explore their own behaviours to find out if they had caused the schizophrenia and problems within the family (Ferriter and Huband 2003). Carers partially disengaged from the person with schizophrenia and focused on their own needs (Rimmerman et al 1999). Similar behaviour to disengagement is reported less positively in Thompson and Doll (1982), where carers excluded the person with schizophrenia in order to cope. Carers who had good social support coped better than those who did not (Crotty and Kulys 1986, Rimmerman et al 1999). Carers who involved their relative with schizophrenia in all aspects of everyday life appeared to cope (Namyslowska 1986, Greenberg et al 1994).

There appears to be a lack of partnership between carers and health professionals. Carers found health professionals unhelpful (Creer et al 1982, Wheeler 1994, Eakes

1995, Howe 1995, Ferriter and Huband 2003). Relationships between carers and nurses were reported as characterised by lack of communication about care and treatment (Creer et al 1982, Howe 1995, Eakes 1995). Carers could not obtain advice on dealing with practical daily problems (Eakes 1995). There was no information or explanation (Howe 1995, Ferriter and Huband 2003), and carers were not included in discussion about care and treatment (Wheeler 1994, Eakes 1995). When carers informed health professionals about problems at home, they were ignored or the problem was denied (Creer et al 1982, Howe 1995). Carers believed they were blamed by health professionals, who informed them that they were over-possessive and were interfering in the delivery of professional care (Howe 1995). It may be the case that there is no shared view of care. Carers may have two roles - carer and patient - and they become patients when carer burden becomes severe (Ward-Griffin and McKeever 2000).

It may be the case that carer burden is the result of emotional difficulties experienced by the carers, independently of the presence of the person with schizophrenia. The carer may never have coped well with stress or it may be a trait in the carer. However the weight of evidence in this literature review does not support this suggestion. Most of the carers in this literature review were in urban families and living in an urban area may be a confounding factor in increasing care burden.

There are implications for mental health nurses. Carers need advice on daily practical problems and better communication. More support services could be made available and more user friendly. Nurses could listen to carers and accept their information as valid. Nurses should display a more caring and sensitive attitude to carers. There should be more recognition of the loss and stress experienced by carers, and these experiences should be validated. There could be more psychotherapeutic interventions to help carers

to cope (e.g. family therapy). Nurses could work with carers to help them manage their lives better to make time for themselves, and reduce the disruption in the home. They could offer emotional support to carers who experience subjective burden. Carers must be more involved in care planning and decisions made about their relative with schizophrenia. Early diagnosis and interventions for the relative with schizophrenia could reduce carer burden. Nurses should not treat carers as workers, working under their supervision. It could be argued that this is abuse of carers and does not view carers as people in their own right, with needs and rights.

4.8 Summary

The weight of the evidence suggests that carer burden occurs in families who have a relative with schizophrenia, although it has also been suggested that there is disruption in normal families as well as in families with a relative with schizophrenia. The proposal that caregiving has negative consequences for caregivers is disputed by some authors but is supported by most of the literature and research. Subjective burden may be rated as low by caregivers, whilst objective burden and unmet need can be identified by health professionals. Adjustment to caregiving may occur in carers. The presence of a social support network and disengagement from the person with the mental illness appears to reduce psychological distress and perceived burden. Finally, the issue that care burden is equally distributed is not well supported in the literature and carers are predominantly female.

In this chapter I have examined various aspects of carer burden, carers' efforts to care for their ill relatives and carers' difficulties. A main finding is that carers do not receive enough support from health professionals and that carers themselves become mental

health service users as a result of carer burden. In the next chapter, I will examine people with schizophrenia's views of mental health nursing.

CHAPTER FIVE:
PEOPLE WITH SCHIZOPHRENIA'S VIEWS OF MENTAL HEALTH
NURSING

Chapter Four examined carer burden and the perception that there is a lack of support and care for carers. This chapter examines the views of users of mental health nursing care. Users have their own ideas about what constitutes good nursing care, which may contradict the views that nurses hold about their work.

A range of studies have explored mental health service users' views of mental health nursing care. Empirical research by Pollock (1989) investigated service users' views and concluded that mental health nursing care was good. This position was challenged by Ritchie and North (1995), Ricketts (1996), Chadwick (1997) and Clinton et al (1998) in their empirical studies. Some authors reported mixed findings in their studies, with good care and unsatisfactory care being reported (Ricketts and Kirschbaum, 1994 Beech and Norman 1995, Wray 1995 and Johansson and Lundman 2002).

Some authors explored service users' views of mental health nursing care and concluded that care involves coercion of service users: Chadwick (1997), Morrall (1998a), Johansson and Lundman (2002) did this via empirical studies. Rogers et al (1993) and Morrall (1998b) undertook overviews of mental health nursing. Hanily (1999), Doyle (1999), Edwards (1999) and Sharkey (1999), in overviews of mental health nursing, which concentrate on the themes of risk and social control, explain why nurses have been given the role of social control of those with mental health problems. Other authors dispute this position in their overviews of nursing theory: for example Benner (1994) and Peplau (1994). Benner (1984) adopts the position that monitoring

can be beneficial for service users and may be part of good nursing care with the goal of preventing harm.

Empirical studies by Wray (1994), Ricketts and Kirschbaum (1994), Beech and Norman (1995) and Ricketts (1996), explored the theme of communication in nursing care between mental health nurses and service users and concluded that good communication was valued by service users.

5.1 Perceptions of what good care means to mental health service users.

Mental health service users' perceptions of ideal care will now be discussed. Beech and Norman (1995), health professional authors, sought service users' views using Critical Incident Techniques (CIT) (Flanagan 1954, Norman et al 1992). This was a qualitative analysis of guided interviews, in a field study, with the goal of collecting examples of high and low quality nursing care, as perceived by 24 patients on two admission wards. Hence it was a small scale exploratory study to elicit participant experiences. The CIT is a systematic, inductive, open-ended procedure for collecting direct observations of human behaviours. This method has advantages, as it facilitates recall and people can identify feelings and meanings attached to the incidents. This study combined an interactive interview with guiding central questions which ensured that all respondents focused on the same issues. The study used a small convenience sample and the findings were not generalisable. Staff guided the researcher in selecting the respondents. Therefore, there was a possibility of bias.

Beech and Norman (1995) reported that good nursing care meant nurses knowing about medication and side effects, good communication, explaining medication to users, and

good management of ward disturbances. According to these users, a nurse who delivered high quality care was one who demonstrated the following personal qualities: being caring, showing an interest in people, enthusiasm for the job, friendliness, and kindness. Other necessary attributes were the ability to promote independence in a compassionate manner and acting as a role model for patients. Quality indicators were identified (n=239) and of these, 62 percent were positive indicators of high quality nursing care. Overall, the factors that patients perceived as contributing to high quality care were; communicating care (68 positive quality indicators); nurses attributes (36 positive quality indicators) and respect for patients (25 positive quality indicators). There was a strong emphasis on nurses' interpersonal skills (Beech and Norman 1995).

5.2 Different views of care

The different views of care expressed by health professional authors and service user authors will now be explored. Users often have a different view of care from health professionals. Benner (1984), a nurse author who offers no research to support her views, asserts that caring is monitoring conditions which are likely to lead to harm, and exerting control over these conditions. For Benner, care and control are the same activity and she appears to perceive that this is a satisfactory situation. However many user authors disagree with this perception. Beech and Norman (1995), and Campbell and Lindow (1997), perceive respect as a positive aspect of caring and assert that in control there is no respect. In a later work, Benner (1994) asserts that caring involves equality, reciprocity and partnership. She does not perceive any contradiction here with her earlier work. She asserts that caring has its origins in empathy and is a mode of thinking and feeling. She identifies protective care, which is driven by concern for the person and involves solicitude and prevention of harm. She identifies engaged care,

which involves self identification, support and acceptance of the person, implying that involvement is part of caring (Benner 1994). Peplau (1988, 1994) asserts that caring is related to nurturing. Upton and Graves (1996), health professional authors, express an unsupported opinion that caring involves a deep moral commitment to the person being cared for.

5.3 Users' views: good care

Users' reports of good care are now examined. Pollock (1989), a health professional author, discussed the views of 70 users of Community Psychiatric Nursing (CPN) services and their carers. Grounded theory, structured interviews and a Personal Questionnaire with Rapid Scaling Techniques (PQRST) (Shapiro 1961) were used and spontaneous comments were collected during interviews. She encountered some problems in the interview (e.g. suspicion and hostility). However, she informed respondents of her CPN background and she believed that this made them less critical of these services. When carers and patients were together, the patients were inhibited and she had to ask specific questions to gain their views. The PQRST was used to gain feedback about their experiences of community psychiatric nursing care. This rating scale consisted of statements requiring a response indicating agreement or disagreement (e.g. 0 for no help to 9 for a very considerable help). She stated that nurses could be perceived as being actively unhelpful as a result of a low rating. In her view, her data did not suggest this. She proposed that we should have reservations about such an interpretation. In this rating scale, the PQRST scores were not related to other participant factors (e.g. age or illness). When a nurse was rated as unhelpful, the reason for this response could not be established. In using rating scales, this author lost the opportunity to probe beyond the statements in the PQRST. Some of the adjectives used

in the PQRST had a negative meaning (e.g. no help scored 0). While this may imply that the nurse was actively unhelpful, Pollock suggested that 'less helpful' did not mean 'actively unhelpful' and she proposed that a 'little help' is better than 'no help', although she did not explain why she included the term 'no help' if she had no confidence that it accurately reflected a situation identified by a service user.

A strength of rating scales is that they allow participants to express a judgment which can then be quantified. Reliability is strong, and this has been reported in rating scales in other studies (Thompson and Doll 1982, Creer et al 1982, Crotty and Kulys 1986, Eakes 1998, Ferriter and Huband 2003),(see Chapter Four). The PQRST was validated by previous studies (Ingham 1965, Mulhall 1976). This was a highly structured assessment tool and examined outcomes. Personalised statements (e.g. my personal level of tension is ...) were presented to participants, who were asked to rate each statement.

There were three ways to rate anxiety, a strategy which may have reduced response bias. Firstly, there was a numerical scale of 1-7, with 1- no anxiety and 7-extreme anxiety. Secondly, a straight line was used, with absence of anxiety at one end and extreme anxiety at the other, and the participant indicated his/her anxiety levels. Thirdly, there was a list of adjectives which described anxiety levels, A-absolutely none and F-very considerable, and the participant selected one adjective. These descriptive terms, 'absolutely none', 'very little', 'moderate', 'considerable', and 'very considerable' were an ordinal scale, but the potential flaw in ordinal scales is that there may be no equality between levels. Every adjective was given a score, 0-absolutely none to 9-very considerable, which meant that every adjective had a numerical value and could be analysed statistically using the Statistical Package for the Social Sciences

(SPSSx) (Nie 1983). This was descriptive statistical analysis. The Chi Squared Test was used to identify factors in the nurses that affected helpfulness. Variables were examined, (e.g. age, gender of nurse). Other statistical analyses were used : scattergrams and multiple regression analysis. A significance level of 0.05 was set. The probability of an association between frequency of contact between nurse and service user and rating of helpfulness occurring by chance was five percent ($P=0.05$).

The PQRST was piloted in two stages, which may have increased validity and reliability. In the first stage the statements to be used were gained from members of self-help groups, service users and their carers ($n=24$). These participants were interviewed using unstructured interviews and the problems stated were converted into statements for the PQRST. In the second stage, ten service user/carer pairs completed the PQRST and answer sheet, after which the PQRST was refined. Pollock tried to reduce interviewer bias by adopting the investigator role, rather than the caring role.

While other researchers who used rating scales have claimed that rating scales have strong reliability, Pollock concluded that as assessment of reliability could not be made after using the PQRST. Frankfort-Nachmias and Nachmias (1996) suggest that in rating scales, the questions or statements may be subjective, which may reduce reliability. It could be argued that the statement in Pollock's study focused on subjective themes (e.g. 'the help I get from the nurse is...'). The term 'helpfulness' was not defined in this study, and there were likely to be different perceptions of its meaning. Pollock acknowledges that the PQRST may not have been an objective assessment of satisfaction. There may have been bias in the findings because participants were receiving support from the ten CPNs, whose work was being evaluated, and participants may have been reluctant to be critical. There may have been sample bias, because the

sample was self-selected, and this may have led to bias in the findings because the sample may have held extreme views. The sample may have been unrepresentative of a wider population (Pollock 1989).

Structured interviews were used with the Repertory Grid Technique (RGT) (Fransella and Bannister 1977). An RGT is useful for measuring an attitude over time (Gilbert 2001). An RGT identifies constructs. Three stimuli (the triad)(e.g. three types of stress) are presented to the participant , who is asked to state which two are alike and how they differ from the third. The construct is meaningful to, and comes from, the respondent (Gilbert 2001).

Pollock (1989) maintained that participants developed constructs or predictive hypotheses. Using the RGT, participants' views of the world can be gained. The RGT was piloted by ten CPNs who were not in the main study. Repeated constructs were acknowledged to be the most relevant and were included in the main study. Constructs were elicited using the triad, or three stimuli. CPNs were asked 'Can you tell me in what important way these two patients are alike and different from the third patient ?' Constructs and elements (e.g. a range of topics to be discussed) were converted into a grid, and participants allocated constructs to elements (e.g. construct-chronic schizophrenia, element- at risk), which meant that some nurses used this diagnostic grouping to describe their clients with chronic schizophrenia as being at risk, and in this way the RGT explored participants' perceptions.

The interview was structured which may have increased reliability, because the interviewer focused on the participants' replies. Researcher bias and influence was likely to be reduced and objectivity was likely to be present. Qualitative data can be

obtained systematically and participants' vocabulary can be examined using this method. Quantitative data supported the qualitative data. The RGT and interviews assisted these ten CPNs to explore and verbalise their perceptions of their work.

There was a laddering procedure which was done with the RGT and interview (Fransella and Bannister 1977). Laddering explores abstract constructs, explores the meaning of a specific construct, and asks the participant 'Why?'. Laddering up was described. The question to the participant was 'Tell me about someone with family support who differs from someone who does not have it'. The researcher then takes each theme that emerges and continues to ask more questions; therefore there is depth of data (Pollock 1989).

The title of this paper: 'Community Psychiatric Nursing: Myth and Reality' was not consistent with a desire to measure effectiveness of CPN interventions. There was no control, comparison or experimental group and interventions were not clearly specified. This made it impossible to link outcome measures to CPN interventions, and while measures of perception were used, because the term helpfulness was not defined, it could be argued that the findings were a subjective evaluation of care. However, Pollock accepted that the data was difficult to interpret because the meaning of 'helpfulness' was not clear and no exploration of responses was possible.

The findings, while positive, related to the work of only 10 CPNs and so could not be generalised to community psychiatric nursing outside the study. Using structured interviews may have hindered data collection, but interviewers' influence on the respondents and interviewers' bias was minimal. According to Pollock, these measures led to her findings having face validity. Some questions were nurse focused and elicited

positive responses about nurses being helpful and taking an interest. However, one should be cautious about interpreting data that has been divided artificially into ‘helpful’ and ‘unhelpful’ where neither term was defined.

Most patients reported positively about nursing care, but no statistics were given. One finding, which the author maintained had face validity, was that the least experienced nurses were more available, helpful and friendly than more experienced nurses. She suggested burnout to explain this trend. All items on the PQRST were viewed as helpful, indicating a positive evaluation of care given at home. Nurses were perceived to be caring, taking an interest and providing support, and the caring nature of nurses was emphasised. There was a clear association between increased frequency of visits and increased reports of helpfulness of CPNs. This, however, did not indicate that the former led to the latter. The study concluded that CPNs did not provide individualised care and had to juggle resources. They did however, focus on developing relationships with patients, and patients did feel cared for and supported, whether or not their problems were solved (Pollock 1989). This finding, that nurses’ interactions were valued by patients, was supported by Beech and Norman (1995) and Campbell and Lindow (1997).

Wray (1994), in a study of service users’ views of services, which involved 79 users who had lived with schizophrenia for less than one year, used a Knowledge About Schizophrenia Interview (KASI), a semi-structured interview guide, which assessed knowledge of schizophrenia (Barrowclough et al 1985), a questionnaire (The Consumer Perception of Mental Health Services) a self completion satisfaction questionnaire, and a likert scale (Barrowclough et al 1985). Users were asked, ‘In general how satisfied are you with the services provided?’ Responses were rated on a 5-point Likert scale,

ranging from very satisfied to very dissatisfied. Of the study population, 23 percent placed individual therapy and 28 percent placed vocational rehabilitation in this response category. The author placed negative and neutral responses together. He noted that 65 percent of the 474 possible responses were negative and neutral responses, indicating that only 35 percent were positive responses. This study was designed to assess services from a users' perspective and achieved this, suggesting strong validity, but the small sample meant a lack of generalisability. In this paper, the pie charts gave slightly different percentage statistics from those in the tables.

In the semi-structured interview, major questions are asked in the same way, but the sequence may be altered and probes are used (Gilbert 2001). A thematic guide can be used. Clarification and elaboration are possible, and possible meanings of statements can be analysed in terms of cultural background and context. However reliability may be limited and there may be potential interviewer bias (May 2001).

Likert scales can reach a large sample, can measure attitudes, and the data is easy to score. Reliability can be tested. The researcher selects enough items for two scales (e.g. 100 items), divides them into two sets, constituting two scales, then uses the split-half reliability test. Odd number questions are placed in one set and even number questions are placed in another set. The two sets are then treated and scored separately. The two sets are correlated and this is accepted as an estimate of reliability (Frankfort-Nachmias and Nachmias 1996). However in this study no comment has been made about the estimate of reliability. The potential flaws of likert scales are lack of opportunity to gain more in-depth data and the middle value 'neither satisfied nor dissatisfied' is not informative.

Overall, 22 percent of these users were dissatisfied and 64 percent were satisfied with services. Community nursing received the highest score with 73 percent being satisfied. Seventy two percent rated CPNs highly and 70 percent rated Day Care highly. Aspects of care which offered personal contact and provided for basic needs were highly valued, while treatment aspects of care (e.g. medication) were less highly valued. Wray (1994) asserted that the dissatisfaction responses were related to treatment aspects of care. Fifty six percent were satisfied with individual therapy and 57 percent were satisfied with crisis interventions, therefore they valued time spent with nurses. The research identified good contact made by nurses with people with schizophrenia in the community, and service users' general satisfaction with services.

According to Lebow (1982), satisfaction with mental health services generally falls between 60 percent and 90 percent, and the results of Wray's (1994) study conformed to this trend. The work of Wray (1994) supported the views of Pollock (1989) regarding the importance of nurses' interactions with people, namely personal contact, individual therapy and crisis interventions.

Research conducted by Ricketts and Kirschbaum (1994), health professionals, explored the views of 17 people with mental health problems who were discharged from a day hospital, and compared these views with the views of seven nurses in the day hospital. The first stage involved a semi-structured interview to gather descriptive data (see Wray 1994). The interactive nature of this method may have led to researcher influence of bias, but may have increased the response rate, according to these authors. The response rate was 88 percent. The second stage involved clients being asked to rank order treatment experiences, which led to analysis of reported experiences. Data analysis was by thematic content analysis in stage one, which led to the generation of

categories. There appeared to be no independent researcher to check the transcripts and categories, a strategy which would have increased reliability (or dependability, an alternative concept in the Lincoln and Guba (1985) model of trustworthiness (see Chapter Seven)). Ricketts and Kirschbaum (1994) acknowledged the potential criticisms of the categorisations because the client and staff responses were analysed separately. However this provided comparative data, which leads to increased validity (or the alternative concept of credibility in the Lincoln and Guba (1985) model). Nevertheless, there are potential weaknesses in comparative data, specifically that it does not help the researcher explain different results in different groups, or fully understand the meaning of the findings within a social context or find causal explanations (May 2001). The response rate was 70 percent, but this was a small sample, with potential sample bias, which limited external validity and the views expressed could not be generalised. The 17 people were self-selected and their views may not be representative because they may have held extreme views. Memory was relied upon, with retrospective evaluation of events, but these users were perceived as experts in their own experiences by Ricketts and Kirschbaum (1994). Their views were focused on, therefore internal validity was likely to be strong, but validity may have been weakened by sample size, self-selection of the sample and retrospective recall, according to these authors.

These users reported positively with regard to one-to-one sessions, being listened to, expressing feelings, being taught by nurses, understanding more about their problems and being helped. Treatment events, which were perceived as helpful, were stress education classes and relaxation. Group work was evaluated positively by 14 of the study sample, and by all the seven staff. Medical treatment was mentioned by only nine users but by all staff as a positive aspect of treatment. Staff were reported to be helpful

and caring, and 14 of the users positively evaluated their day hospital experiences. There was agreement among nurses and users on the helpfulness and benefits of the following: treatment events (for example, one-to-one sessions), individual therapy, practicing new skills in a safe environment and learning different ways of coping with feelings. Individual therapy was reported as the most helpful aspect of treatment, and was rated positively by both users and nurses.

An important conclusion in this study was that nursing staff tried to move away from the medical model, but this was not matched by changes in users' expectations and demands. Some users (n=9) still valued medical treatment and rated it as the second most helpful intervention, while the nurses rated it as the second least helpful intervention.

A Swedish hermeneutic phenomenological study by Johansson and Lundman (2002), which involved audiotaped, unstructured interviews with five clients who were receiving involuntary care, highlighted opportunities and losses. Transcripts were analysed first by naïve reading, then by structural analysis, where the text was explained without consideration of the context or narrator. The context was involuntary care and these participants had all been subject to involuntary care and had been judged to lack competence to express an opinion. If these factors had been considered, the findings may have been considered invalid. The text was then condensed to find a pattern. All interviews were then re-read together, with naïve reading, structured analysis and interpretation of the whole, with the researchers' pre-understanding and previous research being taken into account. The flaws in this study were the small sample, and interviewers' influence on the narrative, because it was a narrative between two people in a discussion. The findings were not transferable beyond the context of involuntary

care. One strength of this study was that it created new opportunities to understand clients' views of involuntary care. Opportunities were highlighted (e.g. participation, decision making about one's care and flexibility in care).

This was interpretive phenomenology (see Chapter Six, 6.4, 6.7). A narrative was created in discussion between participants and interviewer, who must consider interviewer influence on participants and the resulting narrative (see Chapter Six, 6.6) (Johansson and Lundman 2002). This method facilitates sensitive awareness of humans and their-being-in-the-world (see Chapter Six, 6.7) (Speziale and Carpenter 2007). Dependability was enhanced because the second author independently read the list of themes created from the interviews. In these unstructured interviews participants freely related their experiences and described events that seemed significant to them. They defined their situation and revealed their attitudes and opinions. This method was flexible and depth was achieved. Personal meaning which participants attributed to events could be understood. These authors focused on service users' experiences. There was a thematic log and purposeful sampling; therefore credibility was achieved (Lincoln and Guba 1985). There were some flaws in this study, specifically these five participants were selected by the nursing staff, which may have led to an unrepresentative sample and sample bias. Probes were used, but probes may not be neutral (see Chapter Seven, 7.3, 7.4).

5.4 User's views: unsatisfactory care

Less positive views of mental health nursing care will now be examined. Wray (1994), in a study which has been previously discussed, reported deficits in nursing care. Specific professional activities were rated, using rating scales, and the lowest score was

given for the category 'information about illness' with 45 percent (n=35) being satisfied with this. This indicated a communication problem. Users commented on the vagueness of information and complained about contradictory advice given. Fifty one percent (n=40) stated that health professionals did not adequately help them to understand schizophrenia, and 54 percent (n=43) reported that they were not informed of their diagnosis. When asked to rate practical advice, 60 percent (n=47) of the users were dissatisfied. When asked to rate a specific service within a category, 24 percent (n=19) were dissatisfied with the 'medication service' and had doubts about the benefits of medication, perceived side effects to be a major problem and reported they were given no information on this. It could be argued that this finding means that 57% were satisfied with these factors. However, Wray (1994) proposed that this finding had implications for compliance. Deficits were identified in two areas, vocational rehabilitation, where 52 percent of the responses were negative or neutral and there was not enough help to achieve purposeful activity, and information giving and communication generally.

Ricketts and Kirschbaum (1994), in a study which has been previously discussed, reported that users negatively evaluated communication in nursing and found lack of communication frustrating. Users felt let down by staff and the lack of social contact with staff.

Beech and Norman (1995), in a study which has been previously discussed, reported that clients felt afraid and unsafe on wards. Violence on wards was not well managed by nurses. There was a lack of communication, and nursing actions and interventions were not explained. Nurses were unwilling to listen to patients and did not respond to their worries. One-to-one observation was viewed as intrusive and an invasion of privacy,

and the reasons for observation were not explained. There was reduced confidence in staff, and anger and frustration as a result of inadequate explanations. One aspect of nurses' behaviours which led to a "them and us situation" was nurses meeting in the office for long periods of time and laughing, and this reduced trust between users and nurses (Beech and Norman 1995 p.123). The overemphasis on medication was perceived as low quality care. There was rushed or delayed care, and some nurses did not show concern for the person and were insensitive to users' needs. Because of low staffing levels, users were unable to gain nurses attention. Nurses were perceived to have an inadequate knowledge base, especially about schizophrenia, and this reduced users' confidence in them (Beech and Norman 1995).

Ritchie and North (1995) used unstructured interactive interviews with 11 users. The views of this small sample may not have been generalisable. They concluded that these users felt disempowered by the mental health nursing services, were not listened to and had no part to play in the decision making processes.

In a later study, Ricketts (1996), who used a questionnaire survey, reported the views of 81 users who had been discharged from a mental health ward. There was a 40 percent return rate with 199 forms sent out. Participants were asked about their general satisfaction with services received and therapeutic nursing communication. The instrument was an eight question client satisfaction questionnaire (CSQ) (Larson et al 1979). The highest score for any item was four, and the highest total score any user could give was 32, which meant that they were very satisfied. Twenty six completed forms were lost, five returned forms were incomplete and the low return rate may have led to selection bias. It may be the case that people with extreme views returned these questionnaires. The question content of the CSQ caused problems (for example, 'If you

were seeking help again would you come back to our service?’). This was not a good question because there was likely to be no alternative service. People did not have exit empowerment, a theme discussed by Nocon and Qureshi (1996). There was possible bias because the forms were sent out at the point of discharge, and clients may have had a particular view of services then, which may have been different from an earlier view. However bias may also have occurred if questionnaires were given to people when they were in-patients, because of the perceived control element, and people may have been more likely to make positive responses. Some users were given the form and others received it through the post. They did not receive the questionnaires at the same interval from discharge, and the length of time after discharge may have influenced results. These authors proposed that immediately after discharge, the client may feel under pressure to give positive evaluations, and that this tendency may be less strong after being at home for six months (Ricketts 1996).

It may be the case that participants’ responses were based on limited knowledge of treatment options. However, even if this were the case, it does not necessarily mean that mental health service users cannot evaluate their treatment and even a response based on lack of knowledge can help service providers to improve services. The CSQ is effective in generating valid and reliable data, if the questions within it are unambiguous. The question ‘To what extent has our service met your needs?’ could be viewed as ambiguous as the term ‘needs’ is not defined and is open to interpretation. The limited responses available were unlikely to clarify the participants’ perceptions of their own needs. Therefore the responses may not assist service providers in improving services.

There may be a reason why the CSQ may reveal high levels of satisfaction. It may be the case that service users do not expect good treatment and care from mental health services, and the term 'satisfaction' is open to different interpretations by service users and service providers. The determinants of satisfaction may not be revealed in the CSQ. However, the CSQ was a standardised scale which may be repeated to show improvement or change over time or identify continuing problems. There is a high likelihood of reliability because of the standardisation, but there were no opportunities to explore themes further. A pilot study was completed which may have increased internal validity. Some of these participants received the CSQ as a postal questionnaire, which means that large samples can be reached and there is no researcher bias, because there is no researcher-participant interaction.

There was an association between being dissatisfied with general services and being dissatisfied with therapeutic nursing communication. Fifty people answered the therapeutic nursing communication question and of these some were dissatisfied (n=23), whilst others were satisfied with this aspect of care (n=27). Ricketts (1996) focused on dissatisfaction scores because in his opinion it was the best way to make client satisfaction surveys useful to providers of health care who are trying to improve services. Thirty one percent of the respondents were generally dissatisfied with services and 59 percent were satisfied. Two questions had low scores. The question, 'to what extent has our service met your needs?' received a mean response 2.59 and 'how involved were you in the planning of your nursing care?' received a mean score of 2.19. Mean scores for all questions related to general satisfaction and satisfaction with nursing communication were all between 2.19 and 2.98. These service users wanted improvements in nursing staff communication and availability and their own involvement in decision-making. It was noted by the Ricketts (1996) that people still

expressed satisfaction regardless of the services they received. A theme which came up repeatedly was that staff did not have time for them.

Chadwick (1997), a health professional author who is also an ex-user of mental health services, undertook an ethnographic study involving 33 case studies and conversations with 33 people with schizophrenia over ten years in one setting. This was extended fieldwork. Depth of investigation was achieved because of the single setting. The sampling was specific: the time was ten years and the context was individuals with a diagnosis of schizophrenia receiving treatment on one ward. The researcher's own role was acknowledged and an account of the participants' social world was produced. Hammersley and Atkinson (1983), in their overview of ethnography, maintain that formal substantive theory can be developed (e.g. the concept of stigma and the theory of deviancy). Researcher influence cannot be ruled out and there is the potential risk that only data which is interesting to the research will be singled out and more mundane events and data will be ignored (Hammersley and Atkinson 1983). It is possible that all of these factors were present in this study. The views of this small population could not be considered representative of all people with schizophrenia and replicability could not be guaranteed. However this study dealt with themes in depth, which may have led to strong internal validity. The cognitive structures of this population were explored. One potential weakness is that Chadwick's own views may have been imposed on this work. In this approach there was no opportunity to collect expansive data and place it in a background context.

Chadwick (1997) asserted that people felt marginalized and disempowered and that to achieve a feeling of power and escape negative feelings, they adopted the view that psychosis is an attractive state. Chadwick's (1997) finding that there was no

partnership, supported the views of Devaney et al (1998), who offered research evidence, and Hickey and Kipping (1998), Bracken and Thomas (1999) and Tomson (2002), who offered no research evidence. Chadwick's finding on disempowerment supported the views of user authors (MIND National Association for Mental Health 1992, Campbell and Lindow 1997, and Coleman 1997,1999), who assert that mental health service users are disempowered (although they offer no research evidence), and other health professional authors (Barker 1999, Ryan 1999, Patel and Fatimilehin 1999), who state the same conclusions and likewise offer no research evidence.

Clinton et al (1998) used rating scales with people with schizophrenia (n=156) to measure dissatisfaction with life and problems with daily living. Social support was measured by the Arizona Social Support Interview Schedule (ASSIS) (Barrera 1981). Community adaptation was measured by the Brief Psychiatric Rating Scale (BPRS) (Overall and Goreham 1962). They concluded that these people with schizophrenia perceived an inadequate level of support, a view which Clinton and Nelson (1999) propose in a later overview of mental health nursing. Participants reported experiences of loneliness and social isolation. More than half of these participants wanted support in social participation. They wanted someone to talk to about their experiences and feelings. A major finding was that social and personal support appeared to influence successful adaptation in the community, and participants with schizophrenia coped more effectively. However there may be strong objective evidence of social and personal support and participant may still feel unsupported, view their life negatively and not cope in the community. The participants' perception of their lives is an important factor. It is suggested by these authors that mental health nurses need to help people with schizophrenia to develop life skills, positive perceptions of their lives and

help them overcome feelings of loneliness and their daily challenges. Nurses should work collaboratively with these people, using psychosocial interventions.

In these rating scales, exact responses may not be possible. There may be no equality between levels. There may be weak reliability because the questions may be subjective, asking about beliefs or attitudes (Frankfort-Nachmias and Nachmias 1996).

Johansson and Lundman (2002) reported negative aspects of care, specifically: being ignored by health professionals, care being dominated by rules and lack of flexibility, coercion in having to receive treatment one did not agree with, lack of participation and information, and the feeling of being neither seen nor heard.

5.5 Care is coercion

The view that nurses deliver coercive care will now be explored. Within nursing there is an emphasis on equality, reciprocity, concern, partnership, empathy, solicitude, prevention of harm, and involvement (Benner 1994). Peplau (1994) proposes that nurturing is part of care. Both these authors believe that nursing care is empowering. However, these views are contradicted by users' views on care, reported by user and health professional authors. Gorman (1992), a user author who expresses his own views and asserts that care is coercion, gives the example of forced treatment and compliance. This view is supported by Thomas et al (1992) (health professional authors), Rogers et al (1993) (health professionals), Chadwick (1997) (a health professional and a ex-user author) and Morrall (1998a and 1998b) (a health professional author). Morrall (1998a) in his empirical research concluded that the reason for coercive care is that nurses lack professional autonomy and their roles (e.g. social control) are defined and controlled by

medicine. Morrall (1998a) proposed that nurses should reconstruct their practice and become agents of social change, instead of agents of social control.

Morrall (1998a) used mixed methodology: multiple case studies, weekly audio-taped diary-interview schedules and field observation with ten Community Psychiatric Nurses (CPNs). He interviewed 20 colleagues of these ten CPNs, using audio-taped unstructured interviews. At times, he adopted the participant role, and at other times the non-participant role. His participant role may have led to loss of reliability and to some researcher influence and subjectivity in the findings, but he may have gained more data than when in the non-participant role. His non-participant role may have led to increased reliability and objectivity in the findings.

He listened to the audio-taped diary-interview schedule with the goal of appraising his reactivity (e.g. leading questions, value laden questions) and intended to avoid repeating these. In the diary-interview schedule, the data could be checked for internal validity. Internal validity, specifically, face validity, discriminate and content validity were present. However, it is acknowledged in this study that internal validity may have been weakened because of the number of extraneous variables in the study. In the diary-interview schedule, the researcher can probe for incidental data (e.g. 'who?', 'what?', 'how?', 'where?' and 'when?' questions). In the unstructured interviews there was content validity because items measuring the constructs were representative. The field observations and field notebook may have led to reliability or dependability in the Lincoln and Guba (1985) model of trustworthiness, which may be more appropriate for qualitative research. Data triangulation, specifically within-method triangulation may have led to strong internal validity (or credibility in the Lincoln and Guba (1985) model (see Chapter Seven 7.2)). Construct validity was present, specifically convergent

validity, because data was gained from various groups (CPNs, managers and colleagues).

Discriminant validity was present because discriminating questions were present in the diary-interview schedule. Ecological validity was present because there was a match between the everyday world and the research techniques (e.g. the diary-interview schedule and field observation) and the study was longitudinal. Internal validity may have been increased because there was reflexivity in the methods. The research design (the questions) was altered during the research after Morrall tried to appraise his reactivity.

There may have been limited external validity because of the research design. The findings could not be generalised (in the positivistic sense) and the sample was not representative (Morrall 1998a). The reactivity factor may have weakened the external validity (Frankfort-Nachmias and Nachmias 1996). Ecological validity may have been reduced because the unstructured interviews were single interviews.

Internal reliability was achieved because constructs produced from previous research were similar to constructs in this study. There was a full description of data analysis and full interview transcripts and field notes were available. These factors would have assured the presence of dependability, which is the alternative concept in the Lincoln and Guba (1985) model. External validity was achieved because the Burnard (1991) model of data analysis was used (see Chapter Seven, 7.21). The original data and conceptual extractions were examined by two colleagues. The researcher roles were clearly stated. The underlying premises, units of analysis, data collection and analysis were all clearly stated. The participants' characteristics and setting were described in

full. Four case studies were researched consecutively and there was re-testing of methods and results were compared. The presence of a single researcher may have weakened reliability. There was methodological reflexivity, which may have weakened reliability. Data was analysed by thematic content analysis of the data from the diary-interview schedule and descriptive statistics were generated from diary-interview schedule. Burnard's (1991) model was used to analyse the thematic content of field notes and the unstructured interviews.

Hanily (1999), Doyle (1999), Edwards (1999), and Sharkey (1999) health professional authors in an overview of mental health nursing, examine risk assessment and management, and offer a reason for control and overcaution by nurses. Current policy and legislation make mental health nurses responsible for risk assessment and management, and crisis management (Hanily 1999). Public anxiety, professionals' fear of litigation and working within an inquiry or blame culture keep mental health nurses focused on risk assessment and management (Doyle 1999). Risk assessment involves moral and evaluative judgments by health professionals, which may be imposed on service users (Edwards 1999). Nurses may want to adopt a more sensitive enabling approach with no control but are not permitted to (Sharkey 1999). It could be argued that risk assessment and management may lead to crisis prevention, and that, therefore, these may be positive interventions (Edwards 1999). The work of Benner (1984) supports this idea, when she asserts that monitoring exerts control over conditions that may lead to harm to the individual with mental health problems. Repper et al (1995) highlight the increased emphasis on risk assessment and monitoring, but these are perceived, by these authors, to be carried out within a therapeutic, collaborative relationship, valuing people with schizophrenia. None of these studies are based on

empirical research. In Johansson and Lundman (2002), which is empirical research, coercion in treatment was reported.

5.6 Discussion

Morrall (1998a) proposed that nurses should reconstruct their practice. Nurses should change the focus of their practice to empowerment of mental health service users, and help them achieve a better quality of life, with less marginalisation and social and economic disadvantage. In his view, nursing has not produced self-regulated autonomous practice and ideology. If nurses remain under medical dominance and continue to be agents of social control, they will indirectly disempower mental health service users. His views would be supported by Barker (1999), who proposes that the proper focus of mental health nursing is promoting the growth and development of mental health service users. It could be argued that some monitoring is not harmful to mental health service users and prevents a crisis from occurring. Lack of monitoring may be, or lead to, neglect - a view which would be supported by Benner (1984). Risk assessment may prevent a crisis from developing, although the term 'crisis' implies that there is likely to be an undesirable outcome (Edwards 1999). A crisis may be an opportunity for the service user to re-evaluate their situation.

Hanily (1999) offers reasons for social control by nurses. Mental health policy and legislation (Department of Health 1990, DoH 1994b, DoH 1996) can lead to a mental health service user being admitted into a mental health unit for their own safety and welfare. The goal would be to prevent a crisis. The legislation makes mental health nurses responsible for delivering good risk and crisis management, although such an intervention could be perceived as coercion by the mental health service user.

One element of crisis management is the use of the Supervision Register (DoH 1994b). The potential paradox in the use of the Supervision Register is that it may lead to less proactive care, because the presence of the mental health service user on this register may be deemed sufficient, whilst in reality, the mental health service user may receive less proactive care and support which may genuinely help them to cope. The mental health service user, originally judged to be high risk, may go into crisis, and be readmitted involuntarily, an action which may increase other peoples' perception of risk in that mental health service user. The mental health service user may become a revolving door client who is likely to remain on the Supervision Register (Hanily 1999).

The risk of violence is higher in people with the diagnosis of schizophrenia (Sharkey 1999) and nurses who work with this client group are not permitted to ignore this issue and are expected to deliver an effective crisis response. Nurses may want to adopt a supportive, empathetic and sensitive approach because, paradoxically, a crisis response is likely to increase persecutory beliefs and is likely to be perceived as coercion by the service user. Nurses may want to use the psychosocial interventions approach (PSI) or cognitive behavioural therapy, and encourage the participation of service users and family members. This would be enabling rather than coercive and might reduce the risk of violence or relapse. However, in the case of violence occurring or even being predicted in a risk assessment, a crisis admission is the most likely outcome because of the emphasis on public protection (Sharkey 1999).

A range of factors may lead to controlling care. There may be public anxiety and media attention is almost always negative when a mental health service user harms him/herself or a member of the public. There is a general acceptance that risk assessment and management can be achieved, even though risk assessment is not an exact science.

There is acceptance of the concept of no risk, even though this is not a reality in any context. There may be professional fear of litigation, should someone be harmed (Doyle 1999). Johansson and Lundman (2002) reported mental health services users' experiences of coercive care, but the theme of feeling protected and cared for was also a strong finding. It may be the case that an individual wishes to be excused from the normal responsibilities of their life, resents the lack of freedom, but wants care, protection and monitoring simultaneously. This may be a comforting situation for the service user. A similar theme was discussed in Crowe et al 2001 (see Chapter Two, 2.2). However a mental health service user may feel deprived of autonomy and respect (Johansson and Lundman 2002).

Nurses have been given the responsibility to assess risk. Risk is based on probability, not certainty. When examining pure risk, there is a need to consider the following: level of risk, likelihood, immediacy and frequency of harm and severity of possible outcomes. In reality it may not be possible to achieve such a risk assessment because an assessing nurse is unlikely to have full knowledge of all possible influences, factors or variables (Doyle 1999). Many risk assessments involve the use of rating scales which may generate subjective information.

The concept of risk itself may be a value and not a fact, because behaviours, attitudes and views which are acceptable to a service user, and may even be acceptable to some groups in society, may not be acceptable to health professionals. Risk assessment may involve a moral judgment. Crisis and risk are likely to be defined by the health professionals, because interactions between service users and health professionals are dominated by the health professionals, who may impose their evaluative judgments on service users. The values of health professionals may be dominant even where health

professionals believe they have facilitated partnership. Competency of the service user to make a decision may be a value judgment, which may be influenced by the following factors: professional duty of care, paternalism, fears of an inquiry should the service user harm someone (Edwards 1999). It could be argued that we are all subject to value judgments by others and that that it is no different for people with a mental health problem.

A key role for mental health nurses is promoting service users' autonomy. This goal may be difficult to achieve if the focus of mental health nursing care is on risk assessment and management. It could be argued that no-one has full autonomy, because living in society means living with limited autonomy, because other people's rights may be compromised by the behaviour of one person who has unlimited autonomy. It may be the case that partial autonomy is acceptable for mental health service users in whom risk factors are identified (Edwards 1999).

A key issue in mental health nursing is communication. Poor communication and the need for better communication have been reported in empirical studies (Wray 1994, Beech and Norman 1994, Ricketts and Kirschbaum 1994, Ricketts 1996). More personal contact in informal activities was valued by service users (Wray 1994). Caring and good communication appear to be closely related in the perceptions of service users. Service users may evaluate the element of caring, as a personal quality, by how well a nurse communicates with them (Beech and Norman 1994, Ricketts and Kirschbaum 1994). It is argued that within nursing there is concern for the client (Benner 1994). More formal treatment and interventions are also valued (e.g. educational interventions and PSI) (Wray 1994). These approaches may empower service users and increase their autonomy. More support to help service users to adapt to life in the community after

discharge and live with the problems associated with schizophrenia appears to be necessary and is valued by service users. Nurses could use PSI, personal and social support to help service users to achieve increased self esteem and reduced feelings of isolation and loneliness. There may be reasons why PSI is not more widely used. There may be a lack of knowledge and education or resistance to change. Medical dominance may have prevented nurses from using PSI because medicine defines the roles of nurses and delivering PSI may mean a major role change (Wray 1994, Morrall 1998a).

Service users and health professionals appear to have different perceptions of care. Personal care appears to be highly valued by service users, while health professionals may want to focus on new approaches and technical care, which involves goals, specific techniques and theories. Service users may want to be nurtured and protected from the difficult realities of life, a situation similar to parental care, while health professionals attempt to keep service users connected to their lives and related problems, and may pursue the goal of enabling service users to cope more effectively.

Service users with schizophrenia at home or in hospital appear to feel lonely and need someone to talk to. Mental health nurses are expected to adopt this role. However nurses may not be good substitutes for a supportive family or community or friends. However, good mental health nursing involves good communication with service users, which can occur in informal situations. Nurses may not communicate effectively for a range of reasons. They may hold the view that the service user lack competence to understand information, a view which may be supported by mental health categorisations and the Mental Health Act, because within these, it is implicit that some service users lack competence (DoH and Welsh Office 1983). The dominance of the medical model of illness may have encouraged nurses to perceive service users in this way. However, it

could be argued that service users who hear voices, for example, need to be understood as individuals who have an experience which may disturb them, rather than people who are mentally ill, and who have a flawed perception of the world.

5.7 Summary

The weight of evidence suggests that there is some agreement between users and health professionals as to what caring is, with the emphasis on interpersonal skills and partnership. Users who reported good nursing care were reporting on the nurse patient interactions which they valued. Those who reported poor nursing care commented on poor communication, lack of information, lack of contact with nurses, being disempowered, lack of partnership with nurses and overemphasis on medication. More effective communication is required. Some users asserted that nursing care was coercion and control, because they perceived that treatment was forced. Nurses emphasised risk more than caring. Nurses should aspire to become agents of social change instead of agents of social control. Legislation has influenced nurses' roles and this influence may not have led to good proactive care. Nurses are asked to engage in risk assessment, with the goal of protecting service users and the public, yet risk assessment is not an exact science and the data gained may be subjective. Lack of monitoring of mental health service users by mental health nurses may be viewed as freedom by some, but as potential neglect by others. It could be argued that partial autonomy is appropriate for mental health service users as they require monitoring and care.

5.8 Summary of literature review

A case has been made for the social construction of mental illness. It could be argued that medicalisation is oppressive and people become docile bodies. However it may also

be the case that people comply and collude with treatment, as a result of Governmentality, when they are diagnosed with schizophrenia. The clinical features of schizophrenia may be more common in the general population than has been previously acknowledged and some people may live successful lives with those clinical features (e.g. hallucinations and delusions).

There is limited evidence of partnership in mental health nursing. There appear to be a range of barriers to partnership, the main reason being the power imbalance between health professionals and service users. A case has been made for self-determination for mental health service users.

The weight of evidence suggests that subjective and objective carer burden occurs in families who have a relative with schizophrenia. However some research suggests that carers adapt to the caregiving situation. Some disengagement from the person with schizophrenia appears to reduce carer burden. The care burden is not equally distributed in the family, with the trend being that there is one carer, who is usually female.

Service users and health professionals have different perceptions of care. The weight of the evidence suggests that service users believe that mental health nursing care is not good. There is some evidence that some service users believe that care is coercive. Good communication between service users and nurses is valued by service users.

5.9 The need for the current study

There was a need for this study because we needed to know the current subjective reality of living in the community with the diagnosis of schizophrenia, the experiences,

the key issues and what these experiences and issues mean to people with schizophrenia. There was a need to provide service users with a voice. Currently there is an emphasis on partnership, empowering care, social inclusion and a general acceptance of the ethos of consumerism. Mental health service users' views are necessary, if nurses are to have an evaluation of their work. Nurses have adopted a range of psychotherapeutic interventions which have the goal of maintaining mental health service users in the community and helping them to cope with their mental health problems. The weight of evidence suggests that mental health service users' experiences of living with schizophrenia and their evaluations of mental health nursing are predominantly negative. It was necessary to explore current perceptions of service users.

CHAPTER SIX: METHODOLOGY

6.1 Phenomenology

The aim of this chapter is to give a description and analysis of phenomenology in the research question in this thesis which is, ‘how do people live their lives with a diagnosis of schizophrenia?’ The research aim is to gain a greater understanding of the meaning and experience of schizophrenia.

The following areas are addressed: an examination of related ontology and epistemology; the origins of phenomenology; the differences between Husserlian and Heideggerian phenomenology; the interrelatedness between the researcher and the social reality being researched, and also between the researcher and researched. Also examined are definitions and aims of phenomenology, the researcher’s role, perceptions of people, the rationale for phenomenology, strength and potential flaws in this approach and examples of previous research which used phenomenology to gain access to experiences of people with a diagnosis of schizophrenia.

The ontology and epistemology of phenomenology are discussed by Polkinghorne (1988), Leonard (1989) and Norton (1999) who, in their overviews of qualitative research, maintain that focus on internally created ontology and subjective epistemology in this methodology. Smith (1998) supports this idea and explores the interrelatedness between the researcher and the social reality being researched and the researcher and the research participant. A range of authors discuss the origins of phenomenology and conclude that phenomenology is rooted in the philosophical tradition developed by

Husserl, Heidegger and Kant. The influences of a range of thinkers on the development of phenomenology are explored: Kant, Decartes, Brentano, Husserl, Windelband and Rickert, who were influential in developing Husserlian phenomenology; and Heidegger, Shutz, and Dilthey, who supported Heideggerian phenomenology. These influences are discussed in Dummett (1993), Moustakis (1994), Smith (1998), Koivisto et al (2002) and Edwards and Titchen (2003). Phenomenology has its origins in interactionism and challenges positivism (Koivisto et al 2002, Dowling 2004, Smith 1998), Moustakis 1994). This methodology focuses on an individual's life experiences and places emphasis on interpretivism (Koivisto et al 2002). Johnson (2000), Dowling (2004) and Moustakis (1994) explain the differences between Husserlian and Heideggerian phenomenology and emphasise the importance of bracketing in Husserlian phenomenology. Farber (1966), Cohen and Manion (1994), Smith (1998), Polit-O'Hara and Hungler (1999), Burns and Grove (2001), and Spitzer and Uehlein (1992) define and discuss the aims of phenomenology, and conclude that it is an appropriate methodology to describe and analyse an individual's experience. The roles of the researcher in this methodology are discussed by a range of authors who examine the importance of immersion in the data, bracketing and intuition (Wiggins et al 1992, Moustakis 1994, Smith 1998, Klieman 2004, Wall et al 2004, Mishler 1986). In their discussion of bracketing, some authors examine the contrary position that bracketing may not achieve a reduction in interviewer influence (Mishler 1986, Dowling 2004). Therefore the benefits of bracketing are disputed.

Benner (1994), Burns and Grove (2001), Smith (1998), Bowling (1997), Spitzer et al (1992) and Moustakis (1994) in their discussion of perceptions of people, maintain that people are situated in their social and cultural world, people interpret their world and construct their own reality. Thorne (2000) explores the rationale for phenomenology

and maintains that this approach may uncover the essential nature of a phenomenon. The theoretical framework which is drawn from Frankfort-Nachmias and Nachmias (1996) is used to describe and analyse the ontology and epistemology within phenomenology. Some authors explore the strengths and weakness of phenomenology and maintain that key strengths are hypothesis generation and understanding of events or concerns, while accepted weaknesses are researcher influence and lack of control (Benner 1994, Bowling 1997, Polit-O'Hara and Hungler 1999). Esterson (1970), Laing and Esterson (1964/1978) and Koivisto et al (2003), in their empirical research, showed how phenomenology has been used to understand the experiences of people.

6.2 Ontology and Epistemology

Within phenomenology, ontology (reality) is internally constructed and epistemology (knowledge) is subjective (e.g. perceptions and experiences). Polkinghorne (1988) asserts that the reality of human experience should be the object of human inquiry. Social scientists should read, hear, then later interpret human experience. This creates the knowledge, on which depends the understanding of human existence, and this knowledge is not involved in prediction or control of the experience.

Leonard (1989) takes the view that one cannot consider a methodology without first considering ontology. According to Leonard (1989) the important questions to be asked are “what does it mean to be a person?”, “how does one ask the research question?” and finally, “how does one answer the research question?” (Leonard 1989 p.41).

Ontology is an assumption about the form and nature of reality. In phenomenology, reality is not external to the individual's consciousness. Epistemology, the study of

knowledge and how knowledge may be gained, considers the nature and forms of knowledge (e.g. subjective and objective knowledge). Epistemology reflects the relationship between the knower and what may be known, and within epistemology we can decide what is valid and true knowledge. In phenomenology, subjective knowledge (e.g. the experience of living with schizophrenia) is valid knowledge. Burns and Grove (2001) assert that there is no single reality or truth, and each person has their own reality, which is subjective, and each experience is unique to the individual. Truth is an interpretation of a phenomenon, and what may be perceived as truth by one may be perceived as an interpretation by another, and interpretation is influenced by culture.

Norton (1999) expresses the view that ontology defines epistemology and methodology (e.g. if the reality is accepted as internal, the nature and form of valid knowledge must be accepted as subjective), and the methodology can be selected (for example, phenomenology or grounded theory), which in turn determines method (for example, unstructured interviews). Therefore our views on what constitutes reality can determine our views on the nature of knowledge, and these both can determine methodological principles. The interpretivist paradigm stems from the constructivist paradigm, which proposes that all reality is socially constructed, and this paradigm underpins phenomenology. In the constructivist paradigm of reality, people form their own mental constructions of reality. All social reality is produced and reproduced by social actors, an idea similar to structuration theory proposed by Giddens (1989/2001). There are many constructions of reality, and social reality is inseparable from researchers, because researchers construct the world they research. In interpretivism and constructivism, ontology and epistemology merge, because the knower is not separate from that which can be known within the overall construction of a particular reality.

There is an interrelatedness between the researcher and the social reality being researched. This interrelatedness also exists between the researcher and the researched because we are all connected to this social reality and we all create it. The subject-object problem, as proposed by Smith (1998), highlights and explains the issue of interrelatedness between researcher and researched. All interactions are based on shared understandings between subject (researcher) and object (researched). In this study both subject and object believe schizophrenia exists, and therefore it can be researched and discourse on schizophrenia is created. Because of the shared knowledge and understandings, both subject and object can discuss schizophrenia and so enhance understanding, but the preconceptions of the subject/researcher can prevent real exploration of schizophrenia and so hinder further understanding. In the interaction, the object (researched) adjusts to the subject's understanding, and so the subject may change the social phenomenon under study and may fail to explore the intended phenomenon. Society is concept dependent, and a shared understanding of concepts leads to the researcher being part of the phenomenon under study. Verstehen, a concept from hermeneutical phenomenology, means understanding. With verstehen, we see the concept of dependence as a social phenomenon, and an issue which can be acknowledged, whether it is proven as an objective fact or an interpretation, because it is influencing people. The term schizophrenia and the diagnosis influence all carers and people with schizophrenia in this current study. However, conflict also may occur where the researcher thinks that the interviewee's knowledge about schizophrenia is wrong, and vice versa (Smith 1998).

6.3 The origins of Phenomenology

Phenomenology is rooted in the philosophical tradition developed by Husserl (1859-1938) and Heidegger (1881-1976). Phenomenology can refer to a philosophy, a research method or an approach (Dowling 2004). This is an approach which analyses the life experiences of people and places emphasis on the description of the human experience. Husserl developed descriptive phenomenology as a philosophical method for investigation structures of consciousness, or essences. Essences are what make a phenomenon exist in conscious experience (Koivisto et al 2002).

The phenomenological movement arose in Germany before 1914 and challenged positivism, the dominant epistemology of the time, which is a paradigm in which knowledge is perceived to be scientific and authentic (e.g. X leads to Y). Anything can be studied as hard facts and relationships between facts can be established as scientific law. These facts can be empirically verified and observed (Smith 1998).

Emanuel Kant (1724-1804), an Enlightenment thinker, held the view that interpretation and imagination played an important role in the organization of perceptions in the social sciences. From this idea, phenomenology emerged. Kant believed that perceptions exist and make sense within a mental framework. This approach emerged in response to Rationalism and Empiricism, both of which he believed did not explain or analyse anything adequately. The key idea in Rationalism is that reason leads us to the truth and the key idea in Empiricism is that observations and experiments lead us to the truth. Kant believed that people have concepts, constructs and taken for granted assumptions about everything, that make perceptions and experiences intelligible and produce knowledge. Our phenomenal world is a product of our experiences. Therefore the mind

is a creative agent in the production of knowledge. Kant was a critic of positivism and believed that one cannot impose methods of study from natural science in the study of social life (Smith 1998).

Franz Brentano (1838-1917) was a forerunner of the phenomenological movement. Brentano was a philosopher who influenced Husserl. Brentano is the original proponent of the idea that intentionality is a defining characteristic of mental phenomenon. Directedness of the mind towards something, where the mind is focused on a phenomenon, is a feature of intentionality (Dummett 1993). Husserl advanced this idea (Dummett 1993, Moustakis 1994). Husserl proposed that every mental act must have a noema (a phenomenon) and so there must be directedness towards an phenomenon, even if the phenomenon is a delusional phenomenon with no external objective evidence. For example, an auditory hallucination still has the characteristic of intentionality.

Brentano and Husserl agreed on the following: 1. An object may exist in the mind and a mental act be directed towards it, even if the object has no external or physical existence, 2. The mind is not limited by external reality (e.g. there may be a fear of something, but that thing may not exist physically).

Other proponents of phenomenology included Wilhelm Windelband and Heinrich Rickert who promote the use of the idiographic method, the individualising method of the cultural sciences concerned with detailed description of specific circumstances. They propose that social circumstances are unique and there are values in social research. Social scientific knowledge is related to specific historical and social conditions. Another key proponent was William Dilthey who believed that the lived

experience of an individual is the source of understanding. All mental constructions are historically and socially specific and change over time (Smith 1998). Dilthey agreed with Heideggerian phenomenology and believed that emphasis on the historical perspective is necessary to understand the meaning of an experience (Moustakis 1994).

Phenomenology has its origins in interactionism. A key idea in interactionism is that meanings are interpretations. They are the product of practical concerns with practical problems that people encounter in everyday life. In interactionism, people are social actors and their interactions are the basis of all social life and all ideas have meanings which are located in experiential consequences. People define objects and their context, identify courses of action, types of conduct, imagine the consequences of their choices of conduct or action and select a course of action. George Herbert Mead focused on the social context of the shaping of choices and believed that the concept of self changes through interactions. Mead believed that people think about and imagine how they look to others, imagine how others judge them, have an emotional response to this imagined judgement, and in this way monitor themselves. Mental health clients display patterns like this. There are internal processes, where people define themselves, and external processes where people understand their social positions. In this way identity is created by internal and external processes (Smith 1998).

Alfred Schutz (1899-1959) was a contemporary of Heidegger, who developed Husserl's ideas, but with some differences. For Husserl, the natural attitude is a barrier to true understanding, while for Schutz, the natural attitude of the participant is not a barrier and is a relevant focus of inquiry (Edwards and Titchen 2003). Schutz supports Heideggerian phenomenology. Schutz believed that people could construct their life world and understand each other's consciousness and so achieve intersubjectivity. They would

know what was in each other's minds. According to Shutz, there can only be interpretations and when trying to understand a social situation, one needs to explain a range of factors: motives, means, ends, shared relationships, expectations. People have free will and do not conform to a scientific model. Through intersubjectivity, knowledge can be constructed (Smith 1998).

Descartes believed that subjective and objective knowledge were linked and with this idea he influenced Husserl. Descartes, a 17th century philosopher (1596-1650), thinker and mathematician, influenced how knowledge was constructed in western society (Descartes 1912/1988). Descartes believed that objects have objective reality as they are represented in thought and they also have subjective reality. Husserl linked subjective and objective knowledge. Husserl maintains that there is a relationship between consciousness of a thing and what exists in the world. As a result of this relationship, a meaning is created in the mind. Husserl's concepts of epoche or bracketing, which means remaining presuppositionless, was influenced by Descartes, who believed that there was doubt about any unproven knowledge. The importance of returning to the self to discover the nature and meaning of a thing was considered crucial by Descartes and Husserl. Husserl believed that all scientific knowledge depended on "inner evidence" (Moustakis 1994 p.26).

The origins of Heideggerian phenomenology are in art and in philological-historical insights. Philology is a branch of knowledge that deals with the structure, historical development and relationships of a language. Therefore philological-historical insights involve language and knowledge (Moustakis 1994).

6.4 The differences between Husserlian and Heideggerian Phenomenology

There are differences between the Husserlian and Heideggerian philosophies. One difference is in the origin of meaning. Husserl maintains that subjectivity is a foundation for scientific knowledge and is the life world of everyday experiences. He believed that one's perceptions and consciousness structures what is experienced. Bracketing is necessary. The essential features of the concept of experiences are described. Heidegger disagreed with this and maintained that the main focus is on interpretation and reality. He believed that all interpretations have presuppositions and meanings. Meaning is always in the context of something (e.g. culture, a personal situation). Meaning comes from being human, and phenomena are part of an interconnected world of human interest (Johnson 2000).

Dowling (2004) maintains that Husserlian phenomenology, also known as descriptive phenomenology and transcendental phenomenology, aims to obtain a fundamental knowledge of a phenomenon. The practice of bracketing links this school of phenomenology to positivism, and the Cartesian tradition, in which there is an attempt to achieve objectivity. The focus is on knowledge and the emphasis is on description. This author proposes that Heideggerian phenomenology, also called Heideggerian hermeneutics and interpretive phenomenology, is based on the assumption that human beings interpret their world through language and that this language provides both understanding and knowledge. The aim of this school of phenomenology is to interpret phenomena and uncover hidden meanings. There is emphasis on reality and understanding. There is emphasis on focusing on the circumstances in which understanding occurs. Personal involvement by the researcher in a reciprocal interpretation leads to understanding. There is a dialogue and interpretation in the

hermeneutic process and the researcher considers social and other implications. There is no bracketing and presuppositions are not to be eliminated. However the researcher has to be aware of presuppositions. Prejudices have an importance in interpretation. Some prejudices enhance understanding and others obstruct understanding (Dowling 2004).

In Heideggerian phenomenology, there is only interpretation of a phenomenon and the interpretation reveals what is hidden behind an objective phenomenon. The researcher's prejudgments are altered when the text is interpreted. There are multiple interpretations, and interpretation involves focusing on meaning, interpreting the text as a whole and seeing interconnections (Moustakis 1994).

The main differences are as follows: bracketing is integral to Husserlian phenomenology and is not integral to Heideggerian phenomenology (Johnson 2000, Dowling 2004). In Husserlian phenomenology, the emphasis is on description and knowledge, while in Heideggerian phenomenology the emphasis is on interpretation, understanding and reality (Moustakis 1994, Dowling 2004)

6.5 Definitions and Aims of Phenomenology

According to Farber (1966), phenomenology describes structures of experience and gives an account of the part played by the mind in experience. Farber (1966) proposes that phenomenology allows us to analyse and describe the various types of experiences. It is a descriptive method applied to pure experience.

According to Cohen and Manion (1994), phenomenology focuses on primacy of subjective consciousness and the underlying assumption that consciousness is active and bestows meaning on events and situations. Moustakis (1994) also discusses phenomenology and proposes that it is an experiential and qualitative approach and a reflective, structural analysis which portrays the essence of an experience.

Bowling (1997) asserts that social facts are characterised and recognised by their meaningfulness to people. The aim of phenomenology is to discover these social meanings. All human action is a response to interaction with others and the meaning of this to the individual. The research setting in phenomenology is natural, unmanipulated, interactive and jointly participative by researcher and respondent.

Smith (1998 p.164) maintains that in phenomenology we explore the “taken for granted” assumptions of social research and, by describing the experience, we can create an object of analysis (e.g. the lives of people).

Polit-O’Hara and Hungler (1999) assert that phenomenology emphasises the inherent complexities of humans and their ability to shape and create their own experiences. There is emphasis on the human experience as it is actually lived, and on the careful collection and analysis of data. This approach attempts to identify the entirety of the phenomenon, stresses the importance of interpretation, collects information without formal structured instruments and tries to capture the context in its entirety. It tries to capitalise on the subjective as a means of understanding and interpreting human experiences. Phenomenological research is less concerned with control and the emphasis is on the holistic perspective and the individuality of human experience.

Burns and Grove (2001) maintain that phenomenology is a theoretical point of view that advocates the study of direct experience taken at face value. It is an inductive descriptive approach, developed from phenomenological philosophy, with the aim of trying to understand the responses of the whole human being.

Spitzer and Uehlein (1992) discuss phenomenology and psychiatry. Within phenomenology there is no explanatory theory and no inference about possible causes. Phenomenology permits the understanding and interpretation of something. They argue that more than recall of senses occurs and it includes contents of consciousness as experienced by people. Phenomenology is a method of empirical science which attempts to describe the first person subjective experiences, for example, of the psychiatric patient (e.g. description of disturbed emotions).

6.6 The researcher's role

Within a phenomenological methodology the researcher immerses him/her self in the data and tries to uncover commonalities and differences and contexts (Cohen and Manion 1994, Benner 1994). Bracketing (Hycner 1985, Benner 1994, Burns and Grove 2001), which means refraining from judgment, suspending one's beliefs and interpretations of events (Hycner 1985) is attempted. Moustakis (1994 p.33) discusses a similar concept, termed "epoche" which also means "to refrain from judgment". The known facts related to the phenomena are eliminated, which leads to increased awareness and freedom from preconceptions (Moustakis 1994 p.33). Smith (1998 p.164) highlights bracketing, and, according to this author, it means suspending our beliefs and abstaining from making judgments about whether the objective world exists or not (Smith 1998 p.164). Bracketing may be achieved using visual imagery according

to Kleiman (2004). An invisible bracket in the air may be imagined by the researcher, who should place all preconceptions into this invisible bracket. Biases and presuppositions should be written down. Biases and presuppositions should be discussed with colleagues, who should challenge them, so that the researcher is not influenced by past knowledge and does not suffer from the tunnel vision of routine. In the interview, the researcher should consider what is given, exactly as it is given. This involves using active listening skills (Kleiman 2004).

Wall et al (2004) maintains that successful bracketing leads to a presentation of a phenomenon from a participant, in a clear unaltered manner, exactly as the participant describes it, and it is a faithful representation. Then it is analysed using a theoretical and conceptual framework, made sense of and arranged into concepts that relate to theory, using phenomenological reduction (e.g. codes, themes, concepts and theories). The researcher must ask her/him self, 'what am I taking for granted?' The researcher has to open up their perspective and keep a reflective diary. The researcher should be self aware of their own nonverbal behaviours and maintain a neutral facial expression. Wall et al (2004) offer a reflective framework which involves 1. pre-reflective preparation, 2. reflection, 3. learning and 4. action from learning. Firstly, in pre-reflective preparation, the researcher decides the beliefs and issues that require to be bracketed. The researcher plans and documents actions that help in the process of bracketing, for example talking to colleagues who will challenge preconceptions. Secondly, in reflection, the researcher reviews and reflects on situations, including interviews with participants, and on methodological progression of the research. The researcher describes situations in detail, identifies factors that influenced situations, and provides evidence of critical analysis on the extent to which bracketing was achieved. The researcher has to ask if her/his own ideas intruded into the interview. Thirdly, in learning, the researcher can

identify what new learning has taken place as a result of each new situation or interview and its reflection (for example, learning as a result of conducting interviews that the researcher needed to use fewer questions). Fourthly, action from learning involves considering how new learning might be used in other situations or subsequent interviews (for example, learning, from stage one interviews, to fine tuning probes, and considering what themes to explore in more depth in stage two interviews).

