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**NARRATIVES ON THE COURSE OF SCHIZOPHRENIA:  
CLIENT AND FAMILY REFLECTIONS ON PROCESS  
AND THE IMPACT ON SELF**

A thesis submitted in partial fulfilment of the requirements for the degree of the Open  
University for the degree of Doctorate of Clinical Psychology

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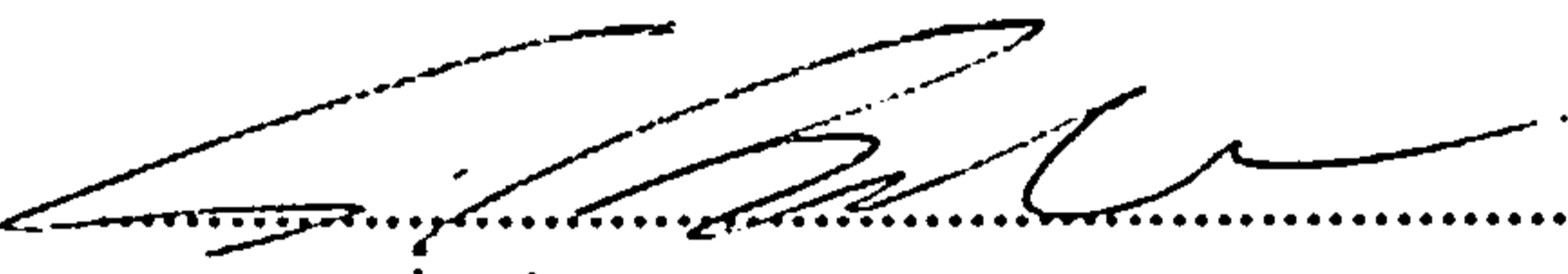
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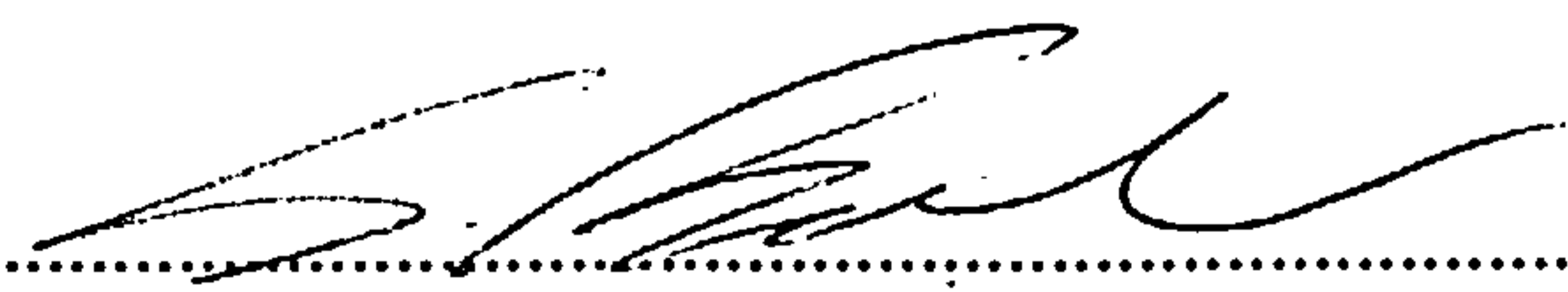
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## **ABSTRACT**

A qualitative methodology was employed to explore the narratives of clients with a diagnosis of schizophrenia. These were used to obtain a subjective perspective on the course of schizophrenia and its impact on a person's sense of self. Narratives from a nominated relative provided an alternative perspective on this process and thus served to increase the validity of the findings. Research questions specifically addressed the process of making sense of the experiences over time and the role of professionals within this, the impact on sense of self and the impact on relationships with others.

Semi-structured interviews were conducted with 16 participants. These were audiotaped, transcribed then grounded theory was used to analyse the data.

Results were used to build a stage model which charts the process over time. It is tentatively hypothesised that earlier vulnerabilities in the formation of self are expressed during adolescence due to the developmental need to separate from parents and develop an adult identity. Implications for clinical work and services are discussed.

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## 1. INTRODUCTION

‘As soon as Sophie had closed the gate behind her she opened the envelope. It contained only a slip of paper no bigger than the envelope.

It read *Who are you?*.’

(Gaarder, 1995).

This fundamental question about identity has been asked by philosophers since the dawn of civilisation. It can be responded to in a multitude of ways, from the simple giving of a name to a weighty biography. Narratives about who we are encompass our aspirations and disappointments, and serve to influence others’ views and behaviours. The activity of structuring one’s actions and presenting them as part of a lived narrative is related to one’s identity and sense of self (Widdershoven, 1994), and is thus an important activity for any individual.

Traditionally the narratives of patients have been treated with scepticism. However, there is increasing recognition that individual frameworks for understanding experience are an important way of placing value on oneself and one’s life, and provide meaning to our social reality (Hyden, 1997). It has been suggested that for those struggling to recover from psychosis, the rediscovery and reconstruction of an enduring sense of self through narrative is an important part of improvement (Davidson and Strauss, 1992). It is possible that factors aiding or impeding this reconstruction of self are linked to the course and outcome of ‘schizophrenia’<sup>1</sup> (Warner, 1994).

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<sup>1</sup> Despite increasing debate about the validity and reliability of the concept of schizophrenia, this term will be used throughout. A fuller discussion of the construct is outlined in section 1.1.

This dissertation aims to elicit narratives on the process of receiving a diagnosis of schizophrenia in order to gain subjective accounts of how 'the self' is affected. The perspectives of both the diagnosed individual and an identified family member are considered important in increasing understanding of this process. By obtaining information on how people talk about the course of mental health problems, it is hoped that knowledge can be gained about which factors aid or impede the maintenance, reconstruction or construction of a sense of self.

The introduction is structured in four sections. The first provides a description of the cognitive and emotional changes which lead an individual to be diagnosed as suffering with 'schizophrenia'. There is considerable debate about this concept, but it is acknowledged that schizophrenia can be included under the umbrella of psychotic disorders (WHO, ICD10, 1992). In the second section an overview of current thinking about the self is presented from psychoanalytic and developmental, cognitive and social constructionist perspectives. This includes a description of the concept of narrative. Personal narratives are an increasingly popular way of researching perceptions of the self, as the activity of describing oneself and experiences over time reflects personal identity (Widdershoven, 1994). This self-narrative is influenced by familial, cultural and historical discourses (Dallos, 1996). As the psychological structure termed 'the self' has been linked to regulating the emergence of pathology (Auerbach and Blatt, 1996), questions about identity and self were seen as central when investigating schizophrenia. The third section explores how theories about the self can be useful in thinking about schizophrenia and elaborates on popular narratives about mental health



and schizophrenia (Chadwick, Birchwood and Trower, 1996). The final section pulls together ideas about narratives and self and describes the rationale for the research.

## **1. 1 THE CONCEPT OF SCHIZOPHRENIA**

The World Health Organisation's International Classification of Mental and Behavioural Disorders (WHO, ICD10, 1992) outlines categories of symptoms that have come to be associated with the construct of 'schizophrenia'. A distinction is made between positive and negative symptoms; the former reflecting an excess or distortion of normal functions, and the latter a deficit or loss of normal functions. Positive symptoms include distortions or exaggerations of inferential thinking (delusions), perception (hallucinations), language and communication (disorganised speech) and behavioural monitoring (disorganised or catatonic behaviour). The negative symptoms include a flattening of affect, poverty of speech and an inability to initiate and persist in goal directed activities. These symptoms must have been present for a one month period.

On the surface this clean description of cognitive and emotional dysfunctions is appealing. However, despite widespread usage, there is increasing debate about the validity and reliability of the concept of schizophrenia. The other major classification system (the Fourth Edition of the American Psychiatric Association Diagnostic and Statistical Manual; APA, DSM IV, 1994) provides a list of similar, although not identical symptoms. The major difference between these two systems is that in DSM IV the important symptoms must have been present for at least six months, whereas with ICD10 only one month is required. The use of different operational criteria

means that the same patients are not always diagnosed as 'schizophrenic' (McGuffin, Farmer and Harvey, 1992). Bentall (1990) suggested that if schizophrenia is a valid scientific construct then agreement should be reached on which criteria are correct. He also noted that diagnostic reliability would not solve the problem of questionable validity. Bentall, Jackson and Pilgrim (1988) found that the differential diagnosis of schizophrenia from other conditions was complex, there was no specific treatment programme for someone assigned this diagnosis and an individual's prognosis was unclear. Other researchers (e.g. Crow, 1980) have suggested that there may be several sub-types of schizophrenia. However, there has been no agreement on how many and what form these sub-types may take, and none of the groupings have received empirical support (Jackson, 1990).

Both the construct of schizophrenia and possible causative mechanisms prove problematic for researchers. Bentall (1990) commented that;

'almost every variable known to affect human behaviour has, at one time or another, been held to be important in the aetiology of schizophrenia'

(p23)

Bentall (1993) noted that the most common way of studying the psychoses involved comparing those diagnosed with schizophrenia with individuals diagnosed as 'normal'. The assumption behind this was that those suffering from schizophrenia would have something in common which was not present in the 'normal' group. However, there has been no clear genetic, biochemical, neurological, cognitive, familial or



psychodynamic cause or causes of schizophrenia identified (Lavender, in press).

The terms 'schizophrenia' and 'schizophrenic' tend to provoke strong reactions in the public. However, it is becoming increasingly apparent that what is precisely understood by this label is unclear. Ambiguity and confusion surrounding the construct of schizophrenia has been expressed by those assigned the label, their families, service providers and academics (Bentall, 1990; Boyle, 1994).

Boyle (1994) suggested that a different approach needs to be taken to the research about 'schizophrenia', as traditional approaches seem to have outlived their usefulness. Within the field of psychosis, it has been increasingly apparent that the rediscovery and reconstruction of an enduring sense of self is an important part of improvement (Davidson and Strauss, 1992; Anthony, 1993). Bearing this in mind it was considered pertinent to consider the psychological structure termed 'the self'. This concept is considered of central importance when considering mental health and pathology (Auerbach and Blatt, 1996), and seemed an appropriate place to start the research.

## **1. 2 THE SELF**

The concept of self is seen as a central psychological structure that has a key role in regulating the emergence of pathology (Auerbach and Blatt, 1996). Academic writing about 'the self' has come from a multitude of perspectives. Biological, cognitive, experiential, social constructionist and psychoanalytic and developmental perspectives have all contributed to this developing body of knowledge (Stevens, 1996). Due to the vastness of the literature, a summary of the perspectives on 'self' that are most

pertinent to a psychological consideration of schizophrenia are outlined.

Psychoanalytic and developmental, cognitive and social constructionist perspectives are discussed below. To aid the reader, a glossary of psychoanalytic terms is presented in Appendix 1.

### 1.2.1 PSYCHOANALYTIC AND DEVELOPMENTAL PERSPECTIVES

Different theorists have debated whether we are born with a core self which then develops, or whether there is a gradual emergence of self out of core experiences which involve other people right from the start. However, both perspectives highlight the important role that interpersonal relationships have in shaping the self (Klein, 1987). The gradual construction of a self-representation requires the ability to reflect on oneself as an object. This self knowledge comes from two sources; subjective and objective self-awareness. The former refers to one's experiential feelings about oneself, and the latter to who one appears to be in the eyes of others (Auerbach and Blatt, 1996). This capacity for reflexive self-awareness emerges during the second year of life, and continues to develop over the life-span (Erikson, 1956; 1963). This reflection can be viewed as the core of the self structure.

The development of this reflective ability occurs through play and affect-laden interactions with the caregiver. The caregivers' role is to reflect on the child's internal state, soothe distress and suggest a way of coping. Thus the infant receives the message that the caregiver's mind is both the same and different from their own mind (Fonagy, Steele, Steele and Target, 1997). The ability to mentalise is important as it enables the individual to distinguish between inner and outer reality, distinguish intra-

personal mental processes from interpersonal communications and influences the richness and diversity of inner experience (Fonagy, Steele, Steele and Target, 1997). It also allows both the child and the caregiver to attain increasing mental and physical autonomy. However, even at an advanced state of development, a tension exists between subjective and objective self-awareness (Auerbach and Blatt, 1996).

### **The construction of self-representation**

Drawing on object relations and attachment theories, DeWaele (1996) suggested that three specific mechanisms are involved in developing this reflexive ability and thus constructing and regulating the self. These are the regulation of relationship boundaries, regulation of affective awareness and regulation of representational space. The paragraphs below describe how these mechanisms start to develop from an early age.