The reflective diary can help develop bracketing skills. This may be achieved by considering Johns's (1994) model of reflection, which involves: 1. bracketing pre-action, 2. bracketing in-action, 3. bracketing on-action. Firstly, bracketing pre-action involves documenting issues, and the bracketing strategies, (e.g. using imaginary brackets, practising neutral nonverbal behaviour and using active listening skills). Secondly, bracketing in-action involves bracketing out the researcher's own thoughts on issues which are nothing to do with the research question, or one's own opinions, when the participant makes extremely strong statements. An example of this is when a participant showed me her art work (she is a self employed artist) and I started to form a favourable impression of this participant. Thirdly, bracketing on-action involves questioning the assumption that the researcher has always asked appropriate questions and questioning the assumptions that one's questions would be understood by all participants. Some questions might have to be rephrased and reformulated to be understood by some participants. One assumption was that all participants would be able to coherently describe how they felt and describe their life prior to schizophrenia and their relationships with others. But this was not always the case. For some this was difficult and some were not comfortable with describing how they felt. One thing that emerged from this was that as more interviews were conducted, the researcher allowed people simply to talk, and asked fewer questions or probes.

The argument for bracketing with the goal of reducing interviewer influence is made by Mishler (1986) and Moustakis (1994). Mishler (1986/1991) proposes that treating participants as informants and as competent observers in their own lives reduces interviewer influence. Participants are collaborators and full participants in the development of the study, in the analyses and interpretation (linked to context) of data. Feedback to participants is consistent with reciprocity, and showing drafts of the report and transcripts to the participants so that they can correct errors of fact and check interpretation will reduce interviewer influence. Moustakis (1994) proposes that when one brackets, the entire research process is focused solely on the research question and this reduces interviewer influence. This author also proposes that, in horizontalizing, which means treating each statement with equal value, interviewer influence is reduced.

Hycner (1985) believes that it is important for the researcher to keep a journal record of general impressions and specific issues to expose preconceptions, suppositions and biases. The researcher can then bracket these and focus on and remain true to participants' meanings.

There is a counter-argument to bracketing, made by Mishler (1986/1991) and Dowling (2004). Mishler (1986/1991) argues that in interviews, there is joint construction of reality. Discourse and narrative are both constructed by interviewer and participant. Participants and interviewers treat each other as significant others. Participants respond to the researcher as a person with personal qualities and views, and their behaviour is similar to their behaviour towards significant others in their lives. Dowling (2004), in discussing hermeneutics, considers this position. Preconceptions and prejudices are part of our linguistic experience and this makes understanding possible. People who express

themselves and people who understand them are connected by a common human consciousness and there is a reciprocal process of interpretation. However the researcher must be open to and accept the meaning held by the participant and be aware of his or her preconceptions so that the text can portray its uniqueness and authenticity (Dowling 2004).

Within a phenomenological study the researcher intuitively (Spitzer et al 1992, Moustakis 1994, Burns and Grove 2001). For Husserl intuition is perception of an object or phenomena. It is a direct awareness of something. The researcher engages in direct self-reflective and detailed presentation of the mental processes under study (Wiggins et al 1992). This means focusing all awareness and energy on the phenomenon. Intuiting is essential to phenomenology and is said to lead to the researcher seeing the phenomenon as it really is, and describing it completely in all its elements and variations of perception. Husserl believes that intuition is necessary because by intuiting, the researcher can derive knowledge of the human experience “free from everyday sense impressions” (Moustakis 1994 p. 32). The researcher is not influenced by everyday knowledge or attitudes. This is essential if one wishes to describe whatever is presenting itself.

6.7 Perceptions of people

People are viewed as being situated in their own cultural, historical and familial world, which is a set of relationships, practices and language which have meaning for people (Benner 1994, Burns and Grove 2001). Benner (1994 p.46-47) terms this “being-in-the-world”. Benner (1994) discusses the concept of situatedness, which means that

people are situated in their specific historical, cultural and familial world. In this world there are language, shared skills and practices and people depend on these for meaning and making their world intelligible. All these shape people and their values (Benner 1994). This situatedness allows them to shape their world, but their world also shapes them, thus constraining them (Cohen and Manion 1994, Burns and Grove 2001). Knowledge is socially and culturally situated, which involves values and it is historically situated (these are traditions of thought) (Smith 1998).

Humans have a consciousness, with which they interpret and experience the world and construct a unique reality (Bowling 1997). People have intentionality, which means they perceive the phenomenon and have evidence from their experience (Spitzer et al 1992, Moustakis 1994). People integrate the “noema” (the perception of the phenomenon), and the “noesis” (the evidence and meaning of the phenomenon), into meanings and essences of the experience, which exists because the person’s mind is focused on it (e.g. noema: hearing voices, noesis: I am afraid and cannot sleep, the voices are frightening) (Moustakis 1994 p.29).

6.8 Rationale for Phenomenology

A methodology based in positivism would have been inappropriate. Within this specific research question the researcher must focus on subjectivity, and subjectivity is congruent with the overall theoretical perspective of phenomenology. Phenomenology lies within the interpretivist philosophy of research. The focus is on the primacy of data. The required data or knowledge is the lived experience of people with schizophrenia. This is subjective epistemology (knowledge) and internally constructed

ontology (reality). Using the theoretical and conceptual framework proposed by Frankfort-Nachmias and Nachmias (1996) it can be described in the following way:

Theoretical system: epistemology

Conceptual framework: subjective knowledge

Structure of assumed propositions: 1. Subjective knowledge of schizophrenia exists. 2. This subjective knowledge is comprised of personal experiences (for example, hearing voices, seeing visions, and their views of others' responses to them). 3. Subjective knowledge is valid knowledge.

Explanation or prediction: Subjective knowledge is gained in the current study. We need to know/understand what people who live with schizophrenia experience.

Theoretical system: ontology

Conceptual framework: internally constructed reality, perceptions, interpretations

Structure of assumed propositions: 1. There is internally created ontology, a person's subjective reality 2. There is a positive construction of the experience of hearing voices. 3. This internally constructed reality is valid.

Explanation or prediction: Positive reporting of the experience of hearing voices. The voices are helpful. Voices make people feel powerful and help them to cope.

Within the interpretivist paradigm there are other qualitative methodologies: ethnography and grounded theory. Using ethnography would have meant being with the participants for a considerable length of time. This would not have been possible for the researcher, who was a part-time student on a PhD programme and did not have an extended period of time. Participant observation could not be carried out as these participants lived in their own homes. The sample the researcher wished to gain access

to would not have allowed this. Grounded theory involves testing out a hypothesis, and there was no hypothesis to be tested. There was a research question to be explored. Abductive reasons could not be used (the cyclical process of : 1. data collection 2. hypothesis formation 3. testing / theorising, followed by further data collection). The research question would not have lent itself to this process.

Phenomenology is participant centred. The aim of this study was to gain a greater understanding of the meaning and experience of schizophrenia for the person with this diagnosis. Phenomenology is the most appropriate methodology for exploring this research aim and question. People evaluate their lives, their responses to situations and other peoples' responses to them. There are events or phenomena, and meanings are given by individuals to these phenomena. People have perceptions of physical and mental phenomena and they reflect on these. Phenomenology captures these reflections. People actively construct the meaning of phenomena. This methodology captures the process of constructions of meanings and interpretations. People construct their own reality, which is portrayed in the findings. One can examine the processes whereby people's constructions of reality are arrived at.

Different people experience the same phenomena in different ways and attach different meanings and interpretations to these. This methodology highlights these different meanings and interpretations, using constant comparison. The researcher sees/perceives beyond the natural attitude or common sense knowledge or understanding of phenomena

In Husserlian phenomenology the focus is on description and this makes phenomenology appropriate for the research question 'How do people live their lives with the diagnosis of schizophrenia?'

Phenomenology highlights the active role that people with schizophrenia play in their socially constructed world. It offers deep insight into experiences and the significance and meaning of these, particularly the social, personal and moral dimensions of living with schizophrenia. This methodology focuses on issues that participants identify. It is good for examining issues and identifying problems. It is suggested that it makes the nurse researcher ask questions about, and reflect on, beliefs, values, roles and nursing practices. It may offer insight into potentially insensitive and untherapeutic practices and it emphasises the complexity of people. It may facilitate empathy and shared humanity. The concerns and common meanings of the participants may be acknowledged. These may be taken for granted, linguistic and cultural meanings that create cultural issues (for example, what it is like to be a woman with schizophrenia, or a successful professional person who is diagnosed with schizophrenia). Questions about human consciousness can be answered. Caring can be examined as opposed to curing, and how people feel about care and caring can be explored. Power sharing and empowerment might be promoted because phenomenology is said to involve true dialogue with equality. Engaged reasoning, which is the ability to approach a situation with a background knowledge and to ask questions of that situation from that background understanding, is facilitated by the researcher. Thorne (2000) proposes that phenomenology may uncover and describe the essential nature of a phenomenon and represent it in a manner in which an outsider may appreciate the phenomenon.

6.9 Strengths of phenomenology

Benner (1994) asserts that phenomenology answers ‘why’, ‘what’ and ‘how’ questions, and questions about human issues and concerns. We gain a better understanding of issues and concerns. A phenomenological study can lead to anticipation of future events and aid in understanding the significance a person, or family, gives to these events. Bowling (1997) asserts that this approach is good where there is little existing knowledge, and involves sensitive or complex issues (e.g. the experience of chronic illness). It describes in words, not numbers, the qualities of social phenomena (Bowling 1997). Polit-O’Hara and Hungler (1999) propose that findings from a phenomenological study can be a starting point for hypothesis generation or theory development.

6.10 Potential flaws

Benner (1994 p.99-125) highlights the issue of the researcher being unable to escape their “taken-for-granted background”, a practical familiarity related to background practices from our world that makes an interpretation possible (for example the researcher’s background in mental health nursing in hospital settings). The researcher begins with a point of view, with which they make their interpretations, and the participants and their viewpoint may never be understood completely by the researcher. This methodology will not aid prediction, is expensive, requires a lot of time and commitment, and not everyone is willing to participate (Benner 1994). This author asserts that preconceptions and biases must be acknowledged beforehand, and there is a possibility that the interpretive work may be biased towards the researcher’s knowledge, not the participants’ lived experience. The researcher may lose the context of the original text when interpreting data.

Polit-O'Hara and Hungler (1999) highlight potential flaws, specifically the issue of control, which is difficult to achieve because data is collected in the naturalistic setting, and the researcher cannot identify or control confounding factors. The lack of control makes it impossible to rule out numerous alternative explanations for findings and so firm conclusions about the critical relationship between variables cannot be reached. None of these potential flaws are specific to phenomenology and exist in all qualitative research.

6.11 How phenomenology has been used in previous studies to understand experiences.

Laing and Esterson (1964/1978) is a phenomenological study involving 11 families which have a female member with a diagnosis of schizophrenia. The research question in this work is 'are the experiences and behaviours that psychiatrists take as symptoms and signs of schizophrenia more socially intelligible than has come to be supposed?' What they explored was: if we examine some behaviours and experiences in the light of family interactions and context, they might make more sense. These authors believed that researchers should be presuppositionless and they bracketed off organic pathology, group pathology and psychopathology. They did not set out to prove family dynamics were a cause of schizophrenia. However they studied the intensive face-to-face reciprocal interactions in the family. They believed that all family members had human agency. Each person in the family and the relations between each person in the family and the family itself as a system were studied. The method used was unstructured interviews, which were audiotaped, transcribed and analysed. The limitations were: there was a small sample, all female, from two hospitals. The interviews were conducted in a consulting room, an artificial setting, and not in the

family home, a more natural setting. The authors cannot guarantee that the interactions observed happened consistently in the family home. Exploration of the family as a system was incomplete because the focus was on the identified patient, or the mother-daughter relationship, or the person in the family network and not specifically on the family network itself.

They concluded that experiences and behaviours of people with schizophrenia are much more intelligible than has previously been supposed by psychiatrists. An example of what these young women appeared to experience was the following: something actually happened, Maya, a participant, knew that it happened, but mother and father colluded with each other to deny it. These parents added to Maya's mystification by telling her that she could not, or did not, think do or remember what she did think, do or remember. These parents said one thing, meant another and invalidated Maya's perceptions or observations. Maya retreated into her own world. These parents explained Maya's behaviour away by attributing it to illness. Maya did not trust her own perceptions. The family's odd communication style was highlighted.

In the Danzig study by Laing and Esterson another family presented the contradiction between verbal and nonverbal communication was highlighted (e.g. verbally, we like you, nonverbally we do not like you, verbally, we want you to come home, nonverbally we want you to stay in hospital for your own good) (Laing and Esterson 1964/1978).

Esterson (1970) used the same study and findings to reach the following conclusions: the young women with schizophrenia had become objects in the world of their parents, families believed that they had sacrificed something for the good of their daughters with schizophrenia, and illness in these young women was a result of family tensions.

Koivisto et al (2003) conducted a phenomenological study on nine patients' experiences in hospital and their views of mental illness. Unstructured interviews were conducted. Participants were interviewed once or twice and open-ended questions were used. These authors used Husserlian phenomenology and they bracketed and suspended their presuppositions. Data were analysed using Giorgi's phenomenological methods, which are based on Husserlian phenomenology (Giorgi 1985 cited in Koivisto 2003 p. 224). This involved identifying meaning units, focusing on the phenomenon, transforming participants' statements into psychological language (with emphasis on the phenomenon), transforming these meaning units into a statement of structure (e.g. being helped). Firstly, structure of the experience is identified (e.g. the experience of being a mentally ill person with psychosis and being helped). Then a general description of this is given. Each individual's structures or experiences are compared and commonalities and differences are reported. Themes are extracted from the general meaning units (e.g. the progress of illness).

The main findings were: loss of control over oneself with resulting emotional distress, feelings of vulnerability while experiencing strange psychological feelings, friends and family were important and meaningful and daily life was difficult to manage. Specific life situations were present prior to the onset of schizophrenia. The progress of the illness exhausted them and was holistic. They felt a need to protect themselves from difficult life experiences. No limitations of this study are acknowledged, although the small sample may be a limitation. Sandelowski's model of rigour has been used (Sandelowski 1993 cited in Koivisto 2003 p. 225). The strengths of this study are discussed. The data is credible and has truth value because every patient has had an experience of a psychotic disorder. The analytical process was described in detail; therefore, consistency and confirmability were present. Applicability or transferability

of findings to other situations was not considered relevant as the aim of the study was to gain in-depth knowledge of the participants' experiences and not to gain knowledge which was generalisable, according to these authors.

6.12 Summary

In conclusion, in phenomenology, subjective knowledge and internally constructed reality are socially constructed by all participants. The original idea of phenomenology emerged from the philosophy of Emanuel Kant, an Enlightenment thinker. There are differences between Husserlian and Heideggerian phenomenology, with the former being descriptive and the latter being interpretive. . The researcher and researched are connected to the social reality because of shared understandings of a phenomenon. Phenomenological research aims to facilitate understanding of another person's subjective experience and social meanings are discovered. The researcher attempts to immerse her/himself in the data, brackets and intuit. This facilitates understanding and description of the phenomenon. People are seen as situated in their own world and construct their reality from the evidence of their experience. Phenomenology is asserted to facilitate empowerment of participants, because it allows equality within the dialogue. It aims to uncover the essential nature of a phenomenon and the significance or meaning someone gives to it. The researcher is unable to escape their background and may introduce bias into the findings.

CHAPTER SEVEN: RESEARCH METHOD

The aim of this chapter is to describe and analyse the research method, which is unstructured interviews. The research question is: ‘how do people live their lives with a diagnosis of schizophrenia?’ The aim of this research is to gain a greater understanding of the meaning and experience of schizophrenia for the person with this diagnosis. This chapter examines issues which are specific to unstructured interviews. The research design is discussed in section 7.1. Section 7.1 describes and discusses characteristics of a successful interview, and the qualitative criteria of trustworthiness proposed by Lincoln and Guba (1985). The following are considered: bias; objectivity, reduction of interviewer influence or bias, and intersubjectivity. Section 7.2 examines validity and reliability, and 7.3 and 7.10 examines representativeness. Section 7.8 examines anecdotalism. Section 7.11 outlines ethical issues (anonymity, confidentiality, informed consent). Section 7.12 examines inductive coding. I will outline the participants in section 7.13, the setting in section 7.14 and recruitment in section 7.15. Sections 7.10 and 7.13 discuss the representativeness of the study population, section 7.16 discusses interviews and section 7.17 discusses engagement in interviews. Section 7.18 outlines data collection; unstructured interviews, and section 7.19 outlines the coding paradigm (Strauss 1987). Section 7.20 examines audiotaping and section 7.21 discusses respondent validation. Section 7.22 outlines data analysis and discusses Burnard’s (1991) framework, and section 7.23 outlines coding paradigm themes. Section 7.24 outlines open coding and section 7.25 outlines axial coding. Section 7.26 summarises the coding paradigm, section 7.27 offers further analysis, and finally section 7.28 offers a summary of the chapter.

May (2001), Frankfort-Nachmias and Nachmias (1996) and Bryman (1988) define and explain the rationale for unstructured interviews. The concepts of validity and reliability in qualitative research are examined by Marshall and Rossman (1999), Polit and Beck (2004), Tucket (2005), Koivisto et al (2003) and Lincoln and Guba (1985). Polit and Beck (2004), Lincoln and Guba (1985) and Tucket (2005) maintain the view that the positivist paradigm, which includes the concepts of validity and reliability, does not apply well to qualitative research. They propose that an alternative model, Lincoln and Guba's (1985) model of trustworthiness is more appropriate. Hammersley and Atkinson (1995), Moustakis (1994), Frankfort-Nachmias and Nachmias (1996), Gilbert (2001) and Bryman (1988) explore bias in unstructured interviews and maintained that bias could occur. Kvale (1996) adopts the position that identifying values in unstructured interviews is one of the strengths of this method. McCann and Clark (2005), Mishler (1986/1991), Holloway and Wheeler (2002) and Silverman (1993) discuss interviewer bias and influence and maintain that these can be reduced. Lincoln and Guba (1985) maintain that bracketing reduces interviewer bias.

May (2001), in his analysis of objectivity, maintains that objectivity can be achieved. Other authors adopt the position that objectivity is not important in qualitative research: Frankfort-Nachmias and Nachmias (1996), Gilbert (2001).

Kvale (1996) maintains that intersubjectivity is appropriate. Holloway and Wheeler (2002), Mishler (1986), Silverman (1993), Gilbert (2001) and May (2001) explore intersubjectivity and maintain that this is acceptable in qualitative research, although Mishler (1986) and Silverman (1993) suggest that it may be difficult to achieve.

Hammersley (1990) and Silverman (2000) view internal and external validity in the positivist sense, with the emphasis on truth and generalisability. Kvale (1996) and

Marshall and Rossman (1999), in their examination of validity, maintain that dependency on subjective impression is acceptable. Silverman (1993:2000), Kvale (1996), Burnard (1991) and Burns and Grove (2001) explore ways of strengthening validity. Empathy is examined by Creasia and Parker (1991), Freshwater (2002), and Kvale (1996), who adopt the position that empathy is acceptable. The contrary position is adopted by Silverman (1993) and Burnard (2005).

Anecdotalism is examined by Bryman (1988) and Silverman (2000), who maintain that it reduces validity, and suggest ways of reducing anecdotalism.

Silverman (2000) examines reliability and suggests ways of strengthening this. Marshall and Rossman (1999) offer an alternative view of reliability, specifically dependability, similar to that of Lincoln and Guba (1985).

Frankfort-Nachmias and Nachmias (1996), Silverman (2000) and May (2001) examine representativeness and suggest ways of increasing this. An alternative view of representativeness is offered by Madison (1988) and Kvale (1996). Inductive coding is examined by Bowling (1997), Burns and Grove (2001) and Silverman (1993). Frankfort-Nachmias and Nachmias (1996) adopt the position that there is no method of estimating the representativeness of a convenience sample, but Burns and Grove (2001) challenge this position and offer a method. They propose that the researcher may use another sampling method, identify known biases and take steps to increase representativeness (see section 7.13). Strauss (1987) propose a coding paradigm which assists a researcher to explore themes in unstructured interviews. Burnard (1991) suggests a general analytical approach to analysing phenomenological data, which involves 14 stages of analysis.

Design

The research design is presented, with discussion of the following: a rationale for unstructured interviews, characteristics of successful interviews, bias, validity, reliability, objectivity, representativeness, ethics, and inductive coding.

Rationale for unstructured interviews

An interview is a face-to-face interpersonal situation in which an interviewer asks respondents questions which are designed to gain responses relevant to the research question (Frankfort-Nachmias and Nachmias 1996). According to these authors, the interviewees are encouraged to relate their experiences and to describe events that seem significant to them. They are encouraged to define situations and reveal their opinions and attitudes (Frankfort-Nachmias and Nachmias 1996). Bryman (1988) highlights the minimal guidance and considerable freedom of expression for interviewees in unstructured interviews compared with other methods.

According to May (2001), unstructured interviews offer flexibility and do not constrain or limit the interview. In such interviews, the researcher's preconceptions may be challenged (May 2001). The interviewee has opportunities to answer questions and, in this way, it is argued depth is achieved with the expectation that personal meaning, which people attribute to events, can be understood. Therefore this is an appropriate method to gain access to peoples' experiences of living with schizophrenia.

Characteristics of a successful interview

May (2001) proposes that engagement is a characteristic of a successful interview, and a sustained relationship is essential. Engagement is the process whereby the respondent is oriented to the process of the interview, and their co-operation as a participant is ensured, as rapport is built. It is suggested that rapport is crucial, as it leads to trust, and trust leads to dialogue, where respondents describe their reality (May 2001).

7.2 The use of the concepts of validity and reliability in qualitative research

Marshall and Rossman (1999) maintain that the social world is always changing and the concept of replication is problematic. However reliability can be addressed in qualitative research. Issues of reliability can be considered through the categories one uses to analyse each text or transcript. Categories should be used in a standardised way, so that any researcher would analyse in the same way. This represents a form of inter-rater reliability. The criterion of refutability is a good way to test the validity of the research. For example, in the current study, the findings could have been refuted when participant validation was carried out, and transcripts might then be refined as a result of participants' responses (7.20) (Marshall and Rossman 1999).

Other authors maintain that the positivist paradigm, which involves the concepts of validity and reliability, does not apply well to qualitative research. To make the statement that qualitative research has weak reliability becomes irrelevant (Polit and Beck 2004).

In the current study, Lincoln and Guba's (1985) model was used to ensure the trustworthiness of the data. The criteria used are credibility, dependability, confirmability and transferability.

Credibility

Participants in research recognise the meaning that they themselves give to a situation or condition, and the 'truth' of the findings within their own social context. Credibility is achieved because the researcher's findings are compatible with the perceptions of the participants and if the study enhances the believability of the findings. Triangulation can enhance credibility. Data triangulation includes space, person and method triangulation. In the current study space triangulation was achieved by collecting data on the same phenomena in many sites. The data was validated from cross site consistency by using participant validation. Person triangulation was achieved by interviewing people with schizophrenia who were in a user group and other who were not, and carers. Multiple perspectives on the phenomena were achieved (e.g. psychological and sociological perspectives). Method triangulation was achieved using unstructured interviews and participants' diaries. Theory triangulation was achieved through the use of competing interpretation of data (e.g. sociological theories to explain findings (social constructionism and labelling theory), and psychological theories (negative self concept)). One can develop competing theories while still collecting data because the flexible design of qualitative research allows opportunities to direct the inquiry (e.g. Phase 1 and Phase 2 with fine tuning of probes in Phase 2 to confirm and explore the emerging themes).

Member checking or participant validation leads to credibility. One problem with this is that participants might agree, or fail to disagree, with the findings because they believe that the researcher knows better than them. Searching out disconfirming evidence or contrary cases or negative case analysis was conducted in the current study, and this leads to credibility (e.g. one participant reported that she wanted more medication) (Lincoln and Guba 1985). The research strategies used to ensure credibility were a field/personal journal, a tape recorder, a thematic log (a list of Nudist nodes), and auditing of transcripts. The operations techniques used were use of negative case analysis (or deviant cases), constant comparison, member checking (participant validation), within-method triangulation, person triangulation, space triangulation and theory triangulation (Koivisto et al 2003, Tucket 2005).

When using this model proposed by Lincoln and Guba (1985), the authenticity or truth value of findings may be determined. However it may be that that what emerges from this type of study is not an authentic experience being recounted but a cultural script being produced (Silverman 1993). It may be that there are two cultural scripts in these findings: 1. a traditional cultural script, 'I am a sick person with schizophrenia, my life has been stopped by illness'; and 2. a new cultural script, 'they tell me I have schizophrenia, I do not believe health professionals, I avoid them and I have moved on in my life'.

Dependability

This means stability of data over time and conditions. An audit trail establishes some degree of dependability. The reader can follow the path of the researcher who demonstrates how he/she reached his/her conclusions. The research strategies and

operational techniques can be repeated, although the circumstances and sample may not be similar. Inter-rater reliability enhances dependability, but it was not possible to achieve inter-rater reliability in the current study, as no other researchers were available (Lincoln and Guba 1985). The research strategies used to enhance dependability were use of a field journal and tape recorder, a thematic log (Nudist nodes), auditing transcripts, and peoples' stories or vignettes. The operational techniques used were atypical case analysis, triangulation and audit trail (Tucket 2005).

Confirmability

This means neutrality of data and this was enhanced by maintaining a reflexive journal. This was further enhanced by bracketing (see section 6.6) (Lincoln and Guba 1985). Confirmability is established by an audit trail. An audit trail consists of the following:

1. Raw data, interview transcripts.
2. Data reduction and products of analysis (e.g. list of Nudist nodes), a conceptual framework (the structure of assumed propositions offered by Frankfort-Nachmias and Nachmias 1996), theoretical notes, documentation on working hypotheses (e.g. other peoples' behaviours caused more distress than having visions or voices).
3. Process notes, notes from member check sessions, methodological notes, what the researcher actually did.
4. Material relating to researcher intentions, information sheet, research aim, researchers' disposition (e.g. reflections 8.31).
5. Instrument development information, fine tuning of probes after stage 1 and before stage 2 interviews.
6. Data reconstruction products, the final report.

1-6 were achieved and hence confirmability (Lincoln and Guba 1985).

The research strategy used to ensure confirmability was writing a field journal and the operational technique was having an audit trail (Tucket 2005).

Confirmability was achieved by describing analytical processes, tape recording interviews, verbatim transcribing, analysis using Burnard's (1991) framework, and bracketing of preconceptions prior to data collection and analysis (Koivisto et al 2003).

Transferability

Transferability means fittingness to another situation or context. It is the responsibility of the original researcher to provide sufficient descriptive data (vignettes, thick description) so that readers can evaluate the applicability of data to other contexts. This was undertaken, but one cannot specify external validity. One can only provide description necessary to enable an interested reader to reach a conclusion about whether transfer of data may be possible. Those who transfer the research into another context can apply concepts in the original research (e.g. stress, loss) into another context (Lincoln and Guba 1985). The research strategies used to ensure transferability were data display (Nudist nodes) and simultaneous literature review and the operations techniques was thick description (vignettes) (Tucket 2005).

7.3 Bias

The researcher's professional mental health nursing background was disclosed to participants, which may have caused a problem in these interviews because the researcher previously believed that stress was caused, consistently, by hearing voices. This belief was altered by the experience of interviewing. The different beliefs about voices and visions may have led to misunderstandings by the researcher, or leading

questions or interviewer bias. The researcher, in this study, is part of the mental health system being commented on, and criticism of the mental health system should not be avoided, because avoidance leads to bias, according to Hammersley and Atkinson (1995). Unintentional bias may have been introduced by focusing on certain themes and not others.

Some authors assert that bias is possible when interviewers focus on issues that match their own personal interest (Moustakis 1994, Frankfort-Nachmias and Nachmias 1996, Gilbert 2001). Frankfort-Nachmias and Nachmias (1996) and Gilbert (2001) believe that bias must be avoided and the researcher must be neutral about the subject being expressed, while displaying an interest in the subject. Similarly Bryman (1988) highlights the need to use minimal guidance in unstructured interviews if such interviews are to be relatively free from bias. Kvale (1996) however, disagrees with this, maintaining that if bias or one's own subjective perspective is acknowledged, it contributes to a multi perspectival construction of knowledge, and is therefore a strength in interviews because values will be highlighted. According to Kvale (1996 p.42) "knowledge is perspectival and dependent on the values of the investigator". Values involve positive and negative labels.

Gilbert (2001) identifies situations that can lead to bias, specifically misdirected probing or prompting, and ignoring the effects of interviewer characteristics (e.g. the likelihood that being female leads to being perceived as more friendly and less threatening than a male researcher, and will lead to more responses). In addition, ignoring the cultural context in which the interviews are taking place can lead to bias.

7.4 Objectivity

According to Silverman (2000), objectivity is the extent to which findings are free from bias and should be the aim of all social science. May (2001) asserts that if the findings are free from our own values, objectivity is achieved. This position assumes a permanent framework of reality or truth, as is accepted in positivism, and that the truth is not connected to values. Objectivity involves the researcher's detachment and one can generalise from observations on a social phenomenon and make statements about a population (May 2001).

Some authors acknowledge that objectivity is not of primary importance in qualitative data collection (Frankfort-Nachmias and Nachmias 1996, Gilbert 2001). Kvale (1996) proposes that a subjective perspective, if acknowledged, can be a strength, and that leading questions and probes can lead to new and worthwhile knowledge (Kvale 1996). This author discusses intersubjectivity, in which there is shared meaning, which is present when the interviewee and interviewer speak and are engaged in a social relationship. According to Kvale (1996), intersubjectivity is more important than objectivity and, through the discourse of participants, valid knowledge is sought and intersubjectivity is achieved. Kvale (1996) asserts that lack of objectivity does not negate the usefulness of the knowledge gained.

7.5 Reduction of interviewer bias and influence

Interviewer bias and influence were reduced by using the following strategies. An interview guide, or aide memoire, was used. This permitted flexibility, while focusing on the research question and aim and consistency was increased (see Appendix 1)

(McCann and Clark 2005). Interviewer guidance and direction was minimal. Full and specific expression of the participant's definition of the situation was promoted. Value laden responses of the participants were encouraged (not the researcher's values), and the implications of these were explored (e.g. family responses to participants with schizophrenia and positive or negative implications). Neutral probes were used (Gilbert 2001).

Interviews were conducted in respondents' own homes and equality was sought in the interviewer-participant interactions. There was joint construction of interview narrative (Mishler 1986/1991). Thus, participants' engagement was more than simply answering an open question. They informed me about their world and their interpretation of events in their life. These were accepted and there was no interviewer dominance or participant acquiescence. Participants were collaborators, and full participants in the study. They were perceived as informants, experts in, and competent observers of, their own lives (Mishler 1986/1991). They were not objects of study, but were instead active subjects, a point supported by Mishler (1986/1991) and Holloway and Wheeler (2002). This is a position of empowerment and equality in which their cooperation and insights were essential to the success of the study. Participants could control the conditions under which their opinions were sought. In these unstructured interviews participants could raise issues that were not contained in the interview guide. Respondent validation, where participants can check errors of fact or interpretation, was part of reciprocity. An open question may have many possible meanings and the meaning given to the open question was accepted by the researcher. An example of this is as follows: some participants responded to the question, 'how do you live your life with a diagnosis of schizophrenia' with an account of their coping strategies, others responded with an account of how difficult their lives were, and others responded with the view that they

heard voices but they were not ill (Mishler 1986/1991). These participants could choose to participate or refuse (Silverman 1993).

The researcher bracketed (see Chapter Six). Silences were permitted, a strategy which allows participants to think and allows full freedom of expression. Within method-triangulation was used (diaries and interviews), a strategy which increased consistency of findings or dependability, and truth value or credibility, criteria used by Lincoln and Guba (1985).

7.6 Intersubjectivity

Intersubjectivity means a shared understanding of a phenomenon. It is temporary inhabitation of each other's world and there is communication between the participant and the interviewer (Holloway and Wheeler 2002). In unstructured interviews there is joint construction of discourse, in which participants inform the interviewer about their world and interpretations of their lives. This can lead to a shared understanding of their reality (Mishler 1986, Silverman 1993, Gilbert 2001). There is mutual understanding of the experience being discussed (Silverman 1993 Gilbert 2001). May (2001) believes that discovery of the meaning of an experience can be achieved.

Holloway and Wheeler (2002) discuss the interviewer-participant relationship, which is based on equality and mutual respect. Both inhabit the same world and culture and have similar understandings of these. Interview questions and answers are based on shared meanings (e.g. the experience of schizophrenia exists). However the subjective ideas of participants are taken into account (e.g. I hear voices, but I am not ill). There is negotiation and sharing of ideas.

Intersubjectivity was achieved in the current study. Both interviewer and participants presented themselves to each other and there was a sharing of perceptions about the nature of the phenomenon and reality (Moustakis 1994).

Some authors express doubt about the possibility of achieving intersubjectivity. Mishler (1986) suggests that some people understand a question differently from the way it is intended. They interpret the question in a way not previously considered by the researcher. This occurred in the current research. However, reformulating the question may lead to the joint meaning being constructed, according to Mishler (1986). Nevertheless, Silverman (1993) suggests that there may be difficulty in reaching and understanding the private world and experience of another person.

7.7 Validity

Validity is now examined. According to Hammersley (1990), validity means truth, which he describes as the extent to which an account accurately represents the social phenomenon being studied. Silverman (2000) states that internal validity is the extent to which findings accurately map the phenomenon, and external validity is the extent to which findings can be generalised to other settings, similar to the one in which the study occurred.

Other authors view validity differently. Kvale (1996) considers validity to be the strength of an assertion, investigation and questioning. This author maintains that dependency on subjective impressions is acceptable, and that knowledge is situated in a social construction of the social world. Marshall and Rossman (1999) maintain that findings are valid, within the limits and settings of the population, if there is in-depth

description of the phenomena and the findings show complexities, variables, and interactions within the data. If problems are explored, internal validity, or credibility, to use their term, has been achieved.

Strengthening validity

How validity may be strengthened will now be explored. According to Burnard (1991), validity can be achieved by inviting uninvolved colleagues to generate categories from transcriptions, and discuss and compare these with the categories generated by the original researcher. Silverman (2000) asserts that validity is strengthened by highlighting contrary cases. In quantitative research these would be termed outliers. These contrary cases may cast doubt on an explanation, may refute a main finding and may offer a set of minority findings. Silverman (1993) proposes that one set of data informs the other within the same setting, and so increases validity. Contrary cases inform another set of majority findings within the same context and phenomena. An explanation may be doubted if the researcher has not attempted to address contrary cases.

Validity is enhanced by using computer assisted coding and analysis of data. The implication of this is that one can be more confident that the patterns reported actually exist throughout the data, rather than just in favourable examples, thus reducing the bias in coding. However it must be acknowledged that the researcher may exert influence over what codes are expanded on and bias may be present in these choices.

The following strategies were used to increase validity in the current study. Computer assisted coding was used to enhance consistent coding of data, which strengthens

validity (Silverman 2000). It assisted in coding and cataloguing (Burns and Grove 2001). Every response and theme which was relevant to the research question was coded and expanded on. This helped the researcher to make connections between codes and categories, to develop higher conceptual structures and theory building (Kvale 1996).

Examples

The diagnosis of schizophrenia led to certain interactions with others. Interactions with others led to consequences, specifically loss. There were social, physical and psychological losses. There were four responses to loss: anger, acceptance/depression, anxiety (consequences), and avoidance of health professionals (a strategy). There is a close relationship evident here between sociological theory and psychological theory. Thus social exclusion led to depression and feelings of low self worth, whilst labelling led to loss, which in turn led to depression. Using Nudist4 the researcher could consistently code for loss and responses to loss.

Kvale (1996) maintains that there is a risk of focusing on coding and ignoring contexts that relate to the interview statement, effectively reporting a theme out of context. However when using Nudist4 the context was easily identified as memos could be written and related to each code and these provided details of the context. In Burnard's (1991) framework of analysis the context was also related to codes in stages nine, ten, twelve and fourteen.

Empathy is the ability to relate to someone else's feelings and have a deep understanding of their experience. It involves identification and being open to the other persons' feelings, internalising these feelings, and comparing their experiences with

one's own past experiences and associated feelings (Creasia and Parker 1991). Empathy is an important part of caring and it allows one to relate to another person's struggle. When one empathises, one achieves intersubjectivity (Freshwater 2002). Some authors maintain that empathy is acceptable. Kvale (1996) maintains that in qualitative research there is empathetic dialogue because qualitative research is sensitive to human situations. Active listening is an element in empathy and is present in phenomenological interviews. Kvale (1996) proposes that the researcher can listen without prejudice and this allows participants' descriptions of experiences to be revealed. The researcher can access the life-world, the emotional content of what is being said and the direct experience of a person. This is relevant in Husserlian Phenomenology. Others hold the view that empathy leads to reduced rigour in qualitative research. Accordingly, empathy was shown after the interview, not in the interview, and this increased validity (Silverman 1993). Silverman (1993) suggests that the researcher's empathy can lead to a focus on the researcher's impressions, rather than on the raw data, and he proposes that data and analysis of data should be clearly separate. Burnard (2005) proposes that therapy and research should not overlap and within research one should focus on collecting data. The current researcher's view is that in empathy one may influence the participant and even lose sight of the research question.

In addition to unstructured interviews, completed diaries were collected from some participants (Silverman 1993). Notebooks were given to all participants, with stamps and envelopes for their return to the researcher. Information from the diaries supported and elaborated on themes that had emerged naturally in the interviews. These notebooks were analysed in the same way as the interview transcripts, with themes and categories being identified. This was done after all the transcripts were analysed. Themes which

were related to the research question were identified (e.g. emotional consequences: depression, suffering and fear). The context was identified (she is very distressed by hostile voices; her neighbours are hostile towards her; she feels alone and feels emotional pain constantly; her only visitors are the CPN and unqualified social worker who helps her with shopping; she perceives that she has lost everything that was good in her life). Open unrestricted coding was used (e.g. isolation, depression, fear). It was translated into a higher order category (e.g. loss). Repetition was removed. Diaries and categories were double checked for accuracy then were typed up and clustered. Any context was made clear. The example given here was present in both the interview and the diary data.

The themes from the notebooks were compared to the themes from the interviews, with the goal of finding similarities or differences (see data analysis section). Contrary cases were highlighted (Silverman 2000). The diary data was added to the main data.

7.8 Anecdotalism

According to Bryman (1988), brief segments of unstructured interviews are used to prove a particular point, and the representativeness of this is doubtful or not proved. According to Silverman (2000) anecdotalism casts doubt on the validity of qualitative data, and he suggests that respondent validation and triangulation (e.g. respondents' diaries and interview data) be used to reduce the problem of anecdotalism.

Respondent validation and within-method triangulation reduced the problem of anecdotalism.

7.9 Reliability

Reliability “is the degree of consistency with which instances are assigned to the same category by different observers, or by the same observers on different occasions” (Hammersley 1992 p.67). May (2001) asserts that research findings must be repeatable and this increases confidence in the original data. Gilbert (2001) asserts that reliability is consistency from one measurement to the next. Reliability involves stability and consistency, but of these two factors, consistency is considered to be more significant.

Strengthening reliability

Silverman (2000) suggests that reliability is strengthened if everything in the interview (e.g. talk, pauses, overlaps) is recorded and transcribed, and full and unaltered transcripts are available. Where there is interpretation of transcripts and where significant pauses are not recorded and acknowledged, reliability is weakened, because pauses have meanings (e.g. reluctance to disclose something). Having independent coders and inter-coder reliability, where two coders agree on categorisation of interview material, strengthens reliability.

Marshall and Rossman (1999) offer an alternative view of reliability. They use the term dependability, proposing that social reality is always changing and that consistency over several studies is less important than trying to account for changing conditions in the phenomena being studied. However Silverman (2000) asserts that the researcher must document procedures and show that categories have been used consistently to prove reliability.

The following strategies were used to enhance reliability. Computer assisted coding (Nudist4) was used to consistently focus on the same themes and categories. The Burnard (1991) framework of analysis was used. Everything in the interviews, including pauses and nonverbal behaviours were recorded and transcribed. (see data analysis section). Nudist nodes were listed as part of the audit trail.

7.10 Representativeness

Frankfort-Nachmias and Nachmias (1996) assert that a representative sample involves ensuring that the study population shares characteristics with the general population under investigation. The results produced would then be similar to the results gained if the whole population were in the study. May (2001) supports the views of Frankfort-Nachmias and Nachmias (1996). Silverman (2000) asserts that representativeness permits a researcher to make broad inferences about a population. Gilbert (2001) asserts that if a sample is not representative bias may be introduced and precise inferences cannot be made from a small study population about characteristics of a wider population.

Frankfort-Nachmias and Nachmias (1996 p.55) offer some criticism of the concept and discuss the “individualistic fallacy, the drawing of inferences about groups.....directly from evidence gathered about the behaviours of individuals” shedding some doubt on the concept of representativeness in research. Madison (1988) and Kvale (1996) suggest that if findings are representative of participants at the time of the study and in the context, findings do not need to be replicated in another study. Madison (1988), in an alternative structure for evaluating phenomenological research data, offers the term contextuality, which means that the historical and contextual nature of the text is

preserved. Kvale (1996) takes the view that it is not necessary for findings to be generalised to wider populations and that contextuality and heterogeneity of knowledge are valuable replacements for generalisability (Kvale 1996).

Increasing representativeness

Silverman (2000) and May (2001) propose that purposive sampling and stratified sampling in the study population achieve representativeness. However, they acknowledge that this is not always possible in qualitative research. Silverman (2000) suggests choosing deviant cases and deliberately selecting cases which are likely to refute one's argument. Deviant cases test theories, hypotheses and generalisations. They inform another set of data within the same study and context (Silverman 1993, 2000). In the current study, deviant cases were analysed and this increased representativeness.

Silverman (2000) suggests increasing the sample later, when generalisations have emerged, and also seeking out deviant cases at this point to test these generalisations. This author suggests combining quantitative measures of populations with qualitative research (e.g. reading about related studies and comparing the cases in the current study with these), therefore obtaining information about relevant aspects of the population of cases, and comparing cases with them. This creates a stronger basis for one's generalisations.

Representativeness of the study population

The study population was small and specific to Bradford with a narrow age range, and all participants were white. Therefore this reduces the representativeness of this group and the findings gained. They may not represent ethnic minorities or younger people with schizophrenia who are likely to be in hospital and in the acute phase of schizophrenia. The participants in this study are older, and have lived with schizophrenia with some success, according to their own evaluation of success.

Convenience sampling and self-selection are features of this sample. Self-selection influences findings and reduces generalisation, but it does increase the likelihood of participants exercising choice and autonomy and giving full voluntary, informed consent.

7.11 Ethical issues

It is important to avoid causing stress to participants, even if it is unintentional. The United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC) (1992a) and UKCC (1996) emphasise safeguarding the interests of clients and avoiding actions that may be detrimental to their condition or to their safety. If someone has a health problem, they still have the status of a client even if they elect to take part in research. According to Robson (1993), encouraging people to talk about unpleasant events can lead to distress. People may negatively reappraise their self view when thinking about events and themselves. They may revisit past traumas, which can cause mental distress (e.g. reducing their self esteem). Engaging with a participant will change them in some way, perhaps in a negative way (Economic and Social Research

Council 2005). However, if trust and respect are present and nursing ethics and values (specifically, the ethical principles of beneficence, fidelity, honesty, confidentiality and autonomy (Singleton and McLaren 1995)) are adhered to, harm will be minimised.

The following strategies were used to address ethical issues. This research proposal was submitted to, and approved by, the Ethics Committee of the School of Health Studies, University of Bradford. The ethical issues that arose in this research were anonymity, confidentiality, informed consent and the possibility of harm to participants. All participants were given all the relevant information prior to the interview, and could choose to withdraw at any time.

Anonymity

Awareness of participants' identities was restricted to the researcher. Anonymity was assured by allocating participants a unique identifying number. Married couples who were parents of a person with schizophrenia received the same number but with a letter added (for example 28a and 28b) because they were interviewed at the same time and shared broadly the same context. Data were pooled and because of a number system, a particular response could not be attributed to a particular person.

Confidentiality

Confidentiality was assured by storing biographical details separately from the other data, in a locked drawer, for the duration of the study. Not stating the name of the participant conforms to the UKCC (1992b) and Nursing and Midwifery Council (NMC) (2002) *Code of professional conduct* and UKCC (1996) *Guidelines for professional*

practice on the issue of client confidentiality and privacy. The quotes that elaborate on themes are numbered.

Harm to participants

It was important to avoid causing stress to participants, even unintentional stress.

Nonverbal and verbal behaviours were observed for signs of stress. One interview was stopped for a short time, because the participant became very stressed when talking about unpleasant experiences.

Informed consent

The researcher sought consent to arrange meetings with participants at a mutually convenient time and place. Informed consent was gained prior to each interview. The aim and purpose of the research was explained to all participants (Appendix 6). The consent form was given to them and they were asked to read, sign and date it. The researcher also signed and dated it (Appendix 7). Biographical details were collected (Appendix 8). Voluntarism was achieved by frequently checking with participants if they were happy to continue. This conformed to Gilbert's (2001) concept of voluntarism, freedom to respond or withhold responses and negotiation, indicating ethical intent and equality of status of participants.

7.12 Inductive coding

Inductive coding schemes are designed on the basis of a representative sample of responses to open-ended questions. The most frequent responses are included in the

coding scheme. Bowling (1997) asserts that inductive coding is a flexible approach that offers richness of codes, although she also criticises inductive coding for lack of rigour. Burns and Grove (2001) point out that rigour in qualitative research is linked to openness, thoroughness in the data collection and consideration of all data. There are potential problems in inductive coding. Inductive coding can be time-consuming and can lead to a mass of unstructured notes which are difficult to organise and analyse (Bowling 1997). There may be problems with validity as a researcher may select data to fit an ideal conception of the phenomenon or select conspicuous instead of the more mundane data (Silverman 1993). Misinterpretations are possible due to cultural differences, and data is subject to observer effects. Bias may occur and replicability cannot be guaranteed.

In the current study the coding scheme was designed on the basis of a representative sample of responses to open-ended questions. Once the coding scheme was identified after interviews 1-10, it was applied to all transcripts. The most frequent responses were included in the coding scheme. A preliminary coding scheme, the coding paradigm, enabled the researcher to classify the raw data and reduce the number of responses to be analysed. All data, including minority themes, were considered.

7.13 Participants

The study sought to recruit participants with a diagnosis of schizophrenia and their carers. An initial sample size of 20 participants with schizophrenia and 20 carers was envisaged. The participants would be self-selected and participants with schizophrenia would be 65 years and below.

The rationale for recruiting people with schizophrenia who were 65 years and below was to maintain the focus on living with schizophrenia and avoid issues related to mental health problems associated with ageing. The rationale for recruiting a self-selected sample was that it was important to recruit people who were genuinely willing to disclose information about potentially delicate matters about their lives (Silverman (2000). The rationale for recruiting from the local community was to gain individual views and generate findings which were likely to be relevant to local mental health care provision.

However, this was a convenience sample and, according to Frankfort-Nachmias and Nachmias (1996), there is no way of estimating the representativeness of a convenience sample. However, Burns and Grove (2001) maintain that there is a way of estimating the representativeness of a sample in qualitative research.

These are: 1. Could the researcher have used another sampling method? 2. Did the researcher identify and describe known biases in the sample and sampling plan? 3. What steps were taken to increase representativeness of the sample and were these steps explained?

The researcher could have used another sampling method (e.g. gaining access to potential participants through an Out Patient Department or Day Hospital) and this sampling plan may have given the researcher a purposive sample. The researcher may have gained access to an equal number of men with a diagnosis of schizophrenia (n=10) and women (n=10), younger (n=10) and older (n=10) participants and ethnic minority participants (n=4) (20% to represent the 15% Asian population in Bradford and 5% African-Caribbean population). However this was not done. Known biases in the sample have been described. The sample is predominantly older people, with only three

participants with a diagnosis of schizophrenia who were aged 20-29 years old, and all were white. Therefore the sample was not representative. No steps were taken to increase the representativeness of the sample. Burns and Grove (2001) maintain that in qualitative research, the researcher attempts to gain information about the experience being studied (e.g. living with schizophrenia) and this was achieved. The sample size was adequate because saturation of data was achieved after fifteen interviews with participants with schizophrenia and seven carers, at which point no new data was forthcoming.

Burns and Grove (2001) propose a way of critiquing the adequacy of the sample in qualitative research: 1. Are the sampling inclusion/exclusion criteria appropriate? 2. Is the sampling plan/sample adequate to address the purpose of the study? 3. Is the sample size adequate, based on the scope of the study, nature of the topic, quality of the data and study design? 4. Are the sample refusal rates and participant mortality rate discussed? 5. Are the characteristics of the sample adequately described? 6. Does the researcher discuss the quality of the study participant? Were they articulate, well informed and willing to share information? 7. Did the sample produce saturation of data in the area of the study? 8. Does the researcher identify the study setting?

In the researcher's view the inclusion and exclusion criteria (participants to be people with a diagnosis of schizophrenia, living in the community, not in hospital, between the ages of 18 and 65 years) were appropriate, as the researcher wanted to focus on the experience of living with the diagnosis of schizophrenia, not the experience of being an older person. The sampling plan and eventual sample were adequate for the purpose of the study. The sample size was adequate based on the scope of the study, the nature of the research question, the quality of the data and the study design. The characteristics of

the sample were adequately described. The sample were articulate and willing to share information and were generally well informed, and some were very well informed and expert on mental health legislation, policy and developments in mental health care. The sample produced saturation of data and the study setting was clearly identified. Out of these eight criteria of adequacy, seven may be responded to positively; therefore, the sample was adequate for this study.

7.14 Setting

Interviews took place in the setting preferred by the participants. These interviews were conducted in Bradford in participants' own homes, with the exception of three participants who wanted to be interviewed in the university.

7.15 Recruitment

In January 2000, an advertisement was placed in a local newspaper, inviting people who lived with schizophrenia in the community to take part in interviews. They were asked to contact the researcher by telephone. Between February and August 2000, 29 interviews had been conducted, with 16 participants with schizophrenia and 13 carers. Six more participants with schizophrenia were recruited from a National Schizophrenia Fellowship conference in Leeds in August 2000. The final total was 22 participants with schizophrenia and 13 carers.

7.16 Interviews

The researcher contacted 35 participants who had replied to her advertisements. The broad purpose of the study was described and outlined. The researcher met with each participant and gained consent for the interview to continue and to be audiotaped. The researcher undertook 33 one hour unstructured interviews, (two married couples were interviewed together), using a brief schedule designed for the purpose. The researcher attempted to ensure participation by asking open questions and asking the participants to describe their lives and experiences, using the procedures outlined by Strauss (1996). All but one interview was tape recorded, and tapes were transcribed by the interviewer.

7.17 Engagement

May (2001) asserts that the establishment of a sustained relationship is essential for engagement. However, in this study, which consisted of single interviews, such a sustained relationship was not feasible. Successful engagement depended on making the right impression at the first telephone contact, explaining the purpose of the research and putting prospective participants at their ease. Later in the interview, any initial apprehension was addressed. Rapport, and a degree of trust, were created again by putting prospective participants at their ease and asking open and descriptive questions about their lives and experiences in order to gain their co-operation, a strategy considered to be effective by Spradley (1979). Genuine interest was shown in their responses. Structural questions were asked about areas of their life (e.g. family relationships) and sequential interviewing helped the researcher to explore events in chronological order (e.g. 'What happened then?').

The engagement was successful in most interviews. Most participants were willing to disclose details of living with schizophrenia and all carers were willing to discuss caregiving issues important to them. One participant displayed ambivalence about being interviewed. He made one appointment, did not attend, telephoned the researcher, made another appointment, did not attend, and again telephoned the researcher. After each non-attendance he asked more questions, and finally attended a third appointment. He did not permit the interview to be audiotaped, but wrote notes and drew diagrams, describing his experiences. This was eventually a successful interview, but lack of trust and some suspicion had to be overcome. The researcher emphasised confidentiality and anonymity and the fact that the participant could withdraw at any time. He was informed that no-one in the mental health services would be contacted about his decision to express his views and that there was genuine interest in, and acceptance of, his views. The researcher's perceived identity as a university researcher, not as a mental health nurse, appeared to make participants feel safe to express their views. In the information sheet, however, the researcher's background as a mental health nurse was fully disclosed and therefore there was no deception.

7.18 Data collection

Unstructured interviews, lasting one hour, were conducted. The main question asked was: 'How do you live your life with a diagnosis of schizophrenia?' To achieve some structure and consistency to the responses, questions and prompts were used, a copy of which was given to the participant. These questions and prompts were from the coding paradigm: conditions, interactions, strategies and consequences, as proposed by Strauss (1987) (Appendix 1). These questions permit exploration of broadly similar themes.

They focus on perceptions and feelings related to events, other people's behaviours, strategies and impact of schizophrenia on participants' lives.

Stage one interviews February to March 2000

Ten participants with schizophrenia were interviewed in this way. The audiotapes were transcribed. The themes (see Chapter Eight) which emerged in stage one interviews assisted the researcher in probing for these themes in stage two interviews. Majority and minority themes were identified when reading the transcripts. The general themes were identified (e.g. consequences, interactions, suggested by Strauss 1987) and any other themes suggested by the data (e.g. loss, exclusion, no power). All the themes were placed under these general themes. Once all the general themes were identified, open coding allowed identification of all elements of, and factors in, the experience (e.g. general theme – consequences; higher order category – loss; then the many types of loss were described using open coding). Repetition was removed (e.g. when social loss had been identified repeatedly and described, and no new information was forthcoming it was no longer focused on). The coding scheme was typed up using Nudist4 and the nodes list (e.g. Consequences: being abandoned, rejected, stress in family, my loss; Interactions: no information, being blamed, nurses controlled me) was created. This was regarded as a provisional list of themes on which future probes and cues would be based.

Stage two interviews April 2000

Twelve participants with schizophrenia and 13 carers had contacted the researcher by this stage and they were interviewed.

Rationale for two stages

The two stages occurred naturally as a result of the timing of the contact made by the participants. The interview data from stage one, when analysed, (see Data Analysis) led to identification of key themes and categories. These themes and categories were probed for and developed in the stage two interviews.

Open ended questions

Open ended questions allowed people to give their preferred responses. These questions were flexible and allowed the interviewer to probe and to seek clarification. They supplied a frame of reference for the participants' answers, but there were no restrictions (Cohen and Manion 1994).

7.19 The coding paradigm

The coding paradigm will now be described. These questions and prompts were derived from the coding paradigm (conditions, interactions, strategies and consequences) proposed by Strauss (1987).

Conditions

- Can you tell me about your life since they told you that you had schizophrenia?
- How did it affect you at first, then later?
- What made you feel happy or unhappy, stressed, good or bad about yourself?
- What was the situation that first led you to being admitted into hospital or first contact with mental health services.

- How did/do you feel about that?
- What did it mean to you at the time?

Interactions

- How do others react to you?
- How do you feel about that?
- When something happened, to do with schizophrenia, what are/were your feelings?
- How did you feel about the other people involved?
- How did/do you deal with the event or the feelings?

Strategies

- What did/do you do and how did/do you feel when you first:
met the psychiatrist/nurse?
had to take medication?
were told you had to stay in hospital?
first went home after being in hospital?
- What do you do when someone (not a doctor or nurse) asks you about your mental health problems or being in hospital?
- What do you do when:
someone wants to talk about schizophrenia?
someone says something negative or insulting about people with schizophrenia?
someone says something positive about people with schizophrenia?

Consequences

- What has schizophrenia done:
to your life?
to your view of yourself?
- How do you feel about this and how do you deal with it?
- What happened in relationships with old friends and work mates?
- How do you feel about that? How do you deal with it?

Open ended questions aimed to allow participants to give their preferred responses. These questions were flexible and allowed the interviewer to probe and seek clarification (Appendix 1).

7.20 Audiotaping

Audiotaping of interviews requires consent. There is a tendency for some interviewees to forget that they are being audiotaped. Therefore the tape recorder must be placed in full view of the participant, even if has an inhibitory effect on them. In some cases it had this effect in the current study. This was manifested by some participants looking intently at the tape recorder and looking a little anxious for a short time. One participant was very anxious about this and would not allow the tape recorder to be used.

7.21 Respondent validation

This is feedback from participants, affirming the accuracy and general truth of the transcript. Respondent validation was achieved by returning all the interview transcripts

to the participants and asking them to confirm that these were their responses. Some participants expanded on themes or added comments (e.g. one participant who had been making many negative statements about their Community Psychiatric Nurse (CPN) later added that the CPN was helpful and had helped her with her Disability Living Allowance application form. The first account was very critical and negative, the second account was a little more positive, yet both accounts were authentic. Altered transcripts were returned again to these participants for respondent validation and were confirmed as accurate. Respondent validation is a strategy which empowers people and gives them their own voice.

7.22 Data analysis

General analytical approach: Burnard's (1991) model

Burnard (1991) offers a framework for organising data. In stage one, notes were made after each interview, identifying topics talked about, and memos were made (e.g. topic: exclusion “*when I came back to work, they all knew I'd been in hospital but they did not talk to me any more*”).

General themes

In stage two all transcripts were read and general themes were identified (e.g. general theme: consequences-related subheadings: social relations-specific category: exclusion).

Immersion in the data allows the researcher to identify the context and 'life world' of the participant (Burnard 1991 p.462). There was a total focus on the raw data and how each

theme related to other themes. Major categories were identified (e.g. consequences). The researcher immersed herself in the data. This meant listening to the tapes, and reading notes and transcripts repeatedly, to ensure concentrated reflection on the data. In the Burnard (1991) model, the transcripts are read in stages two, three, seven, eight, twelve and thirteen. Observations are recalled. In this immersion in the data, the researcher gained access to feelings, emphasis and nonverbal communication in addition to verbal content of interviews. Burns and Grove (2001) term this dwelling with the data and propose that there is a dynamic interaction between self and the data which leads to reflexive thought.

Open coding

In stage three, open and unrestricted coding was used to identify all elements of the experience. The transcripts are read again and many more codes are identified (Figure 1).

Higher order categories

In stage four, higher order headings are created and the categories from the open coding are grouped together into a broader category (e.g. general theme: consequences; higher order category: loss) (Figure 2).

Figure 1. Example of transcript

Transcript text example: participant 6	Open coding
“Ten years ago, well, it (schizophrenia) crept up on me. It’s getting worse.	Getting worse
I haven’t been able to work. I don’t even have a regular sleep pattern (she looks tired, dark circles under her eyes).	Cannot work, poor sleep, do not cope
I’m not a nice person. I’m not normal.	Not normal, flawed identity
I’ve lost all my cheek (confidence). I don’t feel happy enough. It won’t come out.	No confidence, unhappiness
I’m not allowed to touch anything on this earth, nothing. There’s nothing I can do. There’s no need to put me through what I were going through.	Nothing I can do, no power, suffering

Figure 2. Example of stage 4 general theme: consequences

Higher order categories	Open coding
Loss	<p>multiple loss, social loss, family loss, psychological and emotional loss, financial loss, loss of relationships , loss of memory, loss of individuality and personhood, becoming an object, loss of credibility, visibility, choice, control, independence, positive identity. being rejected, loss of employment, being poor, loss of self belief, self confidence and self esteem, family break up, loss of happiness, “lost everything”, can’t move on, lost custody of children,</p>
Response to loss	<p>Distress, anxiety, anger, depression, belief that they are ill, guilt, negative self concept, feel useless, fear of being found out, fear of more loss, compare their past with their present, believe it is all unfair, resentment, acceptance, I’m schizophrenic</p> <p>Resentment followed by acceptance, no trust in health professionals</p>

Stage five consists of removing repetition or redundancies from the categories and subheadings. In stage six, Burnard (1991) proposes that two colleagues examine the transcripts and generate category systems with three resulting lists of categories to be discussed with the aim of reducing researcher bias and enhancing validity. The researcher was unable to achieve this stage.

In stage seven the researcher re-reads the transcripts alongside the categories and subheadings, the aim of which is to check that the categories accurately reflect the interview transcripts, and at this stage changes can be made.

In stage eight the researcher reads each transcript, with the category and subheading list, and (using QSRNUD*IST 4 in this case) the coding scheme is typed up.

In stage nine, all items of each code are collected together or clustered (e.g. no control of my life). To retain the context, Burnard suggests making multiple copies of the coded section of each transcript, and transcript content on either side of the coded content is retained:

Code: Rejection and exclusion:

[“Well, I never went out much but my friends stopped coming round to see me. When I saw them in the street, when W and myself went shopping and I’d see them, they’d walk by. They stopped talking to me. I thought that wasn’t fair”] (Participant 13). These sections should be cut out and collected together.

Stage ten involves taking these cut out sections and pasting them onto sheets under the appropriate headings and subheadings. The above code and context could come under

social relations or social consequences or social loss or burden of schizophrenia. In this study, it is discussed as social relations and burden of schizophrenia.

Stage eleven involves selected participants being asked to check the category system for appropriateness, with the aim of enhancing validity of the categorising process.

In stage twelve, all the cut out sections are filed together to refer to when writing up the findings. Copies of the full transcript are also read at this stage for clarification of themes, codes, categories and contexts. Tapes are listened to again.

Stage thirteen involves writing up the first section, looking up examples of data filed under that section in stage ten, and linking these examples together. It is important here to remain true to the original meanings and concepts. Therefore referring back to the original complete transcripts is necessary at this stage.

In stage fourteen, the researcher has two choices: firstly, to write up the findings, including vignettes that illustrate the sections, then relate findings to the literature separately, making comparisons and contrasts, *or*, secondly, to write up the findings while relating these to the literature (Burnard 1991). In the current study the researcher chose the first option.

7.23 Initial coding: coding paradigm

Initial coding came from the coding paradigm in grounded theory proposed by Strauss (1987) (conditions, interactions, strategies and consequences). This coding created material which was coded into categories, for example:

Conditions	‘Conflict’
	‘Confusion’
Interactions	‘Coercion by health professionals/family members’
Strategies	‘Seek help’
	‘Choose isolation’
Consequences	‘Social’
	‘Psychological’

This coding paradigm also provides the context. Gaining information about the experience from all main areas gives a holistic context, from the original situation to what they did about it. For example:

Conditions	I live my life as a paranoid schizophrenic.
Interactions	Other people know, they call me names.
Strategies	I avoid people.
Consequences	I get no help, I am going to die this way. Depression and anxiety.

(Participant 6)

In this way data was coded for relevance to the phenomenon, being referenced by a given category.

7.24 Open coding

Open coding, which is unrestricted coding, was used initially to open up the enquiry. It helps the researcher to think of explicit concepts and relationships. It involves looking

for terms used by people, and giving them a name (Strauss 1996). Each transcript was read line by line and the key word which encapsulated the meaning of what was said was noted. For example: Loss, which was further categorised into loss of family, loss of employment, loss of freedom and loss of rights (Participant 5).

7.25 Axial coding

Axial coding will now be described and discussed. Axial coding, which is intense analysis of one category at a time (for example, users' perceptions of health professionals), was then used (Glaser and Strauss 1968). Grounded theory offered other codes (e.g. sociological constructs). An example of a sociological construct is high expressed emotion, and this offers a psychological meaning to the event being reported. In vivo codes were used (for example "*I was so into myself*" Participant 6), a phrase used to describe how this participant focuses completely on their internal feelings and experiences and pays no attention to anything outside that). In the Empirical Indicator Model, proposed by Strauss (1996), actual data suggests a concept (e.g. verbal and non verbal data indicate the concept of stress in 6 and 15). Where such empirical indicators are present, in many interviews, the concept of stress becomes more certain, and eventually leads to stress emerging, and being coded as a major theme and a conceptual code.

7.26 Summarising the coding paradigm

Next the coding paradigm is summarised. The coding paradigm was summarised according to:

Conditions-all emerging categories

Interactions-all emerging categories

Strategies-all emerging categories

Consequences-all emerging categories

Example:

Interactions 'Perceptions of health professionals'

'Perceptions of interactions with health professionals'

'Other peoples' responses to me'

'Society in general'

'Family'

'Other peoples' expectations

This provided a summary of these themes across all participants' transcriptions. The naturally emerging themes, identified across all transcriptions, are as follows:

'Causes'

'Conditions'

'Being in schizophrenia'

'Common Concerns'

'The situation'

'Interactions'

'Strategies'

'Power'

'Care'

'Loss': 'social', 'physical', 'psychological', 'family'

'Consequences'

'Time': 'past', 'present' and 'future'

'Internal reality' and 'external reality'

The researcher summarised each theme. All variants of the theme were noted, and all transcriptions which contained a theme (for example, social loss), were examined for the context, using manual analysis and QSRNUD*IST 4. For example the theme of ‘social loss’ was summarised under subheadings: exclusion, unemployment, poverty, loss of status and loss of worker status. Each theme was summarised in this way. Also the essence of each individual interview was captured in a summary (see Appendix 9). This enabled the researcher to see the meaning of the lived experience of schizophrenia for each person, and also find the commonalities (Cohen and Manion 1994). These methods of coding provided a summary of all user and carer data.

7.27 Further analysis

Further analysis involved identifying dichotomies and major differences between dichotomous groups. This is constant comparison.

Examples of dichotomies:

Care is control	Care is not control
Being event led	Being belief led
Seeking support	Choosing isolation
Passivity	Questioning
Being stopped in life	Moving on in life
I am sick	I am not sick
Men with schizophrenia	Women with schizophrenia
In a user group	Not in a user group

A composite picture of each dichotomous group was completed and major differences between the groups identified. Responses, characteristics and biographical factors were examined and identified (Appendices 10, 11, 12). Commonalities present in dichotomies were identified. Group profiles were completed of participants with schizophrenia who reported the themes of passivity, questioning, moving on, being stopped, seeking support, choosing isolation and being event led, not being event led, being belief led, men, women and those who lived alone. Group profiles were completed for carers in a similar manner. A group profile was completed for all participants with schizophrenia and all carers. All outliers were analysed for dichotomies and trends and were summarised.

7.28 Summary

Thirty-five participants with a diagnosis of schizophrenia, and carers, were recruited from a community setting. Data collection was achieved by using unstructured interviews and the coding paradigm proposed by Strauss (1987), which focused responses into four areas: conditions, interactions, strategies and consequences. Ethical issues were considered, namely, anonymity, confidentiality and privacy. Informed consent was gained. Using an interview schedule, based on the coding paradigm proposed by Strauss (1987), data was collected by asking open-ended questions. Research strategies and operational techniques were used to ensure that the criteria of credibility, dependability, transferability and confirmability were achieved (Lincoln and Guba 1985). Participant validation was carried out and data was also collected from participants' diaries, which increased the validity of the findings. Reliability may not have been achieved and unintentional bias could not be ruled out. Strategies were used to reduce interviewer influence and bias. Intersubjectivity was achieved.

Representativeness could not be assured because of the small convenience, self selected sample, and sample homogeneity. Data collection was carried out in two stages and interviews were audiotaped.