#### **i. Regulation of boundaries**

Attachment theorists have noted how neonates seek and initiate stimulation from their environment. They also actively contribute to regulating the amount of stimulation they receive through crying and other affective expressions (Stern, 1985). Throughout life the regulation of self-other exchanges occurs through a variety of mechanisms, and enables an individual to process experience and control interactions with others. The process also enables the individual to maintain a sense of distinctiveness and separateness as well as a sense of togetherness.



## ii. Regulation of affective awareness

Stern (1985) considered that the infant becomes increasingly aware of many forms and qualities of feeling that are intrinsic to survival. It has also been suggested (Tomkins, 1970) that there are innate emotions which can be viewed as primary motives. Basch (1992) suggested that these innate feelings become increasingly more developed and enable us to eventually become aware of others' feelings. In observation of infants, Stern (1985) noted that this regulation of affect occurs from very early on. For example, the infant turns its head away when stimulation becomes too great, and when the level of excitement falls too low, the infant uses gaze and face behaviour to invite stimulation. In children and adults this affect regulation manifests as shifting attention away to modulate arousal or managing external demands which are perceived to exceed individual resources (Eisenberg and Fabes, 1992).

## iii. Regulation of representational space

Developmental theorists have suggested that through interactions with others our 'map of the world' becomes increasingly more differentiated and organised (Klein, 1987). This 'map' consists of conscious and unconscious representations of phantasy systems reflecting our basic needs and desires, representations of how we interact, representations of the self and others and representations related to identity and ambitions (DeWaele, 1996).

As our experience within the world increases, self-structures gradually establish themselves. This leads to increasing differentiation between the self, other people and other things. Over time it is proposed that the personality gains a relatively stable idea

of itself in its environment, and recognises what is not-self. Life experiences are increasingly re-organised and integrated into the existing self-structure and connections are improved between experiences and the feelings that accompanied these (Klein, 1987).

### 1.2.2 COGNITIVE PERSPECTIVES

Within a cognitive framework, 'the self' is formed of core beliefs which are the result of early experience. These beliefs feed the assumptions that the individual has about themselves, other people and the world, and are in turn connected to everyday thought processes. If these assumptions, beliefs and thoughts are 'irrational' or 'maladaptive', they can be associated with problems such as 'low self esteem' (Beck, Emery and Greenberg, 1985). In recent years the concept of a 'schema' (Young, 1990) has been used to describe unconditional beliefs about the relation of the self to the environment. These beliefs are posited to result from experience during the first few years of life.

Within the field, researchers have been investigating the nature of these core beliefs and assumptions. Other work has highlighted that abnormalities in the processing of information related to the self-concept are implicated in pathology (Bentall et al., 1994). One aspect of this research is attribution theory. This describes the processes by which people make cause and effect links about their own and others' experiences. Weiner (1986) reviewed the literature on attribution research and noted that the causes of actions tended to fall into two categories; factors which reside in the individual (internal) and those in the environment (external). Thus cognitive theories suggest that both expectations and biases arising from prior learning and informational processing



abnormalities may be implicated in pathology (Chadwick et al., 1996).

### 1.2.3 SOCIAL CONSTRUCTIONIST PERSPECTIVES

At the heart of constructivism is the epistemological belief that a totally objective reality can never be fully known, and knowledge is a construction of the mind.

Individuals construct and organise meaning from their life experiences, and thus personal 'truth' can not be evaluated by some external criteria (Rosen, 1996). Despite philosophical debate about this assumption (Erwin, 1997), the constructionist perspective can provide a basis from which to explore mental health problems.

Social constructionism is a sub-set of constructivist theory, and examines how meanings are formed and then, through a process of socialisation, are subsumed within the individual. Social construction involves a two stage process that entails construction by society and construction by the individual. We consequently both make of and are made by our social realities (Harding and Palfrey, 1997). Thus the social constructionist perspective would advocate that there is no such 'thing' as the self, but it is continuously constructed and never secure.

This viewpoint was discussed by Chadwick, Birchwood and Trower (1996). They suggest that three conditions are necessary for the construction of self; an objective self, a subjective self and the other. The 'objective self' is the self that is constructed and observed within the public arena. The 'subjective self' chooses what to 'present' to the world, and monitors these behaviours and others reactions. The 'other' is another person who constitutes the 'audience'. Drawing on ideas from Goffman (1959), Chadwick et al.. (1996) suggested that self-construction first occurs with self-



presentation behaviour for others. The second stage is perceived evaluation of this self-presentation by the 'audience'. The third stage constitutes either evaluation of the self based on the others evaluation, or evaluation *by* the self *of* the other.

This perspective highlights that the evaluations we perceive others to make of us are important in constructing our 'self'. The medium of language is thus an essential tool, and narratives relayed about the self by the self or by others impact on the 'self' that is ultimately constructed.

*Narrative theory is an aspect of social constructionism, and it has been suggested that human experience embodies a quest for meaning which is made explicit in narratives (Rosen, 1996). People interpret the world by telling 'stories', and in this way make sense of themselves and their reality. Researching peoples' narratives has been a popular approach in the area of chronic illness (Hyden, 1997) due to the temporal ordering of events that are associated with change of some kind. Despite debate about the concept of schizophrenia and causal mechanisms, there is no doubt that the symptoms experienced have a significant impact on peoples' individual functioning (Perkins and Dilks, 1992). The use of an illness metaphor is thus useful to consider the impact schizophrenia has on a person's functioning, and is utilised by The World Health Organisation (Wood, 1980) and those discussing the concept of recovery (Anthony, 1993).*

In relation to narratives about illness, there are three ways in which the narrator, the illness and the narrative can be interrelated (Hyden, 1997). First, people themselves

can be the narrator, and the narrative they relay describes events that have been experienced personally and pose some problems. Second, 'experts' in the field can be narrators, and the narratives they tell convey knowledge and ideas about the illness. Third, the narrative can be the illness. This occurs when factors combine to impede the individual's ability to connect experiences with particular events, for example when there has been traumatic brain injury.

Within the field of schizophrenia there are many instances of the second type of narrative; ideas and knowledge about schizophrenia are prolific, although not always congruent. The assumption that the narrative is the 'illness' (WHO, ICD10, 1992) has led to neglect of narratives from a personal perspective, and it is this neglected area that this dissertation aims to address. Constructivist models would argue that these three narrative perspectives all influence each other (Rosen, 1996).

In addition to the important role of narratives, the social constructionist perspective also highlights the impact that other social-psychological factors may have on the self that is constructed. Charmaz (1991) noted that the impact of any illness on the self is exacerbated by four social psychological conditions. These are living a restricted life, existing in social isolation, experiencing discredited definitions of self and becoming a burden. It is likely that these factors will ultimately affect the self that the individual perceives themselves to be.

### **1.3 THE SELF, MENTAL HEALTH AND SCHIZOPHRENIA**

The notion of self has often been utilised in understanding schizophrenia, and played a central role in the classical theories offered by Kraepelin (1905) and Bleuer (1950).

More recent publications have argued for renewed attention to be paid to the concept (Davidson and Strauss, 1992). The discussion below examines how the concept of schizophrenia has been related to 'the self'. This is done using the psychoanalytic and developmental, cognitive and social constructionist perspectives outlined in the previous section.

### 1.3.1 PSYCHOANALYTIC AND DEVELOPMENTAL PERSPECTIVES

It has been argued that faults in the basic ways in which individuals regulate their self concept could lead to mental health problems such as schizophrenia (Auerbach and Blatt, 1996). As noted earlier, self-reflexivity is posited to be essential in the development of a self-concept, and it is suggested that disturbances in this function are involved in the development of schizophrenia. Following on from the work of Fonagy et al. (1997), Lake (1997) questioned whether reflexive functioning was underdeveloped. At the opposite extreme, Sass (1992) questioned whether the individual with schizophrenia is hyper-reflexive.

Lake (1997) suggested that people with schizophrenia have difficulty in reflecting on their own and other peoples' mental states. He suggested that this may be due to inconsistencies in early parenting or due to innate cognitive or biological disability. However, Sass (1992), argued that hyper-reflexivity is the primary psychological disturbance in schizophrenia. This is when the individual becomes overly-focused on reflecting on the self and others. This leads to too abstract a mode of self-understanding, as the person with schizophrenia realises that there are multiple ways of making sense



of the world and can not settle on a stable perspective for comprehending reality. In order to restore a sense of security, Sass (1992) suggested that the individual may become overly focused on concrete percepts that have an idiosyncratic, personalised significance. These hypotheses are discussed below in relation to the mechanisms involved in the construction of self representation which were outlined in section 1.2.1.

#### i. Regulation of boundaries

Psychodynamic theories generally hold that schizophrenia involves a disturbance in the regulation of boundaries between the self and non-self (Auerbach and Blatt, 1996). It is possible that disturbances in reflexive functioning lead to difficulties in differentiation between the self and others (Lake, 1997; Sass, 1992). Frosch (1983) considered that the anxiety resulting from a fear of disintegration of the self was crucial in understanding the psychotic process. He suggested that due to inadequate infant care, the individual becomes unable to bear this anxiety and manages the underlying emotions that this fear generates through the defence mechanisms of splitting, denial, fragmentation, introjection, projection and projective identification (see Appendix 1 for definitions). These mechanisms can be observed in many of the symptoms of schizophrenia, for example anger is projected out and experienced as a persecutory delusion. It is suggested that the psychotic aspect of the client's personality comes to dominate where it is used to patch up damaged parts of the ego (Steiner, 1993).

In order to maintain a sense of psychological survival, it is suggested that the person with schizophrenia longs for fusion with others to establish a sense of safety, existence and continuity. However, as fusion also leads to the loss of self, people with

schizophrenia are fearful of interpersonal contact (Auerbach and Blatt, 1996).

#### ii. Regulation of affective awareness

It is suggested that in schizophrenia the self occupies a pathological position in which it does not succeed in regulating the amount of stimulation obtained from the environment. This results in inflexible attempts at processing experience. It is suggested that this is due to the self's ongoing struggle with the need to feel loved, even though defences operate at self/other boundaries and/or representational boundaries (DeWaele, 1996). Consequently, the individual has no means by which to effectively deal with emotionally laden interactions with others.

#### iii. Regulation of representational space

Due to disturbances in reflexive awareness the infant is unable to develop an adequate map of the world. This consequently leads to fuzzy representations of the self, other people and other things. Without the consistency of internal objects there is danger of a slide into full blown psychosis. The disappearance of internal objects is suggested to pose a major threat to identity, and is the reason for a sense of dying and of inner world destruction (Wexler, 1965).

### 1.3.2 COGNITIVE PERSPECTIVES

Within the cognitive literature, several researchers have placed the concept of self at the heart of understanding psychosis (Chadwick et al., 1996).

Garety and colleagues (Garety, Kuipers, Fowler, Chamberlain and Dunn, 1994) have

made attempts to think about the basic assumptions, beliefs and schemas that constitute the core self of people with schizophrenia. Through conducting cognitive-behavioural therapy with people whose psychosis was drug-resistant it was found that assumptions about the self reflected a negative self-image, a sense of hopelessness and perceived psychological threat. The importance of the relationship between self and psychosis has received further recognition with the application of schema-focused cognitive therapy to people with psychosis (Fowler, Garety and Kuipers, 1995).

Work in Liverpool by Bentall and colleagues has focused on specific symptoms and their relationship to attributions and beliefs about the self. Bentall, Kinderman and Kaney (1994) described how persecutory delusions can emerge to preserve vulnerable self-esteem. These are suggested to emerge when negative life events activate apparent discrepancies between ideal and actual self. It is suggested that in extreme situations, the desire to maximise consistency between the actual and ideal situation can only be achieved by grossly distorting reality and perceiving others to have a negative view of them. Bentall, Haddock and Slade (1994) discussed auditory hallucinations, and how perceiving both negative thoughts about the self and feared intentions as being outside of oneself and outside of one's control can reduce anxiety. Together these findings have resulted in the role of self being a key component in cognitive therapy with people who have symptoms associated with schizophrenia. However work specifically investigating how people with schizophrenia process emotionally salient information is still at an early stage (Chadwick et al., 1996).



### 1.3.3 SOCIAL CONSTRUCTIONIST PERSPECTIVES

The concept of biographical disruption (Corbin and Strauss, 1987) is useful when considering how the symptoms of schizophrenia may impact on the self. It is suggested that the question 'how have I come to be like this because it isn't me' (Radley, 1994) is the way this disruption is often expressed. After the occurrence of a disruptive illness it seems to be necessary for people to discover the meaning of the experience and relate it to their life narrative (Hyden, 1995a). Similarly, Davidson and Strauss (1992) noted how over the course of psychosis it is essential to rediscover and reconstruct a sense of self. This process involves reflecting on how one is perceived in the eyes of others and accommodating this within the revised self-concept.

The social constructionist perspective notes the evolving and dynamic aspect of self, and highlights the fact that without others we can not 'be'. This perspective provides a useful umbrella to first explore the impact that narratives relayed by professionals and the public about schizophrenia may have on the individual's self concept. Second, it is also recognised that there are other social-psychological factors which result from having schizophrenia. These are discussed in relation to the impact that they may have on the constructed self.

#### Narratives about mental health and schizophrenia

The idea of a constructed narrative is presented as a means by which individuals come to understand themselves and through which a revised sense of self is constructed. This is seen as an essential aspect of 'recovery' from psychosis (Davidson and Strauss, 1992). It is argued that with any 'illness career' there are critical turning points in

identity (Karp, 1994), and it has been suggested that recovery of mental health is an individual and cultural preoccupation which involves constructing explanatory systems and evolving congruent treatment techniques (Kakar, 1982).

Narratives about the cause and nature of mental health are socially constructed within a particular cultural framework (Eisenbruch, 1990) and are thus highly individual and subjective. Foucault (1965) pointed out that each age of civilisation has its own explanations for 'madness' which closely reflect the social and intellectual preoccupations of the time. These 'models' include the magic/holy vision of madness, the deviant/criminal vision, the medicalised conception and a psychological conceptualisation. Although there has been a move away from the mad/bad explanations, mental illness continues to have a negative image. Within Western societies, narratives of mental health tend to construct peoples' identities as totally comprised of the pathological label (e.g. he is a 'schizophrenic') (Warner, 1994). They also reduce the power of individuals through marginalisation and exclusion; this can occur within the family and/or within the wider social system (Dallos, 1996).

In every culture a health system simultaneously encompasses narratives from several sectors. These include a professional sector (specialised medical knowledge, institutions and its practitioners), a folk system (traditional therapeutic knowledge and its practitioners) and lay knowledge (Zani, 1995). These categories are not mutually exclusive and there are degrees of overlap. Each draws from a number of discourses which reflect cultural beliefs about health.

Currently the three most prevalent discourses appear to be medical (organic or hereditary dysfunctions), individualistic (e.g. personality, weakness or learning) and relational (e.g. as having been ‘damaged’ by parents). It is noted that all these discourses tend to pathologise individuals or relationships to some degree (Dallos, 1996). The literature on schizophrenia is presented below in terms of these three main explanatory discourses, and it is noted that each conceptualisation has an impact on treatment approaches as well as the way the individual comes to understand their difficulties.

#### i. Medical

Medical discourses present schizophrenia as an illness or group of illnesses. Most researchers have assumed that ‘schizophrenia’ is a disorder that is caused by structural neurological or biochemical abnormalities in systems that lead to difficulties in core cognitive processes (Seidman, 1984). This conceptualisation focuses treatment on changing the underlying biological processes through medication. This conceptualisation, however, can lead to the false assumption that unless the biological changes can be rectified no other interventions will be of value (Perkins, 1997).

#### ii. Individualistic

Psychological theories of personality and cognitive processing have also contributed to the discourse around schizophrenia. These two discourses have been elaborated on in sections 1.3.1 and 1.3.2, so this section is used to explore the likely implications that these have on the self.



Psychoanalytic theories assume that genetic factors, early trauma and 'inadequate' parenting result in an unstable psychic structure and a developmentally immature 'self'. The implication of this narrative is that early trauma has to be 'worked through' and consequently the focus of treatment is on reorganising the underlying psychic structure (Wexler, 1965). One of the implications of this narrative is the focus on the pathological relationship between parent and child.

Cognitive theories propose that maladaptive beliefs about the self and deficits in cognitive processing contribute to psychosis. Discourses about 'faulty' information processing could lead to the narratives of people diagnosed with schizophrenia being devalued and undermined.

### iii. Relational

The communication between family members has been linked with the aetiology and maintenance of symptoms associated with schizophrenia (Bateson, Jackson, Haley and Weakland, 1956; Laing, 1965; Leff and Vaughn, 1985). Although not all have stood up to empirical testing, relational explanations have a prominent place in the discourse surrounding schizophrenia.

Bateson et al. (1956) considered that main problem for people with schizophrenia was a severe difficulty in the way they communicated. They suggested that this developed out of contradictory communications between family members, and termed this a 'double bind'. However, this theory did not stand up to empirical testing (Lavender, 1998). Laing (1965) suggested that the content of hallucinations and delusions

contained an 'existential truth', and served to communicate how difficult it was to live in the family environment. However, Laing's hypotheses have not been formally tested (Lavender, 1998). In recent years, the concept of expressed emotion (EE) has been used to describe the critical comments and emotional over-involvement that were considered to be factors in the development and course of schizophrenia (Leff and Vaughn, 1985). This has been linked with relapse and has led to some effective therapeutic interventions (Lam, 1991).

However, all these theories blamed and pathologised families and were based on a narrow view of 'normal' family functioning. Recent research has recognised that a psychotic episode produces a state of disarray within the family system, and psycho-educational approaches have been developed to help the family cope with this change (Bressi, 1996).

#### iv. An interactive conceptual model

In recent years vulnerability-stress models have gained popularity (Clements and Turpin, 1992). The fundamental assumption within these models is that an individual may have a latent predisposition to the illness of schizophrenia, but environmental and individual factors influence the course and outcome (Warner, 1994). These models provide a framework which can be used to link the various theories and discourses about psychosis, and allow for various types of explanation to have greater weight at different times in the individual's development. These models also provide opportunities to link psychodynamic and cognitive conceptualisations of psychosis (Hingley, 1997).

## **Social-psychological factors**

It has been suggested (Anthony, 1993) that the difficulties experienced by those with schizophrenia are exacerbated by social psychological factors. A restricted life can be the direct result of impairment or due to treatments. People with schizophrenia have major disturbances of thought, feeling and behaviour, and this can make it difficult for them to perform activities of daily living (Perkins and Dilks, 1992). In addition major tranquillisers can have many side effects (MIND, 1989) which can restrict functioning. The second condition, social isolation, can occur due to forced restriction but also due to the persons' fears about how others will treat them and whether they can bear the strain. Beels, Butwirth, Berkeley and Struening (1984) described how experiences of being misunderstood, ignored or stared at are common for those with a diagnosis of schizophrenia, and can lead the person to withdraw from social life. The third condition is that of experiencing discredited definitions of self. Hayward and Bright (1997) discussed the stigma experienced by those with mental health problems. The stigma associated with a diagnosis of schizophrenia can lead to discredited definitions of self when others show curiosity, hostility or discomfort in relation to the condition. This is particularly the case when symptoms are visible and open to misinterpretation, for example when people talk to their 'voices'. The fourth condition which can lead to a loss of self is the perception of becoming a burden on others. When people with schizophrenia become unable to fulfil past obligations this can have a profound effect on their social identity (Hatfield, 1989). Thus interactions with others can significantly impact on the way in which people with schizophrenia construct themselves.



## **1.4 RATIONALE FOR THE STUDY**

Boyle (1994) discussed the relationship between the philosophy of science and current research on schizophrenia and suggested that traditional research strategies on schizophrenia represent a 'degenerating research paradigm'. This suggested a need for alternative research approaches. Davidson (1993) suggested that an integration of subjective and objective research strategies would result in a more complete understanding of schizophrenia, and considered that the phenomenological investigation of subjective narratives may provide valuable insights into behaviour that are not available via more objective means.

The idea of narrative has been used as a way of communicating about one's self and one's life (White and Epston, 1990). It has been suggested that one's identity/sense of self is related to the activity of structuring one's actions and presenting them as part of a lived narrative. Thus the narrative is a way of both representing oneself and considering one's relations to others (Widdershoven, 1994). Research on narratives has become an increasingly popular way of understanding how people deal with life situations and problems of identity (Hyden, 1997). Thus in order to research the impact of schizophrenia on the self, eliciting narratives about the process from both clients and family members seemed a suitable methodology.

At an individual level, peoples' personal explanations for why they are ill, distressed and disabled markedly affect what they experience and how they respond (Perkins and Moodley, 1993). A shared conceptualisation of any illness or problem is necessary if interventions and treatments are to have optimal effectiveness (Radley, 1994), and

within services greater attention is being paid to the needs and wishes of those with psychosis. The document 'Building Bridges' (Department of Health, 1991) suggests that clients' opinions are incorporated into their care plan and that relatives are also involved in the process. However, in order to agree on specific goals it is necessary to have a shared conceptualisation of the problem. This is not always the case, and instead the notion of 'insight' is used to describe how much overlap there is between the individual's conceptualisation and that of the clinician (Perkins and Moodley, 1993). 'Lack of insight' therefore equates to having a perception of reality which is held with a degree of conviction and is not subject to disconfirming evidence (Garety, 1985). In the International Pilot study of Schizophrenia (WHO, 1973) the commonest symptom recorded was lack of insight, so this observation has important ramifications for the validity of the concept as well.

It has been suggested that it is very difficult to establish the validity and reliability of clients' own reports; particularly if the phenomena are purely private. There has been a tendency for clients' descriptions of their experiences to be undervalued; it is assumed that they are unreliable or invalid and 'lack of insight' is absolute and does not vary (MacCarthy and Liddle, 1994). However, Strauss (1994) noted that the client's story has the capacity to combine subjective and objective aspects of experience in a temporal context, and for this reason is invaluable.

The biographical disruption associated with any chronic illness is known to affect self-perception (Corbin and Strauss, 1987). This study aims to investigate the impact that having schizophrenia has on one's' identity/sense of self. It is important that those

working with people with schizophrenia understand what is being experienced and the meaning of these experiences to the individuals concerned. How people come to understand a change in their state has implications for their behaviour, which in turn affects their symptoms and how their problems are identified and classified (Lewis, 1995). It is also important in terms of communicating about the treatment process and identifying interventions which will most benefit the recipient (Radley, 1994).

Schizophrenia also represents a biographical disruption for the client's family (Bressi, 1996). It is thus important that they too make sense of what happened in a satisfactory way if they are to provide effective support.

#### **1.4.1 Reasons for qualitative methodology**

At the heart of scientific research are core philosophies which guide the researchers choice of methodology and their approach to the questions being addressed (Nicholson, 1995). Constructivist approaches suggest that individual and social realities are constructed according to cultural and historical norms, and the 'truth' ascribed to different 'realities' is heavily influenced by the power and status of those ascribing to them (Foucault, 1965). The relativism implicit within this approach suggests that all accounts of the world are equally 'good'. This approach contrasts with the traditional positivist stance generally adopted by psychology, which emphasises objectivity and aims to create a pool of knowledge about the world (Stevenson and Cooper, 1997).

Qualitative research recognises that the social world is complex and dynamic and is



constructed from multiple realities (Banister, Burman, Parker, Taylor and Tindall, 1994). Rather than relying on the researcher's existing explanatory frameworks, the methodology adopts an inductive approach and attempts to understand from a number of different standpoints.

Research within the natural sciences has been the model for previous enquiries, and has emphasised quantification, measurement, the separation of researcher and participant and the development of general laws. An increasing number of critics suggest that there is a need to pose alternative research questions which attach more importance to subjective experience and 'what it feels like' (e.g. Nicholson, 1995). Also, as noted above, personal narratives are a popular way of researching the impact of an experience on the self. These observations in conjunction with a personal philosophy that favoured a relativist approach, led to the decision to adopt a qualitative methodology. The following questions aimed to elicit narratives, which through their presentation and organisation, would give some insight into the process of receiving a diagnosis of schizophrenia and its impact on the clients sense of self.

## **1.5 RESEARCH QUESTIONS**

1. What narratives do individuals and their closest identified family member construct to explain the emergence of psychotic symptoms characteristic of schizophrenia?
2. How do these narratives develop over time?
3. How are professionals' narratives perceived by clients and their relatives?
4. What do these narratives reflect about the individual's sense of self both before and after the emergence of psychotic symptoms?
5. What do these narratives reflect about the individual's relationships both before and after the emergence of psychotic symptoms?

## **2. METHODOLOGY**

### **2.1 DESIGN**

The study used a cross-sectional within and between groups design. A structured interview format with open-ended questions was employed so that participants could fully express their views and opinions. A qualitative methodology (Banister, Burman, Parker, Taylor and Tindall, 1994) was used to analyse the data.

### **2.2 PARTICIPANTS**

Two groups of participants were sought. The first group consisted of eight people who had been given a diagnosis of schizophrenia by a Consultant Psychiatrist. The second group consisted of the closest named relative of each of the eight people diagnosed with schizophrenia.