In data analysis, initial coding was generated by the coding paradigm proposed by Strauss (1987), followed by open coding then axial coding. Categories emerged from these codes and the naturally emerging themes, from across all transcriptions, were identified. QSRNUD*IST 4 was used to identify nodes and retrieve nodes (themes) for analysis. Each theme was summarised and the essence of interviews was captured in a summary (Appendix 9). From these essences the common lived experience was identified. Data was also organised according to Burnard's (1991) framework of analysis. Codes were then clustered to achieve identification of the major themes, and the common experience of living with schizophrenia was summarised from these major themes. The essence of the phenomenon for each participant was captured. All insights across all transcripts were integrated into the common experience and consistent description of living with schizophrenia. In further analysis, dichotomies and differences between dichotomous groups were identified. Commonalities between these groups were identified and group profiles were completed of dichotomous groups, of the whole group of participants with schizophrenia, and of the whole group of carers.

CHAPTER EIGHT:

FINDINGS

The study population

Twenty two participants with schizophrenia, who were living in the community, and 13 carers, were interviewed. The participants with schizophrenia were 9 men and 13 women (age range 23-57 years, mean age 44 years). The length of time these participants had lived with schizophrenia ranged from 1 year 3 months to 30 years. At the time of diagnosis, eight were married, then later became divorced, two were starting out on their adult relationships, and four, who had lived with a partner had since separated. Five were single and remained single and three later married.(see Appendix 10).

Note on presentation of findings

Two groups were identified in this study:

- the *moved on* group, who had reported they had moved on with their lives after the diagnosis of schizophrenia.
- the *stopped* group, who had reported that they felt stopped in their lives.

In the findings, participants will be identified as being *moved on* or *stopped* where it appears to be relevant. In some findings, gender is referred to, because it seems to be relevant and some findings related specifically to women with schizophrenia (e.g. family, self-blame and guilt). There is repetition and similarity of material under different headings (e.g. the themes 'Care' and 'Interactions with health professionals').

FINDINGS: PARTICIPANTS WITH SCHIZOPHRENIA

These are the findings reported by 22 participants with a diagnosis of schizophrenia. There were 9 females and 13 males. The age range for this group was 23 to 57 years. They had lived with schizophrenia for between 1 year 3 months and 30 years. The emerging themes and categories for these participants are presented in Figure 3 in a manner which reflects the chapter organisation, in order to allow the reader to follow and locate the findings. A similar approach is taken later in the chapter, with regard to carer findings (Figure 4)

Figure 3. Participants with a diagnosis of schizophrenia: emerging themes and categories

Emerging themes	Emerging categories
8.1 Cause	Internal, external, multiple, stress
8.2 Conditions	Working, studying, hospital admission
8.3 Their experiences of being in schizophrenia	8.3.1 Voices and Visions 8.3.2 Being under scrutiny
8.4 Common concerns	Stress, medicalisation, disempowerment, rejection
8.5 The situation	Novelty, confusion, error, conflict
8.6 Common understandings of schizophrenia	Being ill, spiritual or mystical event
8.7 Interactions	8.7.1 Perceptions of health professionals and perceptions of interactions with health professionals 8.7.2 Interactions: society in general 8.7.3 Interactions within the family 8.7.4 Other peoples' responses: society in general 8.7.5 Other peoples' expectations
8.8 Strategies	8.8.1 Acceptance and questioning 8.8.2 Dichotomy: acceptance and questioning and composite picture of both groups 8.8.3 Responses to others 8.8.4 Identity and flawed identity 8.8.5 Dichotomy: choose isolation and seek support 8.8.6 Composite picture of the <i>choose isolation</i> and <i>seek support</i> group

8.9 Disempowerment	8.9.1 Control 8.9.2 Knowledge 8.9.3 Rationality
8.10 Care	8.10.1 People with schizophrenia's views of care 8.10.2 Care-control
8.11 Consequences	8.11.1 Loss: response to loss and impact of loss 8.11.2 Social loss 8.11.3 Physical loss 8.11.4 Psychological loss 8.11.5 Families 8.11.6 Stigma 8.11.7 Sick role 8.11.8 Dependency 8.11.9 Stress 8.11.10 Burden of schizophrenia 8.11.11 Circles of entrapment 8.11.12 Moving on and being stopped 8.11.13 Composite pictures of the <i>stopped</i> group and composite picture of the <i>moved on</i> group 8.11.14 Main differences between <i>moved on</i> group and <i>stopped</i> group 8.11.15 Composite picture of <i>moved on</i> and <i>stopped</i> groups
8.12 Time	Past, present, future
8.13 Perceptions of reality	Internal reality, external reality
8.14 Summary The common experience of living with schizophrenia	

8.1 Causes of schizophrenia

This section highlights the perceived causes of schizophrenia.

External cause

Most participants with schizophrenia attributed their schizophrenia to an external cause, (e.g. stress). Bereavement, and being abused as a child (which was still a significant issue for them) were reported by a few. All the men believed the cause was external while only a few women believed this.

Internal cause

Some older men believed that there was also an internal cause and felt it was a spiritual or mystical event, and most women believed that the cause was internal, biological and that they were sick.

Multiple theories of cause: hierarchy of cause

Some participants with schizophrenia expressed the view that it was caused by both internal and external factors (*stopped group*). They reported that the internal cause came first, then life events occurred to make things worse. A few believed that it was an internal, spiritual, mystical event, but that they later thought that they must be sick, and there was still some ambivalence at the time of the interview. Participant 4 reported that he was always “a bit that way” and that external events (reported as sexual abuse when a small child, and stress at college) came later.

A few participants perceived that the cause was initially external, specifically being abused as a child and their mothers giving them up when they were children, then later they perceived themselves to be sick.

Participant 9 reported:

“Well they call it chemicals but..... chemicals in the brain. That’s not quite right, but I think that’s just another expression for what used to be called evil spirits.”

JH “So what do you think of the biochemical explanation?”

Participant 9 reported:

“Its wrong, I don’t agree with it. I came back from holiday in Spain and erm.... It started about that time. What makes me think that evil spirits are at work is that erm.. I denied the Lord Jesus Christ and I’d started to say the Lord’s Prayer backwards and that somehow stimulated these things, started off the mental problems. Until that I’d been fairly sound.”

He believed that the cause was also internal. He reported:

“Well I think I had a propensity that way as a child but erm..... as I say the ECT made it worse.”

One participant spoke of stress and bereavement, and someone else causing schizophrenia. Participant 1 reported:

“The breakdown was caused by this fellow who I was living with. It was very difficult. I didn’t cope very well with the living together. So I had a very bad breakdown. That was when I.... My grandfather died, which didn’t help me emotionally. I did make a fairly good recovery, but I was told by the psychiatrist that I had schizophrenia and I would have to take pills for the rest of my life.”

The context here is that the participant left home when quite young and lived with a man. The relationship was not successful and she had to return home to her parents when she became ill. Others expressed similar views. Participant 21 reported:

“My father’s death caused me to be ill. It was the shock of it. We weren’t expecting it and I had to make all the arrangements. I was quite young at the time, only 20, and because I was the oldest it all came to me to sort out. At the time everybody thought I could cope, but I couldn’t. I was really stressed at the time.”

8.2 Conditions

All participants were either working or studying and had life plans when they began to be affected by schizophrenia and could not continue with these. Half these participants lost their job or place at university. One participant who did not lose his job was off sick for a long period of time, with support from his employers. Participant 22 reported:

“I was just married at the time and carrying the baby. My husband was very supportive and he stood by me.”

Participant 15 reported:

“I thought I had mystical powers, I was hearing voices. I was living down south with my wife. I had a car and plenty of money and everything. I thought I was getting these powers. There was lots of stress at work. The others didn’t like me doing well, then they called me in and told me to clear my desk. Everything collapsed around me, then my wife had me out of the house. She got an injunction against me. I was in hospital, confused, in a muddle.”

Some participants reported being admitted into hospital, and some were first arrested, then admitted into hospital. Participant 5 reported:

“Well I wasn’t taken into hospital, I was taken to a police station by two police officers. I hadn’t committed any crime or anything. I was going round to see a friend, but I’d been having problems with my family. I’d had this massive fall out with my mum. She reported me missing. It was two weeks to go before I was to go back to university in the summer. I wasn’t missing, the police were looking for me. I was arrested.”

8.3 Experiences of being in schizophrenia

8.3.1 Voices and visions

Participants reported great confusion and not coping with anything. Participant 13 reported:

“I felt very confused about everything. When I felt bad, I’d just stay in bed. The nurses told me to ignore the voices, but I couldn’t.”

Participant 14 reported:

“It was terrible, confusion, I was worried sick, I was frightened. I didn’t feel well, I felt bad. Other people, nurses, didn’t understand. I had no social life, my friends stopped coming round to see me. Hospital was terrible, noisy and dirty. I was afraid all the time, afraid I’d die in there.”

Fear was highlighted. Participant 6 reported:

I remember I didn't know what was happening. I was afraid of going to sleep. I'd sit up all night drinking coffee and smoking. The voices made me scared to sleep."

Visions were reported in different ways. When participants first had the visions, they seemed very real. When the visions came, most participants focused on them and the experience. Most tried to make sense of the visions and some considered them to be religious, spiritual or mystical experiences (*stopped group*). Participants 15 reported:

"I thought it was a psychic experience at the time. I thought I was getting these powers. When it happened I was under stress all the time [It = voices, visions]. I think schizophrenia is a sorting out process. I was taking Largactil, my head felt fuzzy. My eyes were blurred. My body felt strange. I'd go off and drive somewhere. The voices in my mind would tell me to do that. My memory is not that clear now. I remember hearing voices. I realized I was ill."

"I was suddenly in the presence of a lot of invisible people; not a lot, just one. He was in the house with me. He could do anything, it all seemed so real to me. I heard people from work in my mind telling me what to do. There was now in me head between one brother and a lady, an auntie of mine who is dead.... and these voices from work. I think it's a battle, between good and evil. I think it's spiritual. I don't worry about, I'm not afraid of it. The voices are good. When I'm stressed, they tell me how to get out of stress."

For this man, the visions and voices were perceived as helpful, and helped him to re-examine his life and he perceived a positive side to these experiences. Most enjoyed their voices and visions, perceiving them to be positive events. Participant 8 reported:

“My visions are psychic dreams and I don’t want them taken away. When I had my visions I had power. I felt good. They come in dreams and are like dreams during the day. I am just relaxing and it’s like astral flying. Sometimes the visions did worry me. Mostly it was astral flying through space, through a porthole, it was so real. I think they are a test of my faith. I think they are spiritual. At these times I feel so strong.”

A few became afraid of, and confused by, the voices and felt compelled to obey them. Participant 6 reported:

“ I was so into myself.”

This appeared to be about trying to understand what was happening to her. She focused on the internal experiences. She reported:

“I have voices, I’m tormented by them, God and the devil are in my head. They tell me to do things that I don’t want to do, but I have to. I’m scared all the time. I can’t sleep. I get bad sometimes. I was peeling potatoes one day and she (the daughter) was going on about something and I had voices in my head shouting at me and I went aaaarrgh!!!! And I went for her [her daughter]. I had a knife in me hand and I tried to kill her. You’re concentrating on one thing and other noises get in the way.”

Participant 1 reported that she became “careful” with herself. This is a common theme in all interviews and appears to mean being cautious, making decisions to avoid social events in case stress caused more illness. Participants with schizophrenia appeared to use this strategy as part of self-care and stress reduction.

8.3.2 *Being under scrutiny*

Scrutiny as negative

Most participants did not see scrutiny as care and perceived scrutiny as invasive and intrusive control, which prevented them from having life, social and employment opportunities. For these participants, scrutiny led to labelling. Participant 15 reported:

“ When they’d diagnosed me, I found it hard to get a job. You can’t go anywhere or do anything, but they want to know about the schizophrenia and they don’t believe you can work. They think you are incompetent. So now I am unemployed and I’ve got hardly any money and it’s the label of schizophrenia that’s done this to me. ”

Participant 1 reported:

“They labelled me”

“...labelling stops you from going forward.”

In most cases, the views expressed on scrutiny were *concept* and *belief led*. The terms *concept led* and *belief led* have been used here to identify a participant’s knowledge of a concept (e.g. mental illness) and their beliefs about the concept (e.g. some respondents

believed they were not ill). For some participants an event did not precede the belief being expressed. Participant 5 reported:

“The way I see the mental health system is that you are under a lifetime suspended sentence. It’s punishment. You are treated like a criminal. Any type of trouble that might arise, the social services can control you and that if you don’t want to talk to someone you must have something to hide. There’s a lot of talking behind closed doors (in hospitals). The person who has been sectioned is being assessed. They are in the day room watching Richard and Judy while other people, social workers, relatives, everybody is saying things about you, and then they all come out quiet like, look at you, and walk off and that’s it. Decisions are made about your life and nobody asked you.”

Participant 11 reported:

“I thought the CPN was checking up on me. Sometimes I’d think she cared. I used to think I had to say all the things she wanted to hear. What I said to the CPN would get back to the consultant and I worried about that. So I’d say all the right things and do what she wanted. I was worried about how much control the CPN had over my life.”

A few participants were very angry about the scrutiny, saying that the CPN came round to check up on them, their parents would never leave them alone and that they had no privacy or time to themselves. It appeared that the parents saw this anger as part of illness, and not a valid reaction to parental behaviour.

Ambivalence

A few of the older men were ambivalent about scrutiny and resented it, but felt that they needed it also (*stopped group*). Participant 9 reported:

“Hospitals make me feel bad, nurses don’t care.”

However he continued to go to the hospital and reported that he did this out of choice.

He reported:

“I go into Lynfield Mount at weekends, every weekend.”

Ambivalence appeared to prevent moving on.

Scrutiny as positive

A few female participants perceived scrutiny as positive, ensuring care and protection (*stopped group*). Participant 6 reported: “I need a social worker. I’ve got a CPN who does nothing. She tells me everything is because I’m poorly. I’m not getting enough support. No one helps me with daily things. I’ve recently got a carer who takes me shopping because I’m afraid to leave the house alone. I’ve got no money. I’ve applied for DLA [Disability Living Allowance] but my doctor does not support me.”

Comparison between the *scrutiny as negative* and the *scrutiny as positive* group

For the majority, scrutiny was negative. The *scrutiny as negative* group had two opposing concepts. While half of these participants believed that they were sick, others

believed that they were not sick. There appeared to be some ambivalence in some of these twenty participants, which did not allow them to consider themselves as well or normal people. Half of these participants believed that scrutiny had contributed to their loss and that their lives had been stopped by scrutiny. However, for a few participants, their lives had been stopped temporarily. A few of these participants reported that they liked health professionals paying attention to them. The *scrutiny as positive* group believed that schizophrenia had led to their loss. They believed that schizophrenia had stopped their lives permanently. The main concept appeared to be that they were sick.

Responses to scrutiny

Some of the *scrutiny as negative* group avoided health professionals. Of the participants in the *scrutiny as negative* group, a few men displayed some ambivalence regarding their sick identity, and did not avoid health professionals (*stopped* group). There was a varied picture. Most participants sought support, some participants chose isolation, avoiding health professionals and others, and some participants reported doing both. A few reported avoiding everyone but their fellow service users. The *scrutiny as positive* group sought help and more scrutiny.

8.4 Common concerns

All participants were worried about stress, medicalisation, having no power, no control, and no choice. Being ignored, treated badly by others, and multiple loss were major concerns. Most participants worried about rejection and unfair treatment, their views being invalidated, and injustice. Participants believed they had no equality, others were afraid of them, and others coerced and bullied them.

All participants reported rejection by friends and family members. Participant 13 reported:

“When I saw them in the street [her friends] they’d walk by. They stopped talking to me. I thought that wasn’t fair. I think they have these ideas about people with schizophrenia, that people with schizophrenia are nasty and violent. My sister in-law said terrible things about me, right in front of me. She didn’t want me near her two boys.”

Participant 5 reported:

“Because I’d come back from being in a hospital it was hard for me to build up a relationship with anybody. I could tell that people were scared of me.”

JH How did they know?

Participant 5 reported:

“Well it’s kind of a small community. So nobody wanted to know me. People were odd with me. Every week there was a tutorial, a group tutorial and I went but I never socialised with any of the students. Christmas came, the party, and I was never even invited. I have kind of lived my life alone since then. I’d come home, and read a book or watch TV or something. I didn’t have any kind of life outside of that.”

Participant 5 reported negative attitudes in others.

“I was working for a magazine. I’d taken the work from this project [photographs of the hospital he was in] and I mentioned the reason I took these photographs was that I was a patient there and their attitude towards me changed.”

“I was working there full time and it was going to turn into a real job and that didn’t happen. They said ‘you can keep on coming if you want’, but in the meantime I was living on state benefit. Like, in London your state benefit basically pays your rent. I’d have £70.00 a week rent and only get £50.00 a week housing benefit”

Most participants specifically mentioned loneliness and others hinted at loneliness.

Participant 6 reported:

“ I worry about what will happen to me when she [her daughter] leaves home. I’d be alone. I’d like her to stay but she’ll leave. How am I going to end up? [looks anxious]. It’s all right now, but what about when I’ve got no kids around me and I’m left to my own devices.”

Some participants were very distressed about being unable to find employment, a situation which they perceived would lead to poverty. Participant 15 reported:

“I worked out how much money I would have made assuming I was able to earn about £20,000 a year. I lost out on about £400,000. My wife divorced me, she decided she wouldn’t give me the house, and the divorce settlement was just £10,000. Everything collapsed around me, my wife had me out of the house. I just ended up coming back up north because there was nowhere for me to go and I couldn’t get a job in Kent.”

There was a general anxiety about being sick again and most participants felt a need to be careful with themselves, a phrase commonly used. The majority expressed great anxiety about the future. Other people made them feel stressed, which made them avoid others. There was a lot of stress within the family, and stigma was reported to lead to stress. While scrutiny led to stress, people ignoring participants also made them feel stressed. For some there was a fear of being alone, which seemed to contribute to seeking support (*stopped* group), and of partners leaving them, a fear that had its roots in past events. For some participants, voices and visions were a source of stress (*stopped* group).

One participant spoke of his stress, which he thought was caused by being in hospital. Participant 5 reported:

“I said [to the ward nurses] ‘I don’t need medication, I’m very stressed because of all I’ve been under the last few weeks’. I’d been living in a psychiatric ward. It’s not particularly conducive to mental health, is it? It was noisy, dirty, you don’t get proper nutrition, cigarette smoke everywhere.”

One participant spoke of stress at home and work. Participant 15 reported:

“I was married and we used to live in Kent and I couldn’t get along with me wife and there was a lot of stress involved in that, and also at work. I couldn’t get away from it, it turned me mind.”

Other participants experienced stress, but in other areas (for example, a few young men experienced great stress in returning to their old lives) (*moved on* group).

8.5 The situation

When describing their situation, novelty, confusion, error and conflict were the main themes reported. For most participants novelty was highlighted and they found their new situation very difficult to cope with. Half of the participants said that at the time of the first episode, they were in confusion. Participant 15 reported:

“I was just doing silly things. I was it started off..... with..... first of all.... The first time I can remember erm..... Its not all that clear in my head. I remember hearing voices. I thought my wife wanted to kill me. She gave the impression she didn't care if I lived or died.”

Participant 11 reported:

“It was terrible for me. I felt confused, confused about everything. I couldn't get rid of these terrible thoughts that came into my mind, especially at night time. I was mixed up about everything, even the day or the time. I thought everyone hated me. I wasn't sure about anyone. There are bits I don't remember, well, it's all a bit fuzzy.”

Participant 20 reported:

“I was going out with my girlfriend. She was pregnant. She left me. I was scared and all alone, it was confusing. She said I was doing odd things and I can't remember doing them. I lost track of everything, of time. You don't remember things clearly afterwards, with schizophrenia.”

At the time of interview a few participants said that they were still in confusion (*stopped* group). For a few the confusion came first, followed by the belief that the diagnosis must be an error, whilst a few had always believed the diagnosis was an error.

Most participants spoke of conflict, because at some point, they disagreed with others (e.g. relatives, health professionals) about the diagnosis. Participant 5 reported:

“ I wanted to negotiate my medication but they restrained me and gave me it I.M. (intramuscularly) anyway.”

His mother said he was ill, while he said he was not. Participant 5 reported:

“It was my mum saying that I was behaving irrationally, they believed what she said, not what I said. They believed I was a danger to myself. I was very angry. I was being held against my will. I said ‘I am not mad, I am angry’. It was very difficult, the more I tried to protest my innocence, like I am not insane, the more they thought I was.”

8.6 Common understandings of schizophrenia

Two major themes emerged in these findings: *being ill* and *spiritual or mystical events* (see 8.3.1). Initially most participants believed that they must be ill with schizophrenia. This led them to doubt their own judgement. Participant 13 reported:

“I wasn’t feeling well when I came home. If I felt bad I just had to stay in. I’d go to bed, I remember being afraid all the time and worried. Any little thing would upset me. I got upset easily.”

Participant 1 reported:

“I had a very bad breakdown. I did make a fairly good recovery, but I was told by the psychiatrist that I had a mild form of schizophrenia and that I would have to take pills for the rest of my life. So I had to go home and my parents were left looking after me. I let everyone make decisions for me. I had another breakdown (later), I didn’t know where I was or what I was doing. I did feel I needed something. The doctor confirmed the diagnosis.”

JH “How did you feel about that?”

Participant 1 reported:

“Angry, I had hoped they’d made a mistake, but pleased too, I accept it all. In my head there was something wrong with me.”

Later, a few perceived their experiences as spiritual events (*stopped* group). Participants reported their experiences as psychic experiences, psychic dreams or astral flying, which made them feel powerful. One participant believed his voices were a battle between good and evil. He had no fear of these voices, which advised him when he was stressed. Some participants changed their views over time. Initially a few women believed that they were ill, then, later changed their minds, believing that they were not ill.

Some men were ambivalent about whether they were having a spiritual or mystical experience or whether they were ill (*stopped* group). A few of them believed they were

initially ill, but they had recovered and it was now a spiritual experience. One participant thought it was initially a spiritual experience, then later believed that he was ill. Participant 16 reported:

“It [the experience] helped me to sort things out. I had powers. I didn’t feel bad. I was doing things that were out of the ordinary.”

Participant 16 later reported:

“I was hearing voices a lot, and then I realised I was ill.”

8.7 Interactions

8.7.1 Perceptions of health professionals and perceptions of interactions with health professionals

Having no power, no choice and no control, and being coerced in interactions with health professionals were stated as issues by most participants. Medication and treatment had been physically forced upon them. Participant 5 reported:

“I was forcibly admitted into hospital.”

“Being in hospital was a denial of civil liberties.”

“You don’t want to be there, you’re angry. You say ‘I’m angry about this’. They say ‘Oh, give him some Chlorpromazine’ and depot injections, because I wouldn’t take the

medication orally. I said 'I don't want it'. They said 'if you won't take it orally, we'll just inject you.'

Participant 9 reported:

"The staff stop you from doing anything. I was given medication against my will".

"Other people controlled me."

"Your life is not your own."

"They disregard your opinions."

"They rape you with ECT in hospital."

"I was given ECT against my will."

"I had no choice over ECT or over injections."

"I had no control over my life."

Participant 15 reported:

"Largactil was a horrible drug. I was on it for about a month at (the) time in hospital, it really made me feel ill. There was no way to stop them from giving me it."

Most participants reported conflict followed by coercion, as a result of their rejecting the diagnosis of schizophrenia and noncompliance with treatment. Participants reported being restrained. Health professionals told a few of them that they were a danger to themselves, and this belief seemed to justify the intrusion and coercive interventions. A few participants were given medication when they spoke about their visions, actions which they perceived as coercion, and the consequences of which were that they did not trust health professionals, actively avoided them and told them nothing (*stopped* group). A few tried to negotiate their medication but the nursing staff would not permit this. Participant 5 reported:

“The medication is very bad for you. They said I had to take it. I told them about the bad effects, my eye problems, I said I’d take some medication, just not as much. They said I had to take it all and they gave me an injection.”

Participants felt that they had to comply with the Community Psychiatric Nurse’s (CPN) and doctor’s wishes and this meant that they had no power of control. A few participants feared the power of the CPN and the doctor. A few participants perceived the Care Programme Approach as punishment and coercion.

Most participants felt that they were accorded no privacy or confidentiality about issues in their life. Participant 2 reported:

“They know everything about you and can tell anyone else and there’s nothing you can do to stop them. The information about me seems to be available to everybody, the housing officers who allocated flats, social benefits advisors, everybody. The council

has access to my files but the minute I want to see what's in them, no, they make it difficult for me.”

Intrusion into their lives was a major concern for these participants and the majority perceived that health professionals breached confidentiality. Some participants did not question the accepted knowledge of schizophrenia. Participants spoke candidly of the assumption that the doctor is the expert and knows everything and the person with schizophrenia is assumed to know very little, and how this assumption is perpetuated. Participant 1 reported:

“The doctor is the expert, I didn't know anything.”

All participants felt that health professionals promoted negative assumptions about them. Participants believed that health professionals medicalised them and attributed their normal reactions and behaviours (e.g. anger and expression of an opinion) to schizophrenia. Participant 2 reported:

“When you've been diagnosed with an illness, every single thing you do becomes part of the illness, like..., an idea becomes a delusion.”

All participants were angry about being disbelieved because they were diagnosed with schizophrenia. Participants felt that interactions with health professionals and treatments depersonalised them. Participant 1 used the term “depersonalised” and others described the experience. Some participants felt that they were not seen as a person by health professionals, and that they were treated as if they were an object.

All participants reported lack of support. These participants felt that they had been made to shut up and when they tried to tell the nurses about their experiences and distress, they were told to stop talking about it. Participant 1 reported:

“You’re talking a lot of years ago, and there weren’t any support for my parents and me, so we got on with it.”

Participant 12 reported:

“I didn’t feel anyone was supporting me. No-one cared about my needs. When I asked for help, I didn’t get it. I wanted help and didn’t get it. When I was ill in hospital, I had to ask all the time for help. When I came home it was just as bad. Sitting there for days on end, feeling worried and no one understood what I was worried about. No one wanted to listen. Nurses are supposed to support you, aren’t they?”

Blaming and lack of care were reported. Participant 13 reported:

“I couldn’t tell people that I wasn’t feeling well. They didn’t care. I did tell the nurses once, and they told me to ignore the voices, and the bad feelings, but I couldn’t. I just couldn’t. They just didn’t understand. They thought that if you wanted to, you could stop it all [the voices]. They thought you weren’t helping yourself deliberately. They’d only come and talk to me when they wanted me to do something, like, come for your pills, come for your dinner, go to bed.”

Lack of information and involvement in decision-making concerned them. Most participants reported that nurses and social workers did not explain anything, gave them

no information about anything, and nurses just gave medication. A few participants reported being given enough information. A few, who were very depressed and perceived themselves as ill, did not ask for any information.

Participants reported being denied access to their notes. Participant 2 reported:

“I tried to get information but all I got was a leaflet from some office somewhere, ‘Your Rights to Read Your Notes’, Please write to such and such a person. So I wrote. I never heard anything. I never got a reply. I thought that’s not working. After three weeks I went to the main social services head office and said ‘I would like to read my notes’. They wanted the name of my social worker so I gave them the name of my social worker. They said ‘We’ll be in touch’. And then the social worker said, ‘What’s it all about?’ as if you were in some kind of panic. There is something wrong with you because you want to read your file as if you don’t really want to read your notes but you really want to talk to your social worker. I filled in the form and I was given 4 little bits of paper with 1985 on it. They find ways to stop you from reading your file. One of the doctors let me sit down with the actual file I was looking at, the original form, the section, and the social worker had put a line through it and had written ‘not applicable.’ They seemed to fill out the section form like they were filling out a questionnaire.”

This participant felt that when health professionals wrote notes, which in his view were untidy, they devalued him.

Most participants asserted that health professionals excluded them from decision-making and there was no involvement or consultation. Being ignored, not being taken

seriously and trivialisation of their concerns were issues reported by these participants.

Participants 9 reported:

“People ignore your decisions. That sort of thing, with the ECT, I was too poorly to make a decision [health professionals’ opinion], but I think my decision was the correct one, to refuse it and be allowed to recover in my own time. They ignored my decision.”

These participants were upset that nurses were afraid of them and the assumption was that they would be violent. Participant 1 reported:

“People are frightened of you”

JH “Why do you think this happens?”

“Violence. You read things in the papers about people with schizophrenia and everyone thinks all these people are like that. That upsets me, they think we are all the same. The nurse was frightened of me in hospital and all I did was touch her. They all came forward to grab me.”

“And then there was my old friends, I lost touch with most of my friends. Some of them were different with me, they didn’t trust me.”

Some participants were in the National Schizophrenia Fellowship (now renamed Rethink) and they reported that staff treated the symptoms and not the cause of the schizophrenia. This group wanted the cause of schizophrenia to be identified.

Participants believed that they should be treated as individuals by health professionals, something which, in their view, did not occur.

Some participants made some positive statements. Their informal support, delivered by unqualified social services carers, was perceived as very supportive and helpful. During the interview with participant 6, this carer visited during the interview and the participant clearly related very well to him. The CPN was also perceived as helpful and supportive and helped with a Disability Living Allowance application. This help was highly valued by the participant. It is interesting that against a background of severe criticism, some participants made positive comments about nurses, saying that some nurses were “O.K.,” although all participants held the broad view that nurses don’t really support people. One participant said that the nurses were very good but couldn’t help him. A few participants reported that Home Treatment was very good. The staff listened to them, they felt that they were treated as an equal, and there was good communication in home treatment.

8.7.2 Interactions: society in general

Most participants reported that people treated them unfairly and excluded them. Most participants felt anxious when interacting with others in society. Most participants avoided people, in order to avoid stressful or difficult situations. They were angry and resentful at others’ behaviours and responses to them. They reported old friends did not support them, talk to them or trust them anymore. Participants felt unsafe and unprotected in society. Others were derogatory and abusive towards them, and they felt hurt. Half of the participants reported that they had self-disclosed their schizophrenia, an action they later regretted, because it led to rejection (e.g. in relationships and

employment). In their experience, others attributed all their actions and thoughts to schizophrenia. Some participants, who were members of a user group, reported being concerned about unawareness, within society, of mental illness. A few male participants reported feeling embarrassed by other people knowing their diagnosis. Some participants made positive comments. A few participants believed that others did not fear them. A few participants believed that people understood them.

8.7.3 Interactions within the family

All participants with schizophrenia did not feel equal to other family members. They reported that there was not enough support within the family for them. This was true even among those who stated that the family did care for them and protected or overprotected them. Most reported stress within families because of the lack of information about schizophrenia. Participants acknowledged that family members could not cope with them. The family decided everything for them and controlled their lives. Participant 11 reported:

“At home my mum and dad made all the decisions for me. I was angry at them for that. They put that [anger] down to schizophrenia. Everything I did was put down to schizophrenia.”

One parent of this participant justified the control. Participant 28a reported:

“I was so worried about leaving her [participant 11] alone in case she got it all wrong and did something stupid, you know, that’s why I couldn’t leave her alone.”

Participant 11 reported:

“They [parents] would never leave me alone, I’d be OK if they’d leave me alone, but they never would.”

Most participants reported that, they accepted overprotective and controlling family care because it meant that there was no rejection. Participant 1 reported:

“I had to go home and my parents were left to look after me. They were very protective.”

“My parents used to say ‘slow down, you’re doing too much’, things like that. I used to not rely on my own judgment. I was not confident about making my own decisions.”

“I accepted it all. They controlled my life, no, I didn’t have much choice, no one does in that situation, everyone accepted it.”

Participant 5 reported:

“I was living with my parents. I was treated like a 5 year old. It was kind of like protective, being told to tidy up my bedroom, what I could watch on TV, to wash up. It was like being a teenager. I had no control over my life.”

Some reported that family members made derogatory statements about them and to them. Participant 1 reported:

“My sister said, in front of me ‘she is nuts’. I pretended not to hear it. I tried not to let it upset me.”

Some reported that there was conflict in families and some reported that their family blamed them. Family break up was highlighted (e.g. divorce), and a few men reported feeling and being angry and aggressive towards their wives. These men had been arrested. Participant 15 reported:

“I was married and we used to live in Kent, and I couldn’t get along with me wife and there was a lot of stress involved in that and also at work. I couldn’t get away from it. It turned me mind.”

Some female participant reported that they knew their parents felt guilty, because their parents believed that they had caused the schizophrenia. Some participants with schizophrenia felt guilty about their parents’ guilt. Some reported that no one in the family respected them, not even the children.

Some of the participants reported rejection by immediate and extended family and stated that significant family members left them, specifically, girlfriends, husbands and wives. A few participants used the word ‘abandoned’ to describe their rejection by their family. A few women reported that their eldest daughter adopted the carer role.

8.7.4 Other people’s responses: society in general

Most participants held the view that most responses by others were negative and harmful. Their decisions were overridden and they were treated unfairly. People ignored, trivialised and labelled people with schizophrenia. Participants felt punished, and people treated them as mad and irrational all the time. People in society denied people with schizophrenia life, social and employment opportunities. Participants with

schizophrenia were devalued, demeaned and mocked. Interactions with old friends were described and participants spoke of being ignored. Participant 5 reported:

“People walk past you in the street. Yes,... I did notice that. I came out of hospital in November. After two or three months I got into social groups. They’d walk past me going to the toilet. They’d say “how are you doing?” but they’d still walk by me.”

Being protected and ignored occurred at the same time. Participant 1 reported:

“People are protective, overprotective, in case you do something because you’re schizophrenic. They tell you, you can’t do things because you’re schizophrenic. No one listens to you. People assume things about you.”

One person was upset about being ignored. Participant 6 reported:

“No-one listens. They ignore me. They say I do things because I’m poorly and they don’t listen to me, to what I’m saying. The nurses trivialise what I say. I say ” I’m going to die” and they laugh and say “we all are”. They don’t take me seriously.”

One participant spoke of others’ negative views of people with schizophrenia.

Participant 1 reported:

“I’m not a bad person but that’s what gets said about people like me.”

“Violence. You read things in the paper about people with schizophrenia and everyone thinks that all these people are like that [violent].”

8.7.5 Other peoples' expectations of people with schizophrenia

Most participants' perception was that people expect them to be all alike, incompetent, unable to achieve anything. Participants were expected to be irrational and were not to be trusted. Participants held the view that other people believed that their irrationality and their schizophrenia explained everything the person with schizophrenia said or did. Participants believed that others expected them to be violent, viewed them as risky to others and to themselves, and needing to be controlled.

The *National Schizophrenia Fellowship* group were concerned about being considered a social nuisance. Some participants reported that others thought that noncompliance was a sign of illness, a view they strongly disagreed with. Some participants reported that there was an expectation of self-control and that if they wanted to, they could make the voices stop, and this expectation upset participants. A few reported that positive recollections of the past and plans for the future were perceived as delusions by health professionals because people with schizophrenia were not expected to achieve.

8.8. Strategies and responses to others' behaviours

Participants with schizophrenia developed their own strategies and responses to others' behaviours.

8.8.1 Acceptance and questioning

Acceptance involved compliance and questioning involved challenging the diagnosis. Participants described what many did initially when they conformed with others'

wishes. They accepted the expert knowledge that defined them as schizophrenic.

Participant 1 reported:

“I just accepted it all, I accepted the label.”

”I accepted the new identity.”

“I let them [family, nurses and doctors] decide everything for me.”

“I let them tell me who I was, I didn’t question it. I accepted my invisibility.”

Participant 13 reported:

“I let him make all the decisions [her husband], I let everybody make all the decisions. I lost control of my life. Even when my father died, other people did everything. I wasn’t allowed to do anything. I wanted to go to the funeral, but they said I wasn’t well enough. They said I couldn’t cope. So I accepted all this and didn’t go”

Participant 6 reported:

“I try and ignore it all, try not to be angry. I’m useless. I can’t do anything. I can’t concentrate... I’m sick. I need help. Other people control me, the voices control me.”

Participant 11 reported:

“I used to think I had to say all the things she wanted to hear. What I said to the CPN would get back to the consultant and I worried about that. So I said all the right things and I’d do what she wanted. In hospital I’d hide and avoid the nurses, and all the time they said I was sick. Sometimes, I’d just sit in the corner and say nothing. At home I’d stay in bed out of the way. They [parents] would tell me to get up all the time, but I annoyed them when I got up, so I would try and keep out of the way and avoid people.”

Part of acceptance and compliance appears to be agreeing with the biochemical explanation of schizophrenia and accepting that medication is good for them. Some participants described acceptance, then later questioning. Participant 1 reported:

“I let everybody make decisions for me. I had no control of my life. I question the label now. I question it now. Before, I couldn’t. Before,.. they told me who I was. I can see now that was a mistake.”

Participant 1 moved on with her life after accepting the diagnosis of schizophrenia for 25 years. Questioning was described by some. They were aware of the power of professionals’ knowledge yet disagreed with it. Participant 1 reported:

“Everyone had faith in one psychiatrist’s opinion and that got me labelled. Because of this, everyone assumed I’d be violent. I question things now. It’s important to question things. You have to tell other people how you feel about things. That is my innermost thoughts.”

Some participants perceived that their previous strategies of acceptance were not benefiting them, as they were not receiving good care and they questioned the diagnosis, challenged others about coercive treatment and rejected others' negative evaluations of them. They took control of their lives, rejected the sick role, demanded to see their notes, refused and negotiated their medication. Few participants questioned everything from the beginning.

8.8.2 *Dichotomy: acceptance and questioning*

There were participants who questioned the diagnosis and treatment, participants who did not, and participants who displayed some ambivalence between these two positions.

Acceptance group

Acceptance appeared to involve accepting the diagnosis, treatment, believing one was ill and seeking help. In the past most participants had displayed acceptance. Some participants currently displayed ambivalence between acceptance and questioning.

Composite picture of the *acceptance* group

In this group there were 18 people (7 women and 11 men) (age range 29-57 years, mean age 44.3 years), (Appendix 10). Most of this group were older, between the ages of 30 and 57 years and most lived on benefit. Most of this group were in the *seek support* group and, of these, most sought support from health professionals. Only a few of these participants sought support from a user group (Appendix 13).

Passivity appeared to be associated with seeking support, believing that they were ill, living on benefit, and living with someone else or being divorced. Other factors were having a negative self-concept, ambivalence about being ill, little social integration, currently experiencing hallucinations, a more severe experience of schizophrenia, lack of confidence, the presence of fear and anxiety, and long and frequent compulsory admissions.

The *questioning* group

Some factors were associated with questioning. Some participants displayed ambivalence about being ill, while others believed that were not ill. Overall, this group had a positive self-concept, had experienced little family loss, and had few and short admissions. Some were in the *stopped* group, whilst others were in the *moved on* group.

Composite picture of the *questioning* group

In this group most were aged 40-57, with a few in their twenties. Questioning appeared to be associated with believing that they were not sick, living with schizophrenia for a slightly shorter time than the *passivity* group, living alone (more lived alone in the *questioning* group than in the *passivity* group), choosing isolation, not seeking support and being in paid work or studying (Appendix 14).

Composite picture of *acceptance* and *questioning* group: the commonalities

The mean age for both the *questioning* and *passivity* groups was similar (*passivity* group 44.3 years, *questioning* group 43.5 years). The age range was also similar (*passivity* group 29-57 years, *questioning* group 25-57 years).

8.8.3 *Participants' responses to others*

Most participants felt anxious and fearful and this prompted them to avoid social interactions. Some participants were anxious about their future. A few women reported general anxiety about everything.

Most participants were angry and blamed health professionals, and of those, some tried to suppress this anger because it was important to them to maintain their dignity, which precluded expressing anger (*stopped* group).

Negotiation, anger, non-compliance, and avoidance were described. Participant 11 reported:

“I tried to negotiate the tablets but they wouldn’t let me. I refused the tablets and they gave me an injection. I stopped going to the Day Hospital and they made me go again. I tried to avoid the nurses, just hid and did what they wanted. I used to do different things. I’d rebel. I’d complain. I’d hide. I’d avoid people. I’d stay in bed at home. I would try and keep out of the way and avoid people. Mam and Dad would tell me to get up all the

time [out of bed] then they'd be irritated when I did get up cos I was in their way. I got angry with me Mam and Dad for all that.”

Many of these responses appeared to be associated with psychologically negative states in which there was a lack of assertiveness, no channel for anger, a fear of being punished, self-blame and dependency. Examples of psychologically negative states were depression, lack of self-confidence, being afraid and worried all the time, and losing self-belief.

Some participants lied about being diagnosed with schizophrenia while others self-disclosed their diagnosis and found that self-disclosure led to rejection. Avoidance and desire to escape were common themes. Participant 16 reported:

“I'd get in the car and drive around when I got stressed. I'd be working and I'd just go off and disappear somewhere in the car. I drove to Scotland once. I'd sleep in the car, in laybys, to get away from all the stress,...away from all these people who made me stressed.”

Many participants accepted treatment and a few accepted totally others' evaluations of them, and accepted that they could not cope. A few stated that they said what they thought health professionals wanted to hear, and that this was a strategy for avoiding trouble. A few female participants resented and complained about parental control over their lives, but did not leave home, could not move on and displayed some ambivalence about being ill. Psychologically positive states were implied in the following statements. Participant 1 reported:

“I rejected other peoples’ evaluations of me, I rejected the old identity. I became an expert in my own life. I have my identity and individuality back.”

8.8.4 Identity and response to new identity

Acceptance, with resulting negative identity and self-concept, and rejection, with resulting positive identity and self-concept were the two main themes. For most of these participants the new identity came immediately after hospital admission and diagnosis. Those who currently accepted the new negative identity felt useless and ashamed, felt a failure and believed that others perceived them as a failure. They felt they were disabled and perceived themselves to be victims. They reported low self-esteem, depression, poor self-concept, anxiety, fear, stress and poor coping. Participant 7 reported:

“I can’t do anything right. I need help.” “ I can’t get a job because of the schizophrenia. I’m not fit to have kids. I don’t deserve them. It’s hopeless. I’m hopeless, my life is hopeless. My parents can’t be bothered with me, I don’t blame them. Look at me. People with schizophrenia aren’t normal, are they? I’ve got no friends. Nobody likes me, not even my kids.”

Some accepted that others perceived them as different and deviant because of the diagnosis.

Participant 9 reported:

“I’m seen as deviant, it’s a sort of deviance.”

The majority of participants believed that they were not normal and believed that they had a flawed identity. Participants felt that they could not do anything. One participant used the word 'loser' to describe himself. Some participants felt that their schizophrenic identity was known by their neighbours and believed that it embarrassed their children. Participant 6 reported:

“I am an unfit mother, I can't do anything. I am a paranoid schizophrenic. They call me mad Sue.”

This participant believed that she was not normal and all people with schizophrenia were not normal.

Implications of the new identity

All participants believed that they were treated as if they were mad. Participants reported being ignored. Most of these people with schizophrenia seemed to have a very clear awareness of their new identity, which came after the diagnosis, and the implications of this identity. They reported rejection, felt that they had lost their membership of society and felt that others perceived them as bad people. They described leading restricted lives with no choices. They believed that others perceived them to be incompetent, and for this reason, most did not disclose their diagnosis of schizophrenia. Many participants reported that they had been medicalised and one man reported that he medicalised himself and his behaviours using the professional terminology he had learned in hospital. All participants believed that they had suffered great loss.

Rejection of new identity

A few participants rejected the new identity. These participants were in the *moved on* group and did not perceive themselves to be failures. However, they perceived themselves to be excluded from society. Stress and anxiety were reported by this group, but to a less severe degree than those who accepted the new identity. They reported that they had asserted their individuality and appeared to have integrated the experience into their lives. Past experiences became less important than their current situation. They found what they were good at some things (e.g. art, photography), had a positive self-concept and *moved on* with their lives. Participant 5 reported:

“ When I finish my M A I’ll go back down to London. If it all continues without medication, I’ll just forget about it. I’ll just put it down to five years of university instead of four. I think I am not ill and never was ill. They just said it and when I disagreed they said that was part of the illness. I have control of my life now and I’m going to use my art degree to get a job. ”

Participant 1 reported:

“I used to feel a failure, but now I’m in control, I’m a success.”

“Nothing is going to stop me from doing what I want. My life is back in control.”

8.8.5 Seeking support and choosing isolation

Seek support

The *seek support* group reported that stress existed in the home, and they were told to seek support from the hospital by family members in the home. All participants were concept led, believed that they were ill, needed help and did not cope. Some participants sought support from nursing staff, and other clients in the hospital, and some sought support from a user group. Participant 12 reported:

“I went to the Day Hospital, it was quite good, the nurses there listened. They cared. Later at home, the CPN was nice, she listened. That made me feel good. That was after I was discharged. I was glad when she visited.”

Some participants sought support from family members. Participant 16 reported:

“I came to see me brother and I asked him what to do. He said “Go to your doctor”. So I went to the doctor and he gave me tranquillisers. Me brother cared about me and didn’t mind me going to him, and staying overnight sometimes. You need someone to care about you and support you when you have schizophrenia. Having someone to listen to everything that worries you is helpful.”

A few women sought support from community nursing staff and social services staff and openly expressed their anxieties to anyone. Participants explained why they did not seek support from a user group. The men reported that they preferred hospital support. The women had more varied reasons, reporting that they could not go out alone because of anxiety and could not afford to go out because of poverty. User groups were attended by a minority of these participants. Participant 22 reported:

“Going to the National Schizophrenia Fellowship [now called Rethink] made me feel normal again. It boosted my confidence. It’s good to be with likeminded people who understand what you have gone through and who support you. If I ever feel under the weather or a failure I take it to the group and they cheer me up. We are trying to get things changed. I feel as if I am doing something useful for other people too. So I feel like I am part of something important.”

One participant explained why she did not attend a user support group. Participant 6 reported:

“There is no-one to take me,” and “I am not comfortable with poorly people, they are not normal.”

A few participants said that they were not comfortable with many people, which seemed to mean more than four people. Participants who had lived with schizophrenia for more than 20 years found comfort and reassurance by reading the bible. The two younger male participants and six older male participants read *The Divided Self* (Laing 1960).

Composite picture of the *seek support* group

Seeking support appeared to be associated with acceptance, being *stopped*, being divorced or separated, living on benefit, reporting severe depression, believing they were sick, and being angry. This group had lived for a shorter time with schizophrenia than the *choose isolation* group. Eight of this *seeking support* group had lived with schizophrenia for 20 years. Ten of this group were belief led, and beliefs were negative (e.g. I am sick, I cannot cope). The age range was 29-57 years (mean age 40 years).

Some of this group reported that they had moved on with their lives and they belonged to the National Schizophrenia Fellowship. Some of this group were in the *stopped* group (Appendices 15 and 16).

The *choose isolation* group

In this group, two participants *chose isolation* and *sought support* at different times. They *chose isolation* from everyone but their partner, health professionals and other people with schizophrenia. The events stated were: other peoples' reactions to them, being hurt, being rejected and ignored, being disbelieved, being mocked and controlled. They all reported not trusting people any more. Participant 13 reported:

“I just stopped going out, or only going out with W [her husband]. He'd protect me a lot. People were nasty to me or looked through me,people who I'd gone to school with. That was really hurtful. Kids called me names when I went out. I was shocked at that. Once in a shop, the girl in the shop short changed me and I said 'you've short changed me, I gave you a £10 note' and she said, 'no I didn't, we all know you've been in the mental hospital'. So no one believed me about the money. I didn't go to the local shops after that.”

Participant 8 reported:

“I don't talk to anyone now. When they call me names I say nothing. I go away. I was taken into hospital before and nobody believed me. They held me down and gave me injections. They treated me as if I was mad. They laughed at me. I just avoid people

now. You can't trust what they'll do if you tell them anything so I don't tell the doctors or anybody anything."

Composite picture of *choose isolation* group

Choosing isolation was associated with little depression, a strong belief that they were not sick, and being in paid employment. Eight participants were in the *questioning* group and seven of these participants had lived with schizophrenia for 20 years and above. Six of these participants were female and all respondents were belief led. The age range was 23-55 years (mean age 42 years) and more of this group were in the younger age group (Appendices 17 and 18).

There were some differences between the *choose isolation* group and the previously discussed *seek support* group. More of the *choose isolation* group have lived for 20 years and above with schizophrenia than the *seek support* group. The mean age was slightly older in the *choose isolation* group than the *seek support* group, and more of the *choose isolation* group were 30 years and below, than the *seek support* group

8.8.6 Composite picture of seek support and choose isolation group: the commonalities

There were shared characteristics between the *seek support* group and the *choose isolation* group. These were the following: low mood, depression, anger at the way they had been treated, and feeling hurt. Participants were belief led, and the two beliefs were that they were not sick and that they were sick. There was some ambivalence about being a sick person in a few people in the *seek support* group and in a few of the *choose isolation* group. Event led feelings, anger, passivity and questioning existed in both

groups. None had moved location. This lack of geographical mobility was not explored at the time of interview, but it may be that it is due to a perceived need for help and support, or familiar surroundings, or fear of loneliness, or simply a cultural factor. A key factor was the belief that they were, or were not sick. Those who sought support had the belief that they were sick, and those who chose isolation believed that they were not sick, although there was some ambivalence in some participants.

8.9 Disempowerment

All participants reported that they had no power, an occurrence which came immediately after the diagnosis. Participant 5 reported:

“It was two weeks to go before I was to go back to the university in the summer. I wasn’t missing [his mother had reported him missing]. I was driving along and the police stopped me. They said they wanted to talk to me and that I had to come to the police station. They interviewed me, then took me to the hospital. They took my car keys away. It didn’t matter what I said, they treated me as if I was mad and they didn’t believe anything I said, and they didn’t tell me anything. I had to give up my university place. When you become a patient under the CPA [Care Programme Approach (DoH 1990)], you have no power, no credibility. No one believes you. It’s all got to be to do with your madness.”

One participant expressed the belief that he could not change anything, and another stated that health professionals told him that he was ill and he believed them, and from then on they had power over his life. Another participant reported that when she was

informed of the diagnosis, she and all her family believed it. In her view it ‘stopped’ her life for 20 years.

8.9.1 Control

Participants had no control at home, in hospital or in their social life. They all said they had no control in the past. Most said they had no control currently (*stopped* group). The loss of power involved loss of control of one’s life. Most of the participants reported being forced to comply with others’ wishes and having to take medication against their will, and, if they refused, being physically forced to have it. Participants reported that their decisions were ignored and devalued and they had no choices. Participant 5 reported:

“The psychiatrist said if I was better I would have a better relationship with my mum. I realized that the only way to get out of hospital was to become friends with my mum again. So I said ‘yes, you were right mum’. By this time I had to withdraw from university, give up all my plans and go back and live with my mum, with no real contact with the outside world.”

Participant 8 reported:

“People tell you, you can’t do this, you can’t do that. They make you shut up. You have no choice or control. I have no life. I have no control in my life.”

Some participants reported that people who had socialised with them in the past now avoided them and people made derogatory remarks about them, which they believed they had to accept.

Most participants reported that they were rejected when applying for employment because of the diagnosis of schizophrenia. This led to a financial loss of control and they were dependent on benefit, but only the lowest level of benefit, Invalidity Benefit, was available to most. Some participants discussed Disability Living Allowance. To receive higher level benefit they had to apply for Disability Living Allowance, which meant the participant with schizophrenia had to undergo assessment and the higher allowance was within the power of others to give or withhold. When it was withheld, the person had to live on a low income, which in turn affected all other areas of their life.

A few participants reported that current legislation removed their choices. Specifically, they referred to the Care Programme Approach (DoH 1990), since they were required to attend meetings and comply with a care plan, which involved compulsory medication.

Some participants decided to regain control of their lives (*moved on*). External circumstances did not change with these people, but there was a conscious decision to take control of their lives. Participant 1 reported:

“I let everyone make decisions for me. I had no control over my life, I completely forgot about me.” “I was angry that I’d listened to these people. I had no control. It stopped me from going on in life. I have control now, there’s nothing to stop me from doing what I want. My life is back in control.”

8.9.2 Knowledge

Accepted medical knowledge, on which the diagnosis of schizophrenia was based, and how that knowledge affected the participants, were referred to. Expert knowledge which led to the diagnosis of schizophrenia was referred to explicitly by some and implicitly by others. Some participants believed the current knowledge was wrong. Participant 1 reported:

“I was told by the psychiatrist that I had a mild form of schizophrenia and that I would have to take pills for the rest of my life. I accepted it all. I felt angry with them for putting the label on me. You read things in the papers about people with schizophrenia and everyone thinks that all these people are like that, that upsets me. They think we are all the same.”

“My GP accepted it because the consultant said it.”

JH “How do you feel about one person’s opinion having this effect?”

“Angry. I accepted what he said and so did everyone else. He knew and I didn’t know anything. Back to the knowledge of the time. I accepted it was true.”

“When my father died, my sister was upset. They tried to tell her she was manic-depressive. They judged her on my schizophrenia. I don’t think she is.”

JH “How do you feel about the idea that it runs in families?”

“I know *they* do believe it and they did it to my sister. She was really ill because me dad had died and this other doctor had decided to give her a label because of mine.”

This woman now questioned the validity of professional knowledge and linked professional knowledge to labelling, incorrect labelling, although initially she had not questioned it.

Others’ knowledge of the diagnosis of schizophrenia, and assumptions about one’s abilities and rationality, were highlighted. Participant 15 reported:

“I went to the Disability Resettlement Officer at the Job Centre. He said ‘we don’t think you’re capable of holding down a job’. They just classified me as schizophrenia and it went on from there.”

Some participants believed that their experiences were a spiritual event, which was not believed by health professionals, who assumed these participants were irrational. Some participants questioned this expert knowledge and believed that alternative knowledge was valid, specifically the concept of spirituality.

Most participants believed that expert knowledge led to medicalisation of their whole life; everything they did or said was considered irrational and was thought to be part of schizophrenia. Some participants who now believed that they were expert in their own life appeared to have achieved this level of assertiveness. A few younger men were highly vocal in their criticisms of the accepted knowledge of schizophrenia, which, in their view, led to wrong assumptions about irrationality.

Most participants reported that there was a lack of information. They felt that the health professionals did not want to tell them anything. Some participants that reported they were not told the diagnosis, but had to ask, and others spoke of hidden knowledge, of medical jargon and of being refused access to their case notes.

8.9.3 Rationality

Participants discussed accepted ideas of rationality and how these affected them. Over half these participants considered themselves as not rational and in need of help. Others reported that other people, including family members, thought they were irrational. Most reported that assumptions of irrationality meant they were refused employment. These assumptions were also used to invalidate what they said, when they reported the truth as they perceived it. Some participants reported that others perceived them to be incapable of doing anything. Some reported being disbelieved. Participant 8 reported:

“I had these visions and I told people. I fly through space and see amazing things when I go astral flying. They didn’t believe me. I was taken to hospital and they all treated me as if I was mad. They have their ideas of what is normal and rational and they don’t think that I’m rational.”

Participant 5 reported:

“It was my mum saying I was behaving irrationally. They believed what she said not what I said. They believed I was a danger to myself. It was very difficult. The more I tried to protest my innocence like I am not insane, the more they thought I was.”

“I was just about to start my third year at university, when I was taken into hospital. I had this project I was working on for the previous 6 months and everything I was saying about what I was doing, they didn’t believe it. The psychiatrist thought it was delusions of grandeur, that I was going to do this, that I was going to do that.”

Participant 15 reported:

“I lent [a friend] some money and they wouldn’t pay it back. I asked for it back. They said they’d paid it back and that it’s all part of your illness. It’s all part of your illness, you’re not rational.’ they said.”

One participant, who did art work for children’s’ books, showed her artwork to her G.P., who responded with: “you must have been on the magic mushrooms.” This participant came to the conclusion that accepted knowledge, accepted by everyone, was responsible for others’ reactions to her (for example, staring at her in an odd way in the street, others’ fear of her when she was doing nothing, derogatory statements, people making decisions for her and discouraging her from seeking employment).

8.10 Care

8.10.1 Participants’ views of care

Participants discussed their views of care, ideal care, and the care they received. Participants had definite views of what care meant to them. For all these participants with schizophrenia care meant support, specifically, emotional support and practical help on a daily basis. Care meant the other person understood their point of view and

did not devalue them. Care meant not being alone and people keeping in touch with them and listening to them, being helped to belong to society, and meant someone having personal concern for them as an individual. For most participants care did not include medication, although for one participant it did. Participant 6 reported:

“ I don’t like medication. It’s the side effects. I’m scared to take it and I’m scared not to. They’ve tried me on different tablets and things. I need more tablets. I need more support.”

Some participants reported that care meant being treated as an adult and an equal, having privacy and being involved. Male participants held the view that access to meaningful activity and work was part of care. A few men enjoyed occupational and industrial therapy, whilst worker status and identity was very important to the other two men, who were depressed and anxious about being unable to find employment. Home Treatment was perceived as good care by a few participants. A few participants would have welcomed more control if more care was also given.

Lack of care was highlighted. All participants said nurses did not care about them and most reported that there was no care anywhere. Participant 11 reported:

“In hospital they did not care what I wanted, the nurses just cared about rules and regulations. When I was feeling bad and stressed and wanted to talk to someone, they didn’t have time to talk to you. If the medication made me feel bad, they just said I had to take it. If I couldn’t sleep they gave me pills and when the pills didn’t work went to talk to the night nurse and she would just tell me to go back to bed. I was worried about so many things in hospital and they didn’t care.”

Participant 13 reported:

“I was afraid, afraid no one would care. Nurses didn’t really care about you, they were all too busy. It wasn’t just me. I’d look around and see other people who looked really worried, as if they were in a panic, and the nurses would ignore them. The woman in the next room was crying one night and they just let her cry.”

Participant 20 reported:

“Staff [in hospital] don’t care. They leave you to your own devices all day everyday. They have no time for you. Care is people giving you time and understanding you. After care should be better. There should be a programme of therapeutic care with group sessions.”

Participant 6 reported:

“The nurses trivialise what I say, they didn’t take it seriously or me seriously. Life is hard. I can’t cope with practical everyday things. I need help with cooking and cleaning. I need more help and more money. What do they expect? I’m schizophrenic. I need a social worker. I’ve got a CPN but she does nothing. She comes every three weeks and does nothing. She tells me everything is because I’m poorly. She should listen to what I’m saying.”

Hospital care was criticised as being untherapeutic and coercive. All these participants’ reported that nurses did not care about them and were not concerned about them as a person. Participant 8 reported:

“When I was in hospital it was very bad. The night-time was bad. They deny your civil liberties. I was admitted to hospital and it was like being in prison. Nurses and people didn’t listen to you. For others you don’t count in hospital, its all control, the staff stop you from doing everything. There is no care. The nurses don’t care. They don’t believe anything you say. They give you injections against your will. You have no choice, no rights. People at work don’t care. They know I’ve been in hospital. They don’t talk to me now. They treat me as if I’m mad. Sometimes they ignore me. Sometimes they laugh at me”.

There were some positive responses. Some participants felt that friends cared about them and accepted them. One participant felt that she received good care in the form of a social services unqualified carer, who helped her with shopping because she was afraid to leave the house alone.

8.10.2 Care and control

Care was perceived as control. All these participants acknowledged that families and health professionals appeared to believe that they were doing the right thing, but the participants disagreed with the care delivered. Most perceived care as labelling, and current legislation was perceived to be part of a larger control mechanism, in which their wishes were disregarded. For most participants, the care given by hospitals, family and the whole mental health system, amounted to scrutiny and control. In their view, it was not intended to support, or pursue, the interests of people with schizophrenia.

Most participants reported that medication was forced upon them, and that staff who did this believed they were delivering good care. They spoke at length about the bad side

effects of medication and perceived medication as coercion and punishment. They reported that they had no civil rights or choices in hospital. Some participants said that some aspects of care made them feel worse than they had previously felt (e.g. electroconvulsive therapy, medication). Some participants had the experience of being sectioned under the Mental Health Act (DoH and Welsh Office 1983), which negatively influenced their view of care in hospitals. Family care was reported to be overprotective, stifling and to prevented choice. Participant 1 reported:

“People are protective, overprotective for you, in case you do something because you’re schizophrenic. I accepted it. They [the family] controlled my life.”

Some participants highlighted the issue of protective care and family members making the decisions for them. They reported that family care was protective, which effectively led to their lives being ‘stopped’. Participant 1 reported:

[family protective care] “stopped me from going on in life.”

Some participants reported that they lost their confidence because they became accustomed to people making decisions for them and controlling their lives. The women accepted the care and did not see it as control until many years later, whilst a few men saw it as control immediately.

Some participants reported that care was intertwined with family guilt. Parents felt that they must care for their relatives with schizophrenia and believed that they must have done something to cause the schizophrenia. The family exerted strong control over the

life of the participants out of fear of harm coming to the participants and the family wished to prevent further harm or illness.

All of the *moved on* group regained some control of their life, but of these, only some participants retained the family care. Some participants in the *moved on* group regained control of their lives, at a cost of having no family care, and felt lonely and alone. However, they believed this to be acceptable and preferable to previous family care/control. Specific experiences of controlling care were described. Participant 11 reported:

“When I was at home with my parents with this schizophrenia I didn’t feel that anyone was supporting me. Nobody cared about my needs. When I asked for help I didn’t get it, in hospital and at home, mostly nurses just tell you what to do, they control your life.”

Care was perceived as infantilising. Participant 5 reported:

“I was being treated like a five year old. I was twenty-three at the time. It was kind of protective being told to tidy up my room, what I could watch on TV, to wash up [he laughed]. It was like being a teenager again. I had no control over my life.”

JH? And now?”

Participant 5 “No, I have control now.”

JH “Do you have an opinion of the Care Programme Approach?”

Participant 5: “The way I see it, the mental health system is that you are under a life time suspended sentence.”

Some participants reported that their friends, who perceived hospital care as good care, had taken them to hospital. They acknowledged that their friends were concerned for them, but did not agree with the actions of their friends.

Some participants expressed ambivalence about hospital care. They hated it but they thought they needed it. They were outpatients, but they went up to the hospital just to sit with the other patients on the ward, especially at the weekends. The staff told these participants to go home, but they would continue to sit there. They both resented the control and coercion of hospital staff, and the lack of care delivered by hospital staff. For these participants the care system was abusive, and they did not trust the hospital staff, but they continued to want the staff to care for them.

8.11 Consequences

8.11.1 Loss and response to loss

The major psychological losses were loss of self-belief, self-confidence and self-esteem, which were reported as having led to severe emotional distress and anxiety. All participants reported some family loss, which appeared to involve loss of happiness for the whole family, poverty and reduction of coping strategies. The severity of family and relationship loss appeared to be associated with being in the *stopped* group. Participants in this group felt abandoned and a few reported that they had lost everything. Those in the *moved on* group reported much less loss (e.g. less divorce, no family rejection and

no abandonment) than those in the *stopped* group. Participant 15 (*stopped* group) reported:

“Having schizophrenia stops me from getting a job. My wife wouldn’t have me back and I’m running out of money. People say ‘sell your house’, but where am I going to live? I sit here on my own all day, most days and worry about it all. Everything has collapsed around me. I’m stuck. I’ve got no friends here, just my family and they can’t do any more for me. What future have I got, living on social security?”

Impact of Loss

All participants reported losing their planned life and felt socially isolated, having lost their work and social contacts and old friendships. Loss of employment, for most, contributed to social isolation and to loss of future employment prospects and ambition. All participants reported depression to some extent. Some participants were angry, and, of these participants, some were angry about loss as a result of schizophrenia, while others were angry about the behaviours of others, which, in their view, had led to their loss. Those in the *moved on* group expressed more anger than those in the *stopped* group. Lack of confidence was reported by most participants. Some reported fear and anxiety and some were anxious about further loss, about being rejected and about being found out (*stopped* group). A few women felt useless and unfit to be parents. A few women in the *moved on* group reported having lost the ability to make decisions in the past, and felt angry about that now. A few men in the *moved on* group reported difficulties returning to their previous lives and reported intrusion, lack of privacy and of confidentiality.

Different responses to loss.

This section highlights the different responses to loss: depression, anger and anxiety. All participants were depressed and most were angry and anxious. For some participants there was acceptance of the loss and these participants were depressed and requested more help from nurses (*stopped* group). For others there was resentment, then anger followed by current acceptance of their loss. Unhappiness and distress were reported. Participant 6 reported:

“I don’t know how long I’m going to last. It’s all torment and I can’t sleep. I want to die. I don’t feel happy enough now. I worry al the time. I’m going deeper and deeper into it. How am I going to end up? I’ll be alone and I’ll just die.”

This participant believed that if others helped her more she would not have suffered so much loss.

Participant 6 reported:

“If other people helped me more it wouldn’t be this bad but nobody helps me. They know I’m ill and they leave me to sit here on my own, ill, with no money and everything falling apart.”

Avoidance of health professionals was reported by most participants, who did not trust health professionals because they felt that further contact with health professionals could lead to further loss. Some participants, who sought help, perceived themselves as

sick. Those who maintained their positive identity minimised the loss by taking control of their lives and being assertive (*moved on* group).

8.11.2 *Social consequences*

All participants felt very alone, and reported rejection, marginalisation and labelling. Most participants reported exclusion, stigma, prejudice, persecution and abuse. A few were severely distressed about this. Most participants reported poverty. Exclusion was described. Participant 9 reported:

“I’m not in society, I would have liked a social life. When I met people, they looked at me differently.”

“People leave me to my own devices, no-one comes around. I feel lonely, I’m not in society.”

Participant 8 reported:

“For others you don’t count, I go to work, but I don’t belong, and people don’t talk to me now.”

Participant 5 reported:

“I wasn’t invited to the end of term party, I sat on my own every night and read, people rejected me. People I’d known walked past me, ignoring me. People knew I’d been in a mental hospital and I couldn’t get back into my old life again. I could tell that people

were scared of me. I've lived this kind of life since being in hospital. I'd go to university, come home, read a book, or watch T.V. or something. I didn't have any kind of life outside of that."

8.11.3 Physical consequences

The side effects of the medication made most of the participants feel physically ill.

Participant 4 reported:

"Treatment made me feel worse, medication makes me feel tired, and ECT caused me to be depressed. I'd be shaking all over with the medication and my eyes felt fuzzy."

Participant 1 reported:

"The drugs that I were on were not nice, Largactil,... They were making me very....I don't know if it were me or the drugs. I was constantly on the move, feet moving, head moving,and it made me feel sick, and then they gave me more drugs for the sickness."

Physical isolation was reported by all participants.

8.11.4 Psychological Consequences

Rejection, being demeaned and disregarded made all participants feel depressed, stressed and powerless at some point in their lives. Most participants reported that there

was anxiety, dependency and a loss of self-confidence. Fear of future loss was severe in the *stopped* group. Participants felt guilty for the stress they thought they caused their families. Multiple losses led to severe emotional distress for some participants. For some there was low self-esteem, sadness, resentment, unhappiness and a 'stopped' life. Some participants reported they felt useless and a failure. Low self-esteem and depression was described. Participant 6 reported:

"I'm useless, I'm not a nice person, I'm mad, I'm an unfit mother, I can't do anything. I'm not normal. I'll never be normal again. I can't sleep and I can't concentrate on anything. I worry all the time and it will all end badly, when I die. I see no point in going on. Nothing I do ever works out. Well, what do you expect? I'm schizophrenic."