#### **2.2.1 SAMPLING ISSUES**

In quantitative research certain procedures are used to ensure that the sample is representative and generalisations can be made. In contrast, qualitative research utilises the idea of theoretical sampling. Different participants are selected as they serve to shed some light on the population being studied. This permits the inclusion of a wide range of people and those who have access to important sources of knowledge (Mays and Pope, 1996). This sample was drawn from people involved with rehabilitation services for people with severe and enduring mental health problems.

#### **2.2.2 INCLUSION AND EXCLUSION CRITERIA**

Participants in each group met the selection criteria detailed below:

##### **i) The client group**

###### **Inclusion criteria**

1. A current psychiatric diagnosis of schizophrenia.
- 2 Living in a hospital hostel or supported housing.
3. HoNoS score (hallucinations and delusions classified as a mild, moderate or severe clinical problem)



### Exclusion criteria

The following exclusion criteria were applied;

1. The presence of organic brain disease.
2. Clients who did not understand the study and were unable to give informed consent.
3. Clients who did not want their relative to be contacted.

### ii) The relative's group

#### Inclusion criteria

1. The person named as the closest relative by the client.
2. Relatives who had had previous contact with the rehabilitation service.

### 2.2.3 HEALTH OF THE NATION OUTCOME SCALE (HONOS)

To ensure that the symptoms commonly associated with schizophrenia were present, The Health of the Nation Outcome Scale (Wing, Beevor, Curtis, Park, Hadden and Burns, 1998) was used. This 12 item scale (Appendix 2) was designed to measure the health and social functioning of people with mental health problems. Areas covered include aggressive behaviour, suicidal ideation, drinking and drug taking, cognitive problems, physical illness and disability, hallucinations and delusions, depressed mood, other mental and behavioural problems, social relationships, activities of daily living, and opportunities to utilise and develop skills. Problems are rated from zero to four where zero is no problem and four represents a severe clinical problem. Each aspect of the individual's functioning is rated only once and the rater is asked to concentrate on the most severe problem in each category. Four sub-scores and a total severity score are obtained. For the purpose of this study the total score did not include items 11 and 12 as these items provide a measure of the service provided.

The development of the scale occurred in four phases; two pilots, a field trial and analysis of the structure. Checks were made on the acceptability and structure of the scale. Test-retest reliability correlation coefficients for all items fell between 0.74 and 0.88, except aggression (0.61). The Brief Psychiatric Ratings Scale (Overall and Gorman, 1962) and

the Role Functioning Scale (Goodman, Sewell and Cooley, 1993) were used to evaluate comparative validity; the resultant product moment correlation was 0.65. Sensitivity to change was demonstrated through comparisons with retrospective clinical judgement. The final version has proved to be simple to use, is of acceptable reliability, is compatible with other well-established instruments and is clinically acceptable.

#### 2.2.4 CHARACTERISTICS OF THE PARTICIPANTS

Individual participant details are summarised in tables 1 and 2. Participants mean age was 37, the average HoNoS score was 12.5. The mean duration of disorder was 17.75 years.

***Table 1: Characteristics of client group diagnosed with schizophrenia***

Participant	Age	Ethnic origin	Gender	Total HoNoS score	Duration of disorder	Level of support
1	41	non-UK white	M	10	18	CPN only
2	50	UK white	M	11	28	visiting day staff
3	41	UK white	M	14	22	visiting day staff
4	35	UK white	M	13	15	visiting day staff
5	31	UK white	M	15	14	visiting day staff
6	25	non-UK black	M	15	5	24 hour staff
7	42	UK white	F	12	28	24 hour staff
8	29	UK white	F	10	12	24 hour staff

The table below shows the characteristics of the people named as the closest family member by the clients.

***Table 2: Characteristics of identified family members***

Participant	Sex	Relationship to client
1	F	mother
2	F	mother
3	M	father
4	M	father
5	F	mother
6	F	mother
7	F	mother
8	F	mother

The age of family members ranged from 46-75.

## **2.3 MEASURES**

The aim of the interviews was to generate a narrative about the person's life as told by the client and as told by their nominated closest family member. Two semi-structured interviews were constructed; one for clients (Appendix 3) and one for their relative (Appendix 4).

### **2.3.1 DEVELOPMENT OF THE INTERVIEW SCHEDULES**

The suggestions of Wilson (1996) were used as an initial guide in the development of the two interview schedules (i.e. client and family member). A list of topics to cover within the interviews was brainstormed after reading the relevant literature and considering the research questions. These were discussed with three Clinical Psychologists working within the field of rehabilitation and revised following their comments. These comments suggested a format that would better facilitate the expression of a narrative, and the term 'mental health problems' was used instead of 'diagnosis of schizophrenia'.

### **2.3.2 PILOTING THE INTERVIEW SCHEDULES**

The interview schedules were piloted on a professional who role-played a client with whom they were familiar. Their comments were noted and the schedules revised accordingly. These revisions saw the addition of an orienting statement at the beginning of the interview. The interview was then piloted on a client and their nominated family member. This highlighted the importance of initially clarifying what positive symptoms were experienced and using the term 'unusual experiences' instead of 'mental health problems'. It was noted that a question about the client's sense of self before the emergence of psychotic symptoms was needed. The importance of clarifying confidentiality was also raised.

### **2.3.3 THE INTERVIEW SCHEDULES**

Both interview schedules followed the same broad structure outlined below. It was acknowledged that this would not be rigidly adhered to during the course of the interview and served more as a 'checklist' of areas to be covered.



### Section 1: General information

As a starting point, participants were asked some general information about their current circumstances. This included where they lived, who they lived with and the nature of their 'unusual' experiences.

### Section 2: Narrative about unusual experiences

This section aimed to elicit how people made sense of their experiences leading up to the breakdown. Enquiries were made about the salient symptoms and what was happening around the time that these first emerged. This question also aimed to elicit perceived triggers and perception of the experiences.

### Section 3: Impact of time

In order to facilitate information about the narrative of the mental health problems, questions were asked about how their understanding had changed over time. This was to gauge whether there was a fluctuation in the meanings and beliefs attributed to events and client's perceptions.

### Section 4: Perceived usefulness of professional explanations

This category examined how frameworks of understanding were supplemented by professional explanations and what participants retained of professional narratives.

### Section 5: Beliefs about mental health problems

This section aimed to elicit the participants' thoughts on why me/ my family member?'. Prompts to elicit supplementary information regarding beliefs about the world and the impact of significant relationships were included in this section.

### Section 6: Impact on sense of self

This section explored how having long term mental health problems had affected the participants' view of themselves. The impact on how it had affected functional and emotional aspects of their life were used as prompts.

## Section 7: Change in relationships with others

This explored whether participants considered that their experiences had changed how others saw them/their relative. Participants were asked to think of specific people in order to evaluate any change.

## Section 8: Debriefing

Participants were asked about their experience of completing the interview and whether taking part had raised any issues for them. They were also asked if there was anything that they wanted to add.

## **2.4 PROCEDURE**

### **2.4.1 ETHICAL CONSIDERATIONS**

The design of the research was in accordance with the British Psychological Society's Ethical Principles and Guidelines (1993) and the Division of Clinical Psychology Professional Practice Guidelines (1995). An application was made to the local research ethical committee and permission was obtained to carry out the study (Appendix 5). Pertinent ethical issues are dealt with as they arise during discussion of procedures.

### **2.4.2 RECRUITMENT PROCEDURE**

The Consultant Psychiatrist and Consultant Clinical Psychologist from the rehabilitation service were approached to identify clients who they considered were able to participate in the study. The identified clients' key worker was then contacted and the study discussed with them. For each client, the particular psychotic symptoms characteristic of schizophrenia were identified so that the researcher had some understanding of the client's experience.

#### **i) Briefing procedures**

An information sheet was developed for both groups (Appendix 6 and Appendix 7).

These outlined:

- 1) The nature and purpose of the research and what was expected of participants. This stated that with permission the interview would be audiotaped.
- 2) The issue of confidentiality
- 3) The right to withdraw at any time with no impact on the care they or their relative received.

a) Initial briefing given to client

Clients were initially approached by their keyworker and the information sheet given to them and discussed. If they were interested, a meeting was arranged between participant and researcher. The information sheet was again discussed with them at this meeting; participants were encouraged to ask questions and the researcher clarified any areas of confusion. The rationale for tape recording interviews was discussed, and their right to refuse permission for recording was raised. Participants were informed that the tapes would be erased after transcription and transcripts would be destroyed after one year. They were asked whether they would give permission for a relative to be contacted, and if so, the name of this relative.

If they continued to express an interest in participating, they were asked to sign a consent form (Appendix 8)

b) Initial briefing given to relative

When clients had agreed for their relative to participate, the researcher contacted them and discussed the rationale behind the research and what would be expected. If relatives were willing to participate, a meeting was arranged.

With relatives, the study was outlined as detailed for clients above, the information sheet was given (Appendix 7) and questions were encouraged. If they still wished to proceed, the consent form (Appendix 9) was signed before the interview commenced stating that they understood the research and realised they could withdraw at any time.



## **ii) Format of interviews**

### **a) Format of research interview with clients**

Before starting the interviews participants' attention was drawn to the information sheet and they were asked if they wanted to clarify any aspect of the study. The interview then commenced, and lasted from 40 to 80 minutes.

It was noted that if clients have difficulty in organising their internal world, then structure in the external world is important (Perkins, 1997). Consequently, clinical judgement was used to structure the interview. In some cases this necessitated repeating interview questions and prompts, and returning to previous comments in a sensitive way.

After each interview participants were debriefed and any concerns were addressed. The clients' keyworkers were informed if they requested additional psychological interventions. If clients found the interview disturbing more time was spent debriefing and their key worker was informed. Clients were informed that they could contact the researcher if they had any additional questions.

### **b) Format of research interview with relatives**

The interviews conducted with relatives followed the format described for clients. The length of interviews ranged from 60 to 80 minutes. Relatives were informed that they could contact the researcher if they had any questions.

## **2.5 DATA MANAGEMENT**

Grounded theory is a general methodology for developing theory that is grounded in the data. This was the chosen method for analysing the transcripts. A central feature of the approach is simultaneous data collection and [constant] 'comparative analysis' (Glaser and Strauss, 1967).

## 1. Immersion

The first step of data analysis was a detailed reading of the data. This involved examining the transcripts carefully to see if there was anything significant. During transcription ideas were noted in a separate document to make the process as transparent as possible.

## 2. Coding

The data was then coded by asking what concepts or labels were needed to account for the phenomena in a particular paragraph (Pidgeon, Turner and Blockley, 1991). Concepts were formulated at a relatively broad level and noted on a card within the 'cardfile' computer programme. Beside this code a numerical note was made of where this concept could be found within transcripts. Examples from subsequent transcripts were similarly noted under this concept. Any links with other emerging concepts were noted. At this stage segments of the text unrelated to the research questions were discarded.

During this stage hypotheses about the data were explored and the process of the interviews was also considered.

## 3. Categorisation

The third stage involved examining each broad category of coded data in turn and categorising it in more detail or refining the original concepts. The construction of concepts utilised thoughts that had emerged from the research diary and whilst transcribing tapes (Pidgeon et al., 1991).

## 4. Thematic analysis

A temporal framework was used to further structure the categories and emergent themes were noted. An attempt was made to actively search for multiple perspectives (Strauss and Corbin, 1994) and themes were related back to existing literature.



## 5. Theory construction

The fifth stage involved noting possible links between the concepts. Groups of related concepts were diagrammatically represented within the temporal framework; this provided an initial model for understanding the area (Pidgeon et al., 1991). In developing the theory, it was attempted to demonstrate that there had been a steady and explicit dialogue between ideas and evidence (Strauss and Corbin, 1994). Thus more abstract concepts were linked to specific pieces of data. The 'theory' consisted of plausible relationships between concepts and sets of concepts. It did not assume that there was some 'truth' to discover, but that the theory was one interpretation embedded in a particular cultural and historical context.