Although some of the *moved on* group reported that joining the National Schizophrenia Fellowship helped them to move on in life, they did not report that they had achieved as much, in terms of a changed life, as other participants who were not in a user group, but who had become very assertive. In their own perceptions, those in the user group had achieved a lot, but had not achieved integration back into society, which mattered a great deal to them.

For some participants, there were positive outcomes, but only because they gained control of their lives, questioned ideas, challenged others and *moved on*. They returned to work or university and felt happier than in the past. They still felt relatively socially excluded, but had equality in their relationships, independence and personal power.

8.11.5 Family Consequences

Anger within families, directed towards the person with schizophrenia, was common to most participants, and family break up was reported by some (*stopped* group). Some participants reported that there was current burden and stress on carers. Some participants reported conflict, and family members blamed the participants with schizophrenia (women). Self-blame was reported by the families of women, because parents thought they had caused or contributed to the schizophrenia. This trend was not apparent in families of men with schizophrenia. Some families had restricted lives. A few participants reported that there was stress on child carers, and that children adopted the roles of adult carer. Participant 13 reported:

“I lost time, you know. I couldn’t remember days. I’d think ‘it’s Friday, what’s happened to the week?’ I couldn’t remember the last two days. I slept a lot. My girls were growing up and *I slept through it*. I seemed to have missed my girls growing up.”

Participant 6 reported:

“I’ve lost my kids. Their father has them. I only get to see them a few hours a day. I hit them. I didn’t mean to but there was that much going on in my head. Now only the oldest girl stays with me. But she’ll leave when she is sixteen, then what’ll I do?”

8.11.6 Stigma

Most of these participants believed that stigma created social exclusion, rejection, negative assumptions and promotion of fear of people with schizophrenia. There was a

cyclical process in which participants felt trapped. Stigma created negative assumptions about them, which led to further stigma. Stigma caused severe distress. A few men, who did not specifically mention stigma, described it in interactions with others. Participant 15 reported:

“The stigma of having schizophrenia stops me from getting a job. I go down the job centre and they know I’ve been in a mental hospital. They know I’ve got schizophrenia. They tell me I’ll never hold down a job.”

8.11.7 The sick role

There were two main themes under this heading: acceptance of the idea that they were sick, or rejection of this idea. All participants had lived the sick role initially, and most participants currently lived and accepted the sick role. They needed much more support than they currently received. Those who currently lived the sick role believed they were ill, and relied on others to make decisions for them. Participants reported they could not cope with anything and needed help. They reported excluding themselves from society, being stressed and having no self-confidence. They felt anxious, sad, useless, lonely and stopped in life. They were fearful of being alone and abandoned.

Some female participants expressed severe fear, depression and anxiety, felt that the schizophrenia had stopped them, and reported that the voices and visions distressed them greatly. They said that they could not concentrate on anything and could not work. They did not regard themselves as normal. They believed that there was nothing they could do about anything (*stopped* group). Participant 6 reported:

“I need help, I can’t cope, I’m sick, I can’t do anything, I can’t go out, I need a social worker, I’ve got mental problems.”

Participant 9 reported:

“I can’t work.”

Some participants at the time of the interview did not believe that they were sick people. They felt angry at their dependency and resented being treated like a child. Of these, a few felt safe at home but also resented the scrutiny. They made a decision to take control of their lives, and the trigger for this was anger. One female participant stopped taking medication completely. Another was reducing the medication slowly, with a view to stopping it eventually. A few young male participants left home and returned to their previous lives. A few female participants questioned the diagnosis, took control of their lives and saw their past beliefs about being sick as a mistake. They acknowledged their past dependency and reported that they were no longer dependent (*moved on group*). Participant 1 reported:

“I feel very angry. It held me back. At times I have been dependent. There’s nothing to stop me from doing what I want now. My life is back in control.”

A few male participants had never believed that they were ill. They reported that others had said they were behaving irrationally, but these participants disagreed with this and attributed it to interpersonal conflict. When admitted to hospital against their will, they were angry at the way they were treated and reported that their justified anger was perceived by staff as illness. They were forced to comply with treatment, forced to

admit that they were ill in order to be discharged from hospital, and their ideas for their future were thought to be delusions of grandeur by health professionals. However they had since gone on to achieve their goals. They had no control over their lives in the past but did have at the time of the interview. Other people, not schizophrenia, had ‘stopped’ their lives for a while, according to their accounts. They now all had a life plan, but reported a degree of loneliness caused by social isolation.

The ambivalent group

Some participants expressed ambivalence about being a sick person. These were all in the *stopped* group and appeared to accept care and control. A few participants believed that their visions were psychic or mystical events (e.g. astral flying), but also stated that they had lost their self-belief, had no life, were treated as mad, did not feel good in themselves, complained of depression and had been off sick from work due to this. They could not consistently believe that the visions were psychic events. They sometimes believed that they must be ill, although the illness they spoke of was stress and depression caused by their current life and great loss, which was perceived as a direct result of being diagnosed with schizophrenia. They believed that they were ill, but not schizophrenic. They did not believe in the existence of schizophrenia.

A few other participants reported that their experiences and visions were a spiritual event. They also did not believe that they had schizophrenia. However, they self-reported being stressed and ill. One male participant willingly went to hospital to seek support, and he believed he couldn’t work. Therefore there was some belief that he was ill and that this illness had stopped him.

One participant felt that ECT had caused his depression. He slept a lot currently.

Participant 9 reported:

“Lethargy, tired all the time, that’s the main problem, being lethargic. My health got the better of me and I wasn’t able to continue working at all. The drugs and illness resulted in heaven and hell experiences. The illness stopped my ambitions. I came back from holiday in Spain...[he paused] it started about that time,..[he paused] started off the mental problems. Until then, I’d been fairly sound. My concept of schizophrenia is that it is evil spirits.”

Some participants did not fully believe that they were sick, but appeared to live life as a sick person. Participants who believed that they were not sick acknowledged that they had been given a sick identity by others, but they did not accept it.

8.11.8 Dependency

Dependency was highlighted in most interviews. Only some participants in this group identified it themselves and used the word dependency, but others described their dependence on others. Those who identified dependency reported that overprotective care led to dependency. A few who did not initially resent the dependency accepted it along with the care and protection. Some participants reported that dependency led to a loss of control over their life. They complied with everyone’s wishes because they thought it was for the best.

There were similarities between those who talked about dependence and those who did not mention it. There seemed to be no difference in the level of loneliness and

depression in those who identified their dependence, those who did not identify it but were dependent, and those who were not dependent. It may be that, to move on from dependency, one first has to identify it in one's own life and behaviours.

Some participants did not identify dependence for themselves, but did, nevertheless, display it in their actions and statements. One participant said she needed help, could not cope with practical daily things and believed she could not do anything. She depended on health professionals, her oldest child and her mother. This high level of dependency appeared to have been present for many years and this woman stated that she could not go out alone or make a decision. Participant 6 reported:

“I used to have a life, I want to go for tanning sessions, you know what I mean, I just can't, I can remember doing all these things. I need people around me now to help me.”

Another participant was physically and psychologically dependent, initially on his parents, then on his partner. He feared that his partner would abandon him and made many compromises to please his partner. He feared that the hospital staff would reject him when he went there for peer support. He stated that the hospital staff did not care about him and did not want to help him, although, in his view, he needed their care and support. He viewed going to the hospital, even when he was no longer a client, as a permanent arrangement. Like many participants, this man felt too ill to work.

Some participants resented the dependency and perceived it as enforced dependency, a situation which they resolved later (*moved on* group). A few male participants reported being dependent for a relatively short time - 1 year and 3 months and 1 year and 6 months. Some participants who reported enforced dependency expressed a wish to get away from home and hospital, and reported they were treated like children.

Difficulties in regaining independence were noted. Participant 5 reported:

“I found it hard going from scrutiny to being alone.”

Participant 2 reported:

“It was hard to get back into my life.”

A few female participants appeared to want to be independent but to be too afraid to try and achieve it. Newly found independence was lonely and stressful for two young male participants. Independence appeared to have been gained at a price for them; they reported a feeling of loneliness and no family contact or friends. At the time of the interview, two female participants were not dependent, lonely or stressed, and they had given up the belief that they were ill and had gained independence and equality in relationships at home.

.

8.11.9 Stress

All participants discussed aspects of stress: causes of stress, stress within families, and stress experienced by these interviewees at home and in hospital. The hospital environment was perceived as stressful because of the noise, cigarette smoke, lack of privacy and choices, and lack of sleep. Lack of support caused stress. Medication, with its side effects, was a major cause of stress for most participants. Being arrested was reported as stressful. Being detained against their will was the main cause of stress.

The nature of stress within families

Most participants reported that stress was within the family and there were specific circumstances. Participants acknowledged that others could not cope with them. They felt guilty and depressed, because they believed they caused the stress within the family, and that they were a burden.

It was reported by most participants that family members became stressed and could not cope with the participant or the new situation. The families blamed the person with schizophrenia, and there was conflict between the person and their family. Stress in families led to divorce, separation and family loss. Stress, which impacted on carers, was reported as being caused by the behaviours of the relatives with schizophrenia (*stopped* group). There was no support for families, and poverty was reported as a serious problem. All participants discussed causes of stress, which were stated as rejection by family or others, multiple loss, being disbelieved, medication with side-effects, being avoided, being left alone, the belief that they caused the family stress, and people controlling one's life (e.g. the relatives constantly telling them what to do).

Some participants felt that their family members had caused the stress which they felt, and others felt that their stress was caused by their family leaving them. For some participants, stress was still an ongoing feature when they were discharged and living at home. This was because of family conflict, continuing contact with unhelpful health professionals, being alone, and trying to get back into one's old life and being rejected in this attempt. Many participants believed that stress caused their schizophrenia, and both schizophrenia and reactions of others to their schizophrenia caused more stress for them and their family (e.g. blaming, anger and not coping).

Participants discussed their strategies for dealing with stress, specifically avoidance. A few participants avoided people. However, they did not avoid health professionals and actively sought their support. A few women who discussed and self-disclosed their problems to anyone who would support them did not use avoidance to reduce their stress (*stopped* group).

8.11.10 Burden of schizophrenia

These are the experiences reported by specific participants. Participant two spoke of his burden, which was in the form of rejection, labelling, loss of employment opportunities and subsequent poverty, in addition to being forced to comply with treatment and a diagnosis he did not agree with. Being under scrutiny was unpleasant and he had no privacy, and because of rejection, he experienced loneliness and social exclusion.

For participant six there was family break up. Her husband divorced her and had custody of the children. The burden was in the form of poverty, low self-esteem, depression and anxiety. She reported that others called her derogatory names and she felt severe guilt about the possibility of her children being vulnerable to schizophrenia because of genetic inheritance. She was afraid to sleep, believed she was not normal and that she was a failure in life. She felt shame and felt that her children felt ashamed of her, and of themselves for being the children of a mother with schizophrenia.

Participant three reported a great loss of confidence and self-belief. He felt ignored, that he didn't count and that he was devalued. He had experienced severe stress within past relationships, and loss of relationships, and now lived alone. He felt lonely and expressed depression, anxiety and very low self-esteem. His wife divorced him and he

saw his child only occasionally. He spoke of the burden on his ex-wife, who left him. He felt great stigma and shame at being diagnosed with schizophrenia, was socially isolated, and it was his belief that people avoided him because they knew about the schizophrenia.

Participant four felt that he was a great burden to his parents when he first became ill. He felt a burden to his current partner and worried that he/she would leave him as others had done in the past. He felt guilty because, in his view, his behaviours had caused great stress on others. He felt great sadness and loss because of his lost opportunities, and was unable to continue working because of the schizophrenia. He felt tired and depressed all the time, no one visited him and he felt lonely. He suffered from very unpleasant side effects from the medication.

8.11.11 Circles of entrapment

This section highlights situations in which participants with schizophrenia felt they were trapped. Most participants reported that people controlled them. Participants disagreed with this control and refused to comply, which was perceived as evidence of illness, and this led to their life being even more controlled.

Some participants reported that they were poor and living on Invalidity Benefit, did not work and accepted that they were sick. The Disability Resettlement Officer agreed with this and suggested they apply for Disability Living Allowance. They did this but were refused, as they were not seen as sick enough, and they remained poor.

Identification led to social consequences (e.g. stigma and labelling). Most participants with schizophrenia excluded themselves to avoid difficult interactions with others in society and some of these consequences. This led to further invisibility, which led to even less interaction between participants with schizophrenia and others.

Most participants reported great difficulties with employment and finances. If the person with schizophrenia couldn't work, or was rejected in employment, they were forced into living on benefit. If they accepted the label and applied for Disability Living Allowance, they were often refused as they were not deemed ill enough. If they accepted they were not ill enough, and applied for work, they were rejected because of their schizophrenia. They were caught in a societally created poverty trap.

Expert knowledge led to ideas about rationality, which in turn led to negative assumptions about people with schizophrenia. Most reported that their actions were assumed to be irrational and this assumption was supported by the expert knowledge base. Those who agreed with others' evaluation of them were treated no differently from those who disagreed; therefore, complying did not benefit them.

8.11.12 Being stopped

These are the experiences of participants who reported feeling *stopped* in life. In their opinion, their lives had been stopped by health professionals, society and family. This happened after diagnosis and identification. They felt *stopped* in life socially, financially and emotionally, and felt that they were prevented from growing as people, from working and from being independent. Their future ambitions, life plans and choices had been *stopped*, and for these participants it was a permanent situation. In

their view, some became so unwell as a result of the responses of others, that even if their social and employment opportunities and choices were given back to them, they could not take advantage of these because they had been psychologically stopped. Some participants reported that they could not get back into their old lives. Participant 6 reported:

“Schizophrenia stopped me. I worry all the time, I’m too anxious to do anything. I’m too ill to work, I can’t cope, I can’t go out and do things. I need help. There’s no point in going on. I’ve got no future. I’m going to die. I’m stupid and useless.”

For some participants, the social consequences appeared to lead to psychological consequences, and respondents were facing poverty and loss. They felt they needed help, and believed themselves to be disabled. Downward social drift was indicated in two participants, who had been professional people and graduates and who were previously affluent, but who were now experiencing poverty. Downward social drift appeared to lead to anxiety, depression, anger and sense of shame and failure. They believed that the diagnosis of schizophrenia stopped them from progressing in life.

8.11.13 Composite picture of the stopped group and composite picture of the moved on group

Stopped group

There were common factors in participants who reported feeling *stopped* in life. The *stopped* group, six men and six women, made different comments from the *moved on* group. Participants spoke of not feeling normal. They felt disabled, fear, confusion, very

low self-esteem and current severe anxiety. They were afraid of being alone and engaged in self-blame. Being *stopped* appeared to be associated with being event led and expressions of severe depression, acceptance of illness and loss of self-belief. It also appeared to be associated with living with schizophrenia for 20 years and above, being older than the *moved on* group currently, and being older than the *moved on* group at diagnosis. Some sought support and others chose isolation, some were divorced, most were not in paid employment, most lived with someone, none were in a user group and all were in the *acceptance* group. Eight reported events that led to them feeling *stopped* and all were belief led (Appendices 19-22).

Moved on group

There were common factors in the *moved on* group. The *moved on* group consisted of three women and seven men. They reported more a positive self-concept and had achieved more independence. They blamed others, perceived themselves as rational and currently rejected the sick role and flawed identity. They had self-belief, but worried about being sick again, and reported stress on returning to their old lives. Some participants who made a psychological recovery spoke of deciding to take control of their lives and had a very positive self-concept. The successful key strategies appeared to be taking control of one's life, rejecting the negative label, questioning the validity of health professionals' knowledge and maintaining positive self-belief. In addition, those who *moved on* reported great anger, lied about the diagnosis or denied it, blamed others, externalised their feelings, and questioned the diagnosis and knowledge.

Moving on in life appeared to be associated with not being event led, living with schizophrenia for 20 years or less, being 24 years and below at the time of diagnosis,

and being younger at the time of interview. *Moving on* also appeared to be associated with being in a support group (in these cases the National Schizophrenia Fellowship). Most of the *moved on* group lived alone, a few were married (all women), but most were single (all men). A few were divorced or separated, and three men were in paid employment (Appendices 23-26).

8.11.14 Main differences between the moved on group and the stopped group

There were differences between the *moved on* and the *stopped* groups. The *stopped* group were older than the *moved on* group. There were fewer single people in the *stopped* group than in the *moved on* group. Fewer of the *moved on* group were divorced than the *stopped* group. More of the *moved on* group lived alone than the *stopped* group. Most of the *stopped* group lived with someone, although it was unclear whether this was a cause, contributing factor, or consequence of being *stopped* in life. Most of the *moved on* group were in a user support group, while none of the *stopped* group were. Most of the *moved on* group were in paid employment. None of the *moved on* group were event led, but reported that they overcame events, and this seemed to be related to having positive self-belief. The *stopped* group appeared to be unable to overcome events. Most of the *moved on* group had lived with schizophrenia for 20 years and below. Fewer of the *moved on* group than the *stopped* group were in the *acceptance* group (Appendix 27).

8.11.15 Composite picture of the moved on and stopped groups: commonalities

There were commonalities shared by the *moved on* and the *stopped* groups. Some participants in both groups did not belong to any user support group and were not in

paid employment. Similarly, some participants in both groups had lived with schizophrenia for between 10-29 years. In both groups, people sought help and chose isolation, and displayed questioning and acceptance of illness.

8.12 Time

Participants spoke about their past, present and future throughout the interviews.

The past

For some participants their lives were good, prior to the onset of schizophrenia (stopped group). However, the onset of schizophrenia was not perceived by some participants to be the same concept as the diagnosis of schizophrenia, which came later. All participants said that their lives were good prior to the diagnosis of schizophrenia. Most participants in the *stopped* group appeared to have had unpleasant experiences (e.g. hostile voices). Most participants in the *moved on* group appeared to have had more pleasant experiences, and experienced unhappiness when they were informed that they had a mental illness. For participants who had lived with schizophrenia, it was all part of their past. The past was remembered as confusion, and they reported feeling stopped in life.

The present

For most participants, life was full of problems and barriers, and they perceived the present as bad, with much loss. For some participants, the present was good because they had moved on.

The future

Some participants foresaw their future as bad, winding out slowly with restrictions, barriers, rejection, and no pleasure (*stopped* group). Some participants believed that their future would be positive, with opportunities as yet unachieved, and they had goals and hope (*moved on* group). For some the future was perceived as depressing and hopeless, and others saw no future for themselves.

8.13 Internal and external reality

Perceptions of reality were reported by participants with schizophrenia.

8.13.1 Internal reality

Participants described how they perceived themselves. All participants agreed that they were punished, powerless, unfairly treated and controlled by others. Most participants thought that they were both schizophrenic and sick. Some participants felt that they could not do anything, needed help and could not cope. For others this was a past internal reality. They believed themselves to be a burden at home and that the burden on carers was all their fault. Some believed they had lost everything. Some felt that they were not schizophrenic and were not sick. Of her internal reality, participant 11 reported:

“I was punished when I rebelled, I refused to comply, I had no rights when I was in hospital. In the past I used to feel good, I used to feel normal, now I don’t feel normal and I feel bad.”

Of her internal reality, participant 13 reported:

“ I felt terrible with the medication, the side effects, I missed out on seeing the children growing up, I couldn't think, I was ill.”

Of his internal reality, participant 15 reported:

“I am poor, I am sick, stress made me sick. The voices were helpful, advised me at first. I think they are liars now. I have been unfairly treated. I need medication and treatment. I can't go to work with lots of people, it would stress me. I've lost everything. I'm stuck, I'm a loser.”

8.13.2 External reality

All participants described how they perceived others. This was a very negative picture. They all perceived that others perceived *them* as irrational and incompetent. People were coercive, controlling, punished them and did not care about them. They stated that people did not help them or like them and people treated them unfairly. People were cruel and hostile and the world was a hostile place. Participants thought that others excluded them. Of her external reality, participant 11 reported:

“They took away all my choices, they made all the decisions, nobody cared about my needs.”

Of her external reality, participant 13 reported:

“They [old friends] avoided me, they’d walk by me, they stopped talking to me, the world is unfair. No one understood, nurses didn’t care either. [In the past] I could do anything, I went to work, I wasn’t dependent. Now, I let him [her husband] make all the decisions, I let everybody make all the decisions. I lost touch with my family, my family rejected me, my social life stopped.”

Of his external reality, participant 15 reported:

“I had a good job, I had money. Now I can’t make enough to survive and next year, I won’t have enough to run the house. They tell me to sell the house but where will I live? The money is all gone. It’ll get worse in the future.”

8.14 Summary of the common experience of living with schizophrenia

The experiences which were common to most participants with schizophrenia are described here. External causes, specifically stress, were reported as having caused the schizophrenia. At the time of the diagnosis, they were working or studying, then had life plans and could not continue with these. When they experienced their visions and voices, they tried to make sense of these experiences but felt confused. When describing their first episode of schizophrenia, they described the situation as both distressing novelty and confusion. The major source of confusion was whether they should believe they were ill or not. Being in hospital was perceived as punishment and abuse. They reported that medication made them feel ill. Most perceived the scrutiny they were subjected to as intrusive, and not as care. Most believed they were ill and sought support from others. The common concerns highlighted were: isolation, rejection, loneliness, disempowerment and loss of control in their lives, loss, unfair and bad treatment by

others and medicalisation. They reported stress in their lives, after the diagnosis, and there was anxiety about being ill again. Stigma, labelling and the behaviours of others contributed to their stress.

They reported that health professionals coerced them, and removed their choices and control over their own lives. Medication was given against their will, and they reported unpleasant side effects. In their perceptions, health professionals promoted dependency and negative assumptions about people with schizophrenia. Health professionals did not support them or give them information. Participants felt excluded from the decision-making processes.

In their interactions with others, they felt they were excluded, rejected and disbelieved. These participants were angry about being disbelieved by others because of the diagnosis. They felt that others were afraid of them. Some people were abusive and made derogatory remarks to them, and participants with schizophrenia became anxious and chose to avoid social interactions with others. Within the family, participants did not feel equal with other family members. They reported stress within the family. Family interventions and care were perceived as controlling and overprotective, a situation which was accepted by many. Participants acknowledged that the family did not cope with them.

Other people's responses were reported as negative. People made fun of them, punished them, denied them opportunities, trivialised them, treated them unfairly and as if they were irrational. In their interactions with health professionals, participants felt they were not taken seriously and did not like being under observation. These participants felt that

other people expected them to be incompetent, unable to achieve anything, violent, mad all the time and not to be trusted.

Participants developed strategies and responses to others. Most of them remained passive, sought support, conformed and accepted the diagnosis. Most were angry with health professionals. They disliked the care and treatment, but accepted treatment. Most accepted the new identity assigned to them after diagnosis and hospitalisation. There were serious consequences of the new flawed identity: being constantly treated as irrational; stigma; loss of membership of society; social, psychological, emotional, family and personal loss; and leading a restricted life. They believed that others felt justified in their coercion because of the flawed identity.

Loss was a consequence of living with schizophrenia. There was loss of social contacts, of power, of employment, of self-confidence, of positive self-concept, and of a planned life. There was loss of coping in families and family stress and break up occurred. They reported rejection, marginalisation, exclusion, stigma and poverty. Stigma was perceived to create exclusion and promotion of fear of people with schizophrenia. Most participants believed they were irrational, in need of help and wanted more care. Care for most participants meant emotional and practical support, not being left alone, people listening, understanding their point of view and not devaluing them. Hospital care was perceived as untherapeutic. Family and hospital care were perceived as control, under which the participants were made to become submissive. The care given did not support or pursue the interests of the participants. They disagreed with the care, in which their wishes were disregarded. Most participants with schizophrenia lived their lives as sick people, and felt they needed more support than they currently received.

Most participants reported dependency on family members, and most accepted this situation.

There was stress on families, and within families there was stress, conflict and blaming. Hospital environments, detention in hospital and lack of support caused stress among participants with schizophrenia. In order to reduce their stress, most participants avoided people in society.

When discussing the burden of living with schizophrenia, they reported that medication with unpleasant side effects, negative media coverage of schizophrenia, negative flawed identity and social isolation were key features of this burden. Most participants were caught in circles of entrapment (e.g. they felt controlled and their non-compliance was perceived as evidence of illness, which led to more control).

Most participants felt stopped in life, although some felt they had moved on. Most perceived their life was good, prior to the diagnosis or onset of schizophrenia; by contrast, their present life was bad, full of problems, barriers and loss. Their future was perceived as bad, with restrictions, barriers and no pleasure. Those in the *moved on* group felt more positive about their present and future, perceiving potential opportunities as yet unachieved. The internal reality of most participants was that they had schizophrenia, were ill, uncared for, and disempowered. Their external reality was reported as unpleasant. People were coercive, uncaring, unfair, controlling, hostile and did not help them (Appendices 28-29).

FINDINGS: CARERS

These are the findings reported by 13 carers of people with schizophrenia. The carers were six males and seven females. There were eight parents, four husbands and one child carer. Most carers were retired or not in paid employment. The age range for this group was 15 -75 years. They had cared for their relative for between five and 38 years (Appendices 11-12). Following the same approach as for findings for people with a diagnosis of schizophrenia, emerging themes and categories for carers are presented in Figure 4 in a manner which reflects the chapter organisation.

Figure 4. Carers: emerging themes and categories

Emerging theme	Emerging category
8.15 Conditions	
8.16 Common concerns	
8.17 The situation	
8.18 Common understandings of schizophrenia	
8.19 Interactions	8.19.1 Carers' perceptions of health professionals and their interactions with health professionals 8.19.2 Other peoples' responses to carers 8.19.3 Family interactions 8.19.4 Interactions: society in general
8.20 Strategies	8.20.1 Acceptance 8.20.2 Questioning 8.20.3 Composite picture of <i>acceptance</i> group and of <i>questioning</i> group 8.20.4 Seeking support 8.20.5 Composite picture of the <i>seeking support</i> group
8.21 Identity	
8.22 Power and control	
8.23 Care	
8.24 Consequences	8.24.1 Loss and response to loss 8.24.2 Social consequences 8.24.3 Cognitive consequences 8.24.4 Physical consequences 8.24.5 Emotional and psychological consequences 8.24.6 Family consequences 8.24.7 Stigma 8.24.8 The sick role 8.24.9 Dependency
8.25 Care burden	
8.26 Ambivalence about caregiving	
8.27 Going round in circles	
8.28 Time: past present and future	
8.29 Being stopped	
8.30 The common experience of being a carer	
8.31 Reflections	

8.15 Conditions

Conditions and events reported at the time of diagnosis were disruption, fear and anxiety. Most carers tried to continue going to work and having their normal social life, but this became difficult or impossible. Participant 25 reported:

“He became extremely difficult to control, more than difficult, it’s worse now. Over a period of time he got worse, he actually attacked his dad. His dad is 16 stones and wasn’t expecting it. It doesn’t matter what you say to him he looks at you blank and does what he wants. He plays music really loud, smokes all the time, won’t eat with us, and is up most of the night. When I go to bed he gets up, there’s mugs and cups all over the house when I get up in the morning. I can tell what he’s had to eat all night by the mess left around the house, open packets, tins, butter, milk left out.”

8.16 Common concerns

All carers reported that they could not cope and were very stressed. They all believed their relative was very sick. They all reported great loss (to be discussed in more detail in section 8.24.1). They all reported feeling that nurses did not support their relative enough and they acknowledged that there was no cure.

Most carers reported having to support their relative financially. They reported feeling angry and shocked that health professionals treated their sick relative as rational. They believed that their relative was not rational. Their own health was poor (with the exception of the child carer). They reported they worried about what might happen to their relative with schizophrenia when the family was no longer there to care for the relative.

Most carers reported that their relative did not accept that they were ill, which caused distress among carers. They worried about their relatives hurting themselves. Most carers spoke of their restricted life, claiming that they had stopped going out and had lost touch with old friends. Poor judgment on the part of the person with schizophrenia was highlighted by carers. Examples of perceptions of poor judgement were given by carers. Participant 28a reported:

“I was so worried about leaving her alone in case she got it all wrong, did something stupid you know. That’s why I couldn’t leave her alone. They can’t help it. They’re ill. You can’t expect them to make good decisions or know what to do.”

Participant 28b reported:

“I was scared she’d burn the house down. I mean... you never know what’s going through their minds. They get confused.”

Participant 26 reported:

“She [his wife] used to sleep about two hours a night. She’d go to bed at 11 and get up at one. She’d sit up all night drinking tea and smoking. She’d have her breakfast at half past four (in the day) her clock had gone, you know what I mean. She walked home from the hospital once, there were snow on the ground, January, February, just in her slippers and dressing gown.”

Most male carers reported the extended family [of the person with schizophrenia] blamed them, and female carers reported that they were afraid of their relative’s violent

outbursts. Some carers stated that their relatives lied to the doctor, pretended to be well, and so were sent home from hospital. Some said how angry and worried they were about the relatives' application for Disability Living Allowance being rejected. The child carer said she worried about genetic inheritance and knew what this term meant. Husbands were worried about the negative effects of their wives' schizophrenia, inability to be a mother, and on the children. They reported they had to protect their sick wife from other people.

8.17 The situation

Carers described the situation in their lives, at the time their relative was diagnosed with schizophrenia. The trend that emerged was that most parents and spouses reported confusion. Participant 26 reported:

“ For years I never knew what were wrong with her. I knew it were mental illness, but never knew it were schizophrenia. It finished up having a doctor telling me what it was. Two year ago she were in. Psychiatrist said ‘what do you think your wife is suffering from?’ I said ‘she’s got schizophrenia’. ‘Don’t be ridiculous’ she says. That’s the answer I got. Then she went on to talk about confidentiality. I wasn’t supposed to know. I’m her husband. I need to know. ”

Some carers also reported conflict. There was great conflict and loss for participant 25, as her son was 17 years old at the time of diagnosis and at school. She saw his behaviour change and he failed his “O” levels, and she believed his future was lost. For a few husbands there was great loss, as there were young children to care for. The child carer was born into the situation, and knew no other life.

8.18 Common understandings of schizophrenia

All carers said that their relative was ill, not rational, and that there was no cure. Their relatives made bad decisions, but could not be held responsible. Having schizophrenia meant you might hurt yourself, because you were ill. People with schizophrenia do not fit in or conform. Their relative was ill, could not cope with anything and needed care.

Participant 25 reported:

“He’s ill [her son] and when he is very ill, he is unreasonable. He needs 24 hours care but nurses and doctors won’t give him this. They send him home to me and think I can give it. I try to give him the best care I can but it is a lot to give, he needs to be watched all the time. He can’t cope with normal life, or normal things. He’ll never work.”

Participant 33 reported:

“They told me later it was schizophrenia and there was no cure, just the treatment to stop it from getting too bad. I had to take care of her, protect her, she couldn’t cope.”

Health professionals’ decisions and advice worried carers. Participant 25 reported:

“As far as I was concerned he needed to be in hospital, but they wouldn’t agree. I kept asking for him to be taken in. All they do is send him outpatient appointments which he won’t attend. I think he is very ill and they think he is well enough for outpatient appointments and being home. I don’t understand.”

Participant 28a reported:

“Sometimes the hospital staff would give advice. They would say “involve her in your decisions”, but we thought that was a terrible idea, she couldn’t think properly, she wasn’t able.”

For the child carer, her mother being diagnosed with schizophrenia meant she had to do all the work in the house and care for her sick mother.

8.19 Interactions

8.19.1 Carers’ perceptions of health professionals and their perceptions of their interactions with health professionals.

All carers reported that needs were not met by health professionals. Carers reported that health professionals did not understand the carers’ experience of living with a person with schizophrenia. Carers reported that health professionals had let carers and their relatives with schizophrenia down. They felt left alone with the burden of care. Health professionals gave them no information. Parents highlighted the lack of help from nurses and the issue of feeling blamed by nurses. Participant 29b reported:

“We tried so hard to care for her and the nurse [the CPN] did nothing to help.”

Participant 29a reported:

“Yes, more practical help was what we wanted. I felt that the nurse was blaming us for her behaviour.”

Participant 29b reported:

“I didn’t like it when the nurse said we were doing it all wrong. She said that we were making her dependent.”

Carers stated that health professionals let their relative make bad decisions, and carers held different perspectives of care from those of health professionals. Participant 25 reported:

“ I got this letter back from the doctor, which said if he won’t attend, there’s nothing they can do and there’s nothing I can do if he won’t attend outpatient appointments. If I was concerned about him sometime I can ring the duty Social Worker who is 24 hours on call. On Friday night I rang the Social Worker. She came out. He [her son] went out so he wasn’t here when she [the Social Worker] came. She [the Social Worker] said to ring again if I was worried. He [the son] went berserk once and I called the Doctor and the Social Worker came and said he didn’t need sectioning.”

8.19.2 Other people’s responses to carers

Some carers reported that friends and neighbours knew about their relative with schizophrenia, but no one talked about it. It was an open secret but was perceived by everyone to be a private matter. Some carers stated that the family offered no support and did not want anything to do with the relative with schizophrenia. A few older carers said that the neighbours knew all about their relatives with schizophrenia and the carer’s difficulties, but thought that the carer could cope with it all. Participant 34 reported:

“Other people get help but we don’t. They call her [her mother] a weirdo. Nobody helps me. I just try and do some things to help. The neighbours just stare at me. They don’t talk to me. Nobody talks to me about it. I’ve got some friends but they don’t live round here. They don’t talk to me about it, but that’s O.K.”

8.19.3 Family interactions

All carers reported a lot of conflict in families - rows, unhappiness, tension and anger. Carers reported anxiety in family relationships and worried about their relative with schizophrenia. With the exception of the child carer, they tried to control their relatives’ lives. Some carers said that they held the relative with schizophrenia responsible for the conflict in the house and were stressed and disappointed about the way it had all turned out. Participant 25 reported:

“We tried to get him to do normal things... like getting up and having breakfast with us, having tea with us, coming out for walks, but he wouldn’t. It was so stressful trying to work round him. Everything had to be his way, to suit him. If it didn’t suit him, he’d make an argument about it. He’d demand ridiculous things. We kept on trying to involve him in normal family life because we didn’t want him to hide in his room all day, and we worried about him. If he could fit in a little bit, that would be good. Why should we be up all night, just because he is? I used to go in about dinner time and try and get him up, but he’d lie there and use bad language and I’d be upset. I had high hopes for him but that’s all gone. He’s going to waste his life.”

Some carers reported that they protected their relative and tried to make sure that they had nothing to worry about. They tried to ensure that their relative was never left alone,

out of concern for them. This, however, was not seen as a positive or helpful action by their relative and led to conflict.

Some carers reported that their extended family did not help them. They reported anxiety within the extended family, and that the nuclear family was rejected. Participant 33 reported:

“There were times when I’d be tired, and needed time off, for rest, but there was no rest. We had a bad time for about three months then she went into hospital and I was that tired, and I asked her sister to have the kids, but her sister wouldn’t have them. They wouldn’t help us at all. They wouldn’t come near us once it came out that me wife was ill. You’d have thought her own family would want to help, wouldn’t you? And they wouldn’t have us in their house, even at Christmas. They wouldn’t let her near their kids. I don’t know what they thought she’d do. It was as if she had not family, just us.”

The extended family directed hostility at some carers. Participant 26 reported:

“I used to get the blame. Her first two lads blamed me for it. [Her two sons from a previous marriage. He was her second husband]. So did her brother. [They thought he was doing something to her to cause her illness and behaviour.] Her mother and father didn’t blame me, like they knew something.”

The effect of having a relative with schizophrenia made children leave home as soon as they were legally allowed because these children had to adopt adult carer roles at home.

8.19.4 Interactions: society in general

Most carers reported that they were made to feel ashamed and reported that people thought they could cope with the caring. Another carer reported that people were unkind to his relative. Another stated that the local community accepted her regardless of her son's behaviour, but that it was him who avoided people.

Fear of their sick relative hurting someone was highlighted by carers. Participant 24 reported:

“I weren't frightened for me self, I were frightened for other people.”

Participant 24 described her interactions with neighbours.

Participant 24 reported: “Someone told me to forget about him: ‘ you shouldn't do this, you shouldn't do that’ - but how can you? I've lived here 38 years. I'm friends with everybody. He's gone out of here, shouting and carrying on, well, the neighbours know, I know they know, they are all very polite about it. They ask how J is.”

Therefore this mother highlighted the following issues: people knew and gave her advice which she would not follow, everyone knew about the situation and her fear that her son would hurt someone.

Other peoples' ideas about schizophrenia were highlighted. Participant 27 reported:

“I think they have these ideas about schizophrenia, that people with schizophrenia are nasty, violent. These people weren’t worth knowing anyway.”

He and his wife avoided people.

8.20 Strategies

All carers reported using certain strategies to cope with their relatives’ schizophrenia and the burden of care. They did not talk about their relative with schizophrenia outside the home. All carers, except the child carer, said they became stressed but they just lived with it all. They continued to care for their relative with schizophrenia. Most carers blamed the health professionals. They protected their relative. Participant 27 reported:

“People said terrible things about you [his wife] right in front of you, I had to take care of you. I protected you from a lot of things.”

Most carers supported their relatives financially. When things became too difficult at home, carers arranged to have their relatives admitted into hospital. Participant 25 hid her money from her son, locked her bedroom door at night when her son was awake and called the social services and police when she was afraid. She had her son arrested. She was arranging to have her son moved out of her family home and for social services to take care of him. She felt very guilty about her perceived rejection of her son.

One participant reported having become angry and very assertive. He had sat all evening in the hospital insisting that they admit his wife. When she was finally admitted

that same night, he went home, cried and felt sad and guilty. He visited every night after that, even though she refused to speak to him and seemed to hate him. Another participant brought up the children as well as he could, and read about schizophrenia in a book from the public library. Some tried to negotiate with their relative, regarding acceptable behaviour, but this was often unsuccessful. Participant 25 reported:

“I tried to negotiate with him. It doesn’t work.”

Most carers actively tried to solve their relative’s problems and controlled their relative’s life. Control and practical care were perceived as the best care.

Participant 24 reported:

“The tablets were left here [her house] so I could supervise giving them. I won’t say he took one every morning, because he didn’t. Sometimes he’d not take one till tea time, but having said that, so long as he got one a day [her son lives elsewhere]. His incapacity book is here, so last week and this week he’s signed for me to draw it. I supplement it, I really do, I buy all J’s things, I had to pay his rent. I do buying and fetching for him, buy food, cigarettes, pay his bills. There’s all the other things I buy him, new earphones for his personal stereo.”

Most carers actively sought help. One carer said that she called the police and others for help. Participant 25 reported:

“He attacked his dad. We called the police. They treated him like a criminal. I felt bad about that, guilty”.

“He wouldn’t let me in the door. I went next door and called my husband and said ‘please come home, he won’t let me in’. The police came again and we got in the house. The Police were totally supportive, kind and helpful. They were so understanding”.

“I called the doctor. I call all the time. I keep asking for him to be taken in. All they do is send an outpatient appointment which he won’t attend.”

This carer also called the Social Worker for help:

“On Friday night I rang the Social Worker, she came out. He [her son] went out, so he wasn’t here when she came. She said to ring again if I was worried. He went berserk once and I called the doctor and the doctor and the social worker came.”

Some carers sought help for themselves when they became depressed. One carer became very vigilant, watching his wife, and stopped his wife from taking an overdose of sleeping tablets. He was so distressed by this that he called the Samaritans. He protected his wife and did not tell his wife about the derogatory remarks the extended family were making about her. When she died he tried, unsuccessfully, to unite the family.

8.20.1 Acceptance

Most carers accepted without question that they would have to care for their relatives. Carers believed they must adjust to the ways and needs of the person with schizophrenia. Participant 26 reported:

“It’s different cos you can’t do nowt. When she went to bed, I’d go to bed and I’d be out like a light. When she got out of bed, I’d be up too.”

Participant 24 reported:

“ There isn’t any choice, is there? You have to keep watching and looking after them, when they’re ill. I try to make sure everything is right for him, butI don’t know. It doesn’t stay right for long. When he lived here, I’d see what he were doing and try to be there. Up all night sometimes, but I couldn’t do that for long. Then he’d want to talk to me about his ideas when I was asleep, so he’d wake me up and I’d try and listen. He had funny ideas about religion. He isn’t Catholic or Moslem, but he’d want to talk about that, about changing his religion, and he’d want to go the Catholic church and the mosque. It’d be three in the morning!”

8.20.2 Questioning

None of the carers questioned the validity or rightness of the diagnosis. Some carers did question other things. A few asked questions about the diagnosis and effectiveness of the treatment. A few questioned the health professionals’ ability to care for their relatives, and others questioned the idea of community care, saying it was a myth. Others did not question the authority of the health professionals, but questioned their commitment to support the carer and the person with schizophrenia. Participant 24 reported:

“The CPN wouldn’t take J in his car. I looked at him [the CPN] and I said, ‘I have this 24 hours a day, 7 days a week, and you, as a nurse, won’t have him in your car for five

minutes. I tell you what, there's a door there, I can manage quite well without you'. The doctor came to see me, when J wasn't here, [to] see what I thought he should do. I said 'well, I'm no doctor'. I said 'three months it's going worse and worse.' I hate to tell people their jobs. I find that I'm doing that at present. I mean, its common sense, if you're on medication, and it's not working, change the medication, or up it [increase it]."

Some questioned the treatment. One carer reported that the injections gave his wife problems. A few carers reported that the treatment was not working and others questioned the CPN's advice to involve their daughter in decisions. The child carer intended to leave home and her mother as soon as she legally could. Some carers did not accept that they must care for their relative forever.

A few carers reported that their daughter had moved out of the family home and was married with children. From their point of view, she seemed to have recovered from schizophrenia, while they remained tired and depressed after years of caring.

8.20.3 Composite picture of passivity group and of the questioning group

The only factor common to the ten carers who reported passivity was the strong belief that their role was to care for their relative. The only common factor in the questioning group was that they questioned the effectiveness of treatment given to their relative.

8.20.4 The seek support group

This section highlights the people from whom carers sought support. Most carers sought support from health professionals and some sought support from their family, while a few sought support from a carer group. Most carers sought support from health professionals only and some carers sought support from both family and health professionals. The child carer did not choose isolation, but there appeared to be no support for her.

8.20.5 Composite picture of the seek support group

Carers who sought support from both family and health professionals were slightly younger than those who sought support from health professionals only. Seeking support was associated with worrying about their own inclusion in their community or their own poor health and stress. Most carers blamed health professionals and felt they had no time for themselves.

8.21 Identity

Most carers, except older mothers, reported that there was a loss of normal identity. They did not feel normal and appeared to believe that they and their family were not normal because of the presence of the person with schizophrenia. Loss of a normal life was highlighted. Participant 25 reported:

“When my daughter comes home, when she wants to, she’ll notice things. She’ll see what you do, what he does, she points it out. You don’t appreciate it, all the normal

things other people have. I've forgotten what it's like to have a normal life, it was so long ago."

Some carers [husbands] were concerned about how others would perceive their children, because of their wives' schizophrenia. The child carer was anxious about how others would perceive her, because of her mother's illness.

8.22 Power and control

Carers expressed perceptions of who had power and control, and their attitudes to power and control. All carers perceived that they had no power. Most carers reported that they believed that their relative with schizophrenia had power, and health professionals had power, but would not use it to help them. Participant 24 reported:

"I told J [her son], Dr.....said to take two tablets a day. He said 'I'm not taking your word for it. You're trying to overdose me'. So I had to ring and leave a message for Dr..... to ring here and tell J himself that he's got to take his medication."

Participant 30 reported:

"He does what he wants and it's all the wrong thing. I can't do anything about it. I tell the doctors and nurses. They just look at you. They don't do anything. I can't make them see. Can't make them do anything to help him."

Most carers believed that their relative needed to be controlled, but believed that they had no control and that they just reacted to the behaviours of their relatives. One carer reported having to control her daughter. Participant 29a reported:

“We couldn’t leave her alone because she might do something, she’s ill, we cared about her.”

Most carers said that they had to take control of their relatives’ medication and supervise this. Participant 24 reported:

“The tablets were left here, so I could supervise giving them.”

A few carers reported that their relatives with schizophrenia ruled the home, and their illness and delusions ruled the carers’ lives.

Participant 25 reported:

“You’ve got no control. You’ve no alternative. He rules the family. He rules the house. He has to have everything his own way. It is his house and we live with him, in his opinion”.

Carers worried about their lack of control of major care and treatment decisions.

Participant 26 reported:

“When the psychiatrist said ‘do you want to come in, V?’ and V said ‘No’, I were amazed when the doctor agreed with her. I were disgusted. I told them what happened [her behaviour in the house]. It weren’t my decision. It were all her decision.”

8.23 Care

Carers' perceptions of care were discussed. For all carers, care meant doing practical things to help their relative and all carers perceived their own activities to be care. For all carers, except the child carer, care involved controlling their relative, giving medication, monitoring this, and demanding that their relative be admitted into hospital from time to time. Carers did cooking, cleaning, housework and shopping to help their relative. Care involved not leaving their relative with schizophrenia alone. Care was perceived as always being there. Participant 27 reported:

“When she was at home from the hospital, I was too worried to leave her alone. I worried what she'd do. I loved her. I couldn't leave her.”

Participant 25 reported:

“I feel that I must take care of him, it is like the umbilical cord is still there.”

Care involved controlling cigarette consumption and visiting their relative everyday in hospital (husbands). For some carers, care was mixed up with guilt, related to having had their relative admitted and arrested.

One husband reported that one of his children had been a child carer. Participant 27 reported:

“She [the oldest daughter] looked after the youngest a lot [when their mother was sick]. She [the oldest daughter] seemed to know her mother was mentally ill. She had to grow up quick you know? Do things round the house.”

8.24 Consequences

Carers of a relative with schizophrenia described loss, social, cognitive, physical, emotional, psychological and family consequences. They experienced stigma, poor health, and dependency on the part of their relative with schizophrenia.

8.24.1 *Loss and response to loss*

Carers reported social, family and psychological loss. Participant 27 reported:

“I was very depressed, I felt our married life was over, you know? When she wasn’t well, she wasn’t [he paused] herself. Things weren’t right in the house, weren’t normal in the house.”

All these carers appeared to accept the loss. Participant 24 reported:

“I’m not moaning about it. I’ve done psychiatric nursing in Scalebor Park [a psychiatric hospital].”

All carers reported feeling anxious and very tired. Some carers reported that they felt depressed and others reported feeling very sad all the time. Most felt angry about the situation they were in and some reported becoming resigned to the situation. One carer was upset at the loss of her previously normal son. Participant 25 reported:

“He isn’t my son any more, he’s just some creature, some monster. [She wept when saying this]. I told the Social Worker I’m really tired. I can’t have him [her son] living

with me much longer. I've forgotten what it was like to have a normal life. It was long ago. I've taken to locking my bedroom door when my husband's away. I'm afraid of him [her son].”

One carer highlighted his inability to cope and his own poor health. Participant 26 reported:

“She should never have been left to me. I couldn't help her. I couldn't cope. They put me on anti-depressants. They didn't do any good. I tipped them down the toilet. I had a panic attack. I fell down. So I had to go and see the psychiatrist. I was really, really shaking all over.” [This man also wept when he said this].

Participant 24 reported:

“I'm tired and weary. I'm depressed. I'm on pills for depression.”

8.24.2 Social consequences

All carers reported social loss. They had no social contact with others now, and no social support. They had many worries, felt that no one wanted to listen to them and felt alone with the burden. Participant 27 reported:

“I couldn't tell anyone, not the neighbours, and the doctors and nurses were all too busy. They didn't have time for you. I used to go to the working men's club but it got so that I couldn't when she [his wife] was in hospital, because of the kids and when she was home I was too worried to leave her alone with them. I worried what she'd do.”

There were some minority findings. A few carers [husbands] reported that people avoided them. The child carer reported her embarrassment at her mother's behaviour.

8.24.3 Cognitive consequences

Carers expressed thoughts and beliefs relating to their relative's schizophrenia. All carers knew that there was no cure. Most carers believed that their relatives needed to be controlled and that they had to do the controlling. 'Better' was a word used by most carers, and for them it meant absence of schizophrenia, and conforming to normal behaviour, hence their anger when the relative did not improve after treatment. They believed that there was no support. Participant 24 reported:

"Schizophrenia, there's no cure, is there? I definitely think, when he's on the outside, they should give more support to them and to carers."

One carer had thought about a future plan to manage the situation and gain support. Participant 25 reported:

"If he lives alone, it becomes their responsibility [social services]. Apparently someone will come and take him shopping. Let's see if they'll do that at nine o'clock at night with him sleeping all day. I thought that might be a useful exercise to see what actually happens."

Self-blame and guilt were highlighted. Participant 33 reported:

"I think I didn't do enough for her but I didn't know what else to do."

Participant 24 reported:

“Sometimes I wonder if it’s me [who caused it].”

8.24.4 Physical consequences

The physical consequences of caregiving and the presence and behaviours of their relative with schizophrenia were discussed. Most carers were tired and stressed and reported feeling physically ill. Difficulty sleeping was a common theme. Physical and psychological consequences occurred together. Participant 26 reported:

“I was afraid to go to sleep. I were worried about what she’d do.”

Outliers

One husband reported physical rejection, avoidance by others and loss of normal married life, which he explained meant sexual relations. The child carer did not go to school.

8.24.5 Emotional and psychological consequences

The emotional and psychological consequences of caregiving were described. All carers perceived that their lives had been stopped. Carers felt a responsibility to control their relative to prevent harm coming to them and they felt unappreciated. They felt disappointed for themselves and their ruined lives and the ruined lives of their sick relatives. They felt that there was no positive future for them or their relatives. They felt an obligation to be with their relative because they believed the relative had no one else.

Fear and anxiety were reported by most. Most carers were afraid of their relatives' outbursts.

Depression and sadness were also reported by most carers. Participant 33 reported:

"I got to thinking, I can't go on. I couldn't sleep and worried all the time. I couldn't go the work. I were so depressed one day, I sat and cried. I needed to get her into hospital, the kids to somebody else and I needed a rest from it all, but they all left me to it. One day one of me pals took me to the doctor and the doctor put me on pills for depression. He said I need more than pills, but that was all he could do."

Guilt and self-blame were reported by some. Some carers felt guilty at not doing enough, at having their son arrested, and having their relative admitted into hospital. They were concerned for their children, and spoke of stress and the burden of care on the children of the family. One husband experienced relief when his wife died. Lack of support was discussed. Participant 34 reported:

"It's hard, other people get lots of help and we don't. I get embarrassed by her [her mother] and walk away."

Tiredness and stress were reported. Participant 28a reported:

"I was so tired with her. I was stressed. I fitted my life around her"

Her husband, Participant 29b, reported:

“Yes I cared, but I got very tired too. I had great hopes for her. I worried about her. I felt sad when I looked at her the state she was in. I was disappointed, you know.”

8.24.6 Family consequences

All carers stated that there was no support and there was stress in the family home. They did not cope with relatives’ behaviours or with the constant caring. The loss of normal family life and roles was reported. Most carers reported that their relative’s illness and behaviours ruled the house. One carer reported that the extended family, specifically his wife’s relatives, blamed him for his wife’s illness.

Participant 26 reported:

“I used to get the blame. Her first two lads blame me for it. So did her brother.”

This carer reported rejection of his sick wife. Participant 26 reported:

“A few days before she died, she called him [her oldest son] ‘I want to see me grandchild’ [she said to her oldest son]. ‘I won’t bring her again. You’re too old to have my child’ ” [the oldest son’s reply to his mother].

This carer reported that the rejection continued when she was admitted to hospital.

Another carer reported that his eldest daughter engaged in caring activities and housework. Participant 27 reported:

“I felt bad enough that my oldest girl was doing all the work around the house, there was time for all that when she was a married woman.”

He highlighted the lack of support from the extended family. Participant 27 reported:

“I thought her family could have helped a bit with the girls but they didn’t want to know. They blamed me, thought I was making her ill!”

Outliers

A few older mothers reported no loss of normal family life or roles. They continued being mothers to their sons, as before. Children blamed the parent who had schizophrenia and adopted adult carer roles, resulting in loss of childhood. Children left home or intended to leave home early because of this.

8.24.7 Stigma

Stigma was reported by some carers, and was related to the relative’s mental illness. Stigma led to social isolation and loss for the carers and family, to loss of friends. Stigma caused great anxiety. Participant 33 reported:

“You have to remember it was a long time ago and nobody spoke about it. It was a thing to be ashamed of having schizophrenia in the family. I had my daughters to think

about. They were at school I was worried for them, you know? Other people calling them names, because K [his wife] wasn't well, in the mental hospital.”

A few older mothers did not feel stigmatised and they valued the positive relationship they had with friends and neighbours.

8.24.8 The sick role

Poor health and the belief that they were ill as a consequence of caregiving were reported by carers. Most carers believed they themselves were ill. Some stated that stress led to their depression. Some were on medication for depression . Participant 27 reported:

“I was worried sick, I didn't know what was wrong with her. When they took her into hospital I was so tired I had to ask my brother and sister in law to take the kids for a week just so as I could get some rest, I was so tired, drained, worn out.”

Outliers

The child carer did not believe her mother had to accept admission into hospital.

8.24.9 Dependency

Carers' dependency on health professionals was discussed. Participant 28a reported:

“When that CPN came I was relieved. The CPN could deal with it all for a while. I did appreciate that.”

The dependency of the relatives with schizophrenia on carers was discussed. Participant 28a reported:

“Everything went round her. Her needs were met!”

Participant 32 reported:

“I had to do so much for her when she was at home. She couldn’t make decisions, she couldn’t think right. She was never like that before. She depended on me to help her with everything. I had to do it. She was my wife. I couldn’t leave her, but, it was like she were a child again. She couldn’t cope with anything.”

8.25 Care burden

It appeared that in all of these interviews one family member became the carer and carers felt alone. All carers expressed concern for their relative, and reported that there was no support for them or their relative. Participant 27 reported:

“So what with all that, and nobody from the hospital helping us, we just had to get on with it ourselves. When it got really bad, I’d call the hospital. They’d say, go to the GP, get a letter from the Doctor! The GP, he didn’t seem to understand what was wrong with her.”

Participant 26 reported:

“It wasn’t fair to leave her to me.”

“They [nurses] start their shift, finish their shift, go home. They don’t have to live with it. I had it 24 hours a day.”

With the presence of the care burden, most carers had no time for themselves; they supported their relative in every way. These carers cared about the relative, but did not cope. They felt tied to the sick relative.

Participant 25 found a carer support meeting unhelpful:

“I went to carers’ meeting. It made me feel depressed. When will someone take the burden off these people?”

The care burden on children was highlighted by a few parents and the child carer. They all reported that children had to adopt the carer role, delivered practical care, cared for younger siblings, missed school, and received no support from health professionals and little support from adults in the extended family.

8.26 Ambivalence about caregiving

Some carers appeared to display ambivalence to their relative with schizophrenia’s presence in the home, the dependence of their sick relative and the care burden. One mother made it clear that she cared about her son, but wanted him to leave the house. Four parents wanted their daughters to be more independent, but believed that their daughters could not leave home because they were ill and could not be left alone. These parents seemed reluctant to let their daughters go.

8.27 Going round in circles

One husband reported going round in circles and receiving no help. Participant 26 reported:

“I took my wife to the hospital and they said ‘go to the GP [General Practitioner] for a letter, you need a letter’. I went to the GP and he said ‘you don’t need a letter; your wife is an outpatient’ so my wife did not get admitted.”

8.28 Time: past, present and future

Carers’ perceptions of their past, present and future were discussed.

The general view

Most carers reported that prior to their relative being diagnosed with schizophrenia, the carers’ past was good. A minority finding was the child carer who was born into the situation. The present was perceived as bad. All reported anxiety and little help. Most reported severe, multiple loss. They believed that the future would be bad, that there was no hope and only more loss. They thought that there would be more burden for them in the future and more illness for their relative. Participant 25 reported:

“It’s devastated my life, it’s devastated my son’s life. He wanted to be an architect. He wanted to be a quantity surveyor. At school, although he wasn’t doing extremely well, he was doing reasonably well and managed to get 4 ‘O’ levels. He became schizophrenic at 17. It’s devastated the whole family.”

When discussing her present situation, Participant 25 reported:

“I’ve forgotten what it’s like to have a normal life. It was so long ago.”

For this mother, the present was stressful and unpleasant. When asked what she would like for the future, Participant 25 reported:

“More support for him to live not on his own, but in his own place, a room or a flat in a complex where he can go and eat with others. I’ve been pushed into a corner and all I can think of is to put him in this house round the corner [a house she is buying for him]. I mean, if it doesn’t work we’ll have to think of something else. I don’t expect it to work.”

8.29 Being stopped

All carers reported that their life had been stopped. One married couple reported that after many years of caring for their daughter with schizophrenia, she married and left home and they were still worrying about her.

8.30 The common experience of being a carer

The common experience of being a carer involved having to live with odd behaviours and a lack of support from anyone. Carers felt tired, stressed and powerless and believed that everyone else had all the power (for example, their relatives and health professionals). They felt alone with the burden of care, suffered from depression, anxiety, poor physical and mental health, and lived a restricted life. There was a great

deal of confusion and carers felt a need to control and protect their sick relative. Within families there was conflict, stress and blaming. Caring involved practical daily activities and there was an assumption in society that carers could cope with anything. However, they did not cope. Carers sought help from health professionals, who did not help them. Carers believed they and their family were not normal because of the presence of their relative with schizophrenia.

Their sick relative made bad decisions and this upset them, especially when health professionals allowed this situation. Carers believed their relative was not rational. There were severe negative consequences and loss in the following areas of life: social, identity, emotional, psychological, family, physical and cognitive. Carers felt trapped in difficult situations and received no help. Their lives were stopped and their current lives were very difficult. Carers believed that no one cared about them and that the future would bring more difficulties.

8.31 Reflections

These are the reflections of the researcher on issues that emerged from the findings.

Power

Everyone thought that others had all the power. The people with schizophrenia thought that the carers and health professionals had all the power. The carers thought that the sick relatives and health professionals had all the power. Everyone felt disempowered.

‘Playing the game’

Two participants with schizophrenia reported ‘playing the game’. They did not agree with the diagnosis, but sought support and successfully demanded interviews with their social workers, often with no previous appointments. They claimed these interviews were for the purpose of research, as part of a course they were studying, of which the social workers and others were unaware. Some went to the hospital with life problems and asked the nurses to deal with them. They appeared to accept patient status, but they didn’t really accept it and they tried to gain some advantage out of a disadvantaged situation. It appeared that accepting patient status could relieve them of the responsibility of resolving the life problem.

Medicalising oneself

Some participants with schizophrenia spoke of themselves in the same terms as health professionals did, describing themselves as paranoid schizophrenic, thus appearing to accept the diagnosis of schizophrenia and a negative evaluation of themselves. [This was the researcher’s interpretation]. Some were conscious that they did this, because they reported it, and others seemed to be unaware of this behaviour.

Drug induced psychosis

Only the young men with schizophrenia reported being asked if they had taken drugs. There appeared to be an assumption by health professionals that only younger people with schizophrenia used illicit drugs.

Shame

Most participants with schizophrenia reported feeling ashamed of having schizophrenia. The few who did not report shame as an overriding concern were seeing frightening visions and hearing frightening voices, and appeared to be too distressed to worry much about social shame, while the others had less severe symptoms and could consider their lives in a wider social context.

Shame was also experienced by carers. Family members (including children) felt that others judged them negatively because of the presence of the relative with schizophrenia.

Forgiveness

Many participants with schizophrenia felt very aggrieved at the perceived malicious behaviours of others, yet were willing to forgive others.

Excessive gratitude

All these participants appeared to be very grateful that someone was taking an interest in their lives. They gave the impression that no one had wanted to listen before these interviews.

Boundaries

There was one occasion in these interviews when the boundaries between researcher and mental health nurse were blurred. One woman was distressed, spoke of wanting to die and appeared to be hallucinating, so that I thought I might have to contact the local CPN service. The interview was stopped once because of the obvious distress. However the unqualified social services carer visited at the end of the interview and the woman seemed less distressed. I was therefore able to maintain my researcher status and not change anything about this woman's behaviour.

Reading about schizophrenia

Some participants with schizophrenia read about schizophrenia (e.g. *The Divided Self* and other books intended for health professionals, which discussed theories of schizophrenia) in an effort to understand what was happening to them. For a few, this helped them to move on and cope but for most it did not help them to move on. I believe some gained some comfort from reading *The Divided Self* (Laing 1960), and perhaps gained a validation of their own views.

It is a spiritual experience

Some participants with schizophrenia reported the perceptions of seeing visions and hearing voices as spiritual experiences. Some refused to believe that they were ill and placed a spiritual interpretation on their experiences. One spoke of demonic activity in his mind, which made him feel bad, and another spoke of astral flying, which made him feel good. The conventional view of schizophrenia is likely to lead to such

interpretations being perceived as symptoms of schizophrenia. What is interesting here is that these interpretations of voices and visions did not protect the person from negative emotional, psychological and cognitive consequences, and to some extent they still believed that they were ill.

Abuse at home or a considered compromise?

Some participants with schizophrenia gave total control of their home and assets to a partner [not a family member], who then insisted that the person with schizophrenia return to the hospital to give them a break. One participant with schizophrenia appeared to experience anxiety that his partner would leave him, an anxiety which seemed to be based on partners leaving him in the past. The partner appeared to have more power within the relationship than the participant with schizophrenia. However, the partner was not interviewed. It may be that the person with schizophrenia was making a considered life choice, and that such a compromise was better than the partner leaving. I am unsure if these participants with schizophrenia were victims of abuse by the partner, a possible conventional view of people with schizophrenia as vulnerable and needing protection, or if these participants with schizophrenia were equal and willing partners in a domestic arrangement which involved compromise.

Abused carers

Carers appeared to perceive themselves as abused people, yet many chose to perpetuate their current situation. They were making a choice to continue caring, despite the difficulties. When carers described the behaviours of their relatives with schizophrenia,

they also described disempowerment and fear of the person with schizophrenia ruling the home.

Child carers

One fifteen year old girl was caring for a very distressed mother, who was diagnosed with schizophrenia and reported very frightening visions and voices at the time of interview. The child carer looked tired and depressed and had been the target of violence by her mother at the time of interview. The child carer received no support and did not seek it. She had not experienced a normal upbringing and had adopted the role of pseudo-parent to younger siblings and her ill mother. It may be that I underestimated the ability of this girl to cope with this situation.

Being careful with oneself

This was a strategy that participants with schizophrenia appeared to use to avoid stress. Many participants with schizophrenia highlighted the theme of being careful with themselves, an explanation of why they did not interact with others, and chose to remain alone at home, living a quiet life and avoiding any risk or stress. The author's own reflections on this are that perhaps as health professionals we are too enthusiastic in promoting social engagement for people with schizophrenia and should consider why they chose this behaviour. It appeared to be part of self-care, stress reduction and management.

Acceptance and moving on, questioning and being stopped

Acceptance was associated with moving on, yet this seemed, initially, an unlikely association. Some participants with schizophrenia were in the acceptance group, and in the National Schizophrenia Fellowship, and did not question the diagnosis of schizophrenia, yet had moved on in their lives. It may be that they accepted the diagnosis, focused on living their lives despite it, focused on bettering the lot of others with schizophrenia and had a purpose in life. They did not appear to perceive schizophrenia as a disability or barrier to achievement in life, and appeared to perceive it as a health problem to be managed. One possibility is that, by accepting the diagnosis, they gained support from all formal and informal agencies and therefore were able, in their perceptions, to move on in their lives. Perhaps accepting the diagnosis had some personal survival benefit for some.

Some participants with schizophrenia questioned the validity of the diagnosis, treatments and legislation, and yet were stopped in life. It appears that, for some, questioning, at an intellectual level, was not enough, without the confidence or determination to make a decision to move on in life regardless of what others thought. Questioning may be a first step, but alone, it did not lead to self-empowerment or change for some. The second step appeared to be making the decision to move on in life, leaving the past behind.

Questioning and moving on

Of the *moving on* group, four were in the *questioning* group. Questioning appeared to be associated with moving on in some participants with schizophrenia. Questioning

appeared to help a person to retain a normal identity and may have offered some protection from the imposition of a flawed negative identity. Questioning may have prevented a participant from living their life as a sick person, or a life in which the diagnosis of schizophrenia is the central focus. There may have been personal survival benefits in having a questioning attitude. Questioning, however, was likely to be perceived by health professionals as lack of insight, potential non-compliance and a problem. It may therefore have been discouraged.

What processes have shaped people with schizophrenia?

External and internal processes may have shaped these participants with schizophrenia. It may be that exposure to mental health services created people who displayed passivity and dependency. It may be that practices at the time of the diagnosis led to them accepting the diagnosis and the new sick identity, and also that they could not work, and should seek support. Living with a family member who believed that the person with schizophrenia was ill may have made it impossible for the person with schizophrenia to consider any other perception of themselves. It may be that if you live long enough with a diagnosis, and enough people tell you that you are ill, you accept it, become passive and acquiescent.

Participants with schizophrenia who chose isolation questioned the diagnosis, treatment, and roles of health professionals. By living with schizophrenia for a shorter time, being diagnosed younger and more recently (because they are younger currently), and possibly being less exposed to the mental health system, they may not have been exposed to the same processes as those who displayed acceptance. Living alone may

have allowed them freedom to define themselves as people who were not ill. The resilience of youth may have been a factor in helping them to question the diagnosis.

Anger, choosing isolation and moving on

Anger appeared to help some participants to move on, yet anger was likely to be perceived as part of schizophrenia by health professionals who may wish to diminish or treat anger (e.g. medication and anger management groups). Some of the *moved on* group were angry about the diagnosis and disagreed with it. They were angry about other issues: coercion involved in medication, stigma associated with schizophrenia, and other peoples' behaviours. Some participants were involved in violent incidents in hospital, after refusing medication. Anger appeared to help some participants to question the diagnosis, and refute perceptions of themselves as sick people. When anger was combined with choosing isolation and avoiding health professionals, this appeared to facilitate moving on.

Pleasant visions and voices

It may be assumed by health professionals that visions and voices must be unpleasant and distressing, and treatment must be given to reduce or eliminate them. However, in this study, it became clear that in some participants with schizophrenia, this is not the case and they avoid or misinform health professionals because they do not want their visions and voices eliminated. It may be that health professionals enter into interactions with such people in a potentially insensitive manner.