## 2.6 VALIDITY AND RELIABILITY ISSUES

Within a quantitative paradigm, scientific rigor is gauged by limiting the effects of researcher bias as much as possible. Turpin, Barley, Beail, Scaife, Slade, Smith and Walsh (1997) provided suggestions on how to conduct qualitative research of good quality. The notions of reliability (the replicability and consistency of the findings) and validity (the apparent 'truth' of the findings) are used to assess rigor. However, within qualitative research it is recognised that there is always a personal aspect to a topic, and multiple truths are implicit within the design. Rigor is consequently judged more on the process of the research and its evaluation by participants and other researchers (Henwood and Pidgeon, 1992). The following procedures suggested by Banister, Burman, Parker, Taylor and Tindall (1994) and Henwood and Pidgeon (1992) were adopted to maximise good practice:

### Reflexivity

This is perhaps the most distinctive feature of qualitative research (Banister et al, 1994), and is an attempt to make the process of the research as explicit as possible. Within qualitative research it is acknowledged that the process of research shapes the conclusions being drawn; it is important to build up an account of what is done and why (Stevenson and Cooper, 1997). It is recommended that a 'reflexive journal' is kept in order for

readers to track the thinking process of the researcher. This outlines the reflections of the researcher and the rationales for methodological decisions. Researchers should document initial concerns and how these change, sampling decisions, ideas about the quality of the data and observations about data collection. This 'confirmability trail' (Erlandson, Harris, Skipper and Allen, 1993) then permits external audit by peers. This is presented in Appendix 10.

### **Reliability**

Perakyla (1997) noted that this refers to whether or not the researcher would expect to obtain the same findings if the study was repeated. The concept of reliability was thus considered throughout the research process.

### **The use of audio-tape**

Interviews were tape recorded to minimise researcher bias in detailing the content of the conversation.

### **The importance of fit**

To ensure that the model fitted the data it was essential for the text to be clearly linked to more abstract categories. Segments of text were coded and assigned a numerical label to enable easy referencing between categories and text. This permitted the researcher to return to earlier transcripts and ensure that the best fit had been obtained for quotes in light of codes and categories that had emerged from later analyses. Emergent codes and categories were discussed with the researcher's supervisor to make the process of conceptual classification more explicit.



### Inter-rater reliability

An independent rater was given a summary of codes and categories for the time period of 'current experiences' (Appendix 11). They were also given a summary of the quotes used to inform these, and asked to match quotes with codes. Percentage agreement was calculated.

### Triangulation

#### Data triangulation

Data triangulation involves collecting accounts from different participants involved in the chosen setting (May and Pope, 1996). These different 'positions' demonstrate how experiencing and understanding are context bound and make the conclusions drawn potentially more valid (Banister et al., 1994). To this end, accounts were obtained from both those diagnosed with schizophrenia and a nominated relative.

#### Investigator triangulation

Banister et al. (1994) suggested that if research was conducted alone it was advisable to get friends and colleagues to comment on and challenge work at various stages. The researcher's supervisor took on this role, and the independent rater was also asked to challenge the researcher on areas of disagreement within the analysis. These alternative viewpoints provided additional insight into possible ways in which the data could be conceptualised.

### Respondent validity

It is suggested that researchers attempt to construct a joint negotiated reality with participants. This permits the exploration of reasons why decisions and interpretations may differ and serves to elaborate emerging theory (Appleton, 1995). In this study the emerging analysis was discussed after interviewing two clients and two family members towards the end of data collection.

### **Rhetorical power**

This refers to the extent to which others are persuaded by its results and conclusions. This was evaluated by examining participants feedback on the emerging analysis and consulting with staff working within the field. The question asked was how well did the findings explain the process of developing schizophrenia.

### **3. RESULTS**

#### **3.1 OVERVIEW**

From the initial analysis over 450 codes were produced pertaining to the research questions, and were grouped together to form broader categories. These categories were then related to the original research questions and organised into a temporal framework.

The complete list of codes and categories is presented in Appendix 11.

The first two research questions asked what narratives do clients and family members construct to explain the emergence of symptoms of psychosis, and how do these change over time. Subsequent research questions asked what explanatory frameworks are used by professionals to help supplement understanding, how do the symptoms impact on the clients sense of self and how are their relationships with others affected.

The temporal nature of narratives suggested that the structure of a stage model would be helpful in addressing the research questions. This stage model is presented in four sections. The first describes categories pertaining to the salient events preceding the first psychotic episode. The second outlines the categories developed from events around the time of the first psychotic episode. The third section describes the process of admission and the fourth outlines current experiences. This latter section is larger than the others, and contains six sub-sections which emerged from the data; the impact on life, ways of coping, thoughts on services and professional support, the impact on self and relationships with others. As explanations from professionals were received over time, these are

subsumed within the relevant stage. For each stage the categories were structured into three parts. The first represents clients' narratives, the second family members' and the third explores similarities and differences between them.

### **3.2. EVENTS PRECEDING THE FIRST PSYCHOTIC EPISODE**

#### **i. Clients**

##### **Previous character**

Three clients discussed how before the first psychotic episode they had led a relatively normal life;

*'I was just a normal teenager you know'*

Two emphasised how they had had relationships with members of the opposite sex. Three discussed having religious beliefs, although these were not considered to be a major part of their lives.

##### **Low self-esteem, loss and problematic relationships immediately preceding first psychotic episode**

Six clients described feeling unhappy with their circumstances immediately preceding the first psychotic episode. Two described having low self esteem;

*'I was too under the world to stand up for myself'*

and four discussed how they had not been happy with their life at that time due to unsatisfactory relationships. Three specifically noted that there had been a change or loss in their social network;

*'my cousins got married. Cos we used to hang out together. We used to go to the pub and the pictures. So I was all alone'*



## Drug taking

Two clients described how they had taken illegal substances. For one client this was an escape from difficult circumstances at home;

*'the only thing that had an impact on me at the time was the acid, that was the exciting rather than the dreary of being at home'*

## ii. Family

### a) Previous character

Family members gave an idea of how their relative had been before things started to get difficult. Four family members explicitly stated how 'good' their child had been when younger;

*'before this all happened he was very good, perhaps too good!'*

Two noted that their relative had been very active, and two said how they had been outgoing and friendly, again stressing normality;

*'As a child he made friends, went out and did what normal children do'*

### b) Problematic relationships and too many demands immediately preceding first psychotic episode

All eight family members noted that although their child's life had been relatively normal beforehand, there were difficult circumstances immediately before the first psychotic episode. Two described difficult relationships with fathers;

*'it was mostly fighting with his dad, step-dad'*

Both these fathers had been ill at the time.

Two described how their child had been experiencing difficulties with girlfriends and boyfriends;

*'sort of that kind of teenage boyfriend kind of behaviour, what happens when you are a teenager sort of thing. That sort of thing. I think she 'd got upset about some boys'*

and one said how her child had had to adapt to new circumstances and peers;

*'So he had to adapt to a new culture, a new language, different schools'*

Three parents described how they considered that their child was finding academic and social demands too difficult to cope with;

*'she was going to college and she always got nervous when she took exams. And I think she was doing too many subjects actually, that was my opinion'*

### c) The onset of observable changes in character and symptoms of anxiety

Leading up to the first psychotic episode all relatives witnessed changes in the client which marked a difference with their previous character and functioning. Two relatives described how the client had developed somatic symptoms;

*'(x) started getting allergies, pain in the tummy and things went wrong at school'*

and one described the onset of obsessions and compulsions.

Three relatives discussed how their child had started to challenge parental boundaries;

*'he was beginning to stay out later than he was allowed to'*

and two said that their relative had not been themselves. One family member questioned whether there had been a change in brain chemistry as her daughter's epilepsy had ceased and one said that her child had started to show concern about his self-image.

#### d) Parental love and protection

Parents coped with these changes by continuing to offer love and protection;

*'We seemed to spend our time trying to please her which didn't do any good anyway'*

Three others clearly felt responsible, and either worried or explicitly offered guidance and advice;

*'he wouldn't come home at all and I would be waiting for him to come in; lying awake and suspecting that he was actually round at a certain persons house and I would go round there'*

#### iii. Similarities and differences

Both clients and family members stressed that until adolescence, circumstances had been relatively normal. However, they also both agreed that immediately before the first psychotic episode there had been difficulties; citing problematic relationships. Clients described feeling unhappy; on occasions this was recognised by relatives but where the client had challenged boundaries this tended to be the focus of discussion for parents.

### 3.3 EVENTS AT THE TIME OF THE FIRST PSYCHOTIC EPISODE

#### i. Clients

##### i. Perceptual changes

Six clients described in detail their changing perception of reality. Three described the onset of hearing voices; these were all saying negative things;

*'The voices were good and evil and I just sort of collapsed that night. I was getting overwhelmed with voices in my head; thought bombardment.'*

Three discussed experiences that involved God;

*'From there I had a weird experience. God said 'this is revelations' - you know the end of the world. God said 'this is a different world you're in (name).'*



For two of these clients these experiences involved an ending of the world as they knew it, and one felt that their sense of self had disappeared.

## ii. Emotions

These perceptual changes led clients to experience a wide range of emotions. Three felt fearful, either of the experience or of other people;

*'Its really frightening at first for some people, they don't know what it is that's happening to them'*

One felt special, one felt calmer and one constantly felt he was being watched.

## iii. Behaviour

Two clients described how these changes and emotions led them to avoid people;

*'one day I just didn't want to get up again'*

Two said they had become aggressive;

*'all of a sudden I snapped. There was this police car coming down the road towards me. I picked up this stone, smashed it straight through the window'.*

One client had approached his GP himself;

*'I went home I felt all right for the day. I'd been to see my Doctor and got some Valium and um, well the Valium calmed me down.'*

## iv. Others responses

At this time four clients described the responses of others. One emphasised how his experiences were not understood;

*'my mum didn't know that people heard voices. She didn't understand the illness; she didn't know what was wrong with me.'*

One was sent away, one received offers of help from friends and one said he had just been perceived as different.



## ii. Relatives

Family members found it harder to pinpoint when a change had occurred, and the process was thought to be more gradual than occurring at a discrete time.

*'its very difficult to put a finger on the actual year'*

However, the perceptual changes experienced by the client were accompanied by observable behavioural change, and this had a significant effect on the family.

### i. Behavioural changes

Four family members explained that there had been discussion about the symptoms being experienced;

*'the last few days before he sent her to hospital, she started to tell me that the girl downstairs was talking about her and I was a bit confused because I couldn't hear her'*

Two family members said that they had thought something was wrong due to the behaviour of their relative;

*'he was doing everything that was abnormal so he had to be ill!'*

Family members described how difficult it was to be faced with the emerging symptoms;

*'He said 'you're not my mum, you're an alien, they took my real mum. Someone has come in her place'*

### ii. Observable changes

Five family members were struck by the physical changes they witnessed in their relative as the symptoms got worse. Three described how white their relative looked;

*'That night he woke up and he crawled over to me and he was like this and was all white'*

They also described behavioural changes, in particular aggressive incidents;

*'he was terrible at first he was smashing the mirrors'*

and avoiding contact with themselves and professionals;

*'he said leave me alone mum, leave me alone.'*

### iii. Initial attributions

Five relatives discussed how they had attempted to make sense of the changing behaviour.

One thought it was teenage stupidity, one thought her child had been trying to impress people;

*'we used to think she was trying to give an impression, telling stories'*

Two thought their children had been testing boundaries and one thought her son was being lazy.

A lack of knowledge and understanding was acknowledged by six relatives;

*'of course we didn't understand at the time'*

### iv. Attempts to engage services

Relatives described how they had attempted to engage services at this point;

*'I said to him I will make an appointment with someone for you to talk about seeing God'*

One had seen a neurologist before being referred on to a psychiatrist, one had come into contact with psychiatric services via the police, two had been involved with the Prison service and four had sought help from either A and E or from their GP.

## v. Emotions

Five family members mentioned feeling frightened; for both themselves and for the client;

*'I was so scared I used to try and lock my door with no lock on. I used to wedge it. I was so scared he would come in when I was laying down in the afternoon'*

*'We were fearful that he may have come a cropper and been killed and just disposed of'*

Three described feeling despondent, and one felt guilty;

*'it was the worst time, it really was the worst time'*

*'I started to blame myself'*

Three family members also highlighted how immersed they became in the process;

*'for the first few years of his illness I lived it day and night and I got very little sleep or if I did the first thought on waking was X'*

## iii. Similarities and differences

Descriptions of the experiences from the perspective of family members closely matched those of clients; particularly involving hearing voices. Clients accurately perceived that their experiences were not understood; relatives tended to attribute behavioural change to 'teenage' behaviour. Both relatives and clients felt fearful, but family members also reported feeling despondent and guilty.

## 3.4 EVENTS AT THE TIME OF ADMISSION

### i. Clients

#### a). The process of admission

Whether the process of admission was voluntary or enforced, six of the eight clients described this process;

*'I sort of thought to myself mummy I want to be hospitalised, and that's when the treatment started. I asked voluntarily for the treatment'.*

## b) Emotions

Feeling distant from the process of admission and feeling confused were common experiences for clients;

*'So they took me to the hospital and all I could remember was being out in a chair and being carried along. I was miles away'*

Three clients described how upsetting the experience was for them and their families;

*'mum took me down to (hospital) to (ward). She was crying and I was crying'*

One client reported that he was not believed and his parents had to corroborate his story.