8.32 New and original findings

The researcher accessed a population of people with a diagnosis of schizophrenia, who were not in touch either with health services or user groups, and who appeared to cope with life and their experiences of visions and voices. The research achieved a fresh perspective on the behaviours of people with schizophrenia. Insights have been gained into the responses of participants with schizophrenia who were informed that they had a diagnosis of schizophrenia, yet chose to avoid health professionals and who believed that they were not ill. They defined themselves as well and their lives as successful. They used their human agency and rejected the sick identity, which, in their view, was being imposed on them by others. In this research, the participants responded in their own words and within their own frame of reference. Their responses were based on their subjective perception of their lives and experiences. This involved maintaining a positive self-concept and rejecting the idea of the experience of visions and voices as being part of mental illness. Carers were critical of nursing interventions because their ideas about recovery from schizophrenia were different from those of nurses.

The findings were related to theoretical perspectives, specifically: psychology, with related concepts of humanism and self-concept; sociology and the related concepts of labelling theory, stigma, social constructionism, self-formation, medicalisation, the Panopticon, the clinical gaze; nursing theory and types of care; theories of schizophrenia and the related concepts of stress vulnerability theory and high expressed emotion.

Thus, the research has made a synthesis that has not been made before. Findings have been derived from theory, and findings have not been imitated or translated. Known

material has been presented but with a new interpretation (e.g. around the presentation of human agency).

The findings have analytical significance. Peoples' behaviour can be understood better. Some participants did not accept the diagnosis of schizophrenia, chose isolation and disengagement from mental health services. Social avoidance was a consequence of other peoples' behaviours, not a symptom of illness. In other participants with schizophrenia there was some ambivalence about whether they were ill or not ill, and this ambivalence appeared to be influenced by an inability to consistently believe that they were well, normal people. These participants had lived with the experience of schizophrenia for many years, appeared to have become dependent, appeared afraid to risk losing the support of the health services, appeared anxious about being alone and so appeared unable to move on in life.

The findings have practical significance. Health professionals need to alter practice and perceptions of people with a diagnosis of schizophrenia and their behaviours. Specifically, we must accept what people with schizophrenia tell us and what they think they need. The current research has studied processes as well as outcomes, meanings and potential causes of health outcomes. The processes involved in becoming a person with schizophrenia were explored - specifically, external processes (e.g. medicalisation, coercion, and social culturalisation) and internal processes, (e.g. self-formation, acceptance of the diagnosis and of treatment, negotiation of treatment, internalisation of new identity and believing one was ill, integration of new public identity into one's life and joining a user group). The positive and negative meanings of being a person with schizophrenia, of being unemployed or disabled, and of having visions and voices were explored. The current research explored themes which are currently being discussed in

public policy documents - specifically, social exclusion of people with schizophrenia (Laurance 2002, DoH 2001, ODPM 2004), recovery (DoH 2001), stigma attached to schizophrenia, (DoH 2001, Laurance 2002, ODPM 2004), carer burden and lack of support for carers (DoH 2002).

New and original findings, major trends and minority findings which emerged from participants (people with schizophrenia and their carers) are summarised below.

8.32.1 Major trends: participants with schizophrenia

These are major trends in these findings. Participants with schizophrenia appeared to understand the implications of their new negative identity, and it was associated with further mental health problems and distress (e.g. depression). A potential implication of this is that depression may be mistaken for a symptom of schizophrenia (e.g. social withdrawal or apathy). This finding is important because it is often considered that the presence of schizophrenia is responsible for people with schizophrenia failing to make a recovery or achieve life goals. The presence of depression may lead to this situation. However, depression may be the consequence of the new negative identity, and the health professional's response to depression may be inappropriate.

According to most participants' accounts, the responses of society and other people caused more distress than the experience of schizophrenia (e.g. hearing voices). This is important because when mental health professionals meet a person with schizophrenia who appears distressed, they may assume that the experience of schizophrenia is causing the distress and focus on this. This may be an insensitive and inappropriate response which does not meet the needs of people with schizophrenia.

Participants with schizophrenia reported that nurses were not interested in their visions or voices and actively discouraged people with schizophrenia from talking about these. This raises the issue of how nurses can assess or help a person with schizophrenia if they refuse to acknowledge these inner experiences or listen to what people with schizophrenia are concerned about. This is important because nursing involves engaging with, and focusing on, the concerns of clients. Home treatment was reported as very good and empowering because people felt that nurses listened to them. A related finding is that participants with schizophrenia did not receive sufficient or appropriate care, as they defined and perceived care. Participants with schizophrenia and nurses appeared to have different perceptions of good and appropriate care. Likewise participants with schizophrenia and their carers appeared to have different perceptions of good and appropriate care. This lack of a shared perception and common ground is important because the different perceptions of care were associated with non-compliance on the part of participants with schizophrenia.

Choosing isolation and not seeking help appeared to be associated with living with schizophrenia for 20 years and above. This may be a new perspective on the issue of client disengagement with services. Participants who chose isolation were likely to have been perceived as clients who refused to engage with services. It may have been the case that participants with schizophrenia sought support, perceived the support to be unhelpful, inappropriate or insensitive, and then developed coping and life management strategies of their own, which were effective (e.g. avoiding other people with the goal of reducing stress). An implication is that an increased awareness of why people with schizophrenia choose isolation may help nurses to work with them.

Moving on in life after the diagnosis of schizophrenia appeared to be associated with being under 24 years old at the time of diagnosis, living with schizophrenia for 20 years and below and having less contact with mental health services. This may indicate that hospitals were unhelpful for some participants with schizophrenia.

Moving on was also associated with a positive self-image and blaming others. Blaming others was likely to be perceived as 'paranoia' by health professionals, and the participant with schizophrenia was likely to receive treatment and be discouraged from blaming others. In this way, the responses of health professionals may have unintentionally created a situation whereby participants with schizophrenia could not move on in life.

There appeared to be an association between not moving on in life and being diagnosed at 23 years of age and above, living with schizophrenia for 20 years or more, and having many admissions into hospital. It was also associated with having the belief that schizophrenia had an internal cause and that they were ill, suggesting that some participants with schizophrenia had no perception of their own agency and therefore did not move on in life.

8.32.2 Minority findings: participants with schizophrenia

Youth appeared to be an important factor in moving on in life. This finding is important because in the past it has been accepted by health professionals that being diagnosed when older leads to a better prognosis. However younger participants, who had lived with schizophrenia for 10 years and below reported the best outcomes, which were a positive self-concept, no passivity at any time, employment, and a return to their old life

even though this was not without difficulties. This is important for nursing practice. An implication of this is that focusing on the needs of younger people with schizophrenia and implementing sensitive, empowering and appropriate interventions may reduce the probability of disability and negative outcomes for people with schizophrenia.

Some participants with schizophrenia expressed the view that receiving Disability Living Allowance would resolve many of their current problems, but when they received it their problems were not solved. These participants were still very depressed and isolated. This finding indicated that psychological, emotional, cognitive and social factors influenced and affected them more severely than financial problems. This finding is important because people with schizophrenia are considered by the mental health system and society as disabled. There is a general acceptance that Disability Living Allowance improves the quality of a disabled person's life. However these findings indicate that this may not occur and that other interventions are required.

8.32.3 Dichotomies: participants with schizophrenia

A new finding was the different responses to male and female participants with schizophrenia. According to their accounts, male participants were rejected by their families and lived alone, while female participants were accepted and supported by their families and lived at home. This has implications for care and outcomes for men with schizophrenia. Men with schizophrenia may have poorer outcomes and require hospitalisation more frequently because of their isolation and lack of support. Female respondents with schizophrenia reported that they believed that they were a burden to their families. The implications of this may be increased stress within family

relationships and potential for high expressed emotion, which in turn are likely to lead to negative outcomes and reduced quality of life for women with schizophrenia and their carers.

8.32.4 Major trends: carers

There were major trends in the findings reported by carers. Whole family stigma and a strong sense of a flawed identity were reported by carers. This appeared to be part of their subjective burden. According to their accounts, carers believed that they and their families were not normal, because of the presence of the relative with schizophrenia, leaving these carers stressed and depressed. Extended families rejected the nuclear family with the sick relative, leaving these carers feeling unsupported and rejected. This is an important finding because it suggests that families may lack the emotional and psychological resources to adequately support their relative with schizophrenia, a situation which may lead to relapse in the person with schizophrenia and poor health in their carers. The negative effect of family stigma may not be sufficiently appreciated or understood by mental health professionals.

8.32.5 Minority findings: carers

The negative impact of caregiving on carers was evident in the finding that parents remained depressed long after their offspring with schizophrenia made a recovery and left the family home. However, it might be assumed by health professionals that once the person with schizophrenia has made a recovery, or has left the family home carers do not need support. There might be insufficient appreciation by mental health professionals of the nature of carers' subjective burden.

Younger carers reported that they did not accept the caregiver role unquestioningly. Those who had cared for their relative with schizophrenia for a short time reported that they were afraid of their relative, and likewise did not accept the caregiver role unquestioningly. This may indicate a new, different attitude amongst these carers, and possibly less willingness to be a carer, or perhaps an adjustment process exists, which these carers may not have undergone.

The child carer did not receive or seek help, worried about genetic inheritance and intended to leave home as soon as possible. She believed that her mother was ill and that she herself was perceived as abnormal by others, because of her ill mother. It may be the case that health professionals were unaware of this child carer's care-giving role. This is important because there may be a general lack of awareness of the number of child carers who are caring for their ill parents, and the stresses that care-giving creates for these child carers.

Some female carers reported that they went to a carers' support meeting and found it unhelpful and depressing and did not attend again. The current trend is to encourage carers to seek support in carer support groups. This finding disputes the benefits of carer support groups.

8.32.6 Dichotomies: carers

According to their accounts, male carers appeared to receive a less supportive response from family members and health professionals than female carers. Extended families blamed male carers, but did not blame female carers. This finding may be related to an accepted assumption that carers are more likely to be female, an assumption which is supported by research. However, it is an important finding because it suggests an

insufficient understanding of the needs and burden of male carers, and the potential negative consequences (e.g. compromising of their continued ability to cope with care-giving, and poor health). It may be that male carers require a supportive response which is different from that given to female carers.

LIVING WITH SCHIZOPHRENIA

A phenomenological study of people with schizophrenia living in the community

Volume 2

Joanne HARRISON BSc

submitted for the degree of Doctor of Philosophy

Division of Nursing

University of Bradford.

2008

CHAPTER NINE:

DISCUSSION AND CONCLUSIONS

This chapter will present a verification of theoretical systems, analysis of findings, discussion of the findings related to literature, discussion of findings related to the literature and the implications of these findings. In addition, a summary of the main findings and important outliers, recommendations and conclusions are presented.

9.1 Verification of theoretical systems

A verification of the theoretical system is now presented. The theoretical and conceptual framework offered by Frankfort-Nachmias and Nachmias (1996:38-40) proved helpful in linking statements from the literature review to the empirical findings and analysing these findings. The theoretical system can be accepted if its propositions can be empirically verified. The conceptual framework lies within the theoretical system, and involves descriptive categories/taxonomies, which are placed within a framework of explicit propositions which can be empirically verified. There is an explanation or prediction, or empirical observation and evidence for this. An example is included below.

Theoretical system: Social constructionism, (main proponent: Foucault)

Conceptual framework: medicalisation of people with schizophrenia, docile bodies

Structure of assumed propositions:

1. People have to accept the diagnosis of schizophrenia which is assigned to them by medical experts and is based on medical knowledge and categories.
2. Medicalisation does not permit people to reject the diagnosis, and people are oppressed.

3. People who are medicalised are docile bodies.

Explanation or prediction, and empirical observation or evidence for this: The term ‘medicalised’ was used and the process was described. Participants reported that their lives had been stopped by this process.

9.1.1 Analysis of findings reported by participants with schizophrenia.

Acceptance and questioning of the diagnosis and treatment

Of the participants with schizophrenia, most displayed or reported acceptance. Some questioned everything and some reported both acceptance and questioning. This ambivalent position occurred frequently in the current study. Only a few participants questioned, showing no ambivalence. Those in a user support group displayed acceptance (Appendix 13).

Acceptance and compliance may be explained by social constructionism and the specific concept of self-formation, wherein people accept known medical knowledge and diagnosis. People choose to transform themselves into a well person and people accept care and treatment with this goal in mind. There was empirical observation or evidence for this. Some participants reported that they complied because it was expected of them. Coercion was not necessary. They gained some benefit from this behaviour (e.g. support, better health).

A possible explanation may be found in structuration theory and the concept of complementarity. People who are diagnosed accept and use the external structures and systems. These structures and systems shape and create people with schizophrenia.

People with schizophrenia become dependent on these structures and systems. This appeared to be the case with some of these participants.

Some participants questioned the diagnosis and need for treatment. Most of them had lived with schizophrenia for a short time, were employed and lived alone. A possible explanation may be that those who live with schizophrenia for a shorter time and choose isolation are less likely to be influenced by others' perceptions of them and are less likely to define themselves as mentally ill. By being in employment and living alone, one consequence was they had no family at home to define them as mentally ill every day, and so could question the diagnosis and move on in life within their own frame of reference, and define themselves as well people.

A possible explanation for questioning may be found in the main idea within social constructionism, which is that all medical and psychiatric categories are socially constructed. Schizophrenia may be considered a socially constructed category. These participants rejected the validity or truth of that category. They did not want treatment. They considered themselves to be well and coped well with their personal experiences of visions and voices without professional help.

Moving on and being stopped

The *moved on* group reported a more positive self-concept, independence, blamed others, chose isolation, viewed themselves as rational, rejected the sick role and sick identity, and had self-belief (Appendix 14). A possible hypothesis and explanation is that being diagnosed younger was associated with moving on because there was less loss in this group. It may be that living with schizophrenia for a short time was

associated with moving on because these respondents did not lose their self-belief, or that treatment was timely and appropriate and led to recovery. This second potential explanation was not reported in the findings.

Being in a support group was associated with moving on, possibly because the support group promoted positive self-belief. A possible explanation for this positive self-belief may lie in the respondents' coping strategy. They joined a user group, integrated their diagnosis into an altered public identity, and adapted their style of living or adjustment. The consequence was that they maintained or increased their positive perception of themselves. They normalised their positive identity and self-worth. This process was clear from the findings.

Another possible explanation from psychological theory and humanism is that one's self-concept is influenced by the evaluation of others. Self-concept affects mental health and a positive self-concept leads to improved mental health and better coping skills. Some of those who had a positive self-concept rejected the idea that they were ill and chose isolation. They would therefore not be influenced by the negative perceptions of others. This was not explicitly reported in the findings by anyone but was implicit in the comments of those who had moved on.

A possible explanation for moving on is that individual human agency, a sociological concept, is present. People want an outcome, such as rights, power and control over their lives. People reject structures and systems and institutions as repressive and unhelpful. They resist being defined as mentally ill and develop new roles for themselves and new power relations between themselves and health professionals. Therefore by using individual agency, they may have resisted medicalisation and

retained some control over their lives. Within their own frame of reference they have moved on in their lives.

Another possible explanation for moving on is that some participants resisted medicalisation and challenged medical power, ideas which are present in social constructionism. People do not accept the expert knowledge, and at times they collude with and at other times challenge medical power and knowledge, and use their own subjugated knowledge. People negotiate treatment and support. Negotiating treatment was reported by some participants, and those in the user group challenged medical power and expert knowledge.

Some participants believed that their lives were stopped by the diagnosis of schizophrenia. A possible explanation for this may be that they had become dependent. Dependency theory lies within sociological theory. People who become dependent may find it difficult to envisage a life without support. If people have a diagnosis, they are entitled to support from health professionals, although lack of support was a common finding. It may also be the case that there are degrees of medicalisation and people cannot fully reject the diagnosis.

The psychological concept of learned helplessness may explain why some people believed their lives were stopped. People are informed that they have schizophrenia and need help and treatment. They accept this as a fact and stop solving their own life problems. They learn to depend on health professionals and others to solve all their problems. They accept the sick role, another sociological concept, and live their lives as sick people.

Social learning theory, a psychological theory, may explain why participants believed their lives were stopped. People are diagnosed with schizophrenia, and expert knowledge affirms and reinforces the idea that a person with schizophrenia is ill and cannot cope. Consequently people with schizophrenia believe this and learn to live their lives as sick people.

Within social constructionism, medicalisation is discussed, and this may explain why some people believe their lives have been stopped. Through oppression, medicalisation does not permit people to reject the diagnosis, which is assigned to them by experts and is based on expert knowledge. People who are medicalised are docile bodies. This process is referred to in the findings and it appears that some participants' lives have been stopped by this process.

Another possible explanation for their believing that their lives were stopped is that prolonged exposure to the mental health system led to participants believing that they were ill and needed help. It may be that exposure to the mental health system caused more problems than the schizophrenia, or they had been more ill than the moved on group. Clinical iatrogenesis, a concept from sociology, may explain this finding. According to this account, the mental health system identifies and diagnoses people, and in its interventions, unintentionally causes more harm to people than the original diagnosis or health problem. Being diagnosed when older was associated with being stopped, and this may be because there was more perceived loss, which people did not recover from.

Another possible explanation for believing that their lives have been stopped by schizophrenia is cultural bias, a sociological concept. People with a diagnosis of

schizophrenia are likely to internalise cultural norms and rules and have a shared understanding of mental illness. This leads them to accept the validity of the diagnosis and they will not question the need for treatment or their status as a sick person.

Acceptance of theories and models of health may explain why some participants believed that their lives had been stopped by schizophrenia. Within the functional model of health proper functioning is related to good mental health. Good health involves normal daily and social functioning. A person with schizophrenia is likely to be perceived by themselves and others as ill and to be unable to function properly. The deficit model of health, which is strongly associated with the biomedical model of health and where a person's deficits are focused on, would have an equally negative impact. It is a dichotomous view of health and illness, or a view in which disease is defined as an absence of health. These participants would be considered to have an absence of mental health. Some participants reported that they believed this of themselves.

Labelling theory, a sociological concept, may explain why participants reported stopped lives. People are labelled as ill by a more dominant group (e.g. health professionals, experts). There is shared knowledge in society and people have no defence against labelling, and accept and internalise the label (e.g. mentally ill, schizophrenic) with all its connotations (e.g. people with schizophrenia are not normal, well or rational). The lives of those labelled now change. They are given a devalued status and accept this. This was reported in the findings.

Theories of power and the concept of expert power may explain the theme of a stopped life. Expert power contributes to defining people with schizophrenia. They are defined

as ill and in need of help and treatment. This leads to practices which can disempower a person with a diagnosis of schizophrenia, and which remove control over ones life. This leads to feelings of disempowerment, and even victimhood, and people may feel that their life has been stopped by this process.

Gender

Men with schizophrenia reported different issues from women. In the current study, men both reported living alone and living with schizophrenia for a shorter time than women with schizophrenia, and they also reported that they sought support. A possible explanation for this is the perception of men with schizophrenia. It may be that they are perceived as aggressive and risky to others. This perception is evident in the carer findings, when female carers reported that they were afraid of their male relatives with schizophrenia and were prepared to make them leave the family home.

In this study being female was associated with choosing isolation (Appendices 15 and 17). A possible explanation for this is the perception of women with schizophrenia. It may be that women are perceived as needy and vulnerable and a risk to themselves. It is evident in the carer findings that carers accepted their female relatives with schizophrenia at home, and actively encouraged them to remain in the family home. Therefore female participants appeared to have a different experience of living with schizophrenia from male participants.

Seeking support and choosing isolation

Seeking support was associated with living with schizophrenia for a shorter time than choosing isolation (Appendices 15-16). A possible explanation is that people who have

lived with schizophrenia for a shorter time have been rejected by their families and have not had a long enough period to adjust to their new situation of living with schizophrenia.

Those who chose isolation had lived with schizophrenia for longer than the *seek support* group. These participants may have adjusted to their situation or had their own coping strategies (Appendices 17-18). If people believe they are well, are content with their lives, are not depressed, have had time to develop coping strategies, have adjusted to their schizophrenia, do not need or want health professional support, and want privacy from others and autonomy in their lives, they may not seek support.

Being event led

Some participants were event led. When negative events occurred in their lives they were severely affected. The *event led* group were diagnosed when older and may have had more loss than those who were not event led (Appendix 21). Negative external events were present in their lives, but internal factors, for example, loss of a positive self-concept, may have contributed to this finding. Humanism and the psychological concept of self-concept may explain this. The development of a negative self-concept may lead to depression and loss of confidence in other areas of life, specifically solving life problems. Once a person believes that he or she has schizophrenia, there may be a reduction in their self-confidence and any negative life event may overwhelm them.

Cognitive behavioural therapy may also offer an explanation of why some participants were unable to rise above events. Peoples' self-defeating thoughts prevent them from solving their life problems because they develop feelings of hopelessness. They believe

they have no power to influence anything. Another possible explanation is that if a person is diagnosed when older, there is an experience of more severe loss, or a perception of more severe loss, which may lead to depression and feelings of hopelessness. Life events now may overwhelm them.

Being belief led

Most participants with schizophrenia believed they were ill, could not cope and needed help and support from others. They believed that they were not normal (Appendix 14, 18, 21, 24). A possible explanation may be that if a person accepts the diagnosis of schizophrenia, then they develop negative beliefs about themselves and develop a spoiled identity. Both these factors may occur at the same time. Spoiled identity is a sociological concept, in which people are identified as different, defined as mentally ill and assigned a lower value than others. People often accept a spoiled identity in which they believe they are not normal and they need help.

Sociology and the concept of deviancy may offer an explanation. People are defined as deviant. People with schizophrenia could be perceived as deviant, because most people do not have this diagnosis. In secondary deviance people accept a negative evaluation of themselves. Such a negative evaluation could lead to feelings of hopelessness and depression and an inability to cope with negative life events and inhibit problem solving.

9.1.2 Links between factors

The data suggest that current accepted knowledge was linked to flawed identity and involved labelling of people with schizophrenia. Labelling led to negative assumptions about participants with schizophrenia. Assumptions influenced other peoples' perceptions of participants with schizophrenia. Assumptions influenced interactions which led to negative consequences. The negative consequences led to stress. Stress led to strategies including self-exclusion, choosing isolation or seeking support.

The data suggest that current accepted knowledge was linked to beliefs about rationality and participants with schizophrenia were seen as irrational. The consequences of being perceived as irrational were loss of control, power and credibility. This loss of power in turn led to coercion and unfair treatment by others. The coercion led to enforced dependency and removal of choice and autonomy. The data suggest that labelling led to either acceptance or questioning, and both these led to a spoiled identity. People were afraid of participants with schizophrenia and displayed negative responses to them - a situation which caused more stress.

The data suggest that labelling led to medicalisation of all behaviours and views. Medicalisation led to trivialisation and devaluation of participants with schizophrenia and their views. Participants with schizophrenia now felt unsupported, punished, ignored and uncared for. Other peoples' reactions were influenced by their perception of participants with schizophrenia. These perceptions were related to high expressed emotion and stress within families. Society excluded participants with schizophrenia and did not support families. This situation increased the family stress burden, and care burden, and led to increased loss. The data suggest that expert knowledge led to a

flawed identity for participants with schizophrenia, which led to negative social, psychological and cognitive consequences. Labelling led to negative assumptions and ideas about irrationality, which led to decisions being made without the involvement of the participants with schizophrenia.

9.1.3 Carers' views

Gender

Female carers cared for male and female relatives with schizophrenia. Female carers highlighted issues that male carers did not. Female carers expressed severe anxiety and fear of their male relative with schizophrenia. High expressed emotion, an interactionist concept, may explain this. The family caregiver may be so concerned for the person with schizophrenia, that they engage in emotional over-involvement (EOI), one element of high expressed emotion. This is intrusive and the intrusion leads to an aggressive reaction, which in turn leads to more fear in the carers and more EOI. It may be that care burden leads to stress, and stress leads to high expressed emotion, which leads to more conflict, anxiety and attempts to control the person with schizophrenia. Carers may hold the person with schizophrenia responsible for the stress in the home and this blaming may lead to an aggressive reaction by the person with schizophrenia. Perceptions of men with schizophrenia as a risk to others may also account for the fear and anxiety in these female carers.

Carers spoke of the whole family feeling ashamed, having a spoiled identity, and of being stigmatised. This may be explained by the sociological concepts of spoiled identity and stigma. Carers cared for the sick relative at home. Others knew about the

presence of the sick relative at home and shunned the carers. Stigma and spoiled identity are assigned to the person with the schizophrenia and the other family members.

Male carers all cared for female relatives. Some male carers reported that they were blamed by the extended family for causing or contributing to their relatives' schizophrenia. It is possible that high expressed emotion may explain this blaming behaviour by the extended family. Instead of blaming the female relative with schizophrenia, they blame the male carers. The extended family is stressed and feels ashamed and stigmatised at having a member with schizophrenia, and needs someone to blame. The male carers were angry with the extended family and blamed them for lack of support. This may be another type of high expressed emotion, and of behaviours which indicate that a family is not coping. Therefore female and male carers appeared to have slightly different experiences.

Acceptance and carers

Most carers reported acceptance of the diagnosis and of their role in care-giving at home. The theory of loss and the concept of general adaptation syndrome may offer an explanation for this. Carers undergo a process of loss, which is similar to that in bereavement. Carers try to care for the sick relative. The relative is perceived to have been replaced by someone different. The carer feels bereaved and suffers loss. Eventually the carer accepts the person as they are now and this acceptance leads to reduced distress and acceptance. Acceptance was reported but reduced distress was not reported by these carers.

Carers who questioned

Most carers questioned aspects of the experience of caring for someone with schizophrenia, but they did not question the validity of the diagnosis of schizophrenia. They questioned the reality of community care, the effectiveness of treatment and the abilities of health professionals. They were very dissatisfied with the responses of health professionals. An explanation may be that they had their own ideas about health, what good health is, and an expectation that health professionals could help their sick relative to achieve good health. Carers strongly believed in the biomedical model of health. They believed that their relative was very ill, and wanted them to be better and normal, which for them meant an absence of symptoms. Carers were angry and sad that this could not be achieved. It is likely that the health professionals involved were working to a different model of health (e.g. the social model of health). Carers disagreed with health professionals about ideas of normality, rationality, treatment and treatment goals.

Carers who seek support

Most carers in this study sought support. The only exception was the child carer. These carers spoke of their own poor health and stress. A possible explanation is that care burden led to poor health (e.g. depression and stress) in these carers, who then contacted health professionals for help with their own health problems, which was directly influenced by their sick relatives' schizophrenia. Most carers felt obliged to care for their relative, and that they had no time for themselves. This may be explained by the sociological concept of a restricted life. The carer cannot maintain their normal social contacts, because of the continuous care burden. The restricted life leads to loss of

social support, isolation and this leads to poor mental health for the carers (e.g. depression) and less effective coping with the care burden.

Age of carers

A few carers over the age of 60 years made statements which other younger carers did not. They felt they had a positive identity and had come to terms with living with their relative. They perceived that things could not get any worse. A possible explanation may be offered by coping theory and the concept of adaptive tolerance and adjustment. Carers live with and care for the person with schizophrenia. Carers adapt to the need and patterns of the person with schizophrenia and this leads to reduced subjective burden. Therefore, adaptive tolerance leads to better coping by the carer and reduced stress. These older carers have had many years to develop this adaptive tolerance, although they reported stress and subjective and objective burden.

The child carer reported different findings from those of the adult carers. She did not try to control her mother and did not fit her life around her mother's illness. There was no positive past, prior to the schizophrenia, because she was born into the situation. Her life was not devastated, although it was hard. An explanation may be that stress inoculation led to the child carer coping with care-giving. The care-giving situation was all she knew, therefore she may have become immune to the stress of the situation to some degree. She may have become resilient. She may have paid attention to her own needs and at times disengaged from her parent. She may have engaged in problem focused coping by managing daily problems. Her subjective burden appeared to be less severe than that of the adult carers.

Length of time caring for their relative

A few female carers had cared for their relative for 10 years and below, and they reported fear of their relative. They did not feel safe with them and were prepared to be separated from them. They were all female, two mothers and a child carer. There may be a new attitude developing in society currently, with fewer people being willing to accept the carer role and willing to work through and live with the associated problems. Coping theory and the concept of adaptive tolerance offers an explanation. Carers adapt to the needs and patterns of the person with schizophrenia. There is reduced subjective burden, although the objective burden may be significant. This adaptive tolerance leads to better coping with care burden. It may be that these carers have not had time to develop adaptive tolerance.

9.1.4 Links between issues reported by carers

There were some clear links between themes in these findings. Knowledge led to negative identity for carers and negative consequences. Negative identity led to stigma, shame and negative consequences within the family and these negative consequences reinforced the negative identity. The data suggests that carers' fear and anxiety appeared to be related to controlling care of the relative with schizophrenia, which seemed to cause stress and conflict in the family. Blame and control were linked because carers thought that others had all the control and power and blamed others for not using that power to help them.

9.2 Discussion of findings related to the literature

In this section a range of themes are discussed. Empowerment and partnership, hallucinations and delusions as part of normal variation and trauma, and stress as contributing factors in the onset of schizophrenia are discussed. In addition, Bowlby's (1977, 1979) attachment theory as an explanation for vulnerability to schizophrenia and attribution styles of people with schizophrenia, and high expressed emotion are examined. Adaptation to voices, outcomes and recovery, social constructionism and labelling, exclusion, identity and stigma are discussed. High expressed emotion and the Camberwell Family Interview (Vaughn and Leff 1976), care and carer burden are examined. The philosophy of research and methodological issues are discussed, with specific attention being given to trustworthiness (Lincoln and Guba 1985), external validity, representativeness, objectivity and research bias and the ethical issue of harm to participants.

9.2.1 Empowerment and partnership

In this section empowerment and partnership are discussed. All participants with schizophrenia and carers felt disempowered, and believed that they had no control, giving some credence to the views of Nocon and Qureshi (1996), Coleman (1997:1999), Chadwick (1997), Campbell (1997), Campbell and Lindow (1997), Ross (1998), Hickey and Kipping (1998), Moorey (1998), Morrall (1998b) Patel and Fatimilehin (1999), Barker (1999), Hanily (1999), Doyle (1999), Sharkey (1999) who maintain that there is no partnership of empowerment, and Morrall (1998a), Ryles (1999) and Bertram and Stickley (2005) (empirical research) who reported that health professionals disempower mental health service users.

Aspects of professionalism may explain the reported lack of empowerment by mental health nurses in the current study. It may be the case that the lack of power sharing and empowerment is intentional. Health professionals may perceive that their expertise and power are under threat. Genuine involvement of mental health service users, a prerequisite for empowerment, may not be present (Campbell and Lindow 1997). The consumerist approach, in which mental health service users decide and define outcomes, may not be a reality. Health professionals may not perceive mental health service users as citizen-consumers. The implications of being a consumer are that individuals should take part in policy making, define and decide outcomes of care and have full autonomy (Nocon and Qureshi 1996). A citizen has active agency, a sociological concept, and the current mental health legislation may prevent active agency by creating a mental health system where the lives of mental health service users are controlled by health professionals. It may be the case that mental health nurses do not engage in enablement of mental health service users, which would be a developmental activity. Professional barriers to empowerment may be paternalism, emphasis on duty of care which may lead to loss of autonomy and choice for the service user, and the public protection role of mental health nurses, which may lead to service users' rights becoming secondary to the rights of the public (Bertam and Stickley 2005).

Acceptance of particular models of health by society and health professionals may contribute to lack of empowerment. The functional model of health contains assumptions about individuals with a diagnosis of schizophrenia. Proper social functioning is related to good mental health. Good mental health involves effective normal daily and social functioning. Therefore if an individual has a diagnosis of schizophrenia they cannot function properly (Barrowclough and Tarrier 1997). There was support for this view in the current study. Some participants with schizophrenia

reported that they wanted help with their social functioning and most carers held the view that their relative with schizophrenia had poor social functioning. It is possible that nursing continues to focus on the deficit model of health, with the emphasis on mental health service users' deficiencies and problems, which are perceived to explain the mental health problem (Barrowclough and Tarrier 1997). The absence of a positive self-concept, increased self-esteem, self-efficacy and self-control may explain the lack of empowerment. These factors appear to be necessary for empowerment, and may not be facilitated by mental health nurses (Patel and Fatimilihen 1999). It is possible that dependency, a sociological concept, with the emphasis on compliance, not collaboration, is being promoted by mental health nurses (Barker 1999). It may be the case that structuration theory (Giddens 2001) and, specifically, the concept of human agency, explains the lack of empowerment. People and their human agency create external systems and structures. These systems and structures lead to outcomes (specifically control of people diagnosed with schizophrenia), and order is created. Individuals with the diagnosis of schizophrenia are controlled and disempowered. There was support in the current study for this position.

It may be the case that mental health nurses cannot empower mental health service users because nurses themselves are disempowered (Moran 1992, Pontin and Webb 1995, Rodwell 1996, Campbell and Lindow 1997, Keyzer 1988, Morrall 1998a, Ryles 1999, Moore and McCulloch 1999). Nurses may be disempowered for the following reasons. Medicine has controlled nursing roles and boundaries (Keyzer 1988, Morrall 1998a). Nursing is not an autonomous profession and nurses lack collective self-esteem and self-worth, and therefore cannot recognise the worth of others (Pontin and Webb 1995). There is no collective support of action to promote mental health service user empowerment. Nurses are trapped in a system of disciplinary power, are subject to the

same gaze as service users, and cannot challenge the status quo (Ryles 1999). Nurses are low in the hierarchy and are marginalised (Devane et al 1998, Ryles 1999). There is no managerial support for nurses to engage in empowerment of mental health service users (Moran 1992, Campbell and Lindow 1997, Moore and McCulloch 1999). There is a strong emphasis on risk assessment and management which may lead to disempowerment of mental health service users (Hanily 1999, Doyle 1999, Sharkey 1999).

It may be the case that participants reported lack of empowerment, yet may not have wanted empowerment. This may imply dependency, which Barker (1999) suggests is promoted, and which may occur through a process of social culturalisation into the role of a patient. Service users may be content to be a patient, with no active agency (Campbell and Lindow 1997, Hickey and Kipping 1998, Barker and Davidson 1998, Barker 1999). A similar theme is discussed in Crowe et al (2001), who consider the possibility that service users reported resenting lack of freedom while appearing to benefit from nursing care and protection offered, and relief from everyday responsibilities.

Structuration theory and the concept of complementarity may explain this finding (Giddens 2001). Individuals who are diagnosed as mentally ill may accept and collude in the creation of mental health systems and structures. Systems and structures shape and create these individuals, who become dependent on the systems and structures, and those who work within them.

Cultural bias, a sociological concept (Bilton et al 1996), may explain the lack of empowerment. There is an accepted, shared, knowledge about mental illness in all

sections of society. Individuals who are diagnosed as mentally ill accept the shared knowledge and internalise the cultural norms and rules. They accept the validity of the diagnosis of schizophrenia and do not question the diagnosis, their health status or the need for treatment.

This behaviour by a service user could also be perceived as compliance, supporting the position of Rose (1994:1999) who discusses Governmentality. He contends that all those who live in society benefit from compliance and from not resisting professional care. People accept monitoring of illness and promotion of health, though the social processes that exist within Governmentality. Individuals' subjectivity is shaped, and self-regulation, self-transformation and the desirable goal of good health are accepted by most individuals and society (Rose 1994:1999).

Some participants with schizophrenia in the *moved on* group reported that they had become empowered. Some of them felt this way because they had found employment or were studying and had regained their old life, while some were active in a user group. These findings appeared to support the views of Coleman (1999), who states that people can reclaim power and empower themselves. There appeared to be no support for the views of Rogers et al (1993), Benner (1994), Peplau (1994), Gournay (1995), and Barker (1999) who maintain that mental health nursing empowers people, or Pieranunzi (1997), Johansson and Lundman (2002), Pitt and Kilbride (2006), whose empirical research reported that mental health nursing empowers people.

Self-empowerment and factors involved in self-empowerment

Self-empowerment appeared to involve questioning the knowledge and practices of health professionals. Some participants with schizophrenia reported that they had put the past behind them, rejected the diagnosis and expressed anger. They blamed health professionals and maintained a strong self-belief. Some engaged in negotiation as individuals, while others negotiated as members of a user group. Therefore these findings appeared to support the views of Williams and Collins (1999), Coleman (1999) and Coleman and Smith (2005) who assert that people can take control, reclaim power and empower themselves, and Patel and Fatimilehin (1999), who propose that service users can empower themselves by taking the lead in collaboration with health professionals. The strategies of those in the user group appeared to support the views of Hugman (1991), who asserts that people can negotiate power, and Johnson (1997) who implies this in his concept of the social construction of power by the social judgment of people. He proposes that power is a socially constructed resource and that people have “living power” (Johnson 1997 p.110).

Structuration theory, and, specifically, the concept of human agency, may explain why some participants felt empowered (Giddens 2001). People diagnosed with a mental illness exercise human agency and create systems and structures. If these systems and structures do not lead to a satisfactory outcome for mental health service users, they may create new systems and structures. The rise of users’ groups has created new systems and structures which assist service users to empower themselves. It may be the case that these participants redefined themselves and their experiences and achieved a feeling of empowerment (Chadwick 1997, Williams and Collins 1999, Coleman 1999, Coleman and Smith 2005). These participants appeared to be active in their own

recovery, pursued their own personal goals and were connected to an accepting social group (Williams and Collins 1999). They appeared to rebuild themselves, their life and their social support, which involve active agency (Pitt and Kilbride 2006).

Negotiation of power involves human agency. It may be the case that negotiated power existed between these participants and health professionals. Some service users appear to be able to challenge professional power by joining self-help and user support groups and by not complying fully with treatment (Hugman 1991). Occupational power is derived from the social judgment of others (e.g. service users) and it is possible that these participants constructed power through dialogue and changing the social relations between them and health professionals (Johnson 1997).

Self-management of their schizophrenia and self-help appeared to have been achieved by some participants in the *moved on* group. They appeared to have higher self-esteem than those in the *stopped* group. Self-help may be good for individuals because self-help involves giving as well as receiving help. It is an active role and the individual feels socially useful and achieves positive feelings of increased status. Therefore positive psychological and social outcomes may be the result of being in a self-help group (Newell and Gournay 2003). Taking control of one's life and effective self-management may have led to positive psychological outcomes (Bury 1991). There was support in the current study for these views of Bury (1991) and Newell and Gournay (2003).

Psychological theory and positive self-concept, a concept within humanism (Rogers 1951, Haralambos and Holborn 2004), may explain this finding. The presence of a positive self-concept appeared to assist these participants to empower themselves. They

appeared to have a positive self-image and evaluated themselves positively, which may have led to a better recovery (Williams and Collins 1999). They did not perceive themselves as victims.

Self-empowerment appeared to have been achieved by those in the *moved on* group, supporting the work of Houghton (1982) who emphasises internal locus of control, and that self-empowerment involves self-managed care and leads to better recovery. These views were based on his personal experience. The point is supported by a National Schizophrenia Fellowship website (www.nsf.org.uk). There appeared to be a positive correlation between personal empowerment and good recovery, a point made by Beale and Lambric (1995), who offer no empirical evidence. In the current study, service users in the *moved on* group, perhaps using an internal locus of control, regained control of their lives and appeared to make a better recovery than those in the *stopped* group.

The views of those in the user group appeared to support the proposals of Ralph and Lambert (1996) who assert that internal strength, combined with the interconnectedness with others, provides self-help and advocacy. The participants who appeared to have achieved self-empowerment held strong views, had a positive self-concept and had the capacity to rise above difficult situations. Being connected to others appears to be an important factor in making a better recovery and becoming empowered (Ralph and Lambert 1996, Williams and Collins 1999, Pitt and Kilbride 2006).

9.2.2 Hallucinations and delusions as normal human variation

In this section, the position that hallucinations and delusions may be part of normal human variation is discussed. In the current research, some participants with

schizophrenia perceived their visions and voices as a spiritual or mystical event (e.g. astral flying), enjoyed the experience, and did not want it to be stopped by medication. They did not perceive themselves to be ill and were convinced of the objective reality of their experience. Their visions and voices seemed real to them, and one participant reported feeling very strong and powerful at the time of the visions and voices. Another participant reported that his voices advised him. This is consistent with the findings of Roberts (1991) and Van Os et al (2000), and Bentall's (2003) contention that hearing voices is part of human variation.

Bentall (2003) highlights the high levels of subjective well-being in people who have paranormal experiences, and Roberts (1991) reported perceptions of positive meanings and purpose in the lives of people with delusions. At the same time, it might be concluded that the individuals described by Bentall (2003) may be very different from this respondent group, because the hallucinations did not appear to co-exist with other life handicaps. Roberts (1991), in his study offered empirical evidence for this position. In the current study those who reported mystical or spiritual events and who did not want their visions and voices removed, all lived alone, and it may be that, as Bentall (2003) proposes, the presence of the voices reduce their feelings of isolation.

9.2.3 Trauma and stress as contributing factors in the onset of schizophrenia

None of the participants with schizophrenia identified a stimulus for the hallucinatory experience, but some carers identified stress, physical illness and major life change. Bentall (2003) explores the role of trauma in the development of psychosis and concludes that trauma, (e.g. sexual or physical abuse) appears to precede psychosis. He

cites Goodman et al's (1997) overview of research on this theme, the conclusions of which support this theory.

However, Goodman et al (1997) highlighted other explanations for the association between abuse and the onset of schizophrenia. Some women misused drugs, or early trauma interfered with the development of good interpersonal relationships and social adjustment. Both explanations are potential predictors of an outcome of schizophrenia. Therefore, the association between abuse and the onset of schizophrenia is unclear and complex.

Adverse life events were reported by 11 participants with schizophrenia in the current research. Sexual abuse, physical abuse, and bereavement in early adulthood were reported by a few participants with schizophrenia. Abuse as a young child was reported by a few participants with schizophrenia. The explanation for the resulting diagnosis of schizophrenia may be that the abuse led to trauma and stress, then stress led to the onset of schizophrenia. The diagnosis of schizophrenia makes an individual more vulnerable to stress than others. This view is supported by a range of authors (Goodman et al 1997, Chadwick 2000, Leudar and Thomas 2000, Bentall 2003). There is some limited evidence in the current study for this view. Major changes in life circumstances (e.g. getting married and a change of employment) and physical illness in the lives of relatives with schizophrenia were reported by six carers, who had observed the onset of schizophrenia. These findings appeared to support the views of Bentall (2003) and the findings of Leudar and Thomas (2000) who propose that there is a strong causal link between trauma (particularly sexual abuse) and hallucinations.

The stress vulnerability model may also explain this finding (Neuchterlein et al 1992, Birchwood, Fowler and Jackson 2000, Birchwood and Jackson 2001, Bentall 2003). People with the diagnosis of schizophrenia are more vulnerable to stress than others. Stress is present in everyday life. People with schizophrenia have few protective factors, therefore when stress occurs they experience a relapse of their schizophrenia. The social-cognitive model discussed by Neuchterlein et al (1992) may explain this process and outcome. Dopaminergic dysfunction already exists. Dopamine is synthesised from tyrosine. When dopamine is released into the synapse, dopamine binds with the dopamine receptors, D1 and D2. In this way neurones allow the brain to process and integrate information from the environment. It is proposed that in psychosis neurotransmission is dysfunctional and there is an excess of dopamine because there is over-activity of the dopamine system. Another proposal is that there is an excess of dopamine receptors, which leads to an increase in the level of dopamine. The individual with the diagnosis of schizophrenia has cognitive deficits (e.g. memory deficits). The stressful life event causes the cognitive system to become overloaded and there is increased emotional arousal. This leads to a prodromal episode which is characterised by non-psychotic symptoms, such as anxiety, agitation, restlessness, low mood and social withdrawal and low-level psychotic symptoms such as suspiciousness. These prodromal symptoms vary between individuals, indicate reduced well-being and occur prior to relapse (Birchwood and Tarrier 1994). These prodromal symptoms are followed by severe symptoms of schizophrenia and relapse (Neuchterlein et al 1992).

Birchwood, Fowler and Jackson (2000) suggest that life events, (e.g. adverse social circumstances) lead to the onset of stress, and the combination of stress and pre-existing vulnerability or predisposition of biopsychosocial origin lead to the onset of symptoms of schizophrenia. At this point there is disruption of the cognitive processes of attention,

perception or judgment, followed by a subsequent change in emotional state. Relapse now leads to the onset of delusions and beliefs about voices, and an appraisal of these (e.g. controlling voices). The delusions and hallucinations become systematised (Birchwood, Fowler and Jackson (2000).

Birchwood and Jackson (2001) propose that there are three possible explanations. Firstly, life events lead to stress without underlying vulnerability. Secondly, life events lead to an episode of schizophrenia. Thirdly, stressful life events lead to an episode of schizophrenia. They maintain that an increase in life events appears to increase the risk of relapse. However it is difficult to estimate the function or impact of life stress. They propose that the second and third potential explanations are the most likely and there is specific intrinsic vulnerability to stress (Birchwood and Jackson 2001).

The psychopathological model supports the view that individuals are vulnerable to developing symptoms of schizophrenia because they have pre-existing biological or psychological characteristics. The stressful life event then creates the stress response, symptoms of schizophrenia and relapse (Bentall 2003).

The Slade and Bentall (1988) five-factor theory of hallucinations offers an understanding of the processes involved in the onset of schizophrenia. There is initial stress induced arousal. There are predisposing factors (e.g. cognitive deficiencies). There is environmental stimulation (e.g. noise). Hallucinations are reinforced because they may offer relief from anxiety. This leads to expectancy, wherein individuals expect to hear the voices and do hear them more frequently.

It is possible that the participants with a diagnosis of schizophrenia had a predisposition or intrinsic vulnerability prior to the onset of stressful life events. However in the current study only stressful life events have been identified by participants with the diagnosis of schizophrenia and carers.

9.2.4 Family dynamics: Bowlby's attachment theory

In this section family dynamics are discussed. In the current study, only two participants with schizophrenia reported rejection by and separation from parents in childhood. As children, these participants were placed in social services care by depressed mothers who could not cope with them. One of these had lost custody of her children and believed that no one, including her children, liked her. Her relationship with her mother was not good, with her mother being, in her perception, very critical of her. These minority findings indicated difficulties with relationships, and an anxious attachment style, as discussed by Bowlby (1977, 1979). These minority findings offered limited support for the findings of Diamond and Doane (1994) and Paley (2000) (studies which had methodological flaws), or the views of Bentall (2003) and Bowlby (1977, 1979), which were overviews, based on earlier research findings. The parent who has a negative affective style (AS) displays personal criticism, guilt induction and intrusiveness. This behaviour is more related to interactions and relationships with their own parent, than to the actual behaviours of their offspring. The offspring internalises the negative attachment style, of which the negative AS is an element. The parent who experienced little parental emotional support is unable to emotionally support their own offspring. The lack of a close supportive relation may lead to emotional disturbances in their offspring (Diamond and Doane 1994, Paley et al 2000).

Bowlby (1977, 1979) maintains that particular parenting patterns can lead to distress in later life. Rejection by parents can lead to a person developing an anxious attachment style, anxiety, insecurity and over dependency. This deviation in the development of attachment behaviour can lead to psychiatric disturbances in later life. The majority of participants with schizophrenia in the current study did not report that they had emotionally unsupportive parents. Some did report that they had very supportive parents. The minority findings in the current study appeared to offer limited support for the work of Bowlby (1977, 1979), who maintains that early childhood experiences can lead to mental illness (e.g. rejection by parents when the child seeks care, and discontinuous parenting with the child spending time in an institution). However this theme was not explored in the current study.

Bowlby (1977) conceptualises the propensity of individuals to form affective bonds with others, and explains the presence of emotional distress (e.g. anxiety and depression) in later life which unwilling separation and loss may lead to. Current experiences with others may be distorted by past experiences with unsupportive parents. Deviation or failure of development of attachment may lead to later psychiatric disturbances. An anxious, insecure or ambivalent attachment style may lead to an individual dealing poorly with stress or life difficulties in later life. The child may become an adult who displays features of anxiety, attachment, and becomes anxious, insecure and over-dependent, if parents are unresponsive to the offspring's care seeking behaviour, or if the parental responses are disparaging remarks, rejection or threats to withdraw love, or if there is discontinuity of parenting. However, Bowlby (1979) in a later work, acknowledges that many children who grow up with these experiences do not develop mental health problems, and instead become secure, self-reliant, trusting and co-operative individuals. It may be the case that other additional factors are operating when some individuals with negative experiences develop later psychiatric

disorders. Bowlby (1979) does not clearly state that negative experiences lead to schizophrenia, and he suggests that even authors who support attachment theory are unsure what exactly what childhood experiences are relevant.

9.2.5 High expressed emotion

In this section high expressed emotion (HEE) is discussed. Participants with schizophrenia reported hospital care as controlling, and family care as intrusive. Family members made derogatory and critical remarks. This theme is discussed by Birchwood and Tarrrier (1994), who maintain that these factors are part of HEE. Overprotective care was reported by participants with schizophrenia who described care both as stifling and as something that prevented them from making choices. Some resented the overprotective care and this led to conflict in the family (Atkinson and Coia 1995).

Carers reported that unending care led to stress for them, which led to blame, anger and conflict in the family. Participants with schizophrenia blamed carers, who blamed the relative with schizophrenia, and both groups blamed health professionals and felt blamed by the health professionals. Carers reported behaviours which could be interpreted as controlling and intrusive (e.g. monitoring their relative). This appeared to support the views of Atkinson and Coia (1995) and Barrowclough and Tarrrier (1997), who assert that there is evidence of situations within the families of people with schizophrenia which could lead to HEE (e.g. constant monitoring). Participants with schizophrenia reported overprotective care and carers reported worry and concern about leaving their relative alone; a theme highlighted by Atkinson and Coia (1995).

High face-to-face contact situations appeared to be present in families where the relative with schizophrenia remained at home. This issue is reported by the following authors: Brown et al (1962), Leff et al (1982), Croydon-Smith (1982), Leff and Vaughn (1985), Leff et al (1987), Barrowclough and Tarrier (1997), Bradshaw (1997) and Baguley and Baguley (1999).

Carers who had their relative at home reported disagreement and hostility between themselves and health professionals. The health professionals advised carers to involve their relative in the family decision-making. Carers believed this advice was wrong because they believed their relative was not rational and could not make good decisions. Carers felt criticised and believed that health professionals thought that they were delivering the wrong type of care. Carers expressed their anger directly to the CPN on occasions. These reported occurrences appeared to support the views of Croydon-Smith (1982) and Barrowclough and Tarrier (1997), who propose that over-protectiveness is a consequence of hostile communications between carers and health professionals.

HEE may be a result of feeling negatively judged by health professionals. The health professional may express the view that the carer is being too intrusive and controlling. The carer may hold the view that the factors contributing to the individual's schizophrenia are external and may attempt to control the home environment, with the goal of preventing harm. This increased monitoring may lead to increased stress in the individual with schizophrenia and stress may lead to relapse (Croydon-Smith 1982, Barrowclough and Tarrier 1997). There appeared to be support for this position in the current study.

Therefore, the current findings appeared to support the views of authors who maintain that HEE is a reality (Leff and Vaughn 1981, Birchwood and Tarrier 1994, Atkinson and Coia 1995, Gamble 1995, Hughes et al 1996, Barrowclough and Tarrier 1997).

The measurement of HEE is now examined. Some HEE factors are easier to measure than others. Critical comments appeared to be the easiest factor to measure. Difficulties in measuring over-involvement were reported in the Brown et al (1972) study. HEE may not be consistent and may be a short term family response to a crisis (Croydon-Smith 1982, Atkinson and Coia 1995, Barrowclough and Tarrier 1997, which are overviews, and Hughes et al 1996 which was empirical research); however this position was disputed by Leff and Vaughn (1981) in their study.

The potential flaws and strengths of the CFI are now discussed. HEE has been identified by using the Camberwell Family Interview (CFI) (Brown et al 1972, Vaughn and Leff 1976, Leff and Vaughn 1981, Leff et al 1982, MacMillan et al 1986, Leff et al 1987, Paley et al 2000). It is suggested that the measurement of HEE is flawed, specifically the CFI (Vaughn and Leff 1976). The cut-off point for critical comments has been altered leading to potential loss of reliability in the assessment of HEE and potential loss of validity of the concept of HEE (Meuser et al 1992, Atkinson and Coia 1995, Hughes et al 1996). Therefore HEE may be subjective concept. The CFI may have weak validity because it is conducted in a contrived environment (Atkinson and Coia 1995, Barrowclough and Tarrier 1997). Brown et al (1972) acknowledged possible weak validity. The CFI is a semi-structured interview with opportunities to probe, which may lead to a loss of reliability, the introduction of researcher bias and influence and potential subjectivity in the findings. Leff and Vaughn (1981) acknowledged potential weak reliability because there was self-selection in the sample, the sample was not

representative and the findings were not generalisable. A further argument for the subjectivity of HEE as a concept and the loss of validity and reliability of the CFI is that only one response needs to be rated as high (e.g. six or above for critical comments, one or above for hostility, three or above for over-involvement). This may mean that there is a different presentation for each relative and a potential variety of responses. However there are common response patterns which lead to a classification of HEE: critical, or critical and over-involved, or critical and hostile (Barrowclough and Tarrier 1997).

It may be difficult to differentiate elements of the relative-patient interaction using the CFI. It is possible that the patient with schizophrenia is responding to the presence of the HEE relative, even when the HEE relative is not displaying HEE at that time. The non-verbal element of the relative-patient interaction may be missed (e.g. the evasive reaction by the patient to the critical comments made by the relative). The relative's non-verbal behaviour may not be accurately assessed. When examining a relative's non-verbal behaviour, there may be retention of the negative affective style (AS) (criticism, guilt induction and intrusiveness). These are actual behaviours which may be non-specific stressors for the individual with schizophrenia. There was evidence in the current study of these factors - specifically, criticism, guilt induction and intrusiveness by family carers.

Other potential flaws of the CFI are now discussed. Over-involvement is likely to be evident at the point of hospitalisation. It may be a caring response. It is suggested that hostility and criticism may exist prior to, and independently of, the patient's illness or behaviour (Atkinson and Coia 1995, Van Os et al 2001).

The CFI may be a flawed measurement tool. This is important because if it is accepted that the CFI is a valid and reliable assessment tool, HEE is accepted as an objective concept. If the CFI is flawed then the concept of HEE may not be an objective concept. In the past, only factors which could be assessed using quantitative research were examined (Perring et al 1990, Atkinson and Coia 1995). Where qualitative studies have been used in this literature review, there is potential sample bias, the presence of convenience and unrepresentative samples, limited generalisability in findings, and interviewer bias because semi-structured interviews were used.

Van Os et al (2001) acknowledged that the CFI was more sensitive than the Five Minute Speech Sample (FMSS) (Gottschalk and Glesser 1968), which they used. Some authors maintained that the CFI is a valid and reliable instrument and by implication that HEE is an objective valid concept (Brown et al 1972, Vaughn and Leff 1976, Leff et al 1982). High inter-rater reliability in the CFI has been reported because objective events and subjective feelings are differentiated

(Brown et al 1972, Leff et al 1982). Behaviours that cause relatives to become upset are identified in the assessment of critical comments. In the assessment of emotional over-involvement the goal is to assess distress responses and how the relative's quality of life and well-being are affected by the patient with schizophrenia's illness. These are objective factors. The researcher makes no subjective comment on whether the carer's concern is realistic or not. No value judgment is made about a carer's responses (Barrowclough and Tarrier 1997).

CFI has predictive validity in relation to relapse. However, the definition of relapse must be considered. All the HEE studies in this literature review define relapse as admission into hospital. Only Tarrier et al (1989) suggests that admission into hospital

may be a weak indicator of relapse and that there may be other reasons for admission. The predictive validity of the CFI may be increased if relapse is defined as exacerbation of symptoms (Atkinson and Coia 1995). In the current study, most carers appeared to hold the view that when the individual with schizophrenia relapsed (by which the carers meant behaving abnormally), the individual with schizophrenia should be admitted into hospital. Remaining at home with an exacerbation of symptoms was not viewed as an acceptable option by most carers.

HEE relatives display certain behaviours. Coercion and control is related to the goal of restoring desirable behaviour, which is related to beliefs about internal attribution. The need to engage in damage limitation is related to emotional over-involvement, intrusion into the patient's life and external attribution (Barrowclough and Tarrrier 1997). There was evidence for these in the current study. Participants with schizophrenia reported coercion, control and intrusion by family carers. Carers reported that they believed they must control the life of the individual with schizophrenia and appeared to hold strong views about socially desirable norms, goals and behaviours and the need for the individual with schizophrenia to conform to these.

It may be the case that living with a hostile, emotionally over-involved relative leads to low social functioning in an individual with schizophrenia. However it is possible that the low social functioning individual with schizophrenia may cause the relative to become hostile and emotionally over-involved, with high face-to-face contact, in an effort to manage a difficult situation (Barrowclough and Tarrrier 1997). In the current study, carers reported behaviours in their relatives which could be interpreted as low social functioning (e.g. dependency on others, staying in bed all day, social isolation, inability to cope with interactions with others, inability to manage money), and their

own controlling behaviours. Carers appeared to believe that they had to manage, and so had to be very involved in, the individual with schizophrenia's life. During the interviews, carers made critical comments, and at times indicated some hostility to the individual with schizophrenia (e.g. blaming statements). While face-to-face contact was not specifically examined, these carers appeared to believe that they must spend most of each day with their relative with schizophrenia, in order to control and manage the situation in the home. In most of the HEE studies in this literature review, it is concluded that relatives and patients with schizophrenia affect each other negatively. There was supporting evidence in the current study for this position. It is possible that the parents' own attachment patterns are creating the HEE. The parent has a perception of having received high parental care and high protection. The parent perceives their son or daughter with schizophrenia to be needy and displays high emotional over-involvement (EOI) in their care. The individual with schizophrenia feels stressed and relapses as a result of this EOI. Therefore the parent's own perceptions of their parental care may lead to HEE and EOI (Bowlby 1997, 1979, Paley et al 2000). This view was not supported in the current research, but it was not explored.

Family relationships may affect the course of schizophrenia. The family maintenance model of schizophrenia may explain HEE and relapse. High EOI and high face-to-face contact create a stressful environment for the individual with schizophrenia and may lead to relapse (Baguley and Baguley 1999). There was support for this position in the current study.

The individual with schizophrenia may behave in an odd manner, which stresses the relatives who react with close monitoring, criticism, hostility, concern, EOI and HEE,

which then leads to relapse in the individual with schizophrenia (Birchwood and Tarrrier 1994). There was support for this position in the current study.

While HEE appears to lead to a negative situation for individuals with schizophrenia, low expressed emotion (LEE) and lack of involvement may not be a positive situation for the individual with schizophrenia (Croydon-Smith 1982, Hughes et al 1996, Barrowclough and Tarrrier 1997). LEE can lead to loss of social functioning and may indicate that the family is a burnt out or non-coping family. There was no support in the current study for the concept of LEE in families.

9.2.6 Adaptation: learning to live with voices

In this section adaptation to hearing voices is discussed. Some participants in the current study reported that listening to the voices made them feel comforted and less stressed and they accepted the advice of the voices and visions. They appeared to accept the voices and visions as a positive part of themselves and their lives, perceiving the experience as positive and pleasant. These findings appeared to support the view of Bentall (2003), who asserts that voices are perceived as positive if they have an organising role in daily activities and advise the person.

Bentall's (2003) proposal that those who positively evaluate their visions and voices, listen to them, accept them and engage with them, appeared to be borne out in the current study. Those who felt positively about their experience, believing it to be a mystical or spiritual experience, reported engaging with the voices and accepting their advice. They were not convinced they were ill. Adaptation appears to occur when people ignore the voices, listen to them and accept their advice, or perceive them as a

positive part of themselves. Bentall (2003) proposes that those who evaluate their voices and visions as benevolent, accept and engage with them. Engaging with voices is also proposed by Coleman and Smith (1997:2005) as a successful strategy. Bentall's (2003) view that people can feel stronger than the voices, if the voices are benevolent, is not supported by the findings in the current study. None of the participants who discussed hearing voices reported feeling in control of their voices and some reported that the voices were powerful, even if they made positive comments about them. Some reported feeling unable to cope with their voices. They reported trying to ignore the voices, but that, being unable to ignore them, listened to them, which made them feel anxious and stressed. The findings in the current study offer a different perspective because some participants with schizophrenia appeared to have critical, hostile voices and they believed that they could not control their voices.

In the current study, participants with schizophrenia who sought help, reported feeling rejected, isolated and lonely. There was stress within the family. Most reported features of acceptance, being unwilling or unable to make decisions or to question the diagnosis or treatment, accepting that they were ill. They reported severe depression and feeling stopped in life. They made more negative statements about themselves than those who did not seek support, displaying a negative self-concept. They appeared to believe themselves to be non-coping people. Participants with schizophrenia did not report a trigger event (although carers did), but reported stress prior to the onset of visions and voices, which led to great confusion, anxiety, muddle and more stress. Carers reported that stress was an antecedent to their relative hearing voices. Bentall (2003) suggests that emotional stress is a trigger for hallucinations, which in turn lead to feelings of panic, confusion and powerlessness. Bentall (2003) proposes that the factor that determines whether people who report hallucinations seek help or not is how well they

cope with the experience. If they cope well, they do not seek help, but if they cope poorly and become distressed, they do. Participants with schizophrenia in the current study who were convinced they were ill, reported being frightened of the voices. Those who believed the voices and visions were malevolent and all powerful tried to resist them (Bentall 2003).

The flaw in Bentall's (2003) theory appears to be that accepting benevolent voices leads to perceptions of control and better coping, but if the voices are malevolent and the voice hearer accepts and engages with them, it is unlikely that the voice hearer will have perception of control and develop better coping. Bentall (2003) does not discuss this scenario beyond asserting that if voice hearers resist malevolent voices they do not cope and if voice hearers perceive the voices as omnipotent, they feel powerless and do not cope. Bentall (2003) makes two statements. Firstly, accepting voices leads to perceptions of control of the voices and better coping. Secondly, those who perceive their voices as malevolent resist them, while those who perceive the voices as benevolent accept them and engage with them, a situation which leads to perceptions of control. Bentall (2003) does not indicate which factor comes first, the perception of control or the presence of benevolent voices. This is important because if voices are critical and hostile and the voice hearer believes that they have no power to control the voices, they are likely to be overwhelmed by the voices. It is necessary for the perception of control to come first because this leads to the individual taking action.

If the voice hearer perceives that the voices are positive, they will feel powerful and positive about themselves. If psychosis is perceived to be an attractive state, it makes the voice hearer feel powerful (Chadwick 1997). There was limited support in the current study for this position.

A large scale study by Romme and Escher (1994) also found that adaptation to voices occurred. Those who reported that they coped with their voices felt stronger than their voices, were able to ignore their voices, could engage in selective listening, could set limits on their voices, and reported experiencing more positive voices. Ignoring voices, selective listening and dialogue were reported as successful strategies and were part of “the phase of organisation” (Romme and Escher 1994 p.19). This was the second phase of a process which voice hearers appeared to go through. In the third and final ”phase of stabilisation” the voice hearer could accept or reject the content of the voices and adjust to the voices (Romme and Escher 1994 p.22, pp.11-27). Escher (1994) maintained that voice hearers coped better with voices by acknowledging them, rather than by denying them. Romme and Escher (1994) proposed that those who did not cope well with their voices, the non-coping group, felt weaker than the voices, experienced more negative and commanding voices, sought relief from this by using distraction, and experienced less support from others, than those who coped. Those who achieved the third phase of stabilisation considered the voices as a part of themselves and a positive influence. They received advice from the voices. These authors proposed that acceptance of voices contributed to better self-esteem (Romme and Escher 1994). Escher (1994) asserted that accepting one’s voices was an essential first step in the process of taking responsibility for oneself. By accepting the voices one could engage in limit setting, prevent excessive intrusion and reduce feelings of powerlessness. In conclusion, findings in the current study are supported by the findings of Romme and Escher (1994).

Leudar and Thomas (2000) highlighted coping mechanisms used by voice hearers. One cognitive technique reported was paying attention, reflecting on the content of, and accepting the guidance of voices. These authors offered an empirical case study, in

which one individual had a dialogue with her voice. The voice advised and reassured her and her self-esteem and social functioning increased. Therefore, the empirical findings of Leudar and Thomas (2000) appeared to support the view that engagement with voices leads to positive coping by voice hearers.

Successful coping with disability may explain why some individuals with schizophrenia had better outcomes than other individuals. Some individuals with schizophrenia adapted their style of living, in addition to adapting to their voices. (Bury 1991). Some adopted the strategy of normalization, which involved integrating their condition into an altered public identity and joined a user group. They appeared to cope by using cognitive processes to sustain their self-worth. They had a positive self-concept, achieved self-management, received and gave support and reported moving on in life. Therefore, there was support for this position in the current study.

9.2.7 Outcomes and recovery

Outcomes and recovery are discussed in this section. Participants who reported that they had moved on in their lives after diagnosis also reported having positive psychological outcomes (e.g. a positive self-concept, self-belief), and positive social outcomes (e.g. independence, control of their own lives). Some of this group were in a user group and, in their view, had good social contact with others. Some of the moved on group had positive occupational outcomes with two others returning to their university studies. The factors that appeared to contribute to moving on also appeared to contribute to better outcomes. However some psychological aspects of moving on, such as deciding to change and take control of one's life, appeared to come before the social and occupational outcomes in these participants with schizophrenia. It appeared that these

participants had a positive self-concept prior to the social and occupational outcomes. These positive outcomes may have been a result of self-formation (Lupton 1997, Falzon 1998, Rose 1999). It could be argued that these participants used their human agency (Giddens 2001). They may have perceived themselves as citizen-consumers, instead of patients (Nocon and Qureshi 1996). It may be the case that they wanted to empower themselves, while other participants may have been more dependent and were not fully committed to achieving self-empowerment. Participants who were members of a user group may have achieved self-empowerment through dialogue with health professionals and changed the power balance and the social relations between themselves and health professionals (Johnson 1997). In the current study there appears to be evidence for the views of all these authors.

Participants in the *moved on* group appeared to have created a new life for themselves and had created their own structure for everyday living, suggesting support for the views of Houghton (1982). This author gives his own views, which are not supported by research. The views of Beale and Lambric (1995), Coleman and Smith (2005) and the findings of Williams and Collins (1999), who maintain that those who achieve personal empowerment make a better recovery, appear to be supported by the findings in the current study. Participants in the *moved on* group appeared to have less emotional distress and better coping. Only Williams and Collins (1999) offer empirical evidence to support their views.