This had led to a lot of frustration.

## c). Explanations

Three clients had received explanations from professionals which described the symptoms they were experiencing;

*'They all said the very same things; you're hallucinating they said'*

Three received explanations based on the medical narrative, although these were not very elaborate;

*'I thought what's caused this. So they said the damaged area of the head, this bit round here, that's all I was told really. It was quite evasive really'*

Two others had just been told that they weren't well and needed to get better. Two clients had worked out their mental health problem themselves;

*'I think I knew by my illness what I was, manic depressive and schizophrenic when I came on the ward and all the others were schizophrenic and manic depressive and I began to realise that I was'*



## ii. Relatives

### a) Positive professional responses

All relatives described how the professionals responded. Three had been grateful to services for the containment they offered;

*'I think basically (x) felt more secure in hospital. Perhaps they weren't doing anything different except perhaps juggling medication slightly. But that was a kind of security for her, she felt safer in hospital at that time'*

and one described how helpful it was to be offered hope and compassion;

*'I hadn't realised the kindness at the hospital because when we took her in...they said you shouldn't have had this'*

### b) Negative professional responses

However, all had had negative experiences which had compounded the psychotic episode;

*'the original ones were a waste of time, an absolute waste of time'*

This included not listening, not being offered any choice, lack of support and professional incompetence;

*'they just didn't want to listen to the parents side at all; they would make their own diagnosis and that was it'*

One relative described how she had been asked a lot of questions about the way she lived her life, and another felt blamed;

*'We were told its not good for him to be at home; nobody said why. We thought there was something wrong with the home and us'*

One relative had strong opinions that psychiatric wards were not the optimum environment;

*'If you wanted to get better you wouldn't go to a place like (hospital); you need a calm, relaxing place'*

### c). Emotions

Four relatives described how awful it was to witness their child being admitted;

*'I said I can't think of her being in there, its just too upsetting'*

This was particularly difficult for relatives when the person refused to see them.

### d) Explanations

Four relatives had not been given any explanation about what was wrong;

*'They didn't exactly tell me the cause of the problem'*

and four had disagreed with advice they had been given;

*'it was the most awful advice we had then; you must lock her out'*

In terms of explanations that had been meaningful, relatives knew the diagnosis but this meant different things to different relatives;

*'Well, pressure on the brain or something, a pressure, having too much pressure on the brain, with a liquid. Something like that, with a liquid that he shouldn't have. He's got too much. We've all got it they said, but you have to have a certain amount.'*

### iii. Similarities and differences

Relatives tended to concentrate on professional responses at this time, whereas clients were more concerned with the experience of being admitted. Both relatives and clients found the process upsetting. All relatives described negative experiences associated with this time, which had compounded their distress.

## 3.5 CURRENT EXPERIENCES

This section provides an overview of clients' and relatives' current experiences and how they have changed. Section 3.5.1 outlines the impact that symptoms currently have on the client's life. This includes an overview of emotions experienced from the perspective of

both the client and their relative. Section 3.5.2. describes their current views on services and professional support, and section 3.5.3 the coping strategies utilised. Living with the experiences has given individuals time to reflect on the process. Section 3.5.4 describes participants responses to how things have changed over time, and section 3.5.5. outlines current views on possible causal factors. The subjective change in sense of self is explored in section 3.5.6 and the change to relationships in section 3.5.7.

### 3.5.1 THE IMPACT ON LIFE

#### i. Clients

##### a) Disability

Clients described how their symptoms continued to cause problems for them. Themes related to having a disability were frequently mentioned; loss of previous functioning and access to employment, and the effort of having to adapt to this;

*'my state of mind's not what it used to be - everyday is a struggle in the mind with thoughts and voices and all that'*

*'Its a case of actually starting all over again in a way, pick up the pieces that you've got, cos it can be quite wounding actually for some people'*

*'the basic thing about my illness is you've just got to keep ticking over in front of them. You have to keep well in front of people all the time.'*

One client poignantly stated the unfairness of it all;

*'When I'm asleep and that, I'm not really, I'm not really disabled. Everything around me is all normal, I'm not disturbed.....If I was you I'd be normal, its not right'*

##### b) The benefits and improvements

It was surprising to discover that despite their disabilities, all clients mentioned that having their experiences had been beneficial. The major theme was that the experiences had



enabled them to be more ‘themselves’. As this is related to sense of self this is elaborated on further in section 3.5.6.

Three clients described how although they found things difficult, their current situation was better than it could have been if they had continued with their previous lifestyle;

*‘It was completely beneficial all of it. I mean if I hadn’t done that I would have ended up in a worse fate than I already am now.’*

Although this comment could be perceived as ‘denial’, these comments were from the clients who had been taking drugs, and one categorically stated that he thought he would have overdosed had he continued in a similar vein.

Two clients mentioned how their experiences had made them feel less anxious about death;

*‘I’m just thinking you know, not about death, that’s pretty obvious that I’m going to be all right there’*

In addition to this finding about the experience being perceived as beneficial, five clients expressed relief at getting better; either because symptoms had lessened or they had learnt to manage them better;

*‘I feel better about what’s happening in my life because I feel in control a bit more and that people understand me more clearly’*

For the two clients whose voices had got more friendly this was attributed to feeling more comfortable about their self-image and their current environment;

*‘The voices say you don’t need to grow as you’re perfectly formed you know’*

However, clients stressed how symptoms were variable and it was hard to not be continually aware of their presence.

## ii. Relatives

### a) Reflections on symptoms

Relatives recognised how hard it was to live with the symptoms, in particular the impact on attention and mood;

*'when he's not well its a struggle for him to keep his mind on what you're saying'*

Relatives were unsure about the amount of control clients had over the manifestation of their symptoms;

*'sometimes you look at him and you think to yourself how much of that is really your illness or how much is that you conning us'*

Some thought that clients had little control;

*'but I'm not blaming him in a way because its his illness'*

### b) Current emotions

For relatives the response to their child's disability were feelings of regret, anger and loss;

*'in my quieter moments all I do is agonise about what might have been, what could have been'*

*'he was once the apple of my eye but there are times when I actually hate him now'*

Some blamed themselves or felt others blamed them;

*'Other people blame me, say you should have done this, you should have done that, but its not my fault.'*

Two relatives highlighted the importance of acceptance, although another stressed that this was hard;

*'its taken a lot of years to accept'*

*'the whole effect of it is to make the person quite mad themselves if they were living all the time with someone like my son'*

### **iii. Similarities and differences**

Clients and relatives described the difficulties presented of living with schizophrenia. For relatives this was both a recognition of how hard it was for their child, but also how it impacted on themselves. Some clients perceived that there was some benefit in their circumstances; this was not perceived by relatives. However, where the benefits were attributed to lessening of symptoms this was recognised by relatives.

### **3.5.2 THOUGHTS ON SERVICES AND PROFESSIONAL SUPPORT**

#### **i. Clients**

Some clients were very complementary about the support that had been received from staff and emphasised that the support received had helped to build confidence and cope with their illness;

*'With (staff member) he realises that its the illness and he understands that the illness is an illness and needs to be treated in the right way. Because if I hadn't have had the right treatment I don't know what would have happened. But he has really understood it and its understanding it that gives me the opportunity to keep ticking over comfortably, which is all I can manage nowadays.'*

However, others felt that it was difficult to trust staff and there continued to be disagreements about 'reality';

*'my objection to Dr (x) was according to him I had to be straight. He said 'why don't you live in reality and stop hearing voices and everything', you know. And I thought what do you do to enjoy yourself?'*

#### **ii. Relatives**

For relatives it was important to think that the staff cared about the clients as individuals and took the time to listen to their perspectives;

*'its a joy to be able to sit down and talk to someone and they will listen and even if they think you are talking a load of rubbish they will still treat you with respect'*



However, some relatives were still unsure about the reasons for the client's difficulties;

*'I don't fully understand it; nobody's ever explained it to me. I'm sort of ignorant as far as what was happening and why it was happening'*

### **iii. Similarities and differences**

Relatives and the majority of clients were complementary about the support received from staff. However, the differences in 'reality' between staff and clients was noted to cause problems by clients.

### **3.5.3 WAYS OF COPING**

#### **i. Clients**

Ways of coping were dominated by the importance of medication. In particular clients were impressed with the drug 'Clozaril';

*'I'm now on medication, I'm on Clozaril. Its giving me the booster inside my system .I'm now on Clozaril, and my body really seems to calm down. It says to itself I have seen this situation before, and in that respect the Clozaril takes control.'*

However, being reliant on medication was frustrating for one person and side effects were mentioned by another. In terms of psychological ways of coping, distraction was cited by two clients;

*'I watch telly to take my mind off it. I think a walkman would be the absolute sort of thing. Some people turn them on to block the voices.'*

One mentioned working out what had led to the increase in symptomatology and rectifying that.

## ii. Relatives

Relatives described both observations of what was useful for clients as well as how they coped with their own emotions.

### a) Coping with client symptoms

Three relatives mentioned how helpful the medication had been for clients, although side effects were discussed by one relative. In terms of psychological ways of coping with symptoms, one relative cited the helpfulness of using focusing techniques.

Relatives described how they had developed strategies to enable them to cope and adapt to both the person's behaviour and the emotions they felt. In order to cope with the behaviour and assist their child in this process, relatives described using calming techniques, the importance of being honest about what they thought and modifying their usual responses;

*'It has changed in that if I want to say something to him I think before I speak'*

### b) Coping with own emotions

In terms of coping with their own emotions, relatives cited using others parents as supports and the importance of religion. Repression was used by three relatives, who during the interview described how they had tried to forget what had occurred. Four relatives used rationalisation, and found thinking the person's behaviour was caused by an illness was helpful;

*'I wouldn't hurt myself as I know its part of the illness; its not his fault that he says that.'*

One said they found it useful to think of people with schizophrenia as children, and one described becoming more self-reliant;

*'It makes you stronger yourself'*

Although relatives were able to describe how they had learnt to cope and adapt over the years, one highlighted the ongoing nature of this process;

*'You think you are on the road to understanding it better then the next thing you wake up one morning and its gone right back to the beginning again. Its like a see-saw thing'.*

### **iii. Similarities and differences**

Both relatives and clients stressed how helpful Clozaril had been and the difficult side effects that can accompany neuroleptic medication. Clients did not reflect upon the ways of coping used by their relatives.

## **3.5.4 PERCEIVED CHANGES OVER TIME**

### **i. Clients**

Over time one client described how she had learnt more about schizophrenia and learnt to live with it better;

*'I'm learning more things about it all the time, like I get sensations in the head and little pricks in my head and all over my body, things like that. You will learn more and you will learn more about even the voices and you will make friends with them, or if you relax'*

Another said that their family had become more understanding. One client said that they had learnt to emotionally cope better with their symptoms;

*'Over the years I've got less angry and become more soft and know how to behave better because the illness will get better over the years'*

### **ii. Relatives**

Three relatives noted that their understanding of schizophrenia had increased over time;

*'not knowing anything at all about schizophrenia back in 1968 I now know a great deal more'*



Two said that this process was gradual;

*'I suppose its just a gradual dawning on you of what its like'*

### **iii. Similarities and differences**

Both clients and relatives had learnt more about schizophrenia; both in understanding the meaning of symptomatology and in developing ways to cope emotionally.

### **3.5.5 ATTRIBUTIONS FOR CAUSAL FACTORS**

#### **i. Clients**

In terms of causal factors clients had a wide range of explanations. One client thought that people had a predisposition;

*'even normal people have got slight schizophrenia. It comes out like that or it doesn't'*

One questioned her birth;

*'I was a fraud I suppose, a fascist birth.'*

Two clients thought that childhood factors were important and five considered that adolescent factors played an important role;

*'But the way I felt about myself as an adolescent at the age of 13 was reasonably normal despite what the illness is all about'*

Three of these five clients felt that the life they lived had been 'bad' and this had led to the experiences;

*'We were done for breaking and entering... why would someone want to take the mind of a person over a blinken clock. Doesn't make sense to me. It must have been a lesson. I probably drove myself into a state unknown, so they reckon.'*

Adolescent behaviour such as taking drugs or difficult relationships was cited as the trigger by five clients. Two clients did not know why they had had the experiences they described.

## **ii. Relatives**

Relatives tended to consider many factors; three thought that there were multiple causes. Four of those interviewed thought that it was partly due to bad luck and chance factors that schizophrenia developed. Two thought that people were born with a predisposition and two people thought that hereditary factors were involved, citing 'eccentric' family members.