Participants with schizophrenia who were in the *stopped* group reported more and longer admissions to hospital, more severe distress and more social isolation than the *moved on* group. Of the *stopped* group, few were employed. However a few men who experienced visions and voices much of the time were employed. These participants

reported that they were sometimes unable to work because of depression and felt lonely and isolated. Therefore, some participants with a diagnosis of schizophrenia had good outcomes in all three domains, (clinical, social and occupational), while others had good outcomes in terms of occupational outcomes, but poor social and clinical outcomes. Others had good social outcomes, but poor occupational or clinical outcomes, and these findings appear to support the views of Bentall (2003), which are that people can have good social outcomes, but poor clinical and occupational outcomes. In his view, a good social outcome reflects an individual's ability to maintain social relationships. Occupational outcomes are defined by others and are a judgment on how well a person can maintain paid employment. Poor occupational outcomes may be the result of discrimination by others. Clinical outcomes are determined by others and are assessed by examination of symptoms. A focus on the presence of hallucinations and delusions is likely to lead to a health professional making a judgment of poor clinical outcomes. Bentall offers no empirical evidence for his views.

9.2.8 Social constructionism, medicalisation and docile bodies

In this section, social constructionism is discussed. Within social constructionism people and diseases are socially constructed. People are created and defined through differentiation. Positivistic knowledge created truths about insanity, which in turn created taxonomies and categories (e.g. schizophrenia). A new epistemology was created and individuals were subject to the medical gaze and surveillance (Foucault 1995, 1996). Within scientific positivism, objective knowledge is created (Smith 1998). Taxonomies are based on the observable presence or absence of specific symptoms. Facts can be verified or falsified. The objective knowledge of mental illness exists. Within the taxonomy of mental illness there are categories (e.g. schizophrenia), which

in turn can be proved by identification of core symptoms. Therefore individuals with core symptoms of schizophrenia are deemed to have a mental health problem. There was support for the presence of these processes in the current study.

There appeared to be support for the Foucauldian perspective of medicalisation. These participants with schizophrenia reported that all their views and behaviours were attributed by others to mental illness. They reported that they were presumed to be ill, and medicalisation led to unwanted scrutiny by health professionals. The diagnosis of schizophrenia led to loss of rights, loss of power and control in their lives, and loss of inclusion in society. They found it difficult to reintegrate into society after the diagnosis. Most reported being detained against their will. Some participants with schizophrenia reported feeling treated as an object, a finding which appeared to support the view of Armstrong (1994), who proposed that people are objectified and are perceived as less important than the disease. Lack of compliance, coercion and medicalisation were highlighted by participants in the questioning group, offering support for the works of Foucault (1980, 1995, 1996), Rose (1994) and Bunton (1997).

Participants reported that they felt disempowered and believed that health professionals, with their knowledge, had power. This finding appeared to support the work of Armstrong (1994) and Foucault (1980,1995,1996), who propose that patients lose their individual identity and power, that medicine becomes dominant, and that biopolitics and biopower lead to regulation and treatment for people who are perceived to be difficult. Most participants reported medicalisation and coercion,. Therefore, there was support in the current study for the views of some authors who contend that successful medicalisation requires coercion (Foucault 1980, 1995, 1996, Armstrong 1994, Bury 1986, Rabinow 1991, Fox 1993). However, Foucault (1980, 1995, 1996) argues that

within biopolitics and surveillance medicine, in addition to a repressive element, there is a constructive element, which involves participation of all groups and a common shared knowledge of mental illness. There was evidence in the current study for the existence of the repressive element. Power/knowledge and biopower place emphasis on the view that people who hear voices and have visions are mentally ill. One result is the creation of taxonomies and categories, specifically schizophrenia. These individuals are subject to monitoring via surveillance medicine.

There was support for the work of Armstrong (1994) because most participants with schizophrenia reported that were not treated as individuals. This may be explained by objectification, a process in which individuals are treated as objects (Bury 1986, Rabinow 1991, Fox 1993, Foucault 1980,1995). In objectification the illness is focused on and is perceived to be more important than the person.

In the current study, some participants appeared to accept the diagnosis, care and treatment, and this finding may be explained by Governmentality, a concept within social constructionism. This behaviour is discussed by Rose (1999), who suggests that individuals and their subjectivity and views are shaped by Governmentality, which involves a range of social processes. He contends that individuals have freedom and autonomy to choose to accept knowledge, diagnoses, care and treatment. They seek to improve themselves by accepting common shared knowledge, shared norms and treatment goals, and attempt to achieve self-fulfilment. The desirable goals of improved health and social functioning are accepted. Therefore individuals willingly participate in health improving behaviours, engage in self-regulation, submit themselves to the medical gaze and regard themselves as free autonomous individuals.

Foucault previously discussed this behaviour of individuals and used the term self-formation, where individuals willingly transform themselves and conform to social norms. It could be argued that individuals are so strongly influenced that they have little choice but to accept the diagnosis and treatment and conform, but this is not the position of these authors (Rabinow 1991, Fox 1993, Lupton 1997, Falzon 1998, Rose 1999). Their position is that within self-formation individuals accept the diagnosis as valid and choose to transform themselves. They accept care and treatment and gain some benefit from self-formation. There was evidence in the current study for this position.

Cultural bias, a concept from sociology which is discussed by Bilton et al (1993), may explain this behaviour. Individuals with a diagnosis of schizophrenia live in the same community as others, including mental health workers, and accept the current knowledge about mental illness. They internalise the same cultural norms and have a shared understanding of mental illness. Individuals are socialised with the emphasis on rule following, conformity and obedience to higher authority (e.g. medical authority). Mental health nurses are transmitters of medical authority and promote conformity. Therefore, individuals do not question the diagnosis, the need for treatment or the roles of nurses to deliver care and treatment. It could be argued that conformity reduces autonomy, but it may be the case that conformity leads to social inclusion, although in the current study there was no support for the latter position.

Structuration theory and the concept of complementarity may explain reported complicity (Giddens 2001). Individuals with the diagnosis of schizophrenia accept the mental health systems and structures. These shape the individual, who develops a dependence on these systems and structures and does not challenge them.

There was some limited evidence in the current study for the views of Lupton (1997). She maintains that individuals can resist medicalisation. Resistance involves challenging medical knowledge, rejecting advice and negotiating with health professionals (Lupton 1997).

Lupton (1997) proposes that self-formation is a strategy for resistance. Self-formation involves having one's own subjugated knowledge and also a degree of compliance and collusion with medicalisation. One participant termed this '*playing the game*' by which he meant agreeing with the health professionals, complying with treatment with the goal of being free from the mental health system, even though he believed he had no mental health problem.

Within this resistance there is human agency, a sociological concept (Giddens 2001) and there was evidence of this in the reports of the *moved on* group. Individuals diagnosed with schizophrenia reject current systems and structures, and create new systems and structures, for example user support groups. The rise of support groups leads to an increase in partnership and empowerment of service users and influence on services by service users. There was evidence in the current study of this position. Individuals in the user group reported that they believed they had influence and could redefine themselves and the current knowledge of schizophrenia.

In the current study there was evidence to support the work of Barham (1984) and Rabinow (1991), who discuss medicalisation and exclusion, because most participants with schizophrenia reported they felt socially and economically excluded and believed others thought they were ill. These authors assert that people considered to be sick and useless are excluded from society. There was support for this position in the work of

Laurance (2002), a paper on mental illness, and Bonner et al (2002), which was empirical research and in a report from the Office of the Deputy Prime Minister (2004).

Medicalisation and reported non-compliance

In this section, medicalisation and non-compliance are discussed. Some participants with schizophrenia believed they were not ill and refused to comply with treatment, believing that the diagnosis was wrong and applied to them against their will. Some participants who believed they were ill also refused to comply because they disagreed with the treatment. Most of these, in the *questioning* group, seemed unable to be free of the diagnosis or the mental health system, and some, who were in both the *moved on* group and the *questioning* group, reported going along with the ideas of the health professionals in order to be eventually free of the diagnosis. Bury (1986) and Lupton (1997) make the point that it is possible to resist medicalisation, and there was some support for this view in the current study. Some participants in the *moved on* group reported that they complied and colluded, while disagreeing with the health professionals, while others reported that they challenged medical knowledge. Lupton (1997) highlights people's collusion with medicalisation whilst simultaneously resisting it in the medical encounter. Perhaps this is what occurred in the current study.

Medicalisation and reported acceptance and compliance

Medicalisation and reported acceptance and compliance are now discussed. Most participants with schizophrenia initially accepted the medical knowledge and diagnosis. These were the *acceptance* group. They accepted other's evaluations of them and some

referred to themselves as schizophrenic, as having paranoid schizophrenia, or being deviant. Most referred to themselves as ill.

There was evidence of their compliance, because they accepted they were not rational and doubted their own judgment, relying on the judgment of others. All those who sought support believed they were ill. Some went to hospitals, even after discharge, just to spend time with other people like themselves. Some people in a user group believed they were ill, but felt positive about themselves, and, as part of a user group, engaged in discussion and negotiation with health professionals. This strategy appears to support the views of Johnson (1997) and Lupton (1997), who assert that it is possible for people to negotiate power with health professionals. Participants with schizophrenia who complied also displayed acceptance, accepted the diagnosis and sought support from health professionals. This finding appeared to support the views of Foucault (1980,1995,1996), Nicolson and McLaughlin (1987), Fox (1993), Johnson (1997) and Lupton (1997), who discuss self-formation, and Rose (1999) who discusses Governmentality, which argues that people willingly collude with, accept, and participate in medical dominance. Bilton et al (1996), who adopt a sociological perspective, and who discuss cultural bias, also support the view that individuals accept cultural norms and comply with treatment.

In the current study, most participants with schizophrenia may not have been docile bodies because of their apparent compliance. Being a docile body requires oppression, according to Foucault (1980, 1995). Oppressive medicine creates docile bodies. Individuals are oppressed and have no choice but to accept the diagnosis, the treatment and the position in society assigned to them. Surveillance medicine facilitates the medical gaze on the whole population and it facilitates conformity. Uncritical

acceptance of medical knowledge and defining labels are demanded. Compulsory admission into hospital is possible and supported by society. There was support for these processes in the current study.

However it is argued that if an individual has power and negotiates with health professionals, he/she is not a docile body (Johnson 1997, Lupton 1997). Foucault (1980, 1995, 1996) proposes that an individual can become a docile body without oppression or disempowerment. The constructive element of biopolitics, which involves participation of the individual with the diagnosis of schizophrenia, and the common shared knowledge of mental illness, involves uncritical acceptance by an individual leading to compliance. The findings in the current study supported these views. The experience of victimhood and disempowerment was also widely reported by those who reported compliance with health professionals. They appeared to choose to accept medicalisation when they could have chosen to resist it. They appeared to accept the shared knowledge of mental illness. They may have gained benefit from the mutual dependence that Lupton (1997) asserts exists. None of this literature is supported by research. Rather it consists of reviews of the social construction of mental illness, medicalisation and docile bodies.

9.2.9 Labelling

In this section labelling is discussed. The views of Haralambos et al (1993), Giddens (1989/2001) and others are discussed in this section. Most participants with schizophrenia reported that part of being in schizophrenia was being under scrutiny, which, in their opinion, led to them being labelled. Labelling led to loss of employment and rejection by others. Those who were employed felt socially excluded. Most

participants with schizophrenia felt disempowered and felt that others perceived them as incompetent. All reported that others were afraid of them and believed they were perceived by others as dangerous. They reported that they felt labelled. These findings supported the views expressed by Haralambos et al (1993), who maintain that being labelled and defined as deviant depends on interaction and negotiation between the those with the power to label and the labelled (Haralambos et al 1993). The status of deviant (e.g. schizophrenic) overshadows other statuses (e.g. worker or citizen). The labelled person's self-concept comes from how others respond to him/her and the labelled person will perceive him/herself in terms of the label and act accordingly. After public labelling as deviant, the person may be rejected or excluded by others, and lose their employment. According to labelling theory, people are defined as deviant through a process by which labels are attached to their behaviours by those in authority and by others (Haralambos et al 1993).

It could be argued that the clinical gaze, a Foucauldian concept, leads to labelling, and that medical domination has sinister connotations (Armstrong 1994). However Osborne (1994) disputes the view that there are sinister intentions involved in the clinical gaze. All knowledge of social life is created and developed by the gaze via examination by experts (Fox 1993, Nettlelton 1994). It may be the case that the external process of labelling is carried out by health professionals, who are perceived to be experts by society.

Labelling involves individuals with a diagnosis of schizophrenia being identified as different and being assigned a lower value than others. They have no power to prevent this external social process. The accepted knowledge of mental illness supports the

labelling process (Goffman 1963:1968, Giddens 2001). Labelling can lead to social exclusion (Rabinow 1991, Barham and Hayward 1991).

There were minority findings that did not support labelling theory. Participants who were in the *moved on* group who were also in a user group and believed they had schizophrenia, accepted the diagnosis and label. However they did not indicate a negative self-concept in their statements. Therefore it was not shown in the current study that if participants accepted the diagnosis, they had a negative self-concept. Being a member of user group appeared to help these participants to retain their positive self-concept. A few participants in the *moved on* group did not believe they were ill, rejected the diagnosis and had a positive self-concept. However, they reported rejection, exclusion and difficulties finding employment.

The self-concept held by those who are labelled is important because it may influence outcomes. In the current study, negative self-concept was reported. Interactions with others were reported which were characterised by disempowerment, rejection and exclusion. Worker status was denied to participants with schizophrenia. Seeking support from others with the diagnosis of schizophrenia was reported by participants in a user group and others. Haralambos et al (1993) maintain that those who are labelled are forced into deviant communities, perceive themselves as different from wider society, and seek support and understanding from others in the same situation and who share the same problems. This could be a user group. Therefore, in the current study there appeared to be support for the views of Haralambos et al (1993).

Individuals with a diagnosis of schizophrenia are perceived as deviant because they are different from others. Expert knowledge and taxonomies of mental illness confirm their

deviancy. Their deviance is accepted by the majority of the population. The deviant individuals accept their status as deviants and their lower social value, leading to secondary deviance, which is a disempowering situation (Goffman 1963:1968). There appeared to be support for this view in the current study.

Participants in the *stopped* group referred to themselves as schizophrenic, or deviant. They appeared to accept their deviancy and were not in a user group. They reported feeling disempowered, suggesting support for this position and the processes involved in deviancy. This indicates secondary deviance, an idea proposed by Giddens (1989/2001). They asserted that they could not cope or work.

The combination of sociological concepts of deviancy, secondary deviance and labelling, and the psychological humanistic concept of negative self-concept appear to be related, and may explain why some participants reported feeling stopped in their lives. According to Giddens (1989/2001), people who are in a position of authority to impose conventional definitions of morality, engage in labelling. The labels that create categories of deviance reflect power structures in society, and the labelled have no power. Labelling theorists view deviance as a process of interaction between deviants and non-deviants, in which those who are labelled have no power.

An individual's self-concept is influenced by the judgments of others. Self-concept may influence one's mental health. A negative self-concept may lead to poor mental health. Individuals with schizophrenia may be negatively evaluated by others. Individuals with schizophrenia may develop a negative self-concept. This may prevent recovery even if voices and visions are under control. The negative value assigned to an individual with the diagnosis of schizophrenia may prevent them from regaining a positive self-concept

and may prevent a full recovery. There was support for this view in the current study. Participants who appeared to hold a negative self-concept were in the *stopped* group and reported depression. However it may be the case that the negative self-concept was present prior to the diagnosis of schizophrenia.

According to Abrahamson, Seligman and Teasdale (1978), some individuals have cognitive vulnerability factors, specifically a pessimistic attribution style, which is an enduring trait and exists prior to being diagnosed with schizophrenia. The individual is likely to believe that they are ill and lose hope that they may recover. The pessimistic attribution style leads to pessimistic attribution (e.g. I am not normal, I am a failure). They are now likely to feel depressed. Low self-esteem and a negative self-concept appeared to be present in participants with the diagnosis of schizophrenia who were in the *stopped* group, and it may be the case that they had a cognitive vulnerability factor, specifically a pessimistic attribution style (Abrahamson et al 1978).

It may be the case that some participants accepted the sick role (Parsons 1951). The sick role is a social concept and a social role. The person is judged by others to be sick and accepts this evaluation of her/himself. The sick individual now acts in a deviant way compared with the social norm. Being sick is regarded as a social abnormality. In the biomedical model of health, the health professional and expert validates the illness. The sick individual is not blamed, but must accept that they should seek help and work towards getting better. Now the sick individual can be returned to normal functioning. This position disempowers the sick individual and gives all the power to the health professional (Haralambos and Holborn 2004). This may explain why some participants reported that they could not move on in life after the diagnosis and did not challenge the diagnosis.

9.2.10 Why power is incompatible with social constructionism and labelling

There is evidence in the current study that some participants accepted their assigned roles and identities, therefore offering support to the views of Barham and Hayward (1991). In social constructionism, people with mental illness, even if they are compliant, have no power to reject or avoid what is being done to them. Compliance is evident when social and interpersonal processes involve acceptance of assigned roles and identities (Barham and Hayward 1991). The findings of the current study appeared to support the work of Foucault (1988). Participants with schizophrenia were strongly encouraged to accept the concept of mental illness and the validity of expert knowledge. They reported surveillance, disempowerment and medical domination. They accepted common shared knowledge and their socially constructed identity as people with schizophrenia.

External processes (for example, medical domination, power and knowledge, population surveillance, or the Panopticon (the medical or clinical gaze)) may lead to internal processes (e.g. self-formation, where people choose to transform themselves and their self-identity), according to Foucault (1988). However, within the early Foucauldian position, it is not possible to resist these external processes. People who are socially constructed are linked to the society or social body by the common shared knowledge. The Foucauldian position is that positivistic knowledge and medicine creates taxonomies of mental illness. Normality and abnormality are defined by these. Individuals deemed to be abnormal are monitored by surveillance medicine and subjected to the clinical gaze. They are objectified via panoptic power and are medicalised. They are oppressed and become docile bodies (Foucault 1980:1995: 1996, Bury 1986, Rabinow 1991, Fox 1993, Armstrong 1994, Bunton 1997).

Within social constructionism, the concept of power/knowledge explains the disempowerment of individuals. Medical power is supported by biopower and biopolitics, and this support leads to acceptance of medical authority and regulation of the population (Foucault 1980:1995:1996). It may be the case that the lack of power to resist social construction may be explained by the social processes involved in Governmentality, in which an individual's subjectivity and experiences are shaped (Rose 1994:1999).

Foucault later adopted a position that, within the technology of domination, there is technology of individual domination and people can engage in self-formation. The result is that people may not be docile bodies (Foucault 1988, Rabinow 1991, Falzon 1998). Lupton (1997), however, maintains that within self-formation there is compliance and complicity. This is not resistance to the external processes involved in social constructionism, and is a position of disempowerment.

Structuration theory and the concept of complementarity, in which mental health systems and structures shape individuals, who then accept these systems, structures and ideas uncritically, may explain disempowerment (Giddens 2001). The concept of spoiled identity may explain the lack of power. Individuals with schizophrenia are assigned a negative, spoiled identity and a lower value than others, which they accept (Goffman 1963, 1968, Giddens 2001). Stigma may also explain the lack of power. People with schizophrenia are perceived as different and are assigned a lower social value. Stigma leads to negative social consequences (e.g. social exclusion, poverty). Stigma is an internal process with acceptance of the devalued position (Goffman 1963, 1968). All these processes may lead to an individual being disempowered and unable to resist being socially constructed.

Cultural bias may explain this situation, in which individuals internalise social norms and do not question the diagnosis and need for treatment (Bilton et al 2000).

9.2.11 Exclusion

In this section social exclusion is discussed. The findings in the current study offered support to the views of a range of authors who highlight exclusion of those with mental health problems. All participants with schizophrenia, even those who reported moving on in life and who appeared to make a good recovery, felt themselves to be excluded from society. They reported exclusion as part of wider social consequences and as an aspect of loss, a view maintained by a range of authors (Foucault 1980,1995,1996, Barham 1984, Porter 1987, Barham and Hayward 1991,Giddens 2001, Bonner et al 2002, Bentall 2003, Office of the Deputy Prime Minister 2004). Social exclusion leads to reduced quality of life and psychological distress (Bonner et al 2002).

Participants reported that they were rejected in employment and by others in social interactions. The loss of employment appears to contribute to poverty and social isolation and they reported feeling marginalized. Barham and Hayward (1991) and more recently, Bonner et al (2002) and Bentall (2003) assert that poverty, stigmatisation and unemployment are factors that keep psychotic people excluded from society and locked into the role of the mental patient, although only Bonner et al (2002) offered empirical evidence for this view. In the current study participants reported that old friends behaved differently towards them, and people who knew of their diagnosis of schizophrenia avoided them, and perceived them negatively. Therefore, exclusion and rejection had a personal and a social context.

The reasons for, and causes of, exclusion are varied. They include power relations, psychiatric ideology, social prejudice, and perceptions of the mentally ill as dangerous or as socially useless. Public fear and perceived lack of conformity, and exclusion lead to unemployment and poverty, loss, marginalisation, and stigma. The findings in the current study highlighted exclusion on a personal and social level. Participants with schizophrenia felt they were always perceived as ill and different. Participants reported that exclusion led to poverty and marginalisation, supporting the views of Barham and Hayward (1991), Bonner et al (2002), Bentall (2003), and ODPM (2004).

9.2.12 Identity and stigma

Identity and stigma are now discussed in this section. Most participants appeared to accept the new negative identity, which came after identification and hospitalisation. The implication of this for them was that they were fearful of being found out. Those who accepted the new identity reported that they felt useless and a failure. They suffered from a range of negative psychological consequences, specifically low self-esteem, anxiety, fear, stress, self-disclosed lack of coping, shame, embarrassment and a negative self-concept. Participant 6, who had a negative self-concept, accepted the new identity and made 28 negative self-statements, compared with participant 1, who did not accept the identity, had a positive self-concept, and made two negative self-statements. One participant described himself as deviant, and another participant described herself as an unfit mother and a paranoid schizophrenic.

Stigma was a consequence of the new negative identity. Most participants with schizophrenia highlighted stigma in their lives. Self-disclosure of the diagnosis led to feelings of shame and stigma. These findings suggest support for the work of Johnstone

(1999). This author maintains that people with schizophrenia have a negative identity, which is accompanied by shame and stigma. Johnstone (1999) asserts that a psychiatric diagnosis leads to a life of stigma, isolation and discrimination, and the findings of the current study appeared to support this idea. According to Berger and Luckman (1966) and Barham and Hayward (1991), internal processes are involved in the creation of a negative identity. Interpersonal processes involve acceptance of assigned roles and identities. People who are assigned a stigmatised identity have no objective defence because they internalise the value judgments of society, and accept the shame and knowledge of their condition and their devalued position. Barham (1984) proposes that self-disclosure leads to shame and stigma. Therefore, the findings in the current study appeared to support the views of Johnstone (1999), Berger and Luckman (1966), Barham and Hayward (1991) and Barham (1984)

Sociological theory, specifically the concept of stigma, may offer an explanation. People with schizophrenia are perceived as different and are assigned a lower social value. Stigma leads to negative social consequences (e.g. social exclusion, poverty). Stigma is an internal process with acceptance of the devalued position (Goffman 1963:1968). Stigma appears to maintain a negative identity.

A minority of participants with schizophrenia rejected the negative identity and reported feeling positive about themselves and their identity. They held the view that a flawed negative identity has been imposed upon them, despite their rejection of the negative identity. They could not resist a public negative identity, when interacting with others, because everyone they met accepted the negative identity associated with the diagnosis of schizophrenia. This gives some credence to the views of Porter (1987), Rose (1994) and Foucault (1995), who propose that external processes are involved.

Most carers reported stigma, shame, and a loss of normal identity. They attributed this to the presence of their relative with schizophrenia. Only two older mothers did not report this. Most carers believed that their relative with schizophrenia had a flawed identity, and that they were not normal, and because of this the carers felt stigma and shame. Carers appeared to share the flawed identity. They believed their family to be abnormal, and that they were a stigmatised family. Stigma led to loss of friends and loss of social contact for carers. The child carer reported feeling stigma because of her mother. Two husbands reported the impact of stigma on their children because of the wife's schizophrenia. They reported that the children learned to avoid discussing their mothers' illness outside the home. These findings appeared to support the views of Perring et al (1990), who assert that carers of people with mental health problems also feel stigma and shame.

9.2.13 Care

The following issues are now discussed: lack of equality and partnership; service users feeling devalued; intrusion; lack of privacy; lack of common ground between service users and mental health nurses; coercion; disempowerment; exclusion; lack of support by mental health nurses; poor information giving; and poor communication.

The majority findings do not support the views of Benner (1994), who holds the position that partnership occurs in mental health nursing and asserts that caring involves equality, reciprocity and partnership. However, in the current study, a lack of equality and partnership was reported by most participants with schizophrenia.

Often there was an emphasis on preventing harm, and Benner maintains that controlling and monitoring conditions which lead to harm is part of caring. Benner (1994) offers no empirical research and discusses her own views. In the current research, most participants with schizophrenia reported control and monitoring by others but did not agree that this was care. A minority finding was that two women wanted more care and were willing to accept control and monitoring if it meant more support.

Issues raised by Beech and Norman (1995), specifically intrusion and lack of privacy, were supported in the current research. When the participants with schizophrenia discussed ideal care, most reported that, in their view, medication played no part in care. Most participants with schizophrenia reported that nursing care was coercive, supporting the views of Gorman (1992), Thomas et al (1992), Rogers et al (1993), Chadwick (1997) and Morrall (1998a, 1998b). Morrall (1998a, 1998b) maintains that nurses are agents of social control. The reason for this may be that mental health nurses have been given the responsibility to assess and manage risk. Public anxiety, professionals' fear of litigation, and working within a blame culture may maintain the focus of mental health nursing on risk assessment and management of those diagnosed with a mental health problem (Hanily 1999, Doyle 1999, Sharkey 1999). It may be the case that mental health nurses have no power to change the focus of their work (Keyzer 1988, Moran 1992, Pontin and Webb 1995, Rodwell 1995, Campbell and Lindow 1997, Morrall 1998a, Ryles 1999, Moore and McCulloch 1999).

The theme of care as being controlling was reported by most participants with schizophrenia, who believed there was too much control. They felt disempowered. Carers held the opposite view, expressing the view that control was necessary for their relatives with schizophrenia, and that there was not enough control. The views of those

authors who proposed that people with mental health problems are disempowered, excluded from the decision making processes, and the focus of mental health nursing is control, appeared to be supported in the current study. Some authors assert that, in reality, mental health nursing involves control. It is argued by nursing theorists that monitoring and control are part of nursing care (Benner 1984), and of nurturing, and may prevent harm (Peplau 1994, Benner 1994). However the majority findings in the current study strongly refuted this view. The self-selected sample and potential sample bias may, however, have led to this finding.

Most participants with schizophrenia, and all carers, asserted that there was not enough support from mental health nurses. Pollock (1989), in her research, asserted that nurses provided support, a view supported by Clinton et al (1998), and Clinton and Nelson (1999). However, the only support for this position in the current study came from participants who had experienced Home Treatment and reported very positively on this approach to care.

In Wray's (1994) study, a finding was that health professionals did not help people to understand schizophrenia, and this finding is also present in the current research. In the current study participants with schizophrenia and carers reported on the lack of information, and unhelpful information they were given (e.g. a participant with schizophrenia was advised to ignore the voices). All participants with schizophrenia expressed doubts about the benefits of medication and had concerns about the unpleasant side effects. These findings appear to support the views of Wray (1994). Poor communication between nurses and mental health service users was reported in the current study and this finding was supported by the findings in other studies (Ricketts and Kirschbaum 1994, Wray 1994, Ritchie and North 1995, Ricketts 1996).

Part of nursing care is interaction with clients. Nurses who interact with clients in a helpful, friendly manner are perceived to be good nurses and are valued by clients (Pollock 1989, Wray 1994, Ricketts and Kirschbaum 1994, Beech and Norman 1995, Campbell and Lindow 1997). It is argued by nursing theorists that this is engaged care, in which there is involvement with clients and partnership is facilitated between nurses and clients (Benner 1994). There was some support for this position in the current study. Some participants with a diagnosis of schizophrenia wanted more interaction and partnership with nurses.

9.2.14 Carer burden

A range of themes are now highlighted: disputed carer burden and positive care experiences, lack of adaptation to care-giving, negative care-giving experiences, poor health, disengagement, disrupted lives, measurement of carer burden, how carer burden is defined, the different perceptions of care-giving, carers' need, how health professionals view carers, who the care-givers are, and lack of partnership between carers and mental health nurses.

Some studies reported that people with schizophrenia were not perceived as a burden by carers (Creer et al 1982, Greenberg et al 1994). However, in the current study all carers reported subjective and objective carer burden.

Pathophysiology offers the concept of adaptation, specifically the general adaptation syndrome model (GAS) which is discussed by Selye (1956). The lack of adaptation to care-giving may explain subjective carer burden and poor health. There are three stages of GAS. There is the alarm reaction and body changes in response to exposure

to the stressor (e.g. the need to care for the individual with schizophrenia, or the odd behaviour of the individual with schizophrenia). Resistance to stress is diminished. The next stage is resistance to stressors, which is followed by the stage of exhaustion and individuals report a range of factors (e.g. anxiety, depression, tiredness, poor sleep and social isolation). In the current study, all these factors were reported by carers.

A range of authors proposed that adaptation to the care-giving situation occurs (Thompson and Doll 1982, Creer et al 1982, Namyslowska 1986, Perring et al 1990, Wheeler 1994, Adams 1994, Atkinson and Coia 1995, Howe 1995). A minority finding in the current study supports this view. A few older mothers appeared to have adapted after many years of caring for their relative with schizophrenia, and appeared to have less subjective burden and increased adaptive tolerance, but most carers did not appear to have adapted to the care-giving situation. Adaptation was reported in Eakes (1995), where it was reported as an unsuccessful strategy. In all these studies loss and grief accompanied attempts to adapt.

The negative experience of care-giving is supported in the literature. Perring et al (1990) conclude that carers are fearful of the future and worry about the loss of their relative's former self. Most carers in the current study expressed anxiety about the future, perceiving only more loss, stress and burden. They believed there was no hope and no positive future for themselves or their relative with schizophrenia. Carers believed themselves to be a failure, a belief which leads to emotional distress, according to Perring et al (1990). The themes of fear, loss and stress are also discussed in the Ferriter and Huband (2003) study. These parents of people with schizophrenia in the Ferriter and Huband (2003) study did not cope with behaviours that they perceived as difficult.

Poor physical and mental health were reported. Stress was reported to have led to depression in most carers, and some carers reported that they had been prescribed antidepressants. There was a great deal of anxiety, tiredness and exhaustion. They reported that they could not sleep or were afraid to sleep. They felt guilty about their relative's illness. These findings appeared to support the conclusions of Perring et al (1990), Adams (1994), Wheeler (1994), Atkinson and Coia (1995), Eakes (1995), Howe (1995), Provenchar (1996), Ward-Griffin and McKeever (2000) and Ferriter and Huband (2003). Perring et al (1990) and Atkinson and Coia (1995) highlight the association between care-giving and poor physical and mental health. According to Atkinson and Coia (1995) anxiety and depression occurs in carers of people with mental health problems. Other authors were in agreement with this conclusion (Adams 1994, Wheeler 1994, Eakes 1995, Howe 1995, Provenchar 1996, Ward-Griffin and McKeever 2000).

Disengagement appears to be a successful coping strategy. Rimmerman et al (1999) proposed that carers could disengage from their relative with schizophrenia and balance their own needs and the needs of their relative to achieve well-being. However, there was no evidence of this in the current study, even if the relative with schizophrenia did not live in the carer's home. Disengagement may have been re-evaluated as a strategy over time. The Thompson and Doll (1982) study coded 'social withdrawal' and 'emotional withdrawal' under the category 'exclusion of the patient', which appears to be a potentially negative subjective evaluation of this carer response. The degree of withdrawal was not clarified in this study. In Rimmerman et al (1999), the term was clarified and meant 'partial disengagement', which appeared to be viewed as a positive coping strategy which helped carers to find time for themselves. It may be the case that there was a re-evaluation of female carers' responses to sick relatives over time, as most

carers are female (Thompson and Doll 1982, Crotty and Kulys 1986, Aldridge and Becker 1993, Howe 1995, Jones et al 1995, Provenchar 1996).

A range of authors reported that carers had disrupted lives (Thompson and Doll (1982, Creer et al 1982, Wheeler 1994, Adams 1994, Howe 1995, Eakes 1995, Provenchar 1996, Perring et al 1990, Ferriter and Huband 2003). Perring et al (1990) maintain that there is disruption to the following aspects of life: social, personal, employment, financial and emotional. Crotty and Kulys (1986), who did not support the position that carer burden occurred in families, identified disruption in family life, although subjectivity was a potential flaw in this study. In their study, carers appeared to have close positive relationships with the individual with the diagnosis of schizophrenia and this may have led to the finding that there was no carer burden. However, Namyslowska (1986) disputed the finding that there was disruption in families, and proposed that there was no disruption in the lives of carers. There was no support for this finding in the current study. However a self-selected sample and potential sample bias may have led to this finding.

The findings in the current study appeared to support the findings of those authors who identified disruption in families. Carers perceived and reported that, in their view, it was the person with schizophrenia who caused family disruption, and carers reported they led restricted and disrupted lives. One carer, whose son with schizophrenia lived with her, pointed out that when her daughter visited, she highlighted the abnormal lives the mother and father were leading, because everything in the family was focused on the son with schizophrenia. The child carer and her younger siblings have had a disrupted life because of their mother's schizophrenia. One husband reported that when his wife was ill, nothing was normal in the house.

Measurement of carer burden is now discussed. There has been no uniform measure of carer burden (Perring et al 1990). Past studies have used a correlation between physical and psychiatric health as indicators of carer burden. An example of this is the Social Behaviour Assessment Schedule (SBAS) (Platt et al 1980:1983). The Objective Burden Questionnaire (OBQ) used in Provenchar (1996) is a modified version of the SBAS. It could be argued that there is a correlation between physical and psychiatric health indicators and carer burden. However most carers are older people who are more likely to have physical health problems. In the current study there was support for the correlation between physical and mental health problems and carer burden, and most carers were older than 50 years.

It is argued that if carers redefined the care-giving situation, they might perceive their situation in a more manageable and positive way (Adams 1994, Greenberg et al 1994, Atkinson and Coia 1995). However, this position ignores the loss and stress experienced by carers. Whether the term used is burden (Thompson and Doll 1982, Creer et al 1982, Crotty and Kulys 1986, Aldridge and Becker 1993, Eakes 1995, Provenchar 1996, Ferriter and Huband (2003), or impact (Wheeler 1994), or emotional experience (Adams 1994), care-giving has been reported negatively. In the current study, there was support for the view that care-giving is a burden and a negative experience. There was no support for the opposite view. However the self-selected sample and potential sample bias may have influenced the findings.

Health professionals' perceptions of the care-giving situation may be different from those of the carer. In the current study, the findings supported this position. There was support for the views of Howe (1995) and Ward-Griffin and McKeever (2000), who reported that carers were trying to support their relative because they were concerned.

Carers reported that health professionals informed them that they were being too intrusive and over-involved, which are elements of HEE. The focus on HEE when examining carers' experiences may cast doubt on the accuracy of the perceptions of carers. Health professionals may not have a good understanding of carers' subjective and objective burden. It may be the case that carers build up their own expertise and management strategies, which may be ignored or criticised by health professionals.

Health professionals may not focus on a reduction in carer burden or the well-being of carers. Carers' need may not be met and carers may become patients as a result of their carer burden (Ward-Griffin and McKeever 2000). It may be the case that carers are perceived only in terms of their relationship to the person with schizophrenia, and their own needs and rights may be ignored (Perring et al 1990). They may be perceived as co-workers, working under the supervision of the community psychiatric nurse (Ward-Griffin and McKeever 1996). There was support for these findings in the current study.

All carers in the current study, including the child carer, appeared to receive no or little support from other relatives in care-giving activities. However, it was apparent that most carers appeared to willingly adopt the care-giver role. It appeared that one family member was the care-giver and had the largest share of care-giving, as proposed by Perring et al (1990), Howe (1995), and Jones et al (1995).

Howe (1995) and Jones et al (1995) assert that a care-giver is most likely to be female and seven out of the 13 carers were female, offering partial support for this conclusion. However, this sample was a self-selected, convenience sample, which may or may not represent the proportion of female carers in the wider community.

The findings in the current study supported the findings in the Aldridge and Becker (1993) study about child carers, which were that child carers were often female. However, in the current study there were only three child carers, of which two were referred to by adult carers, and only one agreed to be interviewed briefly with her mother's permission and at her mother's insistence. There appeared to be family agreement in allocating the care-giving role to these girls. Parents expressed regret about this situation retrospectively, and the child carer who was interviewed stated that she would leave home as soon as she legally could.

A range of authors found that there was little partnership between carers and health professionals. Carers were not included in care and treatment planning (Creer et al 1982, Wheeler 1994, Eakes 1995, Howe 1995, Ferriter and Huband 2003). Communication between carers and health professionals was reported as poor (Creer et al 1982, Howe 1995, Eakes 1995). Carers did not receive explanations about their relative's behaviours (Howe 1995, Ferriter and Huband 2003) No advice was given to carers on dealing with daily problems (Eakes 1995). Carers believed that health professionals blamed them, because health professionals informed them that they were being too intrusive and possessive and interfered in the delivery of professional care (Howe 1995). In the current study, there was support for the findings reported in these past studies.

In the current study there was support for the view that subjective burden exists (Thompson and Doll 1982, Adams 1994, Wheeler 1994, Eakes 1995, Ferriter and Huband 2003). Carers reported stress, depression and negative feelings about their relative's behaviour. Carers felt physically ill and reported that they did not cope. There was support for the view that objective burden exists (Thompson and Doll 1982,

Provenchar 1996, Ferriter and Huband 2003). In the current study carers described poverty and objective care burden.

9.2.15 The Philosophy of Research and Methodological issues

In this section the philosophy of research and methodological issues are discussed. Within the philosophy of research there is subjective epistemology. Subjective knowledge of schizophrenia exists. This knowledge is comprised of personal experiences, visions and voices, views of these experiences and others' responses to individuals with these experiences. People ascribe meaning to their experiences. Subjective knowledge is valid and can be accessed using qualitative research, specifically phenomenology. Subjective knowledge has been gained in the current study. This is necessary because health professionals need to understand the subjective knowledge and experiences of individuals with a diagnosis of schizophrenia. Internal experiences may be accessed using phenomenology, which describes the structure of these experiences and examines the meanings given to them (Moustakis 1994, Bowling 1997). Participants' lives are a valid object of analysis (Smith 1998).

There is internally created ontology, which may be an individual's internal reality, influenced by their positive or critical voices. In this study the subjective reality of individuals with a diagnosis of schizophrenia has been accessed.

External Validity

It is unlikely that external validity was achieved in the current study because one could not guarantee that these findings were generalisable for the following reasons: the small

study sample was a self-selected sample from a local geographical area and there was a narrow age range. The method, unstructured interviews, meant that a second group of people living in the community with schizophrenia are unlikely to give similar responses, because in this method people may choose what themes to discuss. Therefore external validity may be weak because of the way the sample was recruited, an issue highlighted by Silverman (2000). However external validity may have been strengthened by highlighting contrary cases, because doubt may have been cast on explanations and a main finding may have been challenged (Silverman 2000). Computer assisted coding may have increased validity because it may have enhanced coding of data (Silverman 2000, Burns and Grove 2001).

Deviant or contrary cases

Silverman (1993) proposes that contrary findings, if few, strengthen majority findings because one set of data informs another set of data. In a later work, Silverman (2000) discusses contrary cases and asserts that contrary cases may cast doubt on explanations or refute main findings. Explanations and findings may be doubted if the researcher has not attempted to address contrary or deviant cases (Silverman 1993, 2000).

Representativeness is also strengthened, as a whole, when identifying contrary cases because generalisations are tested out by these contrary cases and this creates a stronger basis for one's generalisations (Silverman 2000). In the current research contrary cases were sought out (e.g. one participant reported that nursing care was good). On exploring this theme, it transpired that she meant Home Treatment was good. This minority finding, therefore supported the majority finding that nursing care in hospital and standard CPN care was not perceived as good. In this instance, the minority and

contrary findings added to, supported and informed the majority findings increasing the validity and representativeness of the majority findings. In conclusion, seeking out contrary cases may have strengthened the majority findings and a stronger case for generalisation from the current study may have been created. These issues are reported and discussed by Silverman (2000).

Representativeness

Frankfort-Nachmias and Nachmias (1996) and May (2001) assert that for findings to be representative the study population characteristics must be present in the general population under study. Gilbert (2001) asserts that if a study population is not representative, bias may be introduced and precise inferences cannot be made from a small study sample about characteristics of a wider population. Frankfort-Nachmias and Nachmias (1996 p.55), however, cast doubt on the idea of representativeness, discussing the “individualistic fallacy, the drawing of inferences about groupsdirectly from evidence gathered about the behaviours of individuals.”

Madison (1988) and Kvale (1996) contradict this view asserting that if the findings are representative of participants at the time of the study and in context, findings do not need to be replicated in another study. Kvale (1996) maintains that findings do not need to be generalised to wider populations and that contextuality and heterogeneity of knowledge are valuable replacements for generalisability (Kvale 1996). However, if one accepts Frankfort-Nachmias and Nachmias’s (1996) original views, and May’s (2001) and Gilbert’s (2001) views on representativeness, the findings of the current research sample may not represent the views of the wider population of people with schizophrenia.

Therefore the findings were unlikely to have been generalisable and this study sample was unlikely to have been representative of the wider population of people with schizophrenia because this was a small, homogenous, self-selected, convenience sample, with a narrow age range. It was possible that this sample expressed extreme views.

The study sample lived in the community and those in hospital are more likely to be in an acute episode of schizophrenia and to be younger. Most of these participants with schizophrenia, and their carers, were born between 1939 and 1959 and were likely to be influenced by beliefs current earlier in their lives. The geographical and ethnic contexts must be considered. All these participants were local to Bradford, and white. Their attitudes and expectations of nurses were part of a wider value system belonging to the local area and culture. Therefore the findings in the current study may not be representative of a wider sample of people with schizophrenia or carers. However the sample size was adequate because it conformed to the criteria of adequacy (Burns and Grove 2001). An evaluation of the adequacy of the sample was based on the scope of the study, the nature of the research question, the quality of the data, and the study design. The sample characteristics were adequately described. The participants were articulate and willing to share information. The sample produced saturation of the data and the study setting was clearly identified.

Objectivity and research bias

Objectivity may not have been achieved because it is possible that researcher bias occurred in the probing and prompting during the interview and in the coding of transcripts and in the selection of themes to explore and analyse, an issue discussed by

Silverman (2000). Minimal guidance was used in the interviews to try and reduce researcher bias. Silverman (2000) asserts that objectivity is the extent to which findings are free from bias.

There may have been bias in the current study due to the researcher's knowledge base. Values may have been imposed upon these findings despite intentions to bracket. It is also possible that interviewer effects introduced bias. Gilbert (2001) discusses how researcher characteristics may introduce bias. The researcher's sex, age, race and class will have an impact on the responses given by the interviewee. It is suggested that the interviewee will give a socially acceptable response if they are different in background from the interviewer (Gilbert 2001). May (2001) also suggests that interviewees give one type of response to an interviewer whom they perceive to be similar to themselves and another to an interviewer whom they perceive to be different from themselves. They will not necessarily give their actual views. Frankfort-Nachmias and Nachmias (1996) are in agreement with these authors.

However interviewer bias and influence may have been reduced by using an aide memoire (McCann and Clark 2005). There was minimal interviewer guidance with neutral probes and a focus on the participants' views on situations (Gilbert 2001). Participants were collaborators and active subjects in the study (Mishler 1991, Holloway and Wheeler 2002). Respondent validation was carried out. The researcher bracketed (Mishler 1986, Moustakis 1994, Smith 1998, Benner 1994, Burns and Grove 2001, Klieman 2004, Wall et al 2004). The researcher identified her biases and preconceptions (e.g. schizophrenia disables people), placing these to one side, focusing on the experiences of the participant and the emerging data. It could be said that the

researcher examined the data with new eyes. Bracketing was carried out prior to and during the interviews (Johns 1994, Klieman 2004).

The Lincoln and Guba (1985) model was used to ensure trustworthiness of the data. One of the criteria within this model is confirmability or neutrality of data, which may have been achieved by bracketing, maintaining a reflexive journal, and establishing an audit trail (Lincoln and Guba 1985, Tucket 2005). Analytical perspectives were described, interviews were tape recorded and transcribed verbatim, Burnard's (1991) framework of analysis was used and the researcher engaged in bracketing (Koivisto et al 2003).

This model permits an evaluation of other aspects of trustworthiness. The strategies used to ensure credibility (truth value) were a field journal, audiotape recording the interviews, creating a thematic log (a list of Nudist nodes) and auditing of the transcripts. The operations techniques were identification of contrary cases, member checking (participant validation). A potential problem with member checking is that the participant may agree with the findings because they believe the researcher knows best. Within-method triangulation, space triangulation and theory triangulation were used to increase credibility. In theory triangulation competing sociological and psychological theories were used to explain findings (Tucket 2005).

The sample was a purposeful sample (Koivisto et al 2003, Tucket 2005). When using the Lincoln and Guba (1985) model, the authenticity or truth value of the findings may be determined. However it is possible that a cultural script was produced and authenticity was not fully achieved (e.g. the traditional cultural script, 'I am a sick

patient, schizophrenia has stopped me’) (Silverman 1993), which may have reduced the credibility of the findings.

Dependability may have been achieved via the use of research strategies specifically, an audit trail, a field journal, a tape recorder, a thematic log, and the auditing of the transcripts, and operational techniques, specifically identification of contrary cases, within-method triangulation and establishing an audit trail.

Transferability may have been achieved by data display (Nudist nodes, themes) and simultaneous literature review and thick description (vignettes) (Tucket 2005). It is the responsibility of the original researcher to provide enough thick description to allow the reader to evaluate the applicability of the data to other contexts. This may have been achieved but external validity cannot be specified. The reader must reach their own conclusions about the transferability of the data and concepts in the original research.

Ethics: harm to participants

Robson (1993) maintains that encouraging a person to talk about unpleasant events can lead to distress and that people may negatively reappraise themselves. One participant negatively appraised himself, describing himself as a “loser”. Distress was obvious in one interview where the participant appeared to be hallucinating and chain smoking. She was tearful and said she wanted to die.

Singleton and McLaren (1995) propose that if trust and respect are present and nursing ethics and values (specifically, the ethical principles of beneficence, fidelity, honesty, confidentiality and autonomy) are adhered to, harm will be minimised. When one

participant became very distressed, the focus changed to beneficence and the interview was suspended and a cup of tea was made for her. Every effort was made to calm this participant. When she was more calm, she agreed to continue the interview because she wanted to speak of her experiences. Had she not been visited by her unqualified social worker, the researcher may have had to telephone the CPN services. The harm done by inviting the participant to talk about her experiences was unintentional and the focus was changed to beneficence when the distress occurred. Stress need not be so obvious. The UKCC (1996) highlights the exposure of clients and patients to unacceptable risk when nurses are involved in research activities. It is possible that stress could be introduced into a research participant's life by research activities and this could be construed as harm. People with health problems retain their client status in a research situation.

9.2.16 Summary of discussion

Most participants with schizophrenia reported no partnership, and felt disempowered. However, it is suggested by a range of authors that they could engage in self-empowerment, with emphasis on the internal locus of control, and that personal empowerment is possible (Houghton 1982, Coleman 1997, Williams and Collins 1999, Coleman and Smith 2005). Being connected to others appears to be essential to become empowered (Ralph and Lambert 1996, Williams and Collins 1999, Coleman and Smith 2005, Pitt and Kilbride 2006). There are minority findings to support this view.

Some participants with schizophrenia experienced visions and voices but felt themselves to be normal and did not want treatment, a finding which appears to support the work of Bentall (2003). More participants, however, reported that their visions and

voices distressed them, and they believed they were ill and wanted help and support. Trauma and stress appeared to contribute to the development of a vulnerability to schizophrenia, a point highlighted by Bentall (2003). There was some very limited evidence to support Bowlby's (1977,1979) attachment theory, as a contributory factor to the development of a vulnerability to schizophrenia. Parental attribution style, which might lead to continuing self-blame by the person with schizophrenia, is also supported, although these are minority findings.

High expressed emotion appeared to exist in the families of these participants with schizophrenia and was described by carers. This supports the work of Birchwood and Tarrrier (1994), Atkinson and Coia (1995), Barrowclough and Tarrrier (1996), Baguley and Baguley (1999). It may be the case that the CFI has flaws and that HEE is a subjective concept (Brown et al 1972, Vaughn and Leff 1976, Leff and Vaughn 1981, Meuser et al 1992, Atkinson and Coia 1995, Hughes et al 1996, Barrowclough and Tarrrier 1997) .

Some participants with schizophrenia appeared to adapt to their visions and voices, supporting the conclusions of Romme and Escher (1994) and Bentall (2003), but most did not, believing themselves to be ill and seeking help. Most participants with schizophrenia felt powerless with others and also felt powerless with regard to the voices and visions. A minority of participants with schizophrenia reported positive psychological, social, occupational and economic outcomes as defined by Houghton (1982), Beale and Lambric (1995) and Bentall (2003). Some had poor outcomes in one domain (e.g. clinical), in that they continued to hear voices and have visions, and good outcomes in other domains, (e.g. occupational) (Bentall 2003).

There appeared to be evidence in these findings for the work of Foucault (1980,1995,1996), who asserts that within social constructionism, medicine is dominant, and power/knowledge, biopower and biopolitics maintain medical power. There was support for the views of Foucault (1980, 1995, 1996), who maintains that biopolitics leads to treatment for those perceived as deviant, and the promotion of insight and the acceptance of the diagnosis. Foucault (1980, 1995, 1996) discusses common shared knowledge between health professionals and others (e.g. those who are diagnosed with schizophrenia), leading to acceptance of the diagnosis, and the findings of this study appeared to support this point.

Various authors maintain that medicalisation exists (Foucault 1980,1995,1996, Fox 1993, Rose 1994, Bunton 1997). According to Foucault (1980, 1995, 1996), Bury (1986), Rabinow (1991) and Fox (1993), docile bodies are created. Some authors emphasise the complicity of society in medicalisation (Porter 1987, Fox 1993, Bilton et al 1996), proposing that there is no oppression if society is complicit. Some authors highlight compliance in patients (Nicolson and McLaughlin 1987, Johnson 1997, Lupton 1997). Self-formation may explain this finding (Rabinow 1991, Fox 1993, Lupton 1997, Falzon 1998, Rose 1999). It is proposed that self-formation is a strategy which helps an individual to resist medicalisation (Lupton 1997). The social processes with Governmentality may explain complicity (Rose 1999). The findings in the current study supported the notion of complicity by society in medicalisation, because most other people the participants with schizophrenia knew accepted the diagnosis. There was some evidence to support the view that patients are compliant and therefore were not docile bodies, because most participants with schizophrenia accepted the diagnosis of schizophrenia, perceived themselves to be ill and sought help.

All participants with schizophrenia felt labelled and described the process of being labelled. The views of Barham (1984), Porter (1987), and Fox (1993) highlight labelling of the mentally ill and the findings appeared to support this view.

Exclusion, and the causes and reasons for exclusion, were highlighted by Foucault (1980,1995,1996), Barham and Hayward (1991), Bonner et al (2001), Bentall (2003) and others. All participants with schizophrenia reported exclusion at a personal and social level and exclusion led to poverty and social isolation.

There appears to be evidence to support the views of Berger and Luckman (1966) and Barham and Hayward (1991) who propose that there are internal processes which lead to acceptance of the new negative identity. Most participants with schizophrenia appeared to have accepted that they were ill with schizophrenia and could not do anything. However there was a minority view that participants did not want this negative identity, did not believe they were ill and maintained a positive self-concept, a finding which appears to support the views of Porter (1987), Rose (1994) and Foucault (1995). Participants with schizophrenia were critical of hospital and Community Care, reporting that care was controlling and this finding appeared to support the work of various authors (e.g. Beech and Norman 1995, Chadwick 1997, Morrall 1998a, Morrall 1998b, Clinton et al 1998, Clinton and Nelson 1999, Johansson and Lundman 2002).

In the current study carer burden emerged in the form of family disruption, anxiety, depression and stress. These findings supported the conclusions of Atkinson and Coia (1995) and others. There was limited evidence to support the views of Thompson and Doll (1982), Creer et al (1982), Namyslowska (1986) and Perring et al (1990), who proposed that adaptation to care-giving occurs. Most carers in the current study

reported findings that were contrary to this view. Typically, a single family member had the largest share of care giving, a point made by Jones et al (1995) and Howe (1995). Measuring carer burden may be problematic because in the past there has been no uniform measure.

External validity could not be guaranteed because of flaws in the sample (e.g. self-selected convenience sample) an issue highlighted by Silverman (2000). However, validity may have been strengthened by highlighting contrary cases (Silverman 2001) and using computer assisted coding (Silverman 2000, Burns and Grove 2001). Bias may have been introduced and reduced objectivity (Silverman 2000), but objectivity may have been strengthened and researcher influence reduced by the following strategies: use of an aide memoire (McCann and Clark 2002), focus on participants' views, use of neutral probes (Gilbert 2001), respondent validation, bracketing and within-method triangulation. Bracketing may also have reduced researcher influence and bias (Moustakis 1994). A range of research strategies and operational techniques in the Lincoln and Guba (1985) model of trustworthiness may have reduced researcher influence and increased objectivity, specifically, through maintaining a reflexive journal, establishing an audit trail, describing analytical processes, tape recording interviews and using Burnard's (1991) framework of analysis (Lincoln and Guba 1985, Koivisto et al 2003, Tucket 2005).

The experience of the interview caused great distress to one participant and the focus had to be changed from data collection in interviews to beneficence as understood in nursing ethics, and the interview was suspended. These findings supported the views expressed by Robson (1993), who maintains that a respondent may feel distress and

negatively reappraise themselves, and Singleton and McLaren (1995) who believe that harm can be minimised if one adheres to nursing ethics.

9.3 Implications of findings and the importance of these

9.3.1 The importance of a positive self-concept

It appeared to be that the participants with schizophrenia, who had moved on, had a positive self-concept and strong self-belief; two factors which none of the *stopped* group reported or displayed. This is important because nurses are in a position to help people with schizophrenia maintain or acquire a positive self-concept. It is important because it appeared that compulsory hospitalisation and coercive interventions seemed to be associated with the development of a negative self-concept, which appeared to stop participants with schizophrenia from moving on.

The potential may exist for people with schizophrenia to engage in self-care, make decisions, retain a positive self-concept, and perceive themselves as well and competent. Timely discharge home and negotiated care could prevent a person with schizophrenia from entering the negative cycle of repeated admissions, dependency and passivity, which leads to lack of self-belief and a negative self-concept.

9.3.2 Stress

Stress was perceived to be a main cause of schizophrenia. Stress and related health problems were not perceived to be adequately addressed by the mental health services. Family stress is highlighted by those who discuss carer burden (Wheeler 1994, Howe 1995, Ward-Griffin and McKeever 2000). Psychosocial interventions reduce stress

according to Brooker et al (1992) Tutty et al (1993), Birchwood and Tarrrier (1994) and Clinton and Nelson (1999). However, for Psychosocial interventions to be delivered, mental health nurses require intensive skill based education (Gamble 1995, McCann and McKeown 1995). This education is expensive and involves time, funding and commitment from nurses and managers. It also involves small case loads, which would highlight the shortage of nurses, and would involve further funding to provide more nurses.

An important finding was that carers who had cared for their relative for under 10 years reported more problems than those who had cared for 10 years and above. These included severe multiple problems and stress. Those who had cared for 10 years and above appeared to work through the problems, finding solutions and compromises. They suffered from stress but reported better coping. One implication of this is that family members in the future may not accept the carer role because of the stress and difficulties. Acceptance of the carer role is a prerequisite of Community Care and if nurses do not address carer stress, fewer people with schizophrenia may be allowed to remain at home, even when relatively well.

9.3.3 Stigma

Carers worried about stigma for the whole family, including children. An implication of this anxiety and the stigma is that stigma placed a severe psychological burden on families. This situation could lead to reluctance of families to adopt the carer role in future, rejection of people with schizophrenia by family members, and reduction of coping in carers. Families, through feelings of shame, tried to keep the knowledge of a family member with schizophrenia a secret from others. This meant that they did not

receive the help they needed. The psychological burden created by the stigma may have added to the existing care burden.

9.3.4 Lone carers and one carer in a family

All carers reported suffering from poor physical and mental health but lone carers appeared to suffer more than others. Even if a carer lived in a family, they had the largest share of carer duties and associated burden. The implication of this is that there may be a sudden, traumatic, change for the relative with schizophrenia when this carer becomes ill and is hospitalised. It may be that carers have to suffer severe ill health to receive any support by health professionals or other family members. Nurses may not be delivering proactive support or targeting the carers who most need the help. The implication of this is that failure to meet carers' needs may lead to family care becoming ineffective.

9.3.5 Negative identity, acceptance of the diagnosis, coercion and disempowerment

The creation of a negative identity for participants with schizophrenia was reported in these findings. Participants with schizophrenia accepted the new negative identity assigned to them. The implication of this is that their roles in life, and their potentialities, are still being defined and restricted (Barham 1984). The psychological consequences were disabling and prevented participants from changing anything in their lives. They appeared to be stopped by the illness and other people's behaviours, but also by their own beliefs and feelings.

Participants with schizophrenia reported that nurses promoted compliance and acceptance of the diagnosis and treatment, and that, while this appeared to lead to less conflict between nurses and people with schizophrenia, it also led to dependency and people being stopped in life. The implications of this may be a greater cost in terms of time spent in care and treatment, increased financial cost, and a personal cost for people with schizophrenia in that they may have a poorer quality of life and poorer outcomes. Enabling care could be focused on, with its developmental activity, helping people to manage schizophrenia, permitting them to make choices; changing the focus of nursing to prevent inertia, an issue highlighted by (Peplau 1988/1994).

Coercion in care by nurses was a major finding. The implication of this is that nurses' roles may not have changed since the creation of psychiatry, with nurses still being perceived as part of the social apparatus of control. Nurses have not given up control or facilitated more personal control for people with schizophrenia. People are still being managed on the basis of their risk potential (Bunton 1997). The situation is essentially the same as described by Foucault (1995), who describes the power imbalance, medicalisation, the creation of docile bodies by psychiatry, with nurses being part of the surveillance society and clinical gaze. This continuing situation may prevent people with schizophrenia having personal power or control in their lives. It may contribute to poor relationships with health professionals, conflict, stress, and people with schizophrenia not seeking timely support when it is necessary. This situation may make a person with schizophrenia avoid health professionals.

Participants with schizophrenia felt disempowered in treatment. Minority findings highlighted equality and empowerment and this related to receiving Home Treatment. Pyke (1999) proposes the need for more Home Treatment with emphasis on self-care,

family support and a psychosocial crisis service and an individualised proactive approach, identifying clients' needs and providing support that facilitates personal growth. Nurses would have to develop additional skills and work more in non-traditional mental health settings. They would have to commit themselves to equality in relationships, develop a genuine working alliance with people with schizophrenia, and relinquish power and authority, in order to develop more openness in interactions with people with schizophrenia. This needs a change in nurse education and a new emphasis on life management.

9.3.6 Invalidation of views

Participants with schizophrenia felt their views were invalidated and this caused conflict in the nurse-participant with schizophrenia relationship. Such conflict may prevent a person with schizophrenia from seeking help. Many in the study chose isolation, and this meant they did not receive help. When a problem becomes a crisis, the intervention is likely to be coercive and intrusive, a situation which leads to more avoidance and isolation. The significance of invalidating people with schizophrenia's views of the condition is that there is no shared understanding of schizophrenia, and none of the common ground necessary for partnership and potential recovery for the person with schizophrenia.

9.3.7 Length of time living with schizophrenia

Participants who had lived with schizophrenia for a shorter time tended to make a better recovery and move on, as they returned to their chosen life. Timely and more sensitive intervention may place more people with schizophrenia in this position. They

may suffer less of the harm, stress and trauma which may occur as a result of repeated and traumatic admissions and interventions which they may perceive as coercive and ineffective. Participants in the current study who had lived with schizophrenia for a shorter time had not lost sight of their chosen life goals and had not lost self-belief. Participants who had lived with schizophrenia for a longer time reported that they had not moved on in life. They had more loss and more severe feelings of failure and disempowerment, which appeared to prevent them from taking control of their lives. They reported suffering more stigma and more frequent and traumatic hospitalisation.

9.4 Summary of main findings and important outliers

9.4.1 Summary of main findings: participants with schizophrenia

Most participants with a diagnosis of schizophrenia reported the following findings. Stress was a cause of schizophrenia and they felt angry and uncared for. Most participants with schizophrenia believed they were ill, although some were ambivalent about this. Others' perceptions of them influenced them in a negative way. Participants with schizophrenia felt ashamed and excluded themselves. When examining interactions between these participants and health professionals, coercion and disempowerment were highlighted. They reported having no choices, control or power. They reported family conflict and hostility from others. They felt they had a flawed identity, which they accepted. This negative identity appeared to prevent them from moving on in life. Most participants with schizophrenia reported having a negative self-concept. A new finding emerging from the current study was that a positive self-concept appeared to be important in moving on in life after the diagnosis of schizophrenia. Carers accepted the expert knowledge of schizophrenia and expected people with schizophrenia to be non-

coping (women) or violent (men). A new finding which emerged from the current study was that carers appeared to be more prepared to care for female relatives with schizophrenia at home than male relatives with schizophrenia. Participants with schizophrenia felt they were rejected and believed they were ill. They reported that they lived restricted lives. For these participants with schizophrenia, good care meant nurses engaging with them. A new finding, which emerged from the current study, was that participants with schizophrenia avoided health professionals and other people. This behaviour appeared to have been a stress reduction and a life management strategy.

In the participants' view, medication was not part of care. There was severe and multiple loss and most participants believed that other people's behaviours had led to this loss. They reported situations in which they felt trapped and barriers were placed in their way. Strong negative emotions (e.g. anger, anxiety) were reported and they hated scrutiny. Their life before the diagnosis of schizophrenia was good, their present life was unpleasant and full of problems, and they believed their future would be unpleasant.

Outliers

Home Treatment was described as very good and was perceived as good care because people felt equal and listened to. Some reported attending a user group, but did not join. This appeared to be lack of confidence, which prevented them from joining. Some felt guilty about the effects of their schizophrenia on their children and the burden of care on child carers emerged as a theme. One mother with schizophrenia and her daughter were worried about genetic inheritance. A new finding, which emerged from the current

study, was that being diagnosed when younger and living with schizophrenia for a short time appeared to be associated with better outcomes.

9.4.2 Carers

Most carers reported the following findings. They believed that their sick relative caused them severe distress and conflict in the family. The relative was sick, not rational, and carers disagreed with health professionals who treated their relative as rational. The care burden was not equally shared by family members. There was severe stress within the family, and carers reported loss, having no power or control, felt blamed by health professionals and others, did not cope and their own health was poor. They reported anxiety, confusion and conflict. In their view, health professionals did not care or understand.

Carers expected help but did not receive help. They felt angry and blamed health professionals for the situation. A new finding, emerging from the current study, was that male carers appeared to feel less supported than female carers. Everyone expected all carers to cope, which carers perceived as unreasonable. However, most carers continued to care for their sick relatives and tried to control their lives; an action which was driven by concern. A new finding, emerging from the current study, was that younger carers and carers who had been caring for a short time did not accept the carer role unquestioningly, because of the stress. Care and control were perceived as the same activity by these carers. Carers reported a loss of normal identity for themselves and sought support from health professionals. Another new finding emerging from the current study was that carers support groups were perceived to be unhelpful. Carers worried about their relatives' loss. Carers led a restricted life because of the presence of

their sick relative, but they considered that they themselves were part of society, while their sick relative was not part of society. Many negative social, family, cognitive, and physical consequences were reported. In their view, the relative with schizophrenia should have accepted the sick role, identity and treatment. Carers felt that they had not moved on in their lives since they had adopted the carer role. Their lives prior to the onset of their relatives' schizophrenia were perceived as good, while the present and future were perceived as unpleasant.

When carers discussed their perceptions of others, it became clear that they perceived health professionals as unhelpful, too busy to care, disbelieving and unsupportive. Carers questioned the ability of health professionals to care for their relatives. Most carers perceived the relatives in the following way: men were violent and dangerous, while women were vulnerable, might harm themselves and needed protection. All people with schizophrenia were ill, needed to be controlled and there was risk in their every action.

Carers believed that their family had been stigmatised because of the presence of the person with schizophrenia. Stigma negatively influenced how others behaved towards these carers and the children in the family. Carers did not discuss their care-giving experiences or relate problems outside the home.

Sick relatives were perceived as dependent on carers. The extended family blamed and rejected male carers for causing the schizophrenia and rejected the nuclear family in which the person with schizophrenia lived. All carers felt misperceived by society. Some interactions between carers and their relatives with schizophrenia were reciprocal (e.g. stress, anger, blaming, irritation). Similarly, when exploring interactions between

carers and health professionals, each group blamed the other and conflict between these two groups was reported.

9.5 Recommendations

A larger more representative study is required and further proposals about care would be on the basis of a larger repeat study. However some tentative proposals are suggested by the findings in the current study.

Some proposals emerge from care issues which were identified. People with schizophrenia could be helped to define their care needs. Nurses could negotiate care more with people with schizophrenia, with the aim of developing a shared understanding of desirable care, which appears to be the following: social and emotional support, help with problem solving, helping people to overcome difficult events in life and negative beliefs about themselves, and helping people to take some control of their lives.

Nurses could negotiate an acceptable level of engagement with people with schizophrenia, which would be perceived as helpful but not intrusive. This might lead to people with schizophrenia feeling more positive about interactions with nurses because they would have some choice and control.

Nurses could facilitate stress reduction in people with schizophrenia and carers, in order to reduce the distress and ill health in both groups. Nurses could facilitate more support with the aim of providing social and emotional support and encouraging networking. Groups could be set up in local health centres. This could promote family coping and

cohesion, maintaining the support network for people with schizophrenia. Nurses could focus on promoting a positive self-concept for people with schizophrenia with the aim of facilitating moving on in life. A positive self-concept appears to be more important than other factors in moving on, and appears to be more important for older people with schizophrenia and people who have lived with schizophrenia for many years.

Nurses could engage more sensitively with people with schizophrenia with the aim of gaining a shared understanding of the experiences of living with schizophrenia. Nurses could accept the views and experiences of people with schizophrenia in order to improve working relationship between nurses and people with schizophrenia. This is likely to involve discussion of the nature and content of voices and visions and what they mean to the person with schizophrenia. Nurses may need to accept that voices and visions are a positive concept for some people with schizophrenia.

People with schizophrenia could be encouraged to be more active in their own care, with self-care, joint goal setting and shared care planning being promoted. This might lead to more satisfaction with services and care received from health professionals and families, less avoidance of health professionals by people with schizophrenia, and, potentially, fewer relapses. The focus of care could be changed from compliance to active user involvement, promotion of self-empowerment, self-management and life management, with the aim of preventing passivity in people with schizophrenia. This means partnership, focusing on the needs and goals defined by people with schizophrenia, and gaining access to their perceptions of empowerment. Home Treatment could be expanded and offered to more people with schizophrenia. Nurses could ensure that resources were available for men with schizophrenia because men appear to be more likely to live alone and be unsupported. Nurses could enable these

men to gain support and help from various sources when they need it, through education and advice. Similarly, nurses could ensure that resources are available for young people with schizophrenia, with the aim of preventing disability, negative outcomes and the development of a negative self-concept. Nurses could encourage membership of user support groups as this appears to lead to a degree of self-empowerment, recovery and reduced conflict at home.

Carers' needs could be met more sensitively and effectively. Nurses could engage with families more in order to help them understand the benefits of disengagement from their relative with schizophrenia and less intrusive family care (e.g. less conflict, less high expressed emotion, better family relationships, improved health for carers, reduced subjective burden).

Identified carers and lone carers could be targeted and supported with the aim of preventing ill health, stress and multiple loss from occurring. New carers and younger carers could be targeted and supported, with the aim of preventing them from becoming so stressed that they refuse to continue caring. Carers of men with schizophrenia could receive more support than they currently receive because men appear to be perceived as a greater burden than women with schizophrenia. Child carers could be identified. With multi-professional support they could be supported in the home or in appropriate groups, and encouraged to keep in contact with the parent with schizophrenia.

9.6 Conclusions

Some participants with schizophrenia reported perceiving their visions and voices positively, while for others it was a distressing experience. Participants with

schizophrenia believed that others perceived them as failed, incompetent and sick people. Most participants with schizophrenia accepted the diagnosis, indicating a common shared knowledge of schizophrenia and some degree of compliance and complicity, despite reports of coercion in mental health care. The findings showed evidence of the social construction of schizophrenia and labelling, with resulting disempowerment of people with schizophrenia.

There was no shared understanding of care between participants with schizophrenia and nurses, or between participants with schizophrenia and their carers. A greater understanding of the meaning of schizophrenia to participants with schizophrenia and carers has been explored in the current study. It has been possible to identify the different perceptions of care and of schizophrenia in the study. Participants with schizophrenia had a perception of what care should be, which was emotional support, practical help on a daily basis and not being alone. Care meant people understanding their point of view and being valued, having some privacy and being treated as an equal and an adult. The care they received was control, coercion and medication, which they criticised. However carers believed that medication and coercion were necessary.

The participants with schizophrenia wanted full involvement in decision making and better communication with health professionals. The findings suggested that participants with schizophrenia's perceptions of care and nurses negatively affected their interactions with nurses and influenced their choice of strategy (e.g. compliance or avoidance). The findings suggested that the carers' perceptions of care and of schizophrenia influenced their choice of strategies in their interactions with their relatives with schizophrenia (e.g. controlling them) and in their interactions with nurses (e.g. seeking support and blaming them).

The findings suggested that many needs were unmet by the nursing services, and stress was prevalent in participants with schizophrenia and carers. The most common and severe problems reported were emotional, psychological and social. Negative identity led to participants with schizophrenia living a restricted life and acceptance of the negative identity led to negative psychological consequences, one of which was being stopped in life. Some participants felt that the behaviours of others had prevented them from moving on in life. Not moving on in life could have been a consequence of serious mental illness or of socialisation into the sick role, caused by frequent admissions, disempowering care, and lack of resilience due to being older. Older people with schizophrenia may have accepted the objective reality of their illness because they belonged to a generation that did not question this and believed that one could not recover from schizophrenia. Living with a family that believed that schizophrenia was an illness one could not recover from might have prevented a participant with schizophrenia from moving on.

Only a few, who had lived with schizophrenia for less than two years, had the best outcomes and the least loss, and were able to return to their old life with some success. Moving on appeared to involve the following: having a positive self-concept, disagreeing with the diagnosis, choosing isolation, being angry (as opposed to sad) and being employed. The feeling of moving on in life may have led to reduced contact with health professionals, while those who felt stopped in life maintained the contact. Reduced socialisation into mental patienthood, or effective and timely treatment may have led to the feeling of having moved on. The exact process is not clear.

Most participants felt disempowered and only some participants with schizophrenia appeared to engage in self-empowerment. The harm done by hospitals and mental

health nurses was highlighted, yet participants with schizophrenia continued to seek support from mental health nurses, suggesting a degree of ambivalence.

Male participants with schizophrenia were more likely than female participants to be perceived as violent, rejected by the family, and live alone and unsupported. Living alone and the avoidance strategy appeared to bring some benefits to some people with schizophrenia.

Actions by families and events in society appeared to cause more problems for people with schizophrenia (e.g. intrusive family care, stigma and exclusion) than hearing voices or having delusions. All carers felt they were not supported by health professionals and were concerned about the lack of support for their relatives with schizophrenia. Adult male carers appeared to be blamed by their extended family and received less sympathy than adult female carers. Younger carers appeared to be less committed to continuing the caregiving than older carers, indicating a lack of adaptation or a different attitude to caregiving in this group. Support groups for carers appeared to be ineffective, but this finding must be treated some caution due to the small number of carers in this study.

REFERENCES

- Abrahamson, L.Y., Seligman, M.E.P., Teasdale, J.D.(1978) Learned helplessness in humans: critique and reformulation. Journal of Abnormal Psychology, 78, 40-74.
- Adams, T. (1994) The emotional experience of caregivers to relatives who are chronically confused- implications for community mental health nursing. International Journal of Nursing Studies, 31 (6), 545-553.
- Ainsworth, M. D. S., Blehar, M. C., Water, E. (1978) Patterns of Attachment: Assessed in the Strange Situation and at Home. Hillsdale, New Jersey: Lawrence Erlbaum.
- Aldridge, J., Becker, S. (1993) Children who Care-Inside the World of Child Carers. Loughborough: Loughborough University and Nottingham Association of Voluntary Organisations.
- American Psychiatric Association (1987) Diagnostic and Statistical Manual of Mental Disorders. Revised Third Edition (DSM-111-R) Washington D.C: American Psychiatric Association.
- American Psychiatric Association (1994) Diagnostic and Statistical Manual of Mental Disorders. Fourth Edition (DSM1V) Washington D.C: American Psychiatric Association.
- Armstrong, D. (1994) Bodies of knowledge/knowledge of bodies. In: Jones, C., Porter, R. eds. Reassessing Foucault: Power Medicine and the Body. London: Routledge 17-27.
- Atkinson, J. M., Coia, D.A. (1995) Families Coping with Schizophrenia: A Practitioner's Guide to Family Groups. Chichester: Wiley.
- Baguley, I., Baguley, C. (1999) Psychosocial interventions. Mental Health Care, 2 (9), 314-317.

- Baker, G.A., Jacoby, A., Smith, D.F., Dewey, M.E., Chadwick, D.W., (1994) Development of a novel scale to assess life fulfilment as part of the further refinement of a quality of life model for epilepsy. Epilepsia, 35 (3), 591-596.
- Barham, P., (1984) Schizophrenia and Human Value. Oxford: Basil Blackwell.
- Barham, P., Hayward, R. (1991) From the Mental Patient to the Person. London: Routledge.
- Barker, P. (1999) The Philosophy and Practice of Psychiatric Nursing. London: Churchill Livingstone.
- Barker, P., Davidson, B. (1998) Psychiatric Nursing: Ethical Strife. London: Arnold.
- Barker, P., Jackson, S. (1997) Mental health nursing, making it a primary concern. Nursing Standard, 11(17), 39-41.
- Barrera, M. (1981) Social support in the adjustment of pregnant adolescents: assessment issues. In: Gottlieb, B.H. ed. Social Networks and Social Support. Beverly Hills, California: Sage Publications 69-96.
- Barrowclough, C., Tarrier, N., Watts, S. (1985) Knowledge About Schizophrenia Interview. Salford: Salford Community Mental Health Project. Cited in: Wray, S. J. (1994) Schizophrenia sufferers and their carers: a survey of understanding of the condition and its treatment and of satisfaction with services. Journal of Psychiatric and Mental Health Nursing, 1, 115-123, 116.
- Barrowclough, C. Tarrier, N. (1997) Families of Schizophrenic Patients: Cognitive Behavioural Interventions. Cheltenham: Stanley Thornes.
- Battista, J., Almond, R. (1973) The development of meaning in life. Psychiatry, 36, 409-427.
- Beale, V., Lambric, T. (1995) The Recovery Concept: Implementation in the Mental Health System. A Report by the Community Support Programme Advisory Committee. Ohio: Ohio Department of Mental Health Office of Consumer Services.

- Beck, J. C. ,Van Der Kolk, B. A. (1987) Reports of childhood incest and current behaviour of chronically hospitalised psychotic women. American Journal of Psychiatry, 144, 1471-1476.
- Beck, A.T., Beck, R.W. (1972) Screening for depressed patients in family practice. Postgraduate Medicine, December 81-85.
- Beck, A.T., Rush, A.G., Shaw, B.F., Emery, G. (1979) Cognitive Therapy of Depression. New York: Guildford Press.
- Beech, P., Norman, I.J. (1995) Patients' perceptions of the quality of psychiatric nursing care: findings from a small scale descriptive study. Journal of Clinical Nursing, 4, 117-23.
- Benner, P. (1984) From Novice to Expert: Excellence and Power in Clinical Nursing Practice. London: Addison-Wesley Publishing Company.
- Benner, P. (1994) Interpretive Phenomenology: Embodiment, Caring and Ethics in Health and Illness. London: Sage Publications.
- Bentall, R. P. (2003) Madness Explained: Psychosis and Human Nature. London: Allen Lane Penguin.
- Beresford, P., Branfield, F. (2006) Developing inclusive partnerships: user-defined outcomes, networking and knowledge-a case study. Health and Social Care in the Community, 14 (5), 436-444.
- Berger, P., Luckman, T. (1966) The Social Construction of Reality, a Treatise in the Sociology of Knowledge. London: Penguin Books.
- Bertram, G., Stickley, T. (2005) Mental health nurses, promoters of inclusion or perpetrators of exclusion. Journal of Psychiatric and Mental Health Nursing, 12, 387-395.
- Bilton, T., Bonnet, K., Skinner, D., Stanworth, M., Webster, A. (1996) Introducing Sociology. Third edition. Basingstoke: MacMillan Education Press.

- Birchwood, M., Tarrier, N.(Eds) (1994) Psychological Management of Schizophrenia.Chichester: Wiley.
- Birchwood, M., Fowler, D., Jackson, C. (2000) Early interventions in psychosis: a guide to concepts, evidence and interventions. Chichester: Wiley.
- Birchwood, M., Jackson, C. (2001) Schizophrenia. Hove: Psychology Press Ltd.
- Bonner, L., Barr, W., Hoskins, A. (2002) Using primary care-based mental health registers to reduce social exclusion in patients with severe mental illness. Journal of Psychiatric and Mental Health Nursing, 9, 585-593.
- Bowers, L.(1991) Don't blame the institution. Nursing Times, 87 (22), 32-34.
- Bowlby, J. (1977) The making and breaking of affectional bonds. British Journal of Psychiatry, 130, 201-210.
- Bowlby, J.(1979) The Making and Breaking of Affectional Bonds. London: Routledge.
- Bowling, A.(1997) Research Methods in Health. Milton Keynes: Open University Press
- Bracken, P., Thomas, P.(1999) Home treatment. Openmind, 95, Jan/Feb, 17.
- Bradshaw, T.(1997) Does family intervention reduce relapse in schizophrenia? Psychiatric Care, 4, 30-33.
- Brooker, C. Tarrier, N. Barrowclough, C., Butterworth, A., Goldberg, D. (1992) Training nurses for psychosocial interventions. British Journal of Psychiatry, 160, 836-844
- Brown, G.W., Monck, E.M., Carstairs, G.M., Wing, J.K. (1962) Influence of family life on the course of schizophrenic illness. British Journal of Preventative and Social Medicine, 16, 55-56.
- Brown, G.W., Rutter, M. (1966) The measurement of human activities and relationships: a methodological study. Human Relationships, 19, 241-263.

- Brown, G.W., Birley, J.L.T., Wing, J.K. (1972) Influence of family life on the course of schizophrenic disorders: a replication. British Journal of Psychiatry, 121, 241-247.
- Bryman, A.(1988) Quantity and Quality in Social Research. London: Unwin Press.
- Bumpass, L., Sweet, J. (1989) National Survey and Families and Household. Wisconsin: University of Wisconsin-Madison, Department of Sociology.
- Bunton, R. (1997) Popular health and advanced liberalism. In: Petersen, A., Bunton, R.(1997) Foucault, Health and Medicine. London: Routledge 233-243.
- Burnard, P.(1991) A method of analysing interview transcripts in qualitative research. Nurse Education Today, 11, 461-466.
- Burnard, P. (2005) Interviewing. Nurse Researcher. 13 (1), 4-6
- Burnet, S. (1994) A new lease of life. Nursing Times, 10 (34), 57-58.
- Burns, N. Grove, S.K. (2001) The Practice of Nursing Research: Conduct, Critique and Utilisation. Third edition London: W. B. Saunders.
- Burke, M.L. (1989) Chronic Sorrow of Mothers of School Age Children with Myelomeningocele Disability. Boston: Boston University Unpublished Doctoral Dissertation. Cited in: Eakes, G.G. (1995) Chronic sorrow: the lived experience of parents of the chronically mentally ill individuals. Archives of Psychiatric Nursing, 1X (2), 77-84.
- Bury, M.R. (1986) Social constructionism and the development of medical sociology. Sociology of Health and Illness, 8 (2), 137-169.
- Bury, M. (1991) The sociology of chronic illness: a review of research and prospects. Sociology of Health and Illness, 13 (4), 451-468.
- Campbell, P. (1997) Citizen Smith. Nursing Times, 93 (1), 31-32.
- Campbell, P., Lindow, V., (1997) Changing Practice, Mental Health Nursing and User Empowerment. London: Royal College of Nursing 3.

- Carver, C. S., Sheier, M.F., Weintraub, J.K. (1989) Assessing coping strategies: a theoretical based approach. Journal of Personality and Social Psychology, 56, 267-283.
- Carver, C.S., Pozo, C., Harris, S.D., Noriega, V., Sheier, M.F., Robinson, D.S. (1993) How coping mediates the effects of optimism on distress: a study on women with early stage breast cancer. Journal of Personality and Social Psychology, 65 (2), 375-390.
- Chadwick, P.K. (1997) Recovery from psychosis: learning more from patients. Journal of Mental Health, 6 (6), 577-588.
- Chadwick,P. (2000) Bullying and Psychosis. Openmind, 103, 24.
- Clinton, M., Lunney, P., Edwards, H., Weir, D., Barr, J. (1998) Perceived social support and community adaptation in schizophrenia. Journal of Advanced Nursing, 27, 955-965.
- Clinton, M., Nelson, S. (1999) Advanced Practice in Mental Health Nursing. Oxford: Blackwell Science.
- Cohen, L., Manion, L. (1994) Research Methods in Education. Fourth edition. New York: Routledge.
- Coleman, R. (1997) Partnership through ownership. Nursing Times, 93 (27), 40.
- Coleman, R., (1999) Recovery: An Alien Concept. Gloucestershire: Handsell Publishing.
- Coleman, R., Smith, M. (2005) Working with Voices: Victim to Victor 11. Second edition. Dundee: P&P Press.
- Craine, L.S., Henson, C.E., Colliver, J.A., MacLean, D.G. (1988) Prevalence of a history of sexual abuse among female psychiatric patients in a State hospital system. Hospital and Community Psychiatry, 39 (3) 300-304.
- Creer, C., Sturt, E., Wykes, T.(1982) The role of relatives. In: Wing, J. K. Long term community care experience in a London borough. Psychological Medicine, 12, Monograph Supplement 2, 29-39.

- Creasia, J.L., Parker, B. (1991) Conceptual Foundations of Professional Nursing Practice. London; Mosby.
- Crotty, P. Kulys, R. (1986) Are Schizophrenics a burden to their families? Significant other's views. Health and Social Work, 11, 173-188.
- Crowe, M., O'Malley, J., Gordon, S. (2001) Meeting the needs of consumers in the community: a working partnership in mental health in New Zealand. Journal of Advanced Nursing, 35 (1), 88-96.
- Croydon-Smith, A.(1982) Schizophrenia and Madness. London: George Allen and Unwin.
- Crumbaugh, J.C., Maholick, L.T. (1964) An experimental study in existentialism. The psychometric approach to Frankl's concept of noogenic neurosis. Journal of Clinical Psychology, 20, 200-207.
- Cutcliffe, J. (1997) The nature of expert psychiatric nurse practice: a grounded theory study. Journal of Clinical Nursing, 6 (4), 325-332.
- Department of Health and Welsh Office (1983) Code of Practice - Mental Health Act. (2nd Edition), London: HMSO.
- Department of Health (1990) The Care Programme Approach. London: DoH
- Department of Health (1994a) Working in Partnership: A Collaborative Approach to Care. London: DoH.
- Department of Health (1994b) Guidance on the Discharge of Mentally Disordered People and Their Continuing Care in the Community. London: HMSO.
- Department of Health (1996) Building Bridges: A Guide to Arrangements for Interagency Working for the Care and Protection of Severely Mentally Ill People. London: HMSO.
- Department of Health (1997a) Developing Partnerships in Mental Health Nursing. London: DoH.

- Department of Health (1997b) The New NHS: Modern and Dependable. London: DoH
- Department of Health (1998) Modernising Mental Health Services, Safe, Sound and Supportive. London: DoH
- Department of Health (1999) National Service Framework for Mental Health. London: DoH
- Department of Health (2000) National Service Framework Our Healthier Nation. London: DoH
- Descartes, R. (1912/1988) A Discourse on Method. New York: E.P Dutton.
- Devaney, S. M., Haddock, G., Lancashire, S., Baguley, I., Butterworth, T., Tarrier, N., James, A., Molyneux, P. (1998) The clinical skills of community psychiatric nurses working with patients who have severe and enduring mental health problems: An empirical Analysis. Journal of Advanced Nursing, 27, 253-260.
- Diamond, D. (1986) Attachment and Separation-Individuation Coding Manual. USA: Yale University.
- Diamond, D. (1987) Attachment, Bonding and Separation-Individuation Scales. Rating Scales for Interview Data. USA: Yale University.
- Diamond, D., Doane, J. (1994) Disturbed attachment and negative affect style: an intergenerational spiral. British Journal of Psychiatry, 164, 770-8.
- Dinges, M. (1994) The reception of Michel Foucault's ideas on social discipline, mental asylums, hospitals and the medical profession in German historiography. In: Jones, C., Porter, R. (Eds) (1994) Reassessing Foucault: Power Medicine and the Body. London: Routledge 181-212.
- Doona, M.E.(1995) Nurses' judgment as they care for persons who exhibit impaired judgment: a phenomenological study. Journal of Professional Nursing, 11 (2), 98-109.
- Dowling, M. (2004) Hermeneutics: an explanation. Nurse Researcher, 11 (4), 30-41.

- Doyle, M. (1999) Organisational responses to crisis and risk: issues and implications for mental health nurses. In: Ryan, T. ed. Managing Crisis and Risk in Mental Health Nursing. Cheltenham: Stanley Thornes Publishers Ltd 40-58.
- Duffy, D. (1997) Partnership revisited. Mental Health Newsletter, London: RCN 6-8
- Dummett, M. (1993) Origins of Analytical Philosophy. London: Duckworth.
- Eakes, G.G. (1995) Chronic sorrow: the lived experience of parents of the chronically mentally ill individuals. Archives of Psychiatric Nursing, 1X (2), 77-84.
- Eakes, G.G., Hainsworth, M.E., Lindgren, C.L., Burke, M.L. (1991) Establishing a long-distance research consortium. Nursing Connections, 4 (1), 51-57.
- Edwards, S.D. (1999) Risk assessment in the context of mental health care: some moral considerations. In: Ryan, T. ed. Managing Crisis and Risk in Mental Health Nursing. Cheltenham: Stanley Thornes Publishers 141-148.
- Edwards, C., Titchen, A. (2003) Research into patients' perspectives: relevance and usefulness of phenomenological sociology. Methodological Issues in Nursing Research. 44 (5), 450-460.
- Escher, S. (1994) Talking about voices. In: Romme, M., Escher, S. Accepting Voices London: Mind Publications 50-59.
- Esterson, A. (1970) The Leaves of Spring: A Study in the Dialectics of Madness. London: Tavistock Publications.
- Economic and Social Research Council (2005) Research ethics framework. [online]. Swindon: ESRC. Available from: http://www.esrc.ac.uk/ESRCinfoCentre/images/ESRC_Re_Ethics-Frame_tcm6-11291.pdf [accessed May 2006].
- Farber, M. (1966) Aims of Phenomenology. New York: Row and Harper.
- Falzon, C. (1998) Ethics, critique and enlightenment. In: Falzon, C. Foucault and Social Dialogue. London: Routledge 57-78, 64.

- Ferriter, M., Huband, N. (2003) Experiences of parents with a son or daughter suffering from schizophrenia. Journal of Psychiatric and Mental Health Nursing, 10, 552-560.
- Flaherty, J.A., Gaviria, F.M., Pathak, D.S. (1983) The measurement of social support: the Social Support Inventory. Comprehensive Psychiatry, 23, 521-529.
- Flanagan, J.C. (1954) The Critical Incident Technique. Psychological Bulletin, 5, 327-358.
- Foucault, M. (1980) The politics of health in the eighteenth century. In: Foucault, M., Power/Knowledge. (Ed. C. Gordon), Hertfordshire: The Harvester Press A Division of Simon and Shuster International Group 166-182.
- Foucault, M.(1980) Truth and power. In: Gordon, C ed. Power/Knowledge. Hertfordshire: The Harvester Press. A division of Simon and Shuster International Group 109-133.
- Foucault, M. (1988) Technologies of the self. In: Martin, L.H.,Gutman, H., Hutton, P.H. eds. Technologies of the Self-A Seminar with Michel Foucault. London: Tavistock 16-49.
- Foucault, M.(1995) Madness and Civilization A History of Insanity in the Age of Reason. London: Routledge.
- Foucault, M.(1996) The Carceral. In: Muncie, J., McLaughlin, E., Langan, M. eds. Criminological Perspectives: A Reader. London: Sage Publications in association with the Open University 392-396.
- Fox, N.J. (1993) Post Modernism, Sociology and Health. Buckingham: Open University Press.
- Frankfort-Nachmias, C., Nachmias, D. (1996) Research Methods in the Social Sciences. London: Arnold.
- Fransella, F., Bannister, D. (1977) A Manual for Repertory Grid Technique. London: Academic Press.

- Freeman, H., Simmons, O. (1961) Feelings of stigma among relatives of former mental patients. Social Problems, 8, 312-321.
- Freshwater, D. (2002) Therapeutic Nursing: Improving Patient Care Through Self-Awareness and Reflection. London: Sage.
- Freire, P. (1970) Pedagogy of the Oppressed. London: The Continuum Publishing Company.
- Gamble, C. (1995) The thorn training initiative. Nursing Standard, 9 (15), 31-34.
- Giddens, A. (1989) Sociology. (First edition) Cambridge: Polity Press.
- Giddens, A. (2001) Sociology. (Fourth edition) Cambridge: Polity Press.
- Gilbert, N. (ed) (2001) Researching Social Life. Second Edition London: Sage.
- Giorgi, A. (1985) Phenomenology and Psychological Research. Pittsburg: Duquesne
Cited in: Koivisto, K., Janhonen, S., Vaisanen, L. (2003) Patients' experiences of psychosis in an in-patient setting. Journal of Psychiatric and Mental Health Nursing, 10, 221-229.
- Glaser, B., Strauss, A.L.(1968) The Discovery of Grounded Theory: Strategies for Qualitative Research. London: Weidenfield and Nicolson.
- Goffman, E. (1963/1968) Stigma: Notes on the Management of Spoiled Identity. Harmondsworth: Penguin.
- Goldberg, D.P., Hillier, V.F. (1979) A scaled version the General Health Questionnaire. Psychological Medicine, 9, 139-145.
- Goldberg, D., Jenkins, R., Sharp, D., Gask, L., Tylee, A., Paton, J. (2000) WHO Guide to Mental Health in Primary Care ICD-10. Geneva: World Health Organisation.
- Goodman, L. A. Rosenberg, S. D., Meuser, K. T., Drake, R.E., (1997) Physical and sexual assault history in women with serious mental illness: prevalence, correlates, treatment and future research directions. Schizophrenia Bulletin, 23, 685-99.
- Gorman, T. Out of the shadows. Nursing Times. 1 (88), 32.

- Gottschalk, L.A., Glesser, G.C. (1968) The Measurement of Psychological State Through an Analysis of Verbal Behaviour. Berkeley: University of California Press.
- Gournay, K. (1995) New facts about schizophrenia. Nursing Times, 91, (25) 32-33.
- Guba, E., Lincoln, E. (1989) Fourth Generation Evaluation. London: Sage.
- Greenberg, J.S. Greenley, J.R., Benedict, P. (1994) Contributions of persons with serious mental illness to their families. Hospital and Community Psychiatry, 45, (5) 475-480
- Hammersley, M. (1990) Reading Ethnographic Research: A Critical Guide. London: Longmans.
- Hammersley, M. (1992) What's Wrong with Ethnography? Methodological Explorations. London: Routledge.
- Hammersely, M., Atkinson, P. (1983/1995) Ethnography: Principles in Practice. Second edition. London: Routledge.
- Hanily, F. (1999) Policy and legislation in the management of crisis and risk. In: Ryan, T. (Ed) Managing Crisis and Risk in Mental Health Nursing. Cheltenham: Stanley Thornes Publishing 26-39.
- Haralambos, M., Smith, F., O'Gorman, J., Heald, R. (1993) Sociology a New Approach. Second Edition Lancashire: Causeway Press Ltd.
- Haralambos, M., Holborn, M. (2004) Sociology: Themes and Perspectives. Sixth Edition London: Harper Collins.
- Hek, G., Blunden, G. (2000) Systematically searching and reviewing the literature. Nurse Researcher, 7 (3), 4-57.
- Hickey, G., Kipping, C. (1998) Exploring the concept of user involvement in mental health through a participation continuum. Journal of Clinical Nursing, 7, 83-88.
- Hirsch, S.R., Leff, J.P. (1975) Abnormalities in Parents of Schizophrenics. London: Oxford University Press.

- Holloway, I., Wheeler, S. (2002) Research in Nursing Issues. Oxford: Blackwell Publications.
- Houghton, J.F. (1982) First person account: maintaining mental health in a turbulent world. Schizophrenia Bulletin, 8 (3), 548-553.
- Howe, G. (1995) Working with Schizophrenia: a Needs Based Approach. London: Jessica Kingsley.
- Hughes, I., Hailwood, R., Yoeman-Abbati, J., Budd, R.(1996) Developing a family intervention service for serious mental illness: clinical observations and experiences. Journal of Mental Health, 5 (2), 145-149.
- Hugman, R. (1991) Power in Caring Professions. London: MacMillan.
- Hycner, H.R.(1985) Some guidelines for the phenomenological analysis of interview data. Human Studies, 8, 279-303.
- Illich, I. (1975) Medical Nemesis. London: Calder and Boyars.
- Jablensky, A., Sartorius, N., Ernberg, G., Anker, M., Korten, A., Cooper, J.E., Day, R., Bertelsen, A. (1992) Schizophrenia: manifestations, incidence and course in different cultures. Psychological Medicine, Supplement 20, 1-97.
- Ingham, J.G. (1965) A method of observing symptoms and attitudes. British Journal of Clinical and Social Psychology, 4, 131-140.
- Johansson, M., Lundman, B. (2002) Patients' experiences of involuntary psychiatric care: good opportunities and great losses. Journal of Psychiatric and Mental Health Nursing, 9, 639-647.
- Johns, C. (1994) Nuances of reflection. Journal of Clinical Nursing, 3 (2), 71-75.
- Johnson, M. (1997) Nursing Power and Social Judgment. Developments in Nursing and Health Care. Aldershot: Ashgate.

- Johnstone, L. (1999) Do families cause 'schizophrenia'? Revisiting a taboo subject. In: Newnes, C., Holmes, G., Dunn, C., (Eds) This is Madness A Critical Look at Psychiatry and the Future of Mental Health. Ross-on-Wye: PCCS Books 119-134.
- Johnson, M.E. (2000) Heidegger and meaning: implications for phenomenological research. Nursing Philosophy, 1,134-136.
- Jones, S.L., Roth, D., Jones, P.K. (1995) Effect of demographic and behavioural variables on burden of caregivers of chronic mentally ill persons. Psychiatric Services, 46 (2), 141-145.
- Jones, S., Tallis, F. (1994) Coping with Schizophrenia. London: Sheldon Press.
- Kai, J., Crossland, A. (2001) Perspectives of people with enduring mental ill health from a community-based qualitative study. British Journal of General Practice, 51, 730-736.
- Kazak, A.E. (1988) Stress and social networks in families with older institutionalised retarded children. Journal of Social Clinical Psychology, 6, 448-461.
- Keyzer, D. (1988) Challenging Role Boundaries: conceptual frameworks for understanding the conflict arising from the implementation of the nursing process in practice. In: White, R. ed. Political Issues in Nursing, Past Present and Future London: Wiley 95-119.
- Klieman, S. (2004) Phenomenology: to wonder and search for meanings. Nurse Researcher, 11 (4), 7-19.
- Koivisto, K., Janhonen, S., Vaisanen, L. (2002) Methodological issues in nursing research :applying a phenomenological method of analysis derived from Giorgi to a psychiatric nursing study. Journal of Advanced Nursing, 39 (3), 285-295.
- Koivisto, K., Janhonen, S., Vaisanen, L. (2003) Patients' experiences of psychosis in an in-patient setting. Journal of Psychiatric and Mental Health Nursing, 10, 221-229.

- Krawieka, M., Goldberg, D., Vaughan, M. (1977) A standard psychiatric assessment for rating chronic psychotic clients. Acta Psychiatrica Scandinavia, 55, 299-308.
- Kreisman, D.E., Simmens, S.J., Joy, V.D. (1979) Rejecting the patient: preliminary validation of a self-report scale. Schizophrenia Bulletin, 5,220-222.
- Kuipers, E. Raune, D. (2000) The early development of expressed emotion and burden in the families of people with first onset psychosis. In: Birchwood, M., Fowler, D., Jackson, C. eds. Early Intervention in Psychosis. London: Wiley 128-40.
- Kvale, S. (1996) Interviews: An Introduction to Qualitative Research Interviews. London: Sage Publications.
- Laing,R.D. (1960) The Divided Self. London: Tavistock.
- Laing, R.D., Esterson, A. (1964) Sanity, Madness and the Family. London: Tavistock.
- Larson, D.L., Attkisson, C.C., Hargreaves, W.A., Nguyen, T.D. (1979) Assessment of client/patient satisfaction: development of a general scale. Evaluation and Programme Planning, 2, 197-207
- Laurance, J. (2002) Pure Madness: How Fear Drives the Mental Health System. London: King's Fund.
- Lebow, J. (1982) Consumer satisfaction with mental health treatment. Psychological Bulletin, 91, 244-45 In: Wray, S.J.(1994) Schizophrenia sufferers and their carers: a survey of understanding of the condition and it's treatment and of satisfaction with services. Journal of Psychiatric and Mental Health Nursing, 1, 115-123.
- Leff, J., Vaughn, C. (1981) The role of maintenance therapy and relatives' expressed emotion in the relapse of schizophrenia: a two year follow up. British Journal of Psychiatry, 139, 102-104.
- Leff, J.P., Kuipers,L., Berkowitz,R., Eberlein-Vries, R., Sturgeon, D. (1982) A controlled trial of social interventions in the families of schizophrenic patients. British Journal of Psychiatry, 141, 123-134.

- Leff, J., Vaughn, C. (1985) Expressed Emotion in Families: It's Significance for Mental Illness. New York: Guildford Press.
- Leff, J., Vaughn, C. (1985) Intervention in families of schizophrenic patients: the London study. In: Leff, J., Vaughn, C. Expressed Emotion in Families: It's Significance for Mental Illness. New York: Guildford Press 123-149.
- Leff, J., Wig, N., Ghosh, A. (1987) Influence of relatives' expressed emotion on the course of schizophrenia in Chandigarh. British Journal of Psychiatry, 151, 166-173.
- Leonard, V.W. (1989) A Heideggerian phenomenological perspective on the concept of the person. Advances in Nursing Science, 11, (4) 40-55.
- Leudar, I. Thomas, P. (2000) Verbal hallucinations in contemporary psychiatry. In: Leudar, I., Thomas, P. Voices of Reason, Voices of Insanity. London: Bruner-Routledge 107-127.
- Leudar, I., Thomas, P. (2000) Working with voices. In: Leudar, I., Thomas, P. Voices of Reason, Voices of Insanity. London: Bruner-Routledge 129-148.
- Lewis, V.S., Zeichner, A.M. (1960) Impact of admission to a mental hospital on the patient's family. Mental Hygiene, 44, 503-509.
- Lincoln, Y.S., Guba, E.G. (1985) Naturalistic Enquiry. Beverly Hills: Sage.
- Lupton, D. (1997) Foucault and the medicalisation critique. In: Petersen, A., Bunton, R. Foucault, Health and Medicine. London: Routledge 94-112.
- MacMillan, J. F., Gold, A., Crow, T. J., Johnson, A.L., Johnstone, E.C. (1986) The Northwick Park story of first episodes of schizophrenia. IV Expressed emotion and relapse. British Journal of Psychiatry, 148, 133-143.
- Madison, G.B. (1988) The Hermeneutics of Post Modernism. Indiana: Indiana University Press.
- Markowska, D. (1980) Kultura Dnia Codziennego Miejskich Rodzin Pracowniczych w Polsce Raport z Badan_ Warsaw: Ifispan Cited in: Namyslowska, I. (1986) Social and

emotional adaptation of the families of schizophrenic patients. Family Systems Medicine, 4 (4), 398-407.

Marshall, C, Rossman, G.B. (1999) Designing Qualitative Research. Third edition. London: Sage.

Martin, S.D.(1995) Coping with chronic illness. Home Healthcare Nurse, 13 (4), 50-54.

May, T. (2001) Social Research Issues, Methods and Processes. Third Edition. Buckingham: Open University Press

Meuser, K. T., Bellack, A. S., Wade, J. H., Sayers, S. L., Rosenthal, C.K. (1992) An assessment of the educational needs of chronic psychiatric patients and their relatives. British Journal of Psychiatry, 160, 674-680.

McCarthy, B., Kuipers, L., Hurry, J., Harper, R., LeSage, A. (1989) Counselling the relatives of long-term adult mentally ill: evaluation of the impact on relatives and patients. British Journal of Psychiatry, 154, 768-775.

McCann, G., McKeown, M. (1995) Applying psychosocial interventions: the thorn initiative in a forensic setting. Psychiatric Care, 2 (4), 133-136.

McCann, T. V. (2004) Advancing self-determination with young adults who have schizophrenia. Journal of Psychiatric and Mental Health Nursing, 11, 12-20.

McCann, T., Clark, E. (2005) Using unstructured interviews with participants who have schizophrenia. Nurse Researcher. 13 (1), 7-18.

Mishler, E.G. (1986/1991) Research Interviewing Context and Narrative. London: Harvard University Press.

MIND (National Association for Mental Health) (1992) Stress on Women Campaign. London: MIND Publications.

Moore, C., McCulloch, A. (1999) Acutely poor services. Openmind, 96, 9.

Moorey, J. (1998) The Ethics of Professionalised Care In: Barker, P., Davidson, B. eds. Psychiatric Nursing: Ethical Strife. London:Hodder 39-56.

- Moran, M. (1992) A user's view of psychiatric nursing. Interactions, Autumn, 14-17.
- Morrall, P. (1998a) Mental Health Nursing and Social Control. London: Whurr.
- Morrall, P. (1998b) Clinical sociology and empowerment. In: Barker, P., Davidson, B. Psychiatric Nursing: Ethical Strife. London: Hodder 249-255.
- Moustakis, C. (1994) Phenomenological Research Methods. London: Sage Publications.
- Mulhall, D.G. (1976) Systematic self-assessment by PQRST. Psychological Medicine, 6, 591-597.
- Namyslowska, I. (1986) Social and emotional adaptation of the families of schizophrenic patients. Family Systems Medicine, 4 (4), 398-407.
- National Association of Health Authorities and Trusts (NAHAT) (1991) Definitions of Health and Social care. Developing an Approach. A West Midlands Study. Care in the Community (Number 5) West Midlands: NAHAT.
- National Institute for Clinical Excellence (2002) Schizophrenia: Core Interventions in the Treatment of Schizophrenia in Primary and Secondary Care Clinical Guideline 1. London: NICE.
- National Health Service Executive (1996) Clinical Guidelines: Using Clinical Guidelines to Improve Patient Care within the NHS. London: NHSE .
- National Schizophrenia Fellowship (2003a) Information. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].
- National Schizophrenia Fellowship (2003b) What you need to know about schizophrenia. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].
- National Schizophrenia Fellowship (2003c) News and views. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003d) Our latest news and your latest views . [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003e) Looking for help. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003f) How to access services. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003g) Living with schizophrenia. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003h) Press releases. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003i) Briefing notes. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003j) Your voice. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003k) Campaigning for change. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003l) Employment bulletin board. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003m) National Schizophrenia Fellowship policies. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

National Schizophrenia Fellowship (2003n) National Schizophrenia Fellowship responses to consultation documents. [online]. London:NSF. Available from: <http://www.nsf.org.uk> [accessed 24th February 2003].

- National Schizophrenia Fellowship (2003o) News and views, bulletin board. [online]. London:NSF. Available from: <http://www.nsf.org.uk/wwwboard/index/html> [accessed 24th February 2003].
- Nettleton, S.C. (1994) Inventing mouths: disciplinary power and dentistry. In: Jones, C., Porter, R. eds. Reassessing Foucault Power Medicine and the Body. London Routledge 73-90.
- Newell, R., Gournay, K. (2003) Mental Health Nursing: An Evidence Based Approach. London: Churchill-Livingstone
- NHS Centre for Reviews and Dissemination (2001) CRD guidance for those carrying out or commissioning reviews: Undertaking systematic reviews of research on effectiveness CRD Report 4. Second edition. York: NHS Centre for Reviews and Dissemination University of York Available from: <http://www.york.ac.uk/inst/crd/report4.htm> [Accessed 23rd February 2003].
- Nicolson, M., McLaughlin, C.,(1987) Social constructionism and medical sociology: a reply to M. R. Bury. Sociology of Health and Illness, 9 (2), 107-126.
- Nie, N.H. (1983) SPSSX Users Guide. Illinois: McGraw-Hill.
- Nocon, A., Qureshi, H. (1996) Outcomes of Community Care for Users and Carers. Milton Keynes: Open University Press.
- Norman, I.J., Redfern, S.J., Tomalin, D.A., Oliver, S. (1992) Developing Flanagan's Critical Incident Technique to elicit indicators of high and low quality nursing care from patients and their nurses. Journal of Advanced Nursing, 17, 590-600.
- Norton, L. (1999) The philosophical bases of grounded theory and their implications for research practice. Nurse Researcher, 7 (1), 31-34.
- Nuechterlein, K.H., Dawson, M.E., Gilton, M., Ventura, J., Goldstein, M. J., Snyder, K. S., Yee, C.M., Mintz, J. (1992) Developmental processes in schizophrenic disorders: longitudinal studies of vulnerability and stress. Schizophrenia Bulletin, 18, 387-425.

- Nursing and Midwifery Council (2002) Code of Professional Conduct. London: NMC
- O'Connor, P., Brown, G.W. (1984) The SESS Manual. Bedford: Bedford Square.
- Office of the Deputy Prime Minister (2004) Mental Health and Social Inclusion. The SEU Report. London: ODPM.
- Osborne, T. (1994) On anti-medicine and clinical reason. In: Reassessing Foucault Power Medicine and the Body. London: Routledge 28-47.
- Overall, J.E., Goreham, D.R. (1962) The Brief Psychiatric Rating Scale. Psychological Reports, 10, 799-812
- Parker, G. (1979) Parental characteristics in relation to depressive disorders. British Journal of Psychiatry, 134, 138-147.
- Paley, G., Shapiro, D. A., Worrall-Davies, A. (2000) Familial origins of expressed emotion in relatives of people with schizophrenia. Journal of Mental Health Nursing, 9 (6), 655-663.
- Patel, N., Fatimilehin, I. A. (1999) Racism and mental health. In: Newnes, C., Holmes, G., Dunn, C. This is Madness: A Critical Look at Psychiatry and the Future of Mental Health Services. Ross-on-Wye: PCCS Books 51-74.
- Peat, S. (2001) Web is the way forward. Northern News, Spring, National Schizophrenia Fellowship, 8.
- Peplau, H.E. (1988) Interpersonal Relationships in Nursing: a Conceptual Frame of Reference for Psychodynamic Nursing. London: MacMillan Press.
- Peplau, H.E. (1994) Psychiatric mental health nursing: challenge and change. Journal of Psychiatric and Mental Health Nursing, 1(1), 3-7.
- Perring, C., Twigg, J., Atkin, K.(1990) Families Caring for People Diagnosed as Mentally Ill: The Literature Examined. London: HMSO/Social Policy Research Unit.
- Phelan, M., Slade, M., Thornicroft, G., Dunn, G., Holloway, F., Wykes, T. (1995) The Camberwell Assessment of Need: the validity and reliability of an instrument to assess

the needs of people with severe mental illness. British Journal of Psychiatry, 167, 589-595.

Pieranunzi, V.R. (1997) The lived experience of power and powerlessness in psychiatric nursing: a Heideggerian hermeneutical analysis. Archives of Psychiatric Nursing, X1 (3), 155-162.

Pitt, L., Kilbride, M (2006) Researching recovery from psychosis. Mental Health Practice, 9 (7), 20-23.

Platt, S., Weyman, A., Hirsch, S., Hewett, S. (1980) The Social Behaviour Assessment Schedule (SBAS): rationale, contents, scoring and reliability of a new interview schedule. Social Psychiatry, 15, 43-55.

Platt, S.D., Weyman, A., Hirsch, S. (1983) Social Behaviour Assessment Schedule (SBAS) The Schedule. Third edition. Berkshire: NFER-Nelson.

Platt, S. (1985) Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. Psychological Medicine, 15 (2), 383-393.

Polit-O'Hara, D., Hungler, B.P. (1999) Nursing Research Principles and Methods. Philadelphia: Lippincott.

Polit, D.F., Beck, C.T. (2004) Nursing Research Principles and Methods. London: Lippincott Williams and Wilkins.

Polkinghorne, D.E. (1988) Narrative Knowing and the Human Sciences. New York: University of New York.

Pollock, L.C. (1989) Community Psychiatric Nursing: Myth and Reality. Royal College of Nursing Research Series, Harrow: Scutari Press.

Pontin, D., Webb, C. (1995) Assessing patient satisfaction: part 2 findings: nursing, the hospital and patients' concerns. Journal of Clinical Nursing, 5 (1), 33-40.

Porter, R. (1987) A Social History of Madness, Stories of the Insane. London: Phoenix Giants.

- Provenchar, H.L.(1996) Objective burden amongst primary care givers of persons with chronic schizophrenia. Journal of Psychiatric and Mental Health Nursing, 3, 181.
- Pyke, J. (1999) Community services and supports. In: Clinton, M., Nelson, M. Advanced Practice in Mental Health Nursing. Oxford: Blackwell Science 77-95.
- Qualitative Solutions and Research Pty (1997) QSR NUD*IST4 User Guide. London: Sage Publications.
- Rabinow, P. (1991) The Foucault Reader, An Introduction to Foucault's Thoughts. London: Penguin Books.
- Ralph, R.O., Lambert, D.(1996) Needs Assessment Survey of a Sample of AMHIME. Maine: University of Southern Maine Institute of Public Affairs.
- Ricketts, T., Kirschbaum, M.N. (1994) Helpfulness of mental health day care: client and staff views. Journal of Advanced Nursing, 20, 279-306.
- Ricketts, T., (1996) General satisfaction and satisfaction with nursing communication on an adult psychiatric ward Journal of Advanced Nursing, 24, 479-487.
- Ritchie, J., North, C., (1995) Factors Influencing the Implementation of the Care Programme Approach: A Research Study Carried out by the Social and Community Planning Research Team. London: HMSO.
- Rimmerman, A., Treves, G., Duvdevany, I. (1999) Psychological distress and well-being of mothers of adults with psychiatric disability: the effects of day treatment, social support networks and maternal involvement. Psychiatric Rehabilitation Journal, 22 (3), 263-269.
- Roberts, G. (1991) Delusional belief systems and meaning in life: a preferred reality? British Journal of Psychiatry, 159, Supplement 14, 19-28.
- Robson, C. (1993) Real World Research. Oxford: Blackwell.

- Rodwell, C.M.(1996) An analysis of the concept of empowerment. Journal of Advanced Nursing, 23, 305-313.
- Rogers, C.R. (1951) Client Centred Therapy-Its Current Practices, Implications and Theory. Boston: Houghton Mifflin.
- Rogers, A., Pilgrim, D., Lacey, R. (1993) Experiencing Psychiatry:Users' Views of Services. London: MIND Publications Issues in Mental Health.
- Rogers, S.E., Chamberlin, J.,Ellison, M.L., Crean, T.(1997) A consumer constructed scale to measure empowerment among users of mental health services. Psychiatric Services, 48 (8), 1042-1047.
- Romme, M., Escher, S.(1994) The new approach: a Dutch experiment. In: Romme, M., Escher. S. Accepting Voices. London: Mind Publications 11-27.
- Rose, N.(1994) Medicine, history and the present. In: Jones, C., Porter, R. eds. Reassessing Foucault: Power Medicine and the Body. London: Routledge 48-72.
- Rose, N. (1999) Governing the Soul: The Shaping of the Private Self. London: Free Association Books.
- Ross, P. (1998) The self and compulsory treatment. In: Edwards, S. D. Philosophical Issues in Nursing. London: MacMillan Press Ltd 181-199.
- Rotter, J., Williams, B. (1947) The incomplete sentence test as a method of studying personality. Journal of Consulting Psychology. 11, 43-48
- Ryles, S.M. (1999) A concept of empowerment: its relationship to mental health nursing. Journal of Advanced Nursing, 29 (3), 600-607.
- Ryan, T. (1999) Managing Crisis and Risk in Mental Health Nursing. Cheltenham: Stanley Thornes Publishers Ltd.
- Sainsbury Centre for Mental Health (1998) Keys to Engagement. London: Sainsbury Centre for Mental Health.

- Sandelowski, M. (1993) Rigor or rigor mortis in qualitative research revisited. *Advances in Nursing Science*, 16, 1-8 Cited in: Koivisto, K., Janhonen, S., Vaisanen, L. (2003) Patients' experiences of psychosis in an in-patient setting. *Journal of Psychiatric and Mental Health Nursing*, 10, 221-229.
- Sayer, A. (1984) *Method in Social Science: A Realist Approach*. London: Hutchinson.
- Schainblatt, A.H., Hatry, H.P. (1980) *Mental Health Services: What Happens to the Clients?*. Washington D.C.: The Urban Institute.
- Schneider, K. (1959) *Clinical Psychopathology*. New York: Grune and Stratton.
- Selye, H. (1976) *The Stress of Life*. Second edition. New York: McGraw-Hill.
- Shapiro, M.B. (1961) A method of measuring psychological changes specific to the individual psychiatric patient. *British Journal of Medical Psychology*, 34, 151-155.
- Sharkey, S. (1999). Crisis and risks associated with schizophrenia. In: Ryan, T. ed. *Managing Crisis and Risk in Mental Health Nursing*. Cheltenham: Stanley Thornes Publishers Ltd. 59-74.
- Shearing, C. D., Stenning, P. C. (1996) From the panopticon to Disney world: the development of discipline. In: Muncie, J., McLaughlin, E., Langan, M. eds. *Criminological Perspectives*. London: Sage 413-423.
- Shields, P. (1985) The Consumer's view of psychiatry. *Hospital and Health Services Review*, May 117-119.
- Silverman, D.C. (1993) *Interpreting Qualitative Data*. London: Sage Publications.
- Silverman, D. (2000) *Doing Qualitative Research A Practical Handbook*. London: Sage Publications.
- Simpson, E.L., House, A.O. (2002) Involving users in the delivery and evaluation of mental health services: systematic review. *British Medical Journal*, 325: 1265-1268.
- Singleton, J., McLaren, S. (1995) *Ethical Foundations of Health Care: Responsibilities in Decision Making*. London: Mosby.

- Slade, P.D., Bentall, R.P. (1988) Sensory Deceptions: A Scientific Analysis of Hallucinations. Baltimore: John Hopkins University Press.
- Smith, M. J. (1998) Social Science in Question. London. Sage.
- Speziale, H.J.S., Carpenter, D.R. (2007) Qualitative Research in Nursing. Fourth edition. London: Lippincott Williams and Wilkins.
- Spitzer, M., Uehlein, F. (1992) Phenomenology and psychiatry. In: Spitzer, M., Uehlein, F., Schwartz, M. A., Mundt, C. Phenomenology Language and Schizophrenia. London: Springer-Verlag 35-45.
- Spitzer, M., Uehlein, F., Schwartz, M. A., Mundt, C.(1992) Phenomenology Language and Schizophrenia. London: Springer-Verlag.
- Spradley, J. (1979) The ethnographic interview. New York: Holt, Rinehart and Winston.
- Cited in May, T., (2001) Social Research Issues, Methods and Processes. Third edition. Buckingham: Open University Press 131.
- Strauss, A. (1987) Qualitative Research for Social Scientists. Cambridge: Cambridge University Press.
- Strauss, A.L. (1996) Qualitative Analysis for Social Scientists. Cambridge: Cambridge University Press.
- Tagg. S. (1985) Life story interviews and their appreciation In: The Research Interview: Uses and Approaches. London: Academic Press 163-199.
- Tarrier, N., Barrowclough, H.C., Vaughn, C., Bamrah, J.S., Porceddu,K., Watt, S., Freeman, H. (1988) The community management of schizophrenia: a controlled trial of a behavioural intervention with families to reduce relapse. British Journal of Psychiatry, 153, 532-534.
- Tarrier, N., Barrowclough, H.C., Vaughn, C., Bamrah, J.S., Porceddu, K., Watt, S., Freeman, H. (1989) Community management of schizophrenia: a two-year follow up of a behavioural intervention with families. British Journal of Psychiatry, 154, 625-628.

The United Kingdom Mental Health Resource Centre (2003a) Mental Health Online Community page. [Online] Swindon: ESRC. Available from: <http://www.info-exchange.org.uk> [accessed 23rd February 2003].

The United Kingdom Mental Health Resource Centre (2003b) The Mental Health Journal. [Online] Swindon: ESRC. Available from: <http://www.info-exchange.org.uk> [accessed 23rd February 2003].

The United Kingdom Mental Health Resource Centre (2003c) Users' and Professionals' Views. [Online] Swindon: ESRC. Available from: <http://www.info-exchange.org.uk> [accessed 23rd February 2003].

The United Kingdom Mental Health Resource Centre (2003d) Users' Views. [Online] Swindon: ESRC. Available from: <http://www.info-exchange.org.uk> [accessed 23rd February 2003].

Thomas, B., Liness, S., Vearnals, S., Griffin, H. (1992) Involuntary cohabittees. Nursing Times, 88 (49), 58-60.

Thompson, E.H. Doll, W. (1982) The burden of families coping with the mentally ill: an invisible crisis. Family Relations: Journal of Applied Family and Child Studies, 35, (3) 375-388.

Thorne, S. (2000) Data analysis in qualitative research. Evidenced Based Nursing. 3, (3) 68-70.

Tomson, D. (2002) The whole challenge, the whole solution. Openmind, 115, 14-15 .

Tucket, A.G. (2005) Part 11. Rigour in qualitative research: complexities and solutions. Nurse Researcher. 13 (1), 29-42.

Tutty, L.M., Gregory, B. (1993) An evaluation of redirection through education: a psychosocial rehabilitation programme for young adults with psychiatric disability. Psychosocial Rehabilitation Journal, 16 (3), 9-25.

- Tredget, J. (1999) Family intervention in the treatment of schizophrenia. Mental Health Nursing, 19 (4), 25-27.
- United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1992a) The Scope of Professional Practice. London: UKCC
- United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1992b) Code of Professional Conduct. London: UKCC.
- United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1996) Guidelines for Professional Practice. London: UKCC.
- Upton, H. Graves, D. (1996) Philosophical Problems in Health Care. Aldershot: Avebury 20-22.
- Valimaki, M. (1998) Psychiatric patients' views of the concept of self-determination: findings from a descriptive study. Journal of Clinical Nursing, 7, 59-66.
- Van Os, J., Hanssen, M., Bijl, R.V., Ravelli, A.(2000) Strauss (1969) revisited: a psychosis continuum in the normal population? Schizophrenia Research, 45, 11-20.
- Van Os, J., Marcellis, M., Germeys, I., Graven, S., Delespaul, P. (2001) High expressed emotion: marker for a caring family? Comprehensive Psychiatry, 42 (6), 504-507.
- Vaughn, C., Leff, J. (1976) Measurement of expressed emotion in families of psychiatric patients. British Journal of Social and Clinical Psychology, 15, 157-165.
- Veit, C.T., Ware, J.E. (1983) The structure of psychological distress and well-being in general populations. Journal of Counselling and Clinical Psychology, 51, 730-742.
- Wall, L., Glenn, S., Mitchinson, S., Poole, H. (2004) Using a reflective diary to develop bracketing skills during a phenomenological investigation. Nurse Researcher, 11 (4), 20-29.
- Ward-Griffin, C., McKeever, P. (2000) Relationships between nurses and family caregivers: partners in care? Advanced Nursing Science, 22, 89-103.
- Weschler, J.A. (1977) In a Darkness. New York: W.W. Norton Company Inc.

- Westwood, M. (1997) Handing back the reins. Nursing Times, 93 (41), 29-30.
- Wiggins, O.P., Schwartz, M., Spitzer, M. (1992) Phenomenological/descriptive psychiatry: the methods of Edmund Husserl and Karl Jaspers. In: Spitzer, M., Uehlein, F., Schwartz, M. A., Mundt, C. Phenomenology Language and Schizophrenia. London: Springer-Verlag 46-70.
- Williams, C. C., Collins, A. A. (1999) Defining new frameworks for psychosocial interventions. Psychiatry, 62, 61-68.
- Wheeler, C. (1994) The diagnosis of schizophrenia and its impact on the primary caregiver. Nursing Praxis in New Zealand, 9 (3), 15-23.
- World Health Organisation (1992a) The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines. Geneva: World Health Organisation.
- World Health Organisation (1992b) WHO co-ordinated multi-centre study on the course and outcome of schizophrenia. Geneva: World Health Organisation.
- Wray, S. J. (1994) Schizophrenia sufferers and their carers: a survey of understanding of the condition and its treatment and of satisfaction with services. Journal of Psychiatric and Mental Health Nursing, 1, 115-123.

APPENDICES

APPENDIX 1: Interview Schedule

These are some questions I will ask. Please feel free to say anything you want. The interview will last one hour maximum. We can stop anytime you want.

1. Can you tell me about your life since they told you that you had schizophrenia?
2. How did it affect you at first, then later? How about now?
3. What has led you to feel stressed, unhappy, happy, good about yourself?
4. How do others react to you? How do you feel about that?
5. When something happened, to do with the schizophrenia, what were your feelings? How did you deal with those feelings or the event that happened? How did you feel about the others people involved?
6. What was the situation that led to your first contact with the mental health services? How did you feel about that? How do you feel about that now? What did it mean to you at the time?
7. Were there any situations that led to you being readmitted into hospital? What were your feelings about that? What did it mean to you at the time?
8. What did you do and feel like when you first met the psychiatrist, the nurse, when you first had to take medication, when they told you that you must stay in hospital and when you first went home after being in hospital?
9. What do you do now when someone (not a doctor or nurse) asks you about:
 - your mental health problem ?
 - being in hospital?
 - when someone wants to talk about schizophrenia?
 - when someone says something negative and insulting about people with schizophrenia?

when someone says something positive about people with schizophrenia?

10. What has schizophrenia done to your life? What has it done to your view of yourself? How do you feel about this and how do you deal with this?

11. What happened about your old friends/workmates? How do you feel about that? How do you deal with that?

APPENDIX 2: Supplementary questions

The supplementary questions were specific to each theme, for example:

What is the context?

What is the health and social policy related to the situation?

What are users', nurses' and carers' roles?

What is the conceptual framework of nursing?

What is the philosophical basis of nursing?

What is the social discourse on schizophrenia?

What is the language of schizophrenia?

This led me into the themes of power, control, care issues, social construction of schizophrenia and views of people with schizophrenia. Family dynamics was then explored and the supplementary question was how are the lives of people with schizophrenia shaped?

Within the nursing theme, the supplementary questions were as follows:

Explore therapeutic interventions and scientific knowledge they are based on

What are the limits of scientific medicine?

What is the social context?

What are the roles and role boundaries for mental health nurses working in today's health service?

APPENDIX 3: Methodology used in literature

Quantitative	Total	Qualitative	Total
Retrospective	1	Case studies	16
Prospective	2	Interviews	15
Experimental non RCT	26	Evaluation of intervention	13
Experimental RCT	31	Clinical study	5
Survey	9	Ethology	2
Rating scales	12	Phenomenology	2
Questionnaires	15	Action research	2
Epidemiological studies	3	ethnography	2
Twin Studies	2	Critical incident technique	1
Biochemical measurement	3	Focus group technique	1
Predictive	3	Needs assessment	1
Genetic research	2		
Adoption studies	1		
Comparative non RCT	2		
Longitudinal studies	2		
Total	114	Total	60
Mixed methodology	5		

APPENDIX 4: Non research based Literature

Brief news and reports	7
Observation by nurses	1
Personal reflection by Peplau (1994)	1
Clinical update	1
Discussion	27
Total non research based literature	37

APPENDIX 5: Web sites

Site content	Number of sites	Site content	Number of sites
Chat rooms	5	Information on symptoms and treatment	25
Cognitive Behavioural Therapy specifically	3	Help for users to gain access to resources	3
Help with self monitoring	1	Help for users to gain access to resources for coping	4
Clinical trials and other research	21	Genetic issues	4
Help for relatives specifically	4	General advice	1
Information on accessing a support group	5	Recommends literature	4
Information on medication specifically	7	Information for clinicians primarily	1
An overview of schizophrenia	1	For older people with schizophrenia	1
Web site which functions as a support group	1	Information and discussion on Community Care Issues	1
Organisations identified	5	The National Alliance for Research on Schizophrenia and Depression	1
The national Alliance of the Mentally Ill	2	New York Online Access to Health	1
Schizophrenic Society of Canada	1		

APPENDIX 6: Participant Information Sheet

Title of study

The lived experience of schizophrenia

Explanation of research activities

This research is part of PhD study and will involve you taking part in an interview to find out your views and experiences.

My name is Joanne Harrison. I am a lecturer at the University of Bradford. My previous employment has been in mental health settings since 1978.

Contact telephone number 01274 236357

Address:

School of Health
Unity Building,
University of Bradford
25 Trinity Road
Bradford BD50BB

Aims of this research

To gain a greater understanding of the meaning and experience of schizophrenia for the person with this diagnosis.

Objectives

To explore the lived experiences of schizophrenia

To increase knowledge of this experience.

To enable nursing and nurses to be more sensitive to the needs of people with schizophrenia

Purpose

To explore the meaning of schizophrenia for people with this diagnosis and what impact this diagnosis has on their lives.

Methods

The methods involve taking part in an interview either in user group premises, your own home or other premises convenient for you. With your permission the interview will be recorded. This will be typed up and you will be given a copy to evaluate and inform me of it's accuracy. You can add or change anything at this point. The main themes will then be identified and this will be typed up. A copy will be given to you.

You will be given a notebook to write an account of your experiences and an envelope and stamps to send this notebook to me.

From the themes identified, key statements will be made.

Potential risks

You may become stressed or distressed, describing unpleasant experiences. Should this happen, the interview will be stopped. I would support you or call someone of your choice if you wish. You may become tired. No interview will take longer than an hour. Breaks will take place as often as you consider necessary. If you wish the interview to stop prior to one hour, your wish will be respected.

Potential benefits

The potential benefits are better more sensitive services and support for mental health service users with schizophrenia. It may provide nurses with information which may enable them to meet your needs more fully. You will have a voice.

Option to withdraw and voluntary consent

You are under no obligation to participate in this study and there will be no coercion of any kind. You may withdraw at any time from this study. If you choose to withdraw all the information you have provided will be removed from the study.

A full explanation will be given in writing and verbally and you will have a week to consider participating in the study.

Anonymity and confidentiality

Your name and personal details will remain confidential. The information from this study will be coded so that no-one can trace the information back to you. Your identity will not be revealed while this study is being conducted or when the results of the study are being reported or published. All the information will be collected by me Joanne Harrison and stored in a secure locked drawer. It will not be shared with any other person without your permission.

Thank you

Joanne Harrison

APPENDIX 7: Participant Consent Form

Consent form

Study Title

The Lived Experience of Schizophrenia

Researcher

Joanne Harrison, University of Bradford

I have read the information sheet.

I have been informed verbally and have discussed this study with Joanne Harrison

and all my questions have received satisfactory answers.

I have understood the purpose of the study and know what my involvement will be.

I am free to request more information at any time.

I can refuse to take part in this study or withdraw at anytime without giving a reason.

I have read the consent form and voluntarily consent to participate in this study

Signature _____ Researcher's Signature _____

Date _____

J.Harrison

APPENDIX 8: Details of person being interviewed

Name

Age

Address

This will be kept separate from the tapes and other data. This is to be used if you decide to withdraw from the research and to send you the transcripts of your interview at the end of this research. If you are willing, I can give you a notebook for you to jot down your thoughts on anything, and you can send it to me. Please feel free to contact me again if you want.

APPENDIX 9: The essence of each interview – people diagnosed with schizophrenia

Participant 1

This woman saw herself for many years as a non-coping sick person. She had no confidence in the past. She felt invisible. She had no control over her life and she had no choices. People, including nurses were afraid of her because of the diagnosis. She lost friends and she felt rejected. The medication made her feel very ill. She was very angry about all that has been done to her. She has moved on in her life. She now questioned the diagnosis schizophrenia and the knowledge on which it is based. She used to believe that others knew best and that the doctor was the expert but now did not believe this. She reported care at home, in the past, as overprotective and stifling.

Participant 2

This man was arrested prior to admission to hospital. Throughout the arrest and admission and after discharge from hospital, he felt powerless with no control over his life. He also used the work invisible about himself and feels demeaned by others. He felt that he was disbelieved from the start. This made him angry and his anger was perceived by health professionals as part of the schizophrenia. He was told that he was a risk to himself. He felt confusion. He was given no information or explanations. No-one took him seriously. He had a very bad experience in hospital with no care and no involvement in decision making. Everything that was done to him was control in his view. The medication made him feel very ill. He tried, unsuccessfully, to negotiate it then refused it but was given medication against his will. He lost touch with his friends. Care at home was very controlling and protective. He reports great loneliness and no support. He feels excluded. He could not get back into his old life. He could not gain employment because of the diagnosis of schizophrenia. He reported real poverty, which

meant for him having insufficient money to live. He wanted to read his notes but was prevented from doing so. He felt angry about what was done to him, about the lack of involvement in decision making, the lack of confidentiality and lack of privacy. He regards himself as having moved on in his life.

Participant 3

This man highlighted a great sense of loss. The past was very good and the present is very unpleasant now for him. Health professionals denied him his civil liberties. He had no power, no choices, no control and no self confidence. His views of his visions were that they were real. For him they were astral flying and a spiritual experience. Medication was very bad for him and he has been given medication against his will. He felt abandoned and rejected now. He disagreed with and questioned the label of schizophrenia. He always had disagreed with this. He felt that did not belong at work. He hated being under scrutiny by health professionals and felt stopped in his life. His memory was very poor and he could not concentrate any more. He could not do the things he could do before the schizophrenia. Everything was a muddle now in his head. People mocked him and abused him because of the schizophrenia. He did tell people at one time about the visions but they treated his as if he were mad and mocked him so now he told no-one. He avoided people now. He painted a picture of isolation, loneliness and having no trust in people.

Participant 4

This man believed he was ill but did express some ambivalence about this. He thought it was evil spirits at work in his mind. He thought that he was not normal prior to the diagnosis. He had been forced to have medication and Electro Convulsive Therapy against his will and was very angry about this. His civil rights had been violated in his

opinion. He believed that he had a very bad effect on other people, who became stressed because of him and they committed suicide. The medication made him feel very ill. He was tired all the time and slept a lot.

He spoke of people leaving him alone. He meant his friends and all those who were in hospital with him. He felt persecuted and abused by people and the “illness had stopped his ambitions”. Work was very important to him and now he could not work. He used to express his anger but they punished him for this and sent him to a Regional Secure Unit (a locked hospital). He has had a lot of loss and fears more loss, specifically the loss of current close relationship. He felt unsupported and abused by professionals, but reported that he went back to the hospital to sit there at weekends and despite being asked to go home, he will continue to do this. He felt that he had no power, choice or control in his life. He felt labelled and it the label of schizophrenia which in his view, will decide what happens to him. He blamed himself and thought that he had brought the schizophrenia on himself.

Participant 5

This man was arrested prior to admission. He feels very angry. Every time he was angry in hospital, he was punished and given medication. In his view he has received no care and no-one ever asked him what he wanted. Everything done by health professionals is control and abuse. Medication made him ill and he was given this against his will. He was told that he was a risk to himself and others and this upset him. He is lonely, isolated and feels excluded from society. Everyone rejected him once they knew that he had schizophrenia. He also reported real poverty and feeling invisible.

Participant 6

This woman highlighted extreme severe loss. She is highly afraid and anxious. For her she has “lost everything”. She feels useless and believes that she cannot do anything now. She cannot concentrate on anything. No-one listens to anything she says and this upsets her. People make fun of her and call her names. She feels ill and she sees herself as a sick person. Her past was good and the present is very bad. She has no future, seeing before her, only loss and early death. She is a bad person, in her opinion and is lonely and isolated. Even her mother does not like her. Other people are afraid of her and this worries her. She cannot work because she is too ill and she is poor because she has to live on benefit. She receives no care of support from anyone. She does feel normal. She knows that her children are embarrassed about her. She worries that they will also have schizophrenia. She is very fearful of more loss and desperately needs people to listen to her. She is afraid to take medication because of the side effects but is also afraid not to because of the voices and visions. She feels complete hopelessness.