Five relatives thought that pre-morbid personality had an influence; in particular being sensitive and a worrier were cited as possible causal factors. One relative questioned a problematic birth and five queried childhood factors. These included standard vaccinations, childhood illnesses, and head injury. Two relatives questioned the adequacy of their parenting;

*'I thought it was pretty sort of unnatural for (x) to spend so much time just with mum she just seemed to want to be with me up until a certain point you know, and probably I overprotected her'*

All relatives cited the importance of adolescent factors in the development of the schizophrenia. These included hormonal changes, teenage development and relationship issues.

One relative expressed her frustration at not knowing;

*'its a bit confusing in that way to know if something would have happened regardless of upbringing or perhaps not. I still don't know do I!'*

### **iii. Similarities and differences**

Both clients and relatives considered a range of factors, from birth to adolescence. The possibility of a predisposition was also queried by both groups. Both groups also blamed themselves in different ways. For some clients attributions concerned being 'bad' during adolescence, and for relatives it was about 'bad' parenting during childhood. Some relatives and some clients acknowledged that they didn't know.

### **3.5.6 IMPACT ON SENSE OF SELF**

This research question provided some interesting responses from clients and relatives.

These comments suggested that there was a strong link between developing a sense of self and improving.

#### **i. Clients**

Six of the eight clients gave responses that highlighted the importance of developing an identity;

*'I cried for it (schizophrenia). I needed it to get better in another way (Me: In what way did you get better?) It makes me another person, the person who I am rather than family'*

*'I think actually acknowledging that, in a sense, saying who am I, you can then start to work on it maybe'*



Another client discussed the need to separate from his parents;

*'I don't harp on it but it was the best thing we could have done. The only thing we could have done move out of a place and just visit. I mean mum and dad can't be there all the time can they. Some people. Its a part of life that they want their freedom as much as you do'*

One client described how although he felt he was the same person, he was a person with an illness.

## **ii. Relatives**

It was interesting to note that three relatives also highlighted separation issues and the importance of the client developing their own identity;

*'He's doing what he wants to do and he's not at home with his mother. He's becoming an entity of his own'*

Four relatives discussed the issue of duality to explain how they perceived their child;

*'I can see this sounds funny; there's two people there. Behind the illness there is the person that really is (x)'*

*'He is still the son that we gave birth to and brought up, but he is also another personality entirely'*

Changes in observable functioning were highlighted; in particular the increase in dependency upon others and a withdrawal from social interactions. Self-esteem was also mentioned by four relatives; two said this had increased and two said it had decreased.

Three relatives stressed how the fluctuation in the schizophrenia affected their perception of their relative as a person;

*'Now that (x) is well in my opinion, now she is yes a similar person'*

One of these relatives linked improvements to gaining knowledge about the self;

*'I think he is beginning to realise a little bit about himself because he is a little better Maybe he is getting older and he has the right company as well you see. He has a good age of the nurses around him. They are mature nurses and they can transmit him some good values'*

One relative found it difficult to answer the question.

### **iii. Similarities and differences**

The importance of separation and the client forming their own identity was stressed by relatives and clients. The theme of duality was discussed by relatives; particularly in relation to when the person was 'ill' and when they were 'well'. Being the same person with an illness was described by one client, and three relatives. Relatives tended to highlight changes in functioning to reflect a change in self.

### **3.5.7 CHANGE IN RELATIONSHIPS WITH OTHER PEOPLE**

#### **i. Clients.**

##### **a) Negative**

Three clients described how they had lost friends;

*'I've nearly lost all my friends. Because they thought I was mentally sick, they thought I was mad or something like that.'*

Possible reasons for a lack of friends were given by six clients. These included the difficulty of relating to and communicating with others;

*'its a problem of understanding how other people are and how they feel its difficult because conversation is always two way and you can't really know when to take the information in and when to take it out'*

The stigma of having a mental health problem was also cited and one client described how with relationships it was often a case of having to forge new friendships.

##### **b) Positive**

However, on the positive side four clients described how their relationship with their mother had improved over the course of their illness;

*'my mother seems to have come back on to my side after all this; she doesn't see me in a bad light. Sort of changed.'*

Two also thought that other people saw them as easier to relate to than before. In general clients highlighted the importance of having other people around and the function this played in helping them to define themselves;

*'my whole reality revolved around everyone else. Its not me alone, its everybody else. Everybody else seems to be here at one time or another'*

Others also played an important role in helping the client to achieve tasks of daily living;

*'Like even to do the washing up, I wouldn't feel like it unless someone was there, somebody was with you I would feel like it more, do you know what I mean? Instead of on your own getting on with it I can't, I need to be with someone to do anything like that'*

## **ii. Relatives**

### **a) Negative**

Eight relatives noted that the client was separate from society. This was due to others' avoiding them;

*'I must admit they haven't been up to visit him; probably because of all that that went on before it kind of split'*

or how the client kept themselves separate. Three relatives described deliberately keeping their child away from others;

*'I haven't encouraged him to come here very much because what happens when he comes here the neighbours usually open the door just to question him'*

Relatives noted how others often modified their conversations and also talked about the stigma of having a mental health problem. This stigma had resulted in three clients being unfairly blamed for things they didn't do;

*'An incident happened here where a little girl. (x) was at (home) and one of the lads in this square told the police that he recognised the person who did it and it was (x)'*



## b) Positive

Three relatives noted that in some areas of life the client was accepted. One relative described the tolerance shown by the police;

*'They (police) asked him where he lived, he told him and they said oh. all right boy, get home then. They let him go. They knew he belonged to the hospital see.'*

Two thought that the fact that the disability was not visible made it easier to initially be treated 'normally' by the public.

One relative thought that the client needed to develop his identity before it would be possible to have more intimate social relations. Three relatives described their wish for their child to have an intimate relationship;

*'I would like him to have a nice girlfriend. I would love him to get married; we'd all get drunk and I'd invite the world'*

## iii. Similarities and differences

Relatives were more pessimistic about the clients' relationships with others. However, both groups recognised that friends had been lost through having a diagnosis of schizophrenia and discussed the stigma associated with having a mental health problem.

The client group discussed how relationships had improved with their others. This change was not talked about by relatives and may have been due to comparing the change in relationships from the onset of symptoms.

### **3.6 INTER-RATER RELIABILITY**

An independent rater was given a summary of the codes and categories assigned to 'current experiences', which detailed how many quotes had contributed to a particular code and category (Appendix 11). They were then given a summary of the quotes that the codes had been derived from and asked to match quotes with codes. Table 3 shows high inter-rater reliability for this process:

***Table 3: Results of inter-rater reliability of basic codes***

<b>Participants</b>	<b>Percentage agreement</b>
<i>Clients</i>	94%
<i>Relatives</i>	96%

## **4. DISCUSSION**

### **4.1 OUTLINE**

From living with a diagnosis of schizophrenia for many years both clients and relatives had reflected on the process and had attempted to make sense of it. Their narratives described this sense-making process over time, and thus provided a temporal model of understanding psychosis and its subjective impact on the self.

The first part of the discussion proposes a tentative theoretical framework to explain the participants' responses to the research questions. This is a temporal stage model and is based on the similarities and differences of the narratives of clients and family members. The model is grounded in the data summarised in the results section and is illustrated in Figure 1. This is supplemented by current literature and attempts to inform understandings of the development of a sense of self and how disruptions in this process may lead to psychotic episodes.

Subsequent sections examine the limitations of the study and the implications for clinical work and service provision. Suggestions for future research are made in the final section.

### **4.2 A STAGE MODEL OF THE EXPERIENCE OF PSYCHOSIS AND ITS IMPACT ON THE SELF**

One of the important themes that emerged from all participants was the necessity of developing an adult identity and separating from parents. One client specifically noted that



schizophrenia enabled them to accomplish this, and one said that forming an identity was a fundamental part of improvement. A tentative hypothesis that emerges could be that clients find it impossible to form an adult identity/sense of self due to an earlier vulnerability. This vulnerability is expressed during adolescence as a psychotic episode.

This hypothesis forms the basis of the model and is elaborated on below. The first section discusses how a vulnerability could emerge from inherited and environmentally acquired factors and would lead to disruption in the formation of self. The second section describes how these difficulties could manifest during childhood as an over-reliance on the parental ego. Additional difficulties in reflecting on the mental states of others would also result in problems in forming peer relationships. The third section describes the developmental need during adolescence to form an identity which is independent of parents. Due to problems in forming peer relationships this results in an unstable internal psychic structure. The fourth section suggests that an increase in emotion would highlight the inadequacy of this structure, and the result would be a psychotic episode. The fifth section posits how admission serves a containing function for the client, and contact with staff is an essential part of starting to form a stable internal structure. The sixth section posits that rehabilitation services serve the function of helping the client to develop their sense of self. Figure 1 is a diagrammatic representation of the model