Participant 7

This woman was very anxious and did not sleep for days at a time. She is afraid all the time. She used to have a job and a marriage but lost it all because of the schizophrenia. She sees herself as bad, sick, not competent, non-coping and useless. She needs more help than she receives. She receives no help of care from anyone. She lives on benefit and reports real poverty. This worries her. She feels abused by everyone. She tries not to be angry but does become tearful and upset. People do not take her seriously and she wants to be taken seriously and listened to. Her visions and voices torment her all the time, increasing her fear and anxiety. People are afraid of her and she hates this. She just wants more help and care.

Participant 8

This man has visions all the time and he welcomes them as positive spiritual events. They have a positive meaning for him and he keenly wants to tell people about them but they laughed at him and now he does not tell people. He was made to take medication against his will after being admitted against his will. It made him feel ill. He thinks that he no longer belongs anywhere now. He feels lonely and rejected. He used to be able to “think properly” and concentrate but cannot do this now. His memory has been affected. He actively avoids health professionals and people in general because he hates being observed and judged. People have abused him and still do. He feels lonely but does not trust anyone enough to let them get close. He has never believed that he is mentally ill with schizophrenia.

Participant 9

This man believed that he was ill and also that his visions and voices were spiritual events. He reported being forced to take medication and this made him angry. He felt and still feels powerless with no control over his life. He believes that health professionals have labelled him to punish him. He feels depressed and thinks that he is a bad person. He feels lonely, tired and abused. He avoids people generally. He has not been able to work for many years and this makes him angry because he enjoyed his work. He used to be very angry and would express this anger. When he was given medication and was punished as a result of this anger, he became isolated and depressed. He is worried about a current relationship. He thinks his partner will leave him. People have left him in the past. He seems resigned to no future and no change and despite his feelings about health professionals, he continues to make contact with them from time to time.

Participant 10

Stress was a key theme in this interview and is seen by this person as a cause and a result of schizophrenia. She used to believe that she had schizophrenia but now she does not. She used to believe all that the doctors told her but not now. Her family prevented her from becoming independent for many years. They treated her as if she were incompetent and sick. She has since moved on in her life. She has her own family and is self employed. She believes that all the family overprotection stifled and controlled her. For many years she had no power or control over her own life. The medication made her feel very ill but she accepted it because she believed that the doctors were right. She is confident now and in control of her life. She lost touch with old friends. They became afraid of her and avoided her. They thought she would be violent. This upset her. She became afraid to be alone and accepted the care/control of her parents. She never lied about the schizophrenia and this honesty prevented her from gaining employment. She now rejects everything she has been told about schizophrenia. She has been trying for years to tell people that she is not a bad person but she has come to believe that people, including her G.P are ignorant. She feels some responsibility for letting others do all this to her but she also accepts that no-one who is in her situation would have had any control or power.

Participant 11

This woman raised the issue of inequality as key theme. She wants equality in relationships with health professionals. She has had no choice, power or equality. She was perceived by others as a risk. No-one listened to her or took her seriously. She felt ignored and uncared for. She had no self confidence for years. No-one gave her any information or explanation about the diagnosis. She reports stigma and has been unable to gain employment. She is angry at her family because they sent her into hospital

against her will where nurses forced her to take medication. For her there was no care in hospital, just control and observation. Her own space, personal time and choices were very important to this participant. She felt equal at a MIND meeting. Her parents saw her as sick and she did see herself this way sometimes. At other times she did not feel this way. Schizophrenia has spoiled her life. Everything she says or does is attributed to the schizophrenia. She hated the CPN visiting her, perceiving this as control. Everyone help her back from living her life her way because of the schizophrenia. She believes that her parents perceive her to be a failure because of the schizophrenia.

Participant 12

This woman highlights the issue of a totally controlled life. When she expressed anger at this the anger was perceived to be part of the schizophrenia. She perceived the hospital staff and her parents as ganging up against her. She had no rights, no power and no control over her life. When she expressed her wishes, her wishes were ignored. She lost self confidence and self belief. She hid from people because they would never leave her alone. She reported stress within family relationships. She felt that she was a burden to her parents and felt guilty about this. She thought that they were always criticising her. She feels very stuck and sees herself as ill. She feels a failure and believes that other people think this too about of her.

Participant 13

This woman reports great confusion. The voices in her head upset her. She goes to bed when this happens. She felt that the nurses did not care. They told her to ignore the voices but could not and felt blamed by them for this. She was isolated. Her old friends walked past her in the street. She worried that people thought she'd be violent. She

hated being in hospital because no-one had any time for her there. She felt misunderstood by nurses and others, with the notable exception of her husband. She worried and still worries about the effects of her schizophrenia on her children. It affected her relationship with them. She sees herself as very ill and needing help. Medication made her feel very ill and she has great gaps in her memory because of it. She felt powerless with no control over her life. She acknowledges that she has become dependent and has allowed everyone to make decisions for her. There was great conflict within the extended family. Her sister in law would not let her near their children. The sister in law was afraid she would be violent. This assumption upset participant 13 greatly. When nasty remarks were made to her and about her, she became small and invisible. She relies on her husband to protect her. Her husband is overprotective. She does not have normal life roles. She sees herself as a non-coping sick person.

Participant 14

This woman remembers great confusion. She was told to ignore the voices and could not and felt blamed for this. For her nurses did not understand what she was going through. She perceives nurses as people who told her what to do but did not help her. Her old friends rejected her. No-one listened to anything she said. She was afraid all the time in hospital. No-one there cared about her and after discharge there was no support. The medication made her feel ill. She “knows” that her schizophrenia created great stress on her family life. Her husband became stressed and depressed. Her extended family rejected her. She lives a very quiet, isolated life. She feels sad and guilty about the effects of this on her children. She spoke of overprotective care which she accepted because she believes herself to be sick.

Participant 15

This man expressed a lot of loss, loss of marriage, of employment of income, of opportunities to work of friends and of confidence. He is now poor. His voices and visions are not frightening. He listens to them for advice. He perceives schizophrenia as a sorting out process. It put many aspects of his life into perspective. He spoke a lot about stress, stress and distress prior to the diagnosis and afterwards as a consequence. He perceives himself as sick. The medication made him feel ill in the past but the current medication suits him. He has had no power and no control over his life since the diagnosis. He had no right to refuse the medication in hospital. He was physically forced to take it. He read about schizophrenia to try and understand it all. His memory and concentration have been badly affected. He cannot gain employment and spoke of stigma and prejudice. He fears future loss, especially poverty because he cannot afford the mortgage while living on benefit. In his opinion, people, including past friends, have been nasty, abusive and unhelpful. Everything he does or says is attributed to schizophrenia and this makes him angry. He feels very stuck and from his point of view this is all due to the behaviour of others and the schizophrenia. He applied for DLA and was told that he is not ill enough yet cannot gain employment because he is too ill. He is sure that people think badly of him. He feels disabled and called himself “a loser”. His life is total loss now. No-one explains anything to him and gives information. People do not like him and he feels punished. His final comment was that the nurses are very good but they can't help him.

Participant 16

This man has experienced a great deal of stress and loss. He has voices and visions but pays no attention to them now. He sees himself as ill and powerless with no control over his life. He has no control over what happens to him now. He would like to work

but cannot gain employment. He speaks of receiving no help, care or support from anyone. He was angry and whenever he expressed this anger he felt punished by health professionals. He feels stopped in his life because of the schizophrenia and is very anxious about his future.

Participant 17

This man perceived himself as a victim, who has suffered great loss in all areas of life. He believed he was ill and remains ill. He reported loneliness, however the only people he spent time with were fellow user group members. He felt angry and punished because of the diagnosis of schizophrenia.

Participant 18

This man believed himself to be ill and felt angry about the resulting exclusion and rejection by others. He used the user group to try and address these issues. He felt controlled by health professionals and the rights and freedom of choice of people with schizophrenia were very important to him.

Participant 19

This man reported anger at the perceived rejection and exclusion by others and the perceived control and abuse by health professionals. He felt punished for being ill. He believed he was ill and wanted a cure for my schizophrenia. The negative social consequences of the diagnosis of schizophrenia were commented on and he felt that the user group was the way forward to address these issues. He felt supported by and accepted by the user group.

Participant 20

This man was in employment but felt that he was rejected and excluded by his co-workers. He reported feeling that society has abused him and others with schizophrenia. He experienced a feeling of loss in all areas of his life. He believed he was ill and wanted a cure for schizophrenia. He felt accepted by others in the user group.

Participant 21

This man was in employment and felt rejected by his co-workers. He believed he was ill. He feared future unemployment and poverty as a consequence of the diagnosis of schizophrenia. He wanted society and health professionals to listen to and become more tolerant of people with schizophrenia.

Participant 22

This woman felt strongly that she was ill. She felt that others treated her as a fool and resented this. She reported that without the support of her family she would not have coped. However, while she appreciated the support of her family, she found it controlling and overprotective at times and enjoyed support without control, which she experienced in the user group. She was angry about being patronised by others and having no involvement in decisions. She believed that care involved more listening to people with schizophrenia and accepting their point of view.

APPENDIX 10: Biographical details - participants with schizophrenia

Participant 1

This woman is 40 years old. She is married with two children and a supportive husband. She has had schizophrenia for 25 years. She works from home. She is a self-employed artist.

Participant 2

This single man, has had schizophrenia for 15 months. He is white. He now lives alone but did live with his mother. He is a student, has worked and is seeking work now. He has had two short hospital admissions of 3 months each, and is in the moving on group.

Participant 3

This man is 45 years old and is divorced and white. He has had schizophrenia for 10 years. He has children but does not have custody of them. He works but is off sick a lot. He is in the stopped group

Participant 4

This man is white, single and 53 years old. He has had schizophrenia for 20 years. He used to work as a printer, but has not worked for 20 years. He lives with a female partner and there is tension in this relationship. He is on Disability Living Allowance. He is in the stopped group.

Participant 5

This is a 23 year old single man who is white and has had schizophrenia for 18 months. He has been under the Care Programme Approach but is no longer under this. He lives alone. He is a student and is also seeking work. He is in the moving on group.

Participant 6

This is a 40 year old white divorced woman. She has had schizophrenia for 20years. She is divorced and has four children. She does not have custody of them. Her eldest daughter stays with her out of choice but otherwise this woman lives alone. She does not work. She is in invalidity benefit. She is in the stopped group.

Participant 7

This woman is 40 years old and is white and divorced. She has had schizophrenia for 25 years. She has two children but does not have custody of them. She sees them regularly. She does not work and is in the stopped group. She is on invalidity benefit.

Participant 8

This is a 55 year old divorced white man . He has had schizophrenia for 20years. He has one child. He does not have custody and sees the child, a daughter, only occasionally. He works and he is in the stopped group.

Participant 9

This is a 44 year old white man. He is on Disability Living Allowance. He has had schizophrenia for 20 years. He lives with his male partner but there is tension in their relationship. He is in the stopped group.

Participant 10

This is a 42 year old woman. She is white and married. She has had schizophrenia for 20 years. She has two children and a supportive husband. She works at home. She is in the moving on group.

Participant 11

This is white, married, 50 year old woman. She lives with her husband. She has children and does not work outside the home. She has lived with schizophrenia for 20 years. She is in the stopped group.

Participant 12

This is a 45 year old, white single woman who lives with her parents. She has lived with schizophrenia for 25 years. She does not work outside the home. She in the stopped group.

Participant 13

This is a 43 year old white woman. She is married and lives with her husband. She has lived with schizophrenia for 23 years. She has children and does not work outside the home. She is in the stopped group.

Participant 14

This is a 52 year old white married woman. She lives with her husband. She has children and does not work outside the home. She has lived with schizophrenia for 30 years. She is in the stopped group.

Participant 15

This is a 53 year old divorced white man who lives alone. He has lived with schizophrenia for 15 years. He does not work and is on invalidity benefit. He has been a professional man with degree education. He is in the stopped group.

Participant 16

This is a 57 year old white divorced man who lives alone. He has lived with schizophrenia for 18 years. He does not work and is on invalidity benefit. He has been a professional man with degree education. He is in the stopped group.

Participant 17

This is a 45 year old, divorced, white man who lives alone. He has had schizophrenia for 25 years. He has children but does not see them. He does not work and is on invalidity benefit.. He is in the moved on group. He is in the National Schizophrenia Fellowship.

Participant 18

This is a 40 year old white divorced man who lives alone. He does not work and is on invalidity benefit. He has lived with schizophrenia for 20 years. He is in the moved on group and the National Schizophrenia Fellowship.

Participant 19

This is a 35 year old white single man who lives alone. He has had schizophrenia for 18 years. He does not work and is on invalidity benefit. He is in the moved on group and the National Schizophrenia Fellowship.

Participant 20

This is a 29 year old white single man. He has one child from a previous relationship but has no access to the child. He lives alone. He has had schizophrenia for 9 years. He is employed. He is in the moved on group and National Schizophrenia Fellowship.

Participant 21

This is a 36 year old white married man who lives with his mother and is separated from his wife. He has no children. He has lived with schizophrenia for 16 year. He does not work and is on invalidity benefit. He is in the moved on group and the National Schizophrenia Fellowship.

Participant 22

This is a 35 year old, married white woman who lives with her husband. She has one child. She lives with her husband. She has lived with schizophrenia for 10 years. She does not work outside the home and is on invalidity benefit. She is in the moved on group and is in the National Schizophrenia Fellowship.

APPENDIX 11: Biographical details - carers

Carer 24 Female

This is a mother and widow aged 75 years old. She does not live with her son but spends a lot of time with him. She lives alone and is depressed. She suffers from arthritis. The person with schizophrenia is her son who was in hospital at the time and was not interviewed.

Carer 25 Female

This is a mother aged 40 years old who lives with her 18 year old son who has schizophrenia. She is married and works part time.

Carer 26 Male

This is a husband and a retired widower aged 66 years old. This man has three sons who visit frequently. He lives alone now since his wife, who had schizophrenia, died. He was a lone carer.

Carer 27 Male

This man is a husband aged 52 years old, married with two children. He is the husband of participant 13. He is not in paid employment and lives with his wife.

Carer 28a Female

This is the mother of participant 11 and the wife of carer 28b. She is 44 years old. This mother lives with her daughter. 28a is not in paid employment.

Carer 28b Male

This man is the father of participant 11 and the husband of carer 28a. He is 54 years old and is not in paid employment. He lives with participant 11 and carer 28a.

Carer 29a Female

This is the mother of participant 12 and the wife of carer 29b. She lives with her husband, carer 29b and participant 12. 29a is 49 years old and is not in paid employment.

Carer 29b Male

This man is the husband of carer 29a and the father of participant 12 and lives with them. He is 56 years old and is not in paid employment.

Carer 30 Female

This women is the retired, widowed mother of a man with schizophrenia. She lives alone. She does deliver care to her son when he is not in hospital and is a lone carer.

Carer 31 Female

This is the mother of a man with schizophrenia. She is 43 years old, married and is not in paid employment.

Carer 32 Male

This is the husband of a woman with schizophrenia. He is 57 years old and lives with his wife. He has two sons who visit regularly and he works in a local factory.

Carer 33 Male

This is the husband of participant 14. He is married and lives with his wife and two children. He works for a local small firm delivering machine parts.

Carer 34 Female

This is the 15 year old daughter of participant 6. She does not go to school and is not in paid employment. She is a lone carer

APPENDIX 12: A summary of carers' biographical details

Gender	
Male	6
Female	7
Total	13

Relationship to person with schizophrenia	
Husband	4
Father	2
Mother	6
Daughter	1
Total	13

Employment status	
In paid employment	3
Not in paid employment/not retired	6
Retired	4
Total	13

Age of carers	
Between 15 and 39 years	1
Between 40 and 59 years	9
Over 60 years	3
Total	13

Where does/did relative live?	
At home	10
Elsewhere	3
Total	13

Carers	Length of time caring for relative in years
Carer 34 n=1	5
Carer 25 n=1	8
Carer 31 n=1	9
Carers 28a and 28b n=2	10
Carer 26 n=1	23
Carers 27 and 33 n=2	24
Carers 31 and 32 n=2	25
Carers 29a and 29b n=2	29
Carer 24 n=1	38
Total n=13	Total 259 years mean 19.9 years, mode 23-25 years

APPENDIX 13

Passivity group n = 18

Participant	Gender	Age	Married Cohabits	Single	Separated Divorced	Employed
3 *	M	45			Div	Yes
4	M	53	Yes			No
6	F	40			Div	No
7	F	40			Div	No
8	M	55			Div	Yes
9	M	44	Yes			No
11 *	F	50	Yes			No
12 *	F	45		Yes		No
13	F	43	Yes			No
14	F	52	Yes			No
15 *	M	53			Div	No
16 *	M	57			Div	No
17	M	45			Div	No
18	M	40			Div	No
19	M	35		Yes		No
20	M	29		Yes		Yes
21	M	36			Sep	No
22	F	35	Yes			No

Mean age 44.3 years

* does both passivity and questioning

APPENDIX 14

Questioning group n = 10

Participant	Gender	Age	Married Cohabits	Single	Separated Divorced	Employed
1	F	40	Yes			Yes
2	M	25		Yes		No
3 *	M	45			Div	Yes
5	M	23		Yes		No
8 *	M	55			Div	Yes
10	F	42	Yes			Yes
11*	F	50	Yes			No
12 *	F	45		Yes		No
15 *	M	53			Div	No
16 *	M	57			Div	No

Mean age 43.5 years

* does both passivity and questioning

APPENDIX 15

Seek Support n=14

<u>Participant</u>	<u>Gender</u>	<u>Age</u>	<u>Marital Status</u>	<u>In Paid Employment</u>	<u>Lives Alone</u>	<u>How long living with Schizophrenia</u>
4	M	53	M/Coha	No	No	20 YRS
6	F	40	b	No	No	20 YRS
7	F	40	D	No	Yes	25 YRS
9	M	44	D	No	No	20 YRS
11	F	50	M	No	No	20 YRS
12	F	45	M	No	No	25 YRS
15	M	53	S	No	Yes	15 YRS
16	M	57	D	No	Yes	18 YRS
17	M	45	D	No	Yes	25 YRS
18	M	40	D	No	Yes	20 YRS
19	M	35	D	No	Yes	18 YRS
20	M	29	S	Yes	Yes	09 YRS
21	M	36	S	No	No	16 YRS
22	F	35	Sep M	No	No	10 YRS

M Married, S Single, D Divorced, Sep Separated, Cohab Cohabiting

APPENDIX 16

Seek Support n=14

<u>Participant</u>	<u>Belief Led</u>	<u>In User Group</u>	<u>Event Led</u>	<u>Moved On n=12</u>	<u>Stopped n=10</u>
4	Yes	No	Yes	No	Yes
6	Yes	No	No	No	Yes
7	Yes	No	No	No	Yes
9	Yes	No	Yes	No	Yes
11*	Yes	No	No	No	Yes
12*	Yes	No	No	No	Yes
15	Yes	No	Yes	No	Yes
16	Yes	No	Yes	No	Yes
17	Yes	Yes	No	Yes	No
18	Yes	Yes	No	Yes	No
19	Yes	Yes	No	Yes	No
20	Yes	Yes	No	Yes	No
21	Yes	Yes	No	Yes	No
22	Yes	Yes	No	Yes	No

*Reported both seeking support and choosing isolation

APPENDIX 17

Choose Isolation n=10

<u>Participant</u>	<u>Gender</u>	<u>Age</u>	<u>Marital status</u>	<u>In paid employment</u>	<u>Lives alone</u>	<u>How long living with schizophrenia</u>
1	F	40	M	Yes	No	25 YRS
2	M	25	S	No	Yes	1.25 YRS
3	M	45	D	Yes	Yes	10 YRS
5	M	23	S	No	Yes	1.5 YRS
8	M	55	D	Yes	Yes	20 YRS
10	F	42	M	Yes	No	20 YRS
11*	F	50	M	No	No	20 YRS
12*	F	45	S	No	No	25 YRS
13	F	43	M	No	No	23 YRS
14	F	52	M	No	No	30 YRS

*Reported both seeking support and choosing isolation
M Married, S Single, D Divorced

APPENDIX 18

Choose Isolation n=10

<u>Participant</u>	<u>Belief Led</u>	<u>In Users Group</u>	<u>Event Led</u>	<u>Moved On n=12</u>	<u>Stopped n=10</u>
1	Yes	No	No	Yes	No
2	Yes	No	No	Yes	No
3	Yes	No	Yes	No	Yes
5	Yes	No	No	Yes	No
8	Yes	No	Yes	No	Yes
10	Yes	No	No	Yes	No
11	Yes	No	No	No	Yes
12	Yes	No	No	No	Yes
13	Yes	No	Yes	No	Yes
14	Yes	No	Yes	No	Yes

APPENDIX 19

Stopped group n = 12

Participant	Gender	Age	Married Cohabits	Single	Separated Divorced	In Employment	Paid
3	M	45			D	Yes	
4	M	53	M/C			No	
6	F	40			D	No	
7	F	40			D	No	
8	M	55			D	Yes	
9	M	44	M			No	
11	F	50	M			No	
12	F	45		S		No	
13	F	43	M			No	
14	F	52	M			No	
15	M	53			D	No	
16	M	57			D	No	

M married, S single, D divorced, C Cohabits

APPENDIX 20

Stopped group n=-12

Participant	In Questioning Group	In Group	Acceptance	Ambivalence
3	Yes	Yes		Yes
4	No	Yes		No
6	No	Yes		No
7	No	Yes		No
8	Yes	Yes		Yes
9	No	Yes		No
11	Yes	Yes		Yes
12	Yes	Yes		Yes
13	No	Yes		No
14	No	Yes		No
15	Yes	Yes		Yes
16	Yes	Yes		Yes

n = 6 Ambivalent (Participants 3,8,11,12,15,16).

APPENDIX 21

Stopped group n=12

Participant	Event Led	Belief Led	Lives Alone
3	Yes	Yes	Yes
4	Yes	Yes	No
6	No	Yes	No
7	No	Yes	Yes
8	Yes	Yes	Yes
9	Yes	Yes	No
11	No	Yes	No
12	No	Yes	No
13	Yes	Yes	No
14	Yes	Yes	No
15	Yes	Yes	Yes
16	Yes	Yes	Yes

APPENDIX 22

Stopped group n=12

Participant	<u>Schizophrenia</u> How many years	Seek Support	Choose Isolation
3	10 yrs	No	Yes
4	20 yrs	Yes	No
6	20 yrs	Yes	No
7	25 yrs	Yes	No
8	20 yrs	No	Yes
9	20 yrs	Yes	No
11	20 yrs	Yes and No	Yes and No
12	25 yrs	Yes and No	Yes and No
13	23 yrs	No	Yes
14	30 yrs	No	Yes
15	15 yrs	Yes	No
16	18 yrs	Yes	No

APPENDIX 23

Moved on group n=10

Participant	Gender	Age	Married	Single	Sep/Div	In Employment	Paid
1	F	40	M			Yes	
2	M	25		S		No	
5	M	23		S		No	
10	F	42	M			Yes	
17	M	45			D	No	
18	M	40			D	No	
19	M	35		S		No	
20	M	29		S		Yes	
21	M	36			Sep	No	
22	F	35	M			No	

APPENDIX 24

Moved On n=10

Participant	Event Led	Belief Led	Lives Alone
1	No	Yes	No
2	No	Yes	Yes
5	No	Yes	Yes
10	No	Yes	No
17	No	Yes	Yes
18	No	Yes	Yes
19	No	Yes	Yes
20	No	Yes	Yes
21	No	Yes	No
22	No	Yes	No

APPENDIX 25

Moved On group n=10

Participant	In a user group	Not in a user group
1	No	Yes
2	No	Yes
5	No	Yes
10	No	Yes
17	Yes	No
18	Yes	No
19	Yes	No
20	Yes	No
21	Yes	No
22	Yes	No

APPENDIX 26

Moved on group n=10

Participant	Schizophrenia How many years	Seek Help	Choose Isolation	In Questioning Group	In Acceptance Group
1*	25 yrs	No	Yes	Yes	No
2	1.25 yrs	No	Yes	Yes	No
5	1.5 yrs	No	Yes	Yes	No
10*	20 yrs	No	Yes	Yes	No
17	25 yrs	Yes	No	No	Yes
18	20 yrs	Yes	No	No	Yes
19	18 yrs	Yes	No	No	Yes
20	9 yrs	Yes	No	No	Yes
21	16 yrs	Yes	No	No	Yes
22	10 yrs	Yes	No	No	Yes

* These two people felt ambivalence between passivity and questioning in the past (Participants 1 and 10)

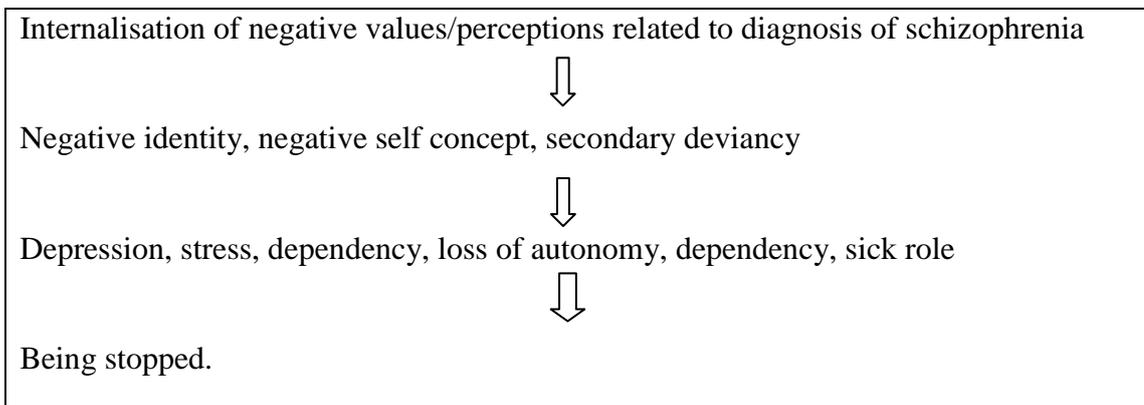
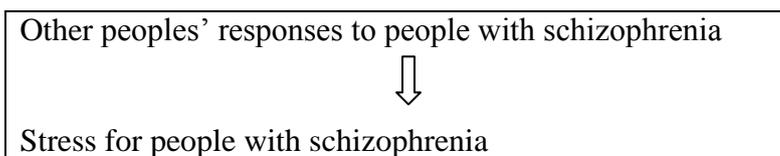
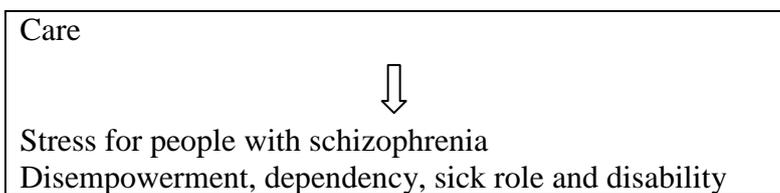
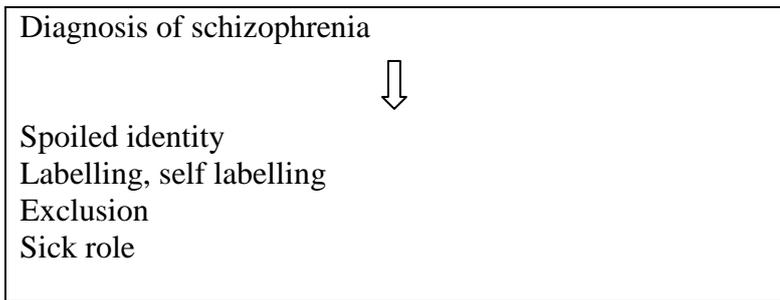
APPENDIX 27

Comparison Between Moved on Group and Stopped Group

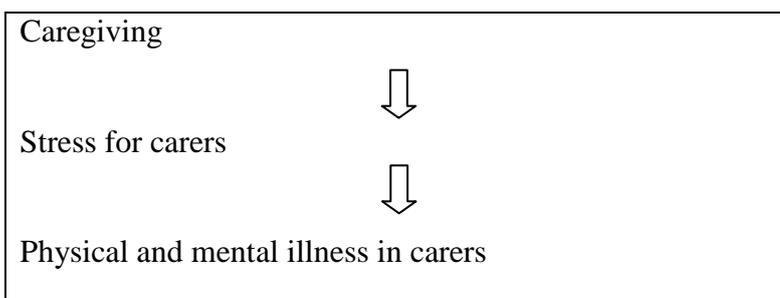
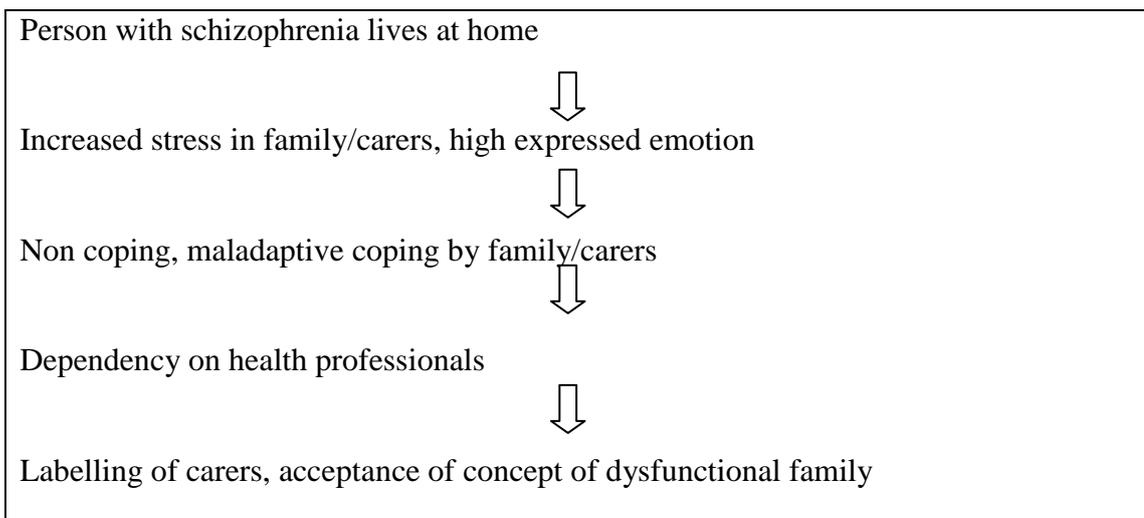
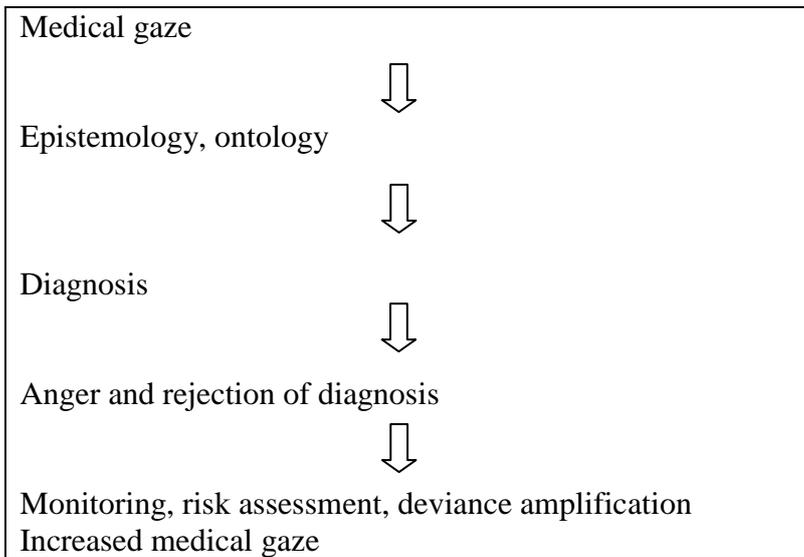
FACTOR	MOVED ON	STOPPED
Female	30%	50%
Male	70%	50%
* Age (Peak) 40 – 44 yrs	30%	25%
* Age Peak 50 - 54 yrs	0%	25%
* Age Peak 25 - 29 yrs	20%	0%
* Age 35 – 39 yrs	20%	0%
* Age 20 – 29	30%	0%
* Age 30 – 39	30%	0%
Age 40 – 49	40%	50%
* Age 50 – 59	0%	50%
Married	30%	33%
* Single	40%	10%
* Divorced	20%	50%
Separated	10%	0%
* Lives alone	60%	25%
* Lives with someone	40%	75%
* In NSF	60%	0%
* Not in any user group	40%	100%
* In paid employment	30%	16.6%
Not in paid employment	70%	83.3%
Belief Led	100%	100%
* Event led	0%	66%
* Both event/belief led	0%	66%
Years living with Schizophrenia		
* 0 - 2 yrs	20%	0%
* 3 - 9 yrs	10%	0%
* 10 - 19 yrs	30%	25%
* 20 - 29 yrs	40%	58.3%
* 30 - 39 yrs	0%	8.3%
	Total: 100%	Total 100%
* Over 20 yrs	40%	66.6%
* Under 19 yrs	50%	25%
Seek Help	60%	75%
Choose Isolation	40%	50%
* Both	0%	16.6%
In Questioning Group	40%	50%
In Acceptance Group	60%	100%
* Both	20%	50%

*indicates a difference in *moving on* and *stopped* groups.

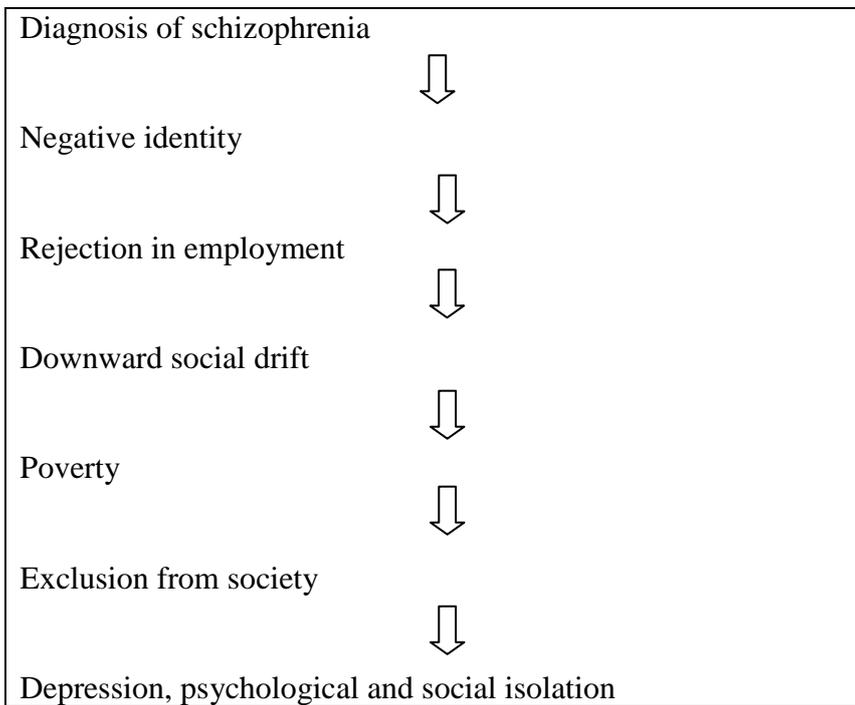
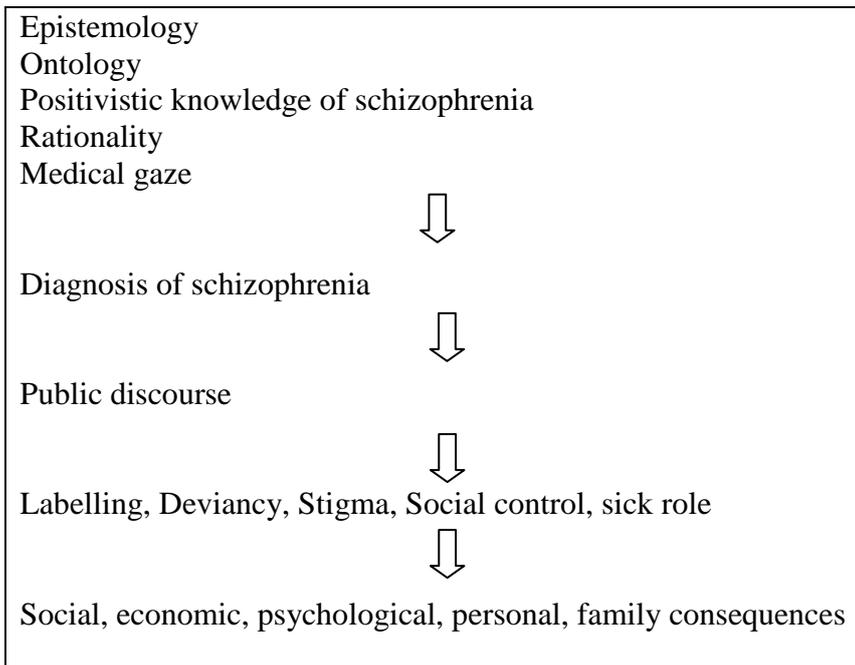
APPENDIX 28: Links Flowcharts



Appendix 28 Links Flowcharts



Appendix 28 Links Flowcharts



Appendix 28 Links Flowcharts

<p>Mother with schizophrenia</p> <p style="text-align: center;">↓</p> <p>No support for child carers</p> <p style="text-align: center;">↓</p> <p>Stress in child carers</p>	<p>Mother with schizophrenia</p> <p style="text-align: center;">↓</p> <p>Children</p> <p style="text-align: center;">↓</p> <p>Knowledge, inheritance</p> <p style="text-align: center;">↓</p> <p>Stress in child carer</p>	<p>Mother with schizophrenia</p> <p style="text-align: center;">↓</p> <p>Children</p> <p style="text-align: center;">↓</p> <p>Internalisation of negative beliefs about people with schizophrenia</p> <p style="text-align: center;">↓</p> <p>Rejection and avoidance of mother</p>
---	--	---

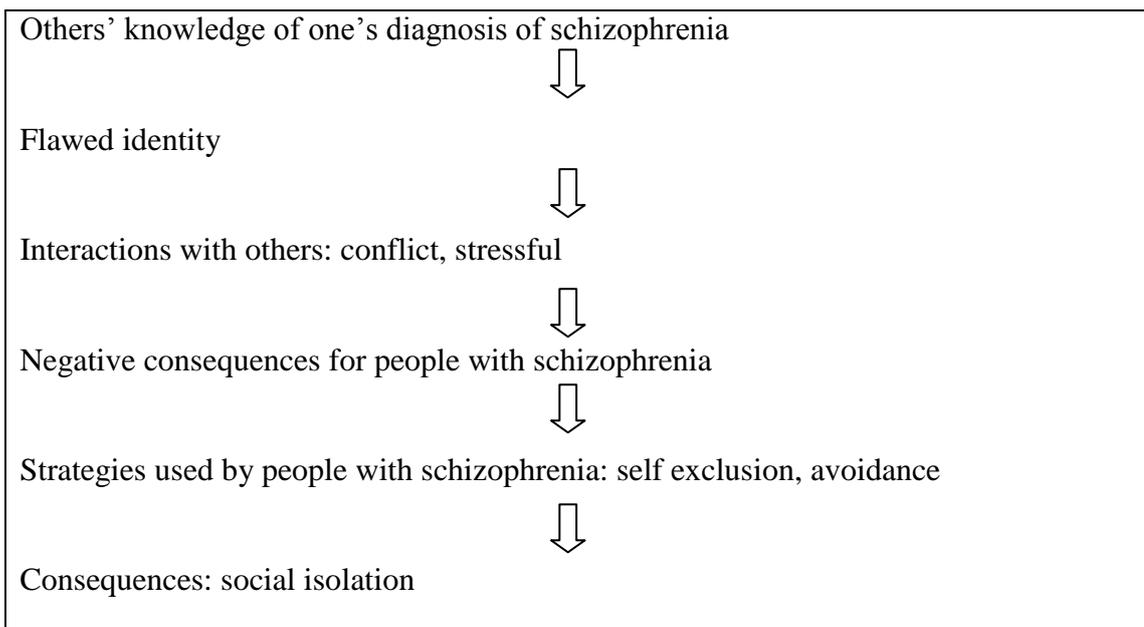
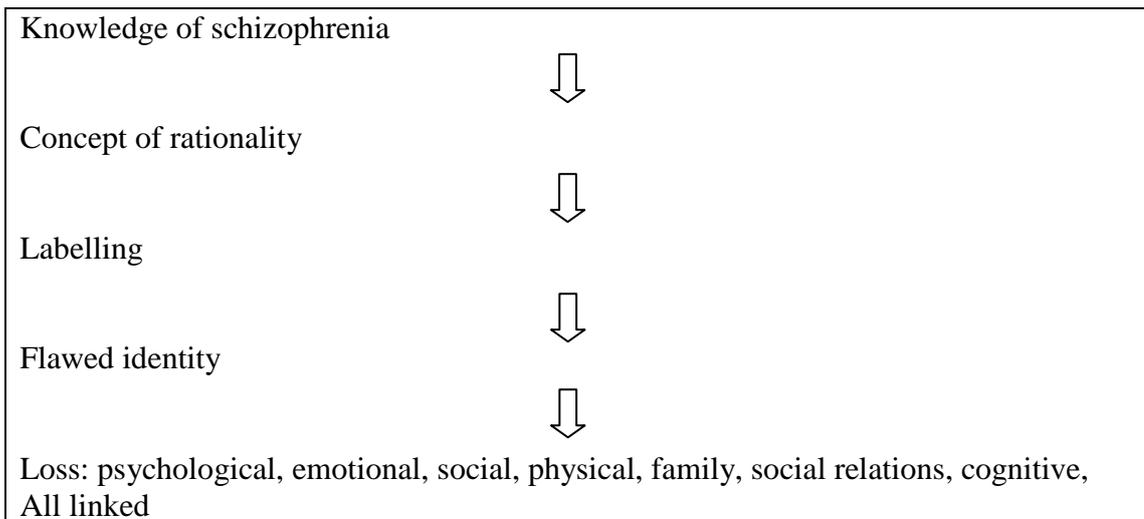
<p>Internal cause of schizophrenia</p> <p style="text-align: center;">↓</p> <p>Spiritual/mystical</p> <p style="text-align: center;">↓</p> <p>Person with schizophrenia feels positively about their experiences. They feel strong.</p>	<p>Internal cause of schizophrenia</p> <p style="text-align: center;">↓</p> <p>Biological, mental illness</p> <p style="text-align: center;">↓</p> <p>Fear, confusion, voices and visions control the person with schizophrenia</p>	<p>External cause of mental illness</p> <p style="text-align: center;">↓</p> <p>Stressful life event</p> <p style="text-align: center;">↓</p> <p>Fear, confusion, voices and visions control the person with schizophrenia</p>
---	---	--

Appendix 28 Links Flowcharts

<p>Identity, labelling</p> <p style="text-align: center;">↓</p> <p>Medicalisation, assumptions about people with schizophrenia</p> <p style="text-align: center;">↓</p> <p>Being ignored, trivialised, devalued disempowerment, choice or control</p>	<p>Identity, labelling</p> <p style="text-align: center;">↓</p> <p>Question the label</p> <p style="text-align: center;">↓</p> <p>It is a spiritual event</p> <p style="text-align: center;">↓</p> <p>Disbelieved, devalued Disempowerment, choice or control</p>	<p>Identity, labelling</p> <p style="text-align: center;">↓</p> <p>Accept the label Accept the flawed identity</p> <p style="text-align: center;">↓</p> <p>Disempowerment, choice or control</p>
---	---	--

<p>Society</p> <p style="text-align: center;">↓</p> <p>Rejects, excludes, devalues people with schizophrenia</p> <p style="text-align: center;">↓</p> <p>Loss and social isolation</p>	<p>Family</p> <p style="text-align: center;">↓</p> <p>Blames and rejects people with schizophrenia</p> <p style="text-align: center;">↓</p> <p>Loss and isolation for people with schizophrenia</p>	<p>Family</p> <p style="text-align: center;">↓</p> <p>Cares for people with schizophrenia</p> <p style="text-align: center;">↓</p> <p>Family burden, families split up Family loss</p>	<p>Society</p> <p style="text-align: center;">↓</p> <p>No support for family who cares for person with schizophrenia</p> <p style="text-align: center;">↓</p> <p>Family burden and stress</p>
--	---	--	---

Appendix 28 Links Flowcharts



APPENDIX 29: Example Transcript

TRANSCRIPT 1

4.2.2000.

JH.

I am turning on the tape recorder. If you want to stop before the hour is up that is fine. I want to hear your story and what schizophrenia means to you.

C.

Right. Back at the beginning I had a “serious” breakdown, (emphasis on word serious), On reflection the breakdown was probably caused by this fella who I was living with.

It was very difficult. I didn’t cope very well with that, the living together, his behaviour. It was very stressful. So I had a very bad breakdown. Then when I was ?...[Pause] my grandfather died which didn’t help me emotionally. I did make a fairly good recovery but I was told by the psychiatrist that I would have to be on pills for the rest of my life.

JH

How did you feel about that?

C

Well. I was quite poorly. I didn’t know what was happening to me and my parents didn’t know what was happening. They were absolutely distraught. To make matters worse, my boyfriend kicked me out. So I had to go home and my parents were left to look after me. They were very protective. The drugs that I were on were not very nice, Largactil, they were making me very..? I didn’t know if it were me or the drugs. I was constantly on the move, feet moving, head moving, and it made me sick and then they gave me more drugs for the sickness.

[She is describing untreated side effects of chlorpromazine].

You’re talking a lot of years ago and there weren’t any support for my parents and me. So we got on with it. And I gradually became better and then this chap that I’d previously had the relationship with, decided that as I was better he wanted to review our relationship. He wanted to start our relationship again. We did and then he decided against and I... My first breakdown was in 1973 and in 1978 I was ill with the second one. I was back home within 10 days with the second breakdown.

JH

How did you feel about the second breakdown?

C

The onset of the breakdown was very similar. I wasn’t sleeping or eating...[PAUSE]... and I [PAUSE]. When I came home I refused to take Largactil. My own G.P. gave me Stelazine. Then my father died and I got very upset, very, very upset and they gave me Largactil. Now initially I didn’t realise

what it was, for 3 weeks, then once I realised what it was, I tipped it down the sink and went back on the Stelazine.

JH

What did all this do to you/How did it make you feel?

C

I worried. I let everybody make decisions for me. I had no control of my life. I completely forgot about me. I had another breakdown and they gave me valium and all I wanted to do as sleep.

JH

What happened then?

C.

I came all right. I did realise... I did feel I needed something, but at the time I didn't know what it was or what I was doing. The doctor confirmed the diagnosis of schizophrenia.

JH

How did you feel about this?

C.

Very angry. I had hoped they'd made a mistake. But pleased too. I was angry that I had listened to them, and to people. I had no control. I kept thinking I'm all right, you know.

JH

Yes, how do you feel about doctors and nurses now?

C

I think they dealt with it the only way they knew at the time, you know, they didn't know much about it then. Now they wouldn't put the label on people that young, 16 years. "I" accepted it all. I felt angry with them for putting the label on me.

JH

What has this done to your life?

C

I wrote a few things down. She takes out a bit of paper. She reads I relied on other people to tell me who I was. My parents used to say slow down, you're doing too much. Things like that. I used not to rely on my own judgement. I was not confident about making decisions. The family, my sister, used to say in front of me "C is nuts", things like that.

JH

What did you do when that happened? How did you feel?

C

I pretended I didn't hear it. I tried not to let it upset me. Regarding career, I never went out to work. I got married and worked at home for years.

JH

Was it your choice?

C

No, I was terrified of being rejected. The label, They ask you about mental illness, the hurt you know.

It stops you from going forward. In my head there was something wrong with me. "She thought there was something wrong with her."

JH

Do you have any thought about what brought on the breakdowns?

C

That chap was the trigger for the first breakdown. He was involved in the second breakdown and again he rejected me. I learned from that. I learned that I was schizophrenic. People are frightened of you.

JH

Do you mean that they think you will do something?

C

Yes, violence. You read things in the papers about people with schizophrenia and everyone thinks that all these people are like that. That upsets me. They think we are all the same. The nurse was frightened of me in LM [a hospital] and all I did was touch her. They all came towards me to grab me.

JH

I see

How you feel about that, people thinking you will be violent?

C

It makes me feel rejected. People are protective, overprotective for you. In case you do something because you are schizophrenic. They tell you can't do things because you're schizophrenic. No-one listens to you. People assume things about you.

JH

What effect did this have on your life?

C

It stopped me from going on, in life. I couldn't bear to be left alone.

JH

What about friends? What were they like with you?

C

I lost touch with most of them. Some were different with me. Some didn't trust me. One stood by me. She accepted me, you know. True friends don't reject you. Then I met my husband. We have two children, two sons. Then I started working, painting and drawing for children's books. I am more confident now. I have always been artistic.

[NON VERBAL BEHAVIOUR . SHE SHOWS ME SOME OF HER DRAWINGS. SHE SEEMS PLEASED . THEY ARE GOOD].

You know it seems almost like I have been careful with me, about myself, because of it all. I don't think I'm ill any more. One particular lady said to me "you seem fine, you should go forward and do things." I question the label, schizophrenia, now.

JH

What's the difference between before and now?

C

Before, I couldn't question the label. They told me who I was. I can see now that this was a mistake. I could have lied about it before with jobs but what's the point? It's got to come out. I had a fear that stopped me from looking for jobs. I won't lie. I know people do this but I won't. The truth is important.

JH

About questioning things now. How difficult is it for you?

C

I question things now. It is important to question things. You have to tell people how you feel about things. That is my inner most thoughts. There's nothing to stop me from doing what I want now. My life is back in my control.

JH

Looking back over it all, how do you feel?

C

I feel very angry. It held me back. At times I have been dependent. I have tried to ...

I always wondered about these drugs, if they in some way made it worse. I was always being told I couldn't do things. About the doctor, my doctor, he often wondered if I had schizophrenia. They didn't know in these days. It comes down the line. My G.P, doctor, accepted it because the consultant said it.

JH

How do you feel about one person's opinion having this effect?

C

Angry I accepted what he said and so did everyone else. He knew and I didn't know anything. Back to the knowledge of the time. I accepted it was true. I had gestalt therapy once and I had to talk to the empty chair. And I shouted at it. You trust them. When my father died, my sister was very upset. They tried to tell her she was manic-depressive. They judged her on my schizophrenia, on me. I don't think she is.

JH

How do you feel about this idea that it runs in families.

I know they, the doctors and nurses, believe it and they did it to my sister. She was really ill when my dad died and this other doctor decided to give her a label because of mine. I am not a bad person, but that's what gets said about people like me.

JH

What do you do when that happens?

C

I question it, now I would. Believe it or not I have learned a lot from this last 25 years, having schizophrenia., about myself.

JH

It does not seem to have been pleasant.

C

No but I met a lovely man who likes me for myself and we have two lovely sons.

JH

What about now? What are people like with you now?

C.

I showed this picture to my doctor. [SHOWS ME A PICTURE IT IS A PICTURE FOR A PRESCHOOL CHILD'S BOOK PRIMARY COLOURS]. He said "you must have been on the magic mushrooms"

JH

It is a nice picture. Just right for kids. What did you do when he said that?

C

I laughed it off. I think he is very ignorant. The rest of my family all accept me now. My husband is a bit overprotective.

JH

Because of the schizophrenia?

C

Yes I think so. They care. My dad blamed himself for it. My mother said "you don't really know your dad. He blamed himself for your problems" He died blaming himself. He thought he had done something wrong. I feel sad about that.

JH

How much choice did you feel you had in your life when you were younger?

C

I accepted it all They controlled my life. No I didn't have much choice. No-one has in my situation. Everyone accepted it. Everyone thinks the doctor knows He is the expert.

JH

Are you an expert in your own life?

C

[LAUGHS] It was difficult at the time. They assumed things about me. I thinks so yes I am an expert in my life now. I let them do it. I didn't question it. I don't think people with schizophrenia really have a choice. Now I question it. Everyone is an individual. That person must say how they feel about it. They, other people, mustn't judge them. People with schizophrenia haven't all got the same personality.

JH

What about the way you were treated?

C

It depersonalises you. You need help. You obviously do have a mental health problem, I don't need a label. My name is my label, that's enough. When you're schizophrenic, you've got a label, It's there.

APPENDIX 30: Example Transcript

TRANSCRIPT 9

This was participant 9. This was a 53 year old man who has been diagnosed with schizophrenia for 20 years. He used to work in the printing industry.

JH
Good morning

B. What do you want to know?

JH
I just want to talk to you and listen to you about your life.

B.
OK

JH
We'll just talk for about 45 minutes to an hour if that's all right.

B
OK My girlfriend left me because she got a bit stressed. She couldn't cope with me. It made her poorly as well.

JH
Oh.

B.
My concept of schizophrenia is that it is evil spirits.

JH
Yes

B.
Well they call it chemicals, but...(pause)... chemicals in the brain. That's not quite right. But I think that's just another expression for what used to be called evil spirits.

JH
Yes, so you don't agree with their biochemical explanation.

B.
No.

JH
Could you tell me what happened to your life when they told you that you had schizophrenia.

B.
Well, they didn't actually say, to start off with. I had a breakdown when I was 23. I came back from Spain on holiday and em,.. it started about that time. What makes me think that evil spirits are at work is that em.. I denied the Lord Jesus Christ and I'd

started to say the lord's prayer backwards and that somehow stimulated these things. Started off the mental problems. Until that I'd been fairly sound. The treatment that I got in hospital made me worse in stead of better. Made me lethargic.

JH.

What treatments did they give you?

B.

ECTs and to my mind that's just another form of evil spirits, the ECT itself and ... (pause) .. for some people, they say it works but it only works in this life. It don't work in eternity.

JH.

So it generally made you feel very bad?

B.

yes

JH.

What about pills. Did they make you feel bad?

B.

They did before I got anything that suited me, Yes, as regards the depression that I had, caused by the ECT, em.. I think the one that had the best effect at that time and I didn't start on it till I'd been anointed in the church and it was only then that it worked with me. It got rid of the depression eventually.

JH.

What about your relationships with people? How are they with you when they know that you have mental problems?

B.

For some strange reason, people have a tendency, even before, em, letting them know I've had mental problems, they start to have mental problems themselves. Some of them have been unfortunate enough to commit suicide. Yes, and a good friend of mine attempted it as well. Up to meeting me he'd been sound as well.

JH.

How can that be your fault?

B.

Well it just seems strange that meeting me can result in them having similar problems. It seems that most people have a tendency this way.

When they told me I were schizophrenic, that means ..eh.. there's two of me. So I'd better make one of them into the lord Jesus Christ. Since then I've always tried to draw one of the evil spirits into the spirit of Christ because to my mind we all have conversations going on in our mind anyway.

JH

Yes.

So ... What I'd really like to know is how you live your life with the mental problems.

B.
Lethargy, tired all the time. That's main problem, being lethargic.

JH
In your mind what caused this?

B.
Well I think I had a propensity that way as a child. But em, the ECT, as I say, made it worse as well.

JH.
Do you sleep a lot?

B.
Yes it's strange, you'd think they'd make people better but they don't. They seem to make things worse.

JH.
So drugs made you feel bad, ECT made you feel bad.

B.
Yes ECT caused depression. I don't know what was wrong with me before that time. Except maybe that I'd tried to deny the lord Jesus Christ.

JH.
Yes

B.
em... long pause

JH.
Were you a regular church goer then, before that?

B.
Well I was, but it was under sufferance. Me mother wanted me to go. It wasn't in fact till I was born again that me mother came into the lord as well. I thought that, em.. because she was a believer, she was a goody, goody sort of thing. But that doesn't seem to be the case. The drugs and the illness seemed to result in heaven and hell experiences.

JH
Really

B.
Yes a bit like, cocaine and cannabis and things of that sort.

JH.
So these experiences, where did these happen tell me about that.

B.
It just seems to have that effect that's all.

JH.

Right.

What about other people? How are they with you? Has anyone treated you badly?

B.

No not really, as I say me friends seem to suffer themselves in the same way.

Or in a similar way and all I can put it down to is the influence of demonic activity.

JH.

What about your relationships and social life?

B.

I just have a moderate number of friends that's all.

JH.

Are they good friends?

B.

Yes. They don't come here(to the house) very often. They leave me to me own devices. But a friend of mine phoned me a few minutes ago. He's had similar problems and I think he's in the same situation. lethargy as well, but he's been to university, done reasonable well at university, although he did have a drink problem.

JH.

How is his life?

B.

OK to a certain degree.

JH.

What about your life?

B.

Well, what we're finding is that once people find out we're Christians, they then try and take it out on us in some way. There's a tendency to persecute Christians.

JH.

Mmmm

So go back 10 years or 20 years. Was there anything you really wanted to do in you life and you haven't been able to do it?

B.

Well I went to college but that was after I had the nervous breakdown and eventually I started getting well again.

JH

Right

B.

I was able to get a pass at the end of the college course. I was studying for a diploma in printing technology and it was a 3 year course, but it wasn't a nationally recognised

course, just a local college diploma in Leeds at that time. Manchester was the other one and I don't know if they still do them.

JH.

Did that lead to anything?

B.

Well I eventually got back to work in the printing trade as a printer's reader. I served me apprenticeship as a compositor. I never really achieved anything at that stage. What wanted to do eventually was to become head of the dept of reading, but that didn't materialise. The illness got the better of me. I wasn't able to keep regular hours and eventually I was made redundant. The illness stopped me ambitions. It annihilated me ambitions, yes.

JH.

How do you feel about that now?

B.

Grieved.

JH.

That job you mentioned, not getting, was it a very good job?

B.

It would have been. There was good money to be had in that sort of job.

JH.

So were there opportunities for you, if you could have stayed?

B.

Yes. It was an interesting job, we got interesting subjects to read about. And there were exam papers that we got to read as well and um.. reproduced books, old manuscripts and things. It was then that I learned to read bad writing. (nvc he laughs)

JH

Well that's an achievement in itself I think. You'll be able to read the doctors writing.

B.

No.

JH.

What? Nobody can read that?

B.

No (nvc he laughs). Some years ago me father told me how this guy got a letter from his GP and he thought well I can't read this letter, I'll take it to the pharmacist and see if he can read it. So he took it to the pharmacist and the pharmacist went into the backroom with it and made up a potion and brought it out to him (he laughs)

JH.

Yes that's a good one

So how long has it been since you've stopped working?

B.

Twenty years

JH.

What have you been doing these 20 years?

B.

For the past nine years I've been in L M (a hospital). I spent 3 years in NL, and I was at SP (a hospital) 20 years ago doing occupational therapy and industrial therapy but Mrs Thatcher closed that down so that ended that sort of work.

JH.

Did you like doing that?

B.

Yes it kept me reasonable active anyway, not very active, but em.. better than nothing. Well not having learned to read of course, I read such things as these-points to books about schizophrenia The divided self. I carry them about with me and read them. I also read the bible. I read for about an hour a day these days. It used to be 8 hours a day.

JH.

That's quite tiring, isn't it.

B.

Yes, as I say eventually my health got the better of me and I wasn't able continue working at all.

JH

What effect did that have on your life?

B.

(He shows me his benefit book) I'm not on benefit on it's own. My parents left me reasonable sound., left me this house with money in trust for me.

JH.

So, that's you set up financially.

B.

Well yes but there's a problem with the solicitors as well.

JH

Oh yes?

B.

When I went into N L (a locked hospital) I found that My income was (too high). I wasn't spending it. So eventually it started heaping up and they reduced my benefit on the strength of it. It doesn't encourage people to save does it? Well, I was saving while I was in N L, and I was putting it into the building society so I thought with them

reducing me income and the trust that me parents set up, I could invest it for the future. It didn't seem to do that. It seemed to disappear.

JH

Really, what happened then?

B.

Well, eventually the solicitor went to work in Manchester. I got another solicitor in the same group and this one seemed reasonable sound. So it's all right now.

JH

So are you comfortably financially?

B.

They took me driving licence off me That's why I ended up in N L . I retaliated against the psychiatrist who treated me years ago and ended up in N L.

JH.

What did you do?

B.

I wrote on the walls of LM (a hospital) "raped in this hospital by a pervert man" They think they are entitled to rape victims of the health service,

JH.

Do you mean rape literally?

B.

No, a figure of speech. ECT is rape. ECT against your will is a kind of rape. It was, in my case, anyway.

JH

What was it like in N L?

B.

It's a evil place, all locked up. (long silence)

JH

How long have you been free of it all?

b. What N L?

JH

Hospitals generally

b.

I go into L M at weekends, every weekend

JH

Why?

B.
It's better than N L.

JH
Is it your choice to do that?

B
Well yes, it lets them administer injections

JH
Oh right
Why else do you go there?

B.
Geoffrey advises it. Geoffrey thinks that as long as I am on the drugs they should have some input into looking after me. He can't look after me because he's not a nurse.

JH
Is he worried about you? Is that why he advises you to do that?

B.
It's more than advises. He thinks he couldn't cope with me at all. So it gives him the weekends free while I'm up there

JH
Does that work for you or do you feel made to go?

B.
I feel put upon.

JH
You don't have to go, do you?

B.
No

JH.
But you do go.

B.
Yes

JH
Why?

B.
To keep the status quo. Geoffrey says that the words status quo is latin for what a mess we're in (he laughs)

JH
So for him it's a good idea and for you it's not a too bad idea.

B
Yes

JH
What are the people like, up at Lynfield Mount, the people you are with at the weekend.

B.
They are OK But they have their own agendas. They're all individuals. We all help to support one another as well.

JH
So do you feel less on your own with your mental problems?

B.
Mmmm

JH.
Is that something that happens to you, feelings all on your own with it?

B.
Oh, yes I certainly feel lonely. (long silence)

JH
Does your friend living here help you to feel less on your own?

B.
No not really no

JH
Do you feel that you get enough support from the health professionals?

B.
I feel that they're only doing it because they are making a living out of it. Not that their hearts in it so much really

JH
Yes right, I see. They are not like your friends?

B.
Mmmm , well they can be but certainly not all. The staff are not all that helpful. Of course they have a tendency to think that you're not that helpful to them. Which I suppose goes back to me stand on going to the hospital each week instead of stopping at home all the time.

JH
Don't they want you to be at the hospital at the weekends?

B.
No, not now, no. They said I should come home. But they like giving the injections, so as long as they are doing that I'll be going back there. The injections cause paranoia.

They say they don't believe that, but it's because I take Benzhexol to counteract the side effects of the injection and that takes away the paranoia. (long silence)

JH

Many people say that the injections make you're body feel bad, unpleasant.

B

Yes that's true (another long silence)

JH

How long will you keep going up the hospital at weekends?

B.

I don't know. I think it's going to be relatively permanent.....

JH

What about your choice, choices in life?

B.

Mmmm (long pause) Well the thing is when I had ECT my choice was to refuse it. They would even allow me to recover in me own time. I don't think I can refuse treatment because they would take steps to ensure that I had it. Bit as I say it makes me paranoid, does the injections.

JH

Yes

B

The paranoia comes as, em... I'm certain it's starting to put a curse on me and I see it as them responding to the curse, the doctors and the nurses and that by inflicting the injection on me.

JH

Yes I see. What about other choices is you life?

Do you have control and choices?

B.

Don't think so, I mean it's up the label what happens to us really. But they seem to me to be denying me access to me soul with the injections.

When I see the doctor at L M. I have no choices. Sometimes they say it's not them, it's the Mental Health Act

JH

What do you think about the mental health act?

B

(long silence)

JH

Do you think it helps you?

B
It's supposed to help society, isn't it. It's rhetoric. It's just that, it's just something that's put together to appease the spirits sort of thing.

JH
What about community care?

B.
It doesn't give me what I want (long silence)

JH
You seem very philosophical about everything.

B
Mmmm.

JH
You don't seem angry or even annoyed. How do you feel about it all?

B
(long silence) I am angry but the scripture says be angry but do not say.. I am angry, I am very angry with what they've done not just to me but to others, like the American doctor that did years ago 5000 lobotomies on patients. Well that's 5000 peoples' lives he's destroyed.

JH
I thought they didn't do this anymore.

B
They don't, They've stopped it to a certain degree. They've stopped administering ECT as well. We're still being subdued with drugs. When all is said and done they are just drugs. You might say they are legal drugs as well.

JH.
You mean foreign to your body

B.
Yes

JH.
If you could make a decision to change something, anything, what would it be?

B.
The main thing is em.. all the people able to refuse treatment.

JH
Right

B.
Because just recently on the media, there 's been a little girl overruled by the authority

When she said she didn't want to have a heart transplant. I think she should have been allowed to refuse. It's just another way of raping somebody.

JH.

Yes I remember that. They thought she was too young and too sick to make a decision

B.

Mmmm.

JH

They ignored her decision

B.

That's right

JH

Is that what happens to you?

B.

Yes well, that sort of thing with the ECT, I was too poorly to make a decision but I think my decision was the correct one to refuse it and be allowed to recover in my own time. They ignored my decision.

JH.

Is there anything else that's happened that's caused you to feel very bad?

B.

Well one of the things that initiated the mental health problem was the fact that as a child I was abused sexually by an older boy.

JH.

Really?

B.

Yes and I think that it's that em...em... after hearing other people's accounts, it's that that initiated the problem because it's not just me, it's other people that em.. well they haven't specified that it's that that made them homosexuals or schizophrenic but it's that sort of deviance you know. You become deviant. People seemed to view me as someone to abuse. Some of the male teachers were good teachers but I didn't do very well with the female teachers at school. I was punished at school for using foul language. It was never explained what the words meant. I couldn't understand why I was being punished.

JH.

So these things started off all your bad feelings. Do you still have bad feelings?, Do you get upset.

B.

Yes I still get bad feelings. Whether it's that or whether it's the doctor raping me with ECT. I don't know.

JH.

What about normal daily things? What about people. Neighbours?

B.

It's relatively OK I think. The neighbours are just people that you see in passing anyway

JH.

So you don't talk much to them?

B.

No, just the elderly man next door

JH

Is Geoffrey a great help to you?

B.

Yes

JH.

That's nice

B.

I still haven't got me driving licence

JH.

How would you go about getting that?

B.

I don't know now....em.. I wrote to Swansea a couple of time 3 years apart and they told me that until me psychiatrist days I'm well enough to drive they're not going to let me have it.

JH.

What have you done about that?

B.

The consultant says I can't have it till I come home. To my mind it's just an excuse, not a reason.

JH.

What do you think about the law allowing a consultant to make that kind of decision?

B.

Well she says she can't [make that kind of decision]. It's still subject to their investigation

JH.

Oh. Right.