FIGURE 1: MODEL OF THE DEVELOPMENT OF THE SELF AND ITS RELATION TO PSYCHOSIS

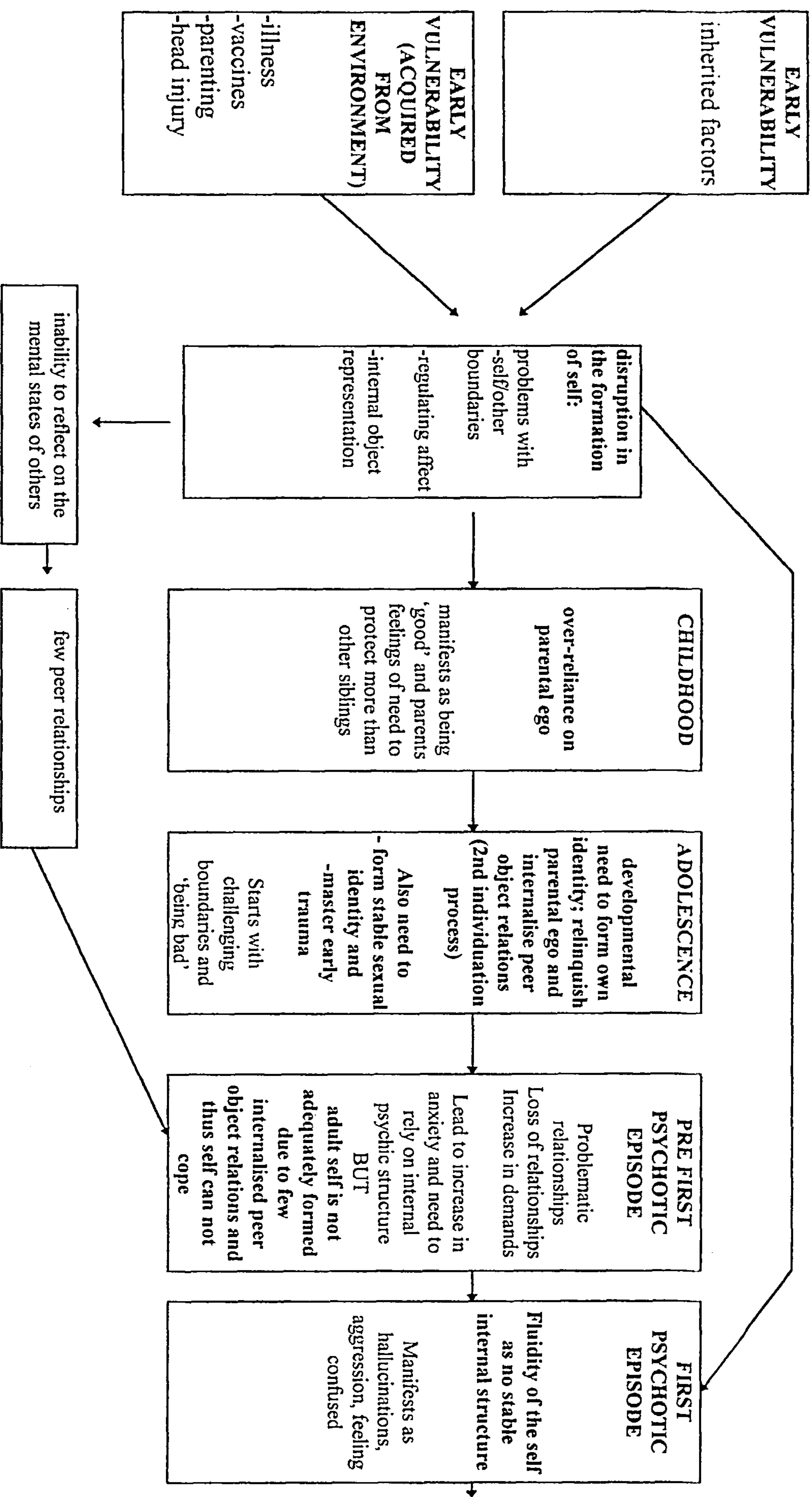
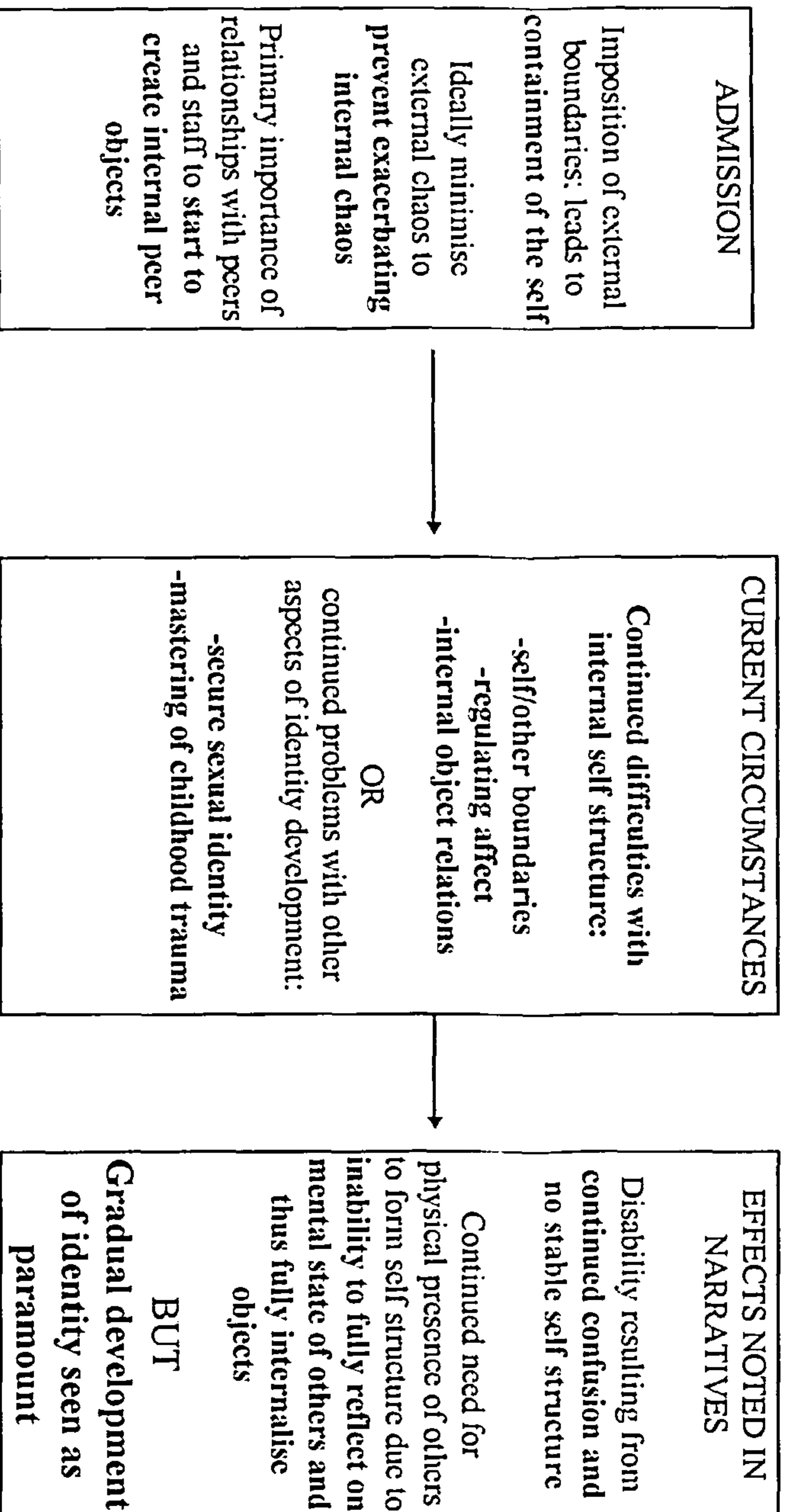


FIGURE 1: CONTINUED





## **1. The effect of early vulnerability**

Participants considered that a multitude of factors; both inherited and environmentally acquired, could be implicated in the subsequent development of schizophrenia. These factors were consistent with academic literature on vulnerability-stress models (Clements and Turpin, 1992).

Traditional vulnerability-stress models take a biological approach to vulnerability (e.g. Nuechterlein and Dawson, 1984). However, Hingley (1997) proposed that psychodynamic ideas could be expressed within vulnerability-stress models, and in this way links between disparate theories could be made. As outlined in the introduction, ideas about the self come from a multitude of perspectives. This model uses psychodynamic ideas about the formation of self to consider if it is possible that early genetic or environmental vulnerability could lead to problems in the formation of an adult identity.

## **2. Disruption in the formation of self**

DeWaele's (1996) work suggests that a disruption in the formation of self would manifest as problems with self/other boundaries, difficulties in regulating affect and problems with the representation of internal objects. These factors would result in difficulties in establishing intimate relationships because of their inherent threats to the self (Hingley, 1997). Research has indicated that people with schizophrenia do have problems in forming intimate relationships (e.g. Hirschberg, 1985; Lake, 1997), and this was described within narratives. The next section considers that if there were problems in the formation

of self, there may be some indications during childhood, but on the whole these would not become fully apparent until adolescence.

### **3. Childhood**

This period of development was not addressed specifically during the interviews, but some family members stressed that they had felt the need to protect their child more than other siblings, and several commented on how 'good' their child had been. These comments could reflect an over-reliance on a parental ego. During childhood, Blos (1979) noted that the individual can legitimately make demands on the parents' ego as it is seen as an extension of its own. Thus it is not until adolescence that 'ego inadequacy' becomes apparent when there is a demand to shed family dependencies, disengage from internal parental objects and form new internal objects through relationships with peers.

### **4. Adolescence**

Both relatives and clients highlighted the role of factors during adolescence. Some parents specifically described how preceding the first psychotic episode their child had started to challenge the boundaries they had set. This could be considered to be a normal part of adolescence as the individual sheds family dependencies, but relatives attributed this to the development of schizophrenia. In addition, three clients attributed 'being bad' to the schizophrenia when asked about causal factors. It could thus be hypothesised that the relinquishing of parental 'ego structures' could be viewed as being implicated in the process of becoming psychotic.

Many writers (e.g. Erikson, 1959) have noted that the formation of identity becomes crucial during adolescence, as this is the time when beliefs, abilities and desires must be reconciled with adult norms. Blos (1979) was interested in the development of self during adolescence; in particular how psychic structure and internal object relations change. He proposed that there were four challenges which were related to the development of self. It was essential for the adolescent to address and resolve these issues in order to function effectively in adult life. These challenges were to accomplish the second individuation process, rework and master early childhood trauma, develop ego continuity and develop a stable sexual identity through coming to terms with the homosexual component of pubertal sexuality. The second individuation process was paralleled with Margaret Mahler's (1971) work with infants. This work suggested that initially the infant sees the mother as an extension of its own self. However, over time a separation occurs and an independent sense of self emerges, based on internalised parental object relations. This is the first individuation process, and Blos then went on to suggest that adolescence was the second, as these internalised parental object relations are relinquished and internal object relations become based on a wider peer network.

### **5. Pre first psychotic episode**

Both clients and family members noted that clients had initially led a relatively normal life. However, it is difficult to know whether this 'normality' is a comparative term used when present functioning is considered. Preceding the first psychotic episode clients were



unhappy with their circumstances; specifically having low self-esteem, problematic relationships or not coping with additional demands being placed on them. For all clients this was during late adolescence. Other research has consistently demonstrated that life events are implicated in the onset of psychosis and are factors which can lead to relapse (Miller, Ingram, Kreitman, Surtess and Sashidarhan (1987). What is it about adolescence that means the individual breaks down at this time, and why do life events precede psychosis?

It is suggested that it is only when the second individuation process occurs that problems with the formation of self would become apparent. Due to problems with the core self-structure, the individual would have a history of difficulties in forming intimate relationships. This would mean that the person with schizophrenia would not have available sufficient internal peer objects to support the loss of internal parental objects. There would consequently be an over-reliance on friendships that are forged to provide internal objects with which to construct a sense of self. If these were lost or disrupted due to problems in the relationship a void would be created. Wexler (1965) discussed how the disappearance of internal objects would lead to a sense of dying and inner world destruction.. This may explain the subjective endings of the world and the self described by three clients. The increase in anxiety and emotion associated with life events would also 'test' the internal psychic structure, and any 'weakness' would be exposed. Problems with regulating internal affect (DeWaele,1996) would compound the difficulties that adolescence presents for any individual.

## **6. The first psychotic episode: Exposure of impaired self-formation**

It is suggested that a psychotic episode is indicative of problems in the formation of self (Auerbach and Blatt, 1996). The perceptual experiences described by clients and relayed by relatives could be seen to reflect the fluidity of internal psychic structures and thus the self. Blos (1962), on writing about normative adolescent experience, noted that the adolescent typically experiences the world with heightened perceptual awareness and mood swings are commonplace, and suggested that these are manifestations of changes in the self's psychic structure. Clients and relatives described somewhat similar perceptual and behavioural changes. It could be possible that the symptoms of psychosis are an exaggeration of normative adolescent experiences, and reflect problems in the formation of self as discussed by the clients and relatives within this study.

## **7. Admission: The placing of external boundaries**

Clients described the confusion they experienced when they were admitted to hospital. Relatives considered that admission to hospital was essential in helping the client to feel safe. It is possible that the hospital provides external boundaries for the client, and this containment is the first step in constructing a self which is separate from parents.

Ward staff may function as alternative internal objects to parents; interactions with staff were noted by clients to be helpful aspects of improvement. Adshead (1998) described how psychiatric staff could be perceived as attachment figures. She suggested that at an

unconscious level staff fulfil a containing function for clients. It was posited that caregivers may be internalised and can then be used by the client to relieve anxiety.

However, at times this containment function was not present. Both clients and family members noted that information was not always given in a sensitive way, and family members described feeling blamed, not listened to and not supported. Comments from relatives suggested that staff may need to have structures in place to enable them to deal with their own anxieties. Chiesa (1994) noted that on acute admission wards, staff anxieties, feelings of guilt and responsibility were dealt with through psychological defence mechanisms such as projection, splitting and denial. It is possible that the comments of family members reflect the use of these defences to cope with the difficult feelings aroused by mental health work.

## **8. Current circumstances**

Clients and relatives described how the client had developed their sense of self since the first psychotic episode. However, there continued to be major difficulties in functioning and relating to others. One client acknowledged that this was due to difficulties in reflecting on the mental states of others;

*'its a problem of understanding how other people are and how they feel'*

In addition, clients highlighted how the presence of other people was essential in helping them to define themselves. Thus there appears to be a continued need to develop an identity; this was recognised by one relative;

*'he needs to develop himself before he could meet a group, to make friends, both sexes of*



It is possible that the extent of earlier vulnerability determines how able the person is to construct a sense of themselves without a constant need for the presence of others. The difficulty of resolving early trauma or an inability to develop a stable sexual identity would all impede this process of identity development (Blos, 1979).

### **Summary**

The model presented is a tentative account of how the development of schizophrenia may be linked to the individual's sense of self. Suggestions were made as to how services may be implicated in this process. The next section outlines the limitations of the study.

## **4.3 METHODOLOGICAL CRITIQUE**

### **4.3.1 EVALUATING THE FINDINGS OF THE STUDY**

It is recognised that the issue of research credibility is a complex one, as the relationship between theory and data is two-way and fluid and the personal is always present in the research (Henwood and Pidgeon, 1992). For these reasons, the meaning of the data and its relationship to the emergent model cannot be judged against a norm of objectivity.

However, the strategies outlined in the methodology were used to guide the progress of the research and can be used to evaluate its strengths and weaknesses. The strategies of reflexivity, reliability, triangulation, validity and rhetorical power (Banister et al, 1994; Henwood and Pidgeon, 1992) are detailed below.

## **Reflexivity**

Throughout the process of the research it was attempted to make explicit how particular assumptions and interpretations may influence the emerging model. This was done in two ways. Firstly, the introduction section outlined the researcher's conceptualisation of this area. Secondly, a research diary (Appendix 10) was written to document the process of research. This outlined ideas which emerged from seminars, from reading relevant literature and from discussions with other people. This provided a context in which the emerging ideas could be set. The process of reflexivity was illuminating; particularly in highlighting how knowledge was interpreted in light of ones' own interests and biases.

## **Reliability**

The audio-taping of interviews ensured that the conversation that took place was accurately represented and would be available for scrutiny by independent researchers.

An independent rater matched codes to quotes for the section on 'current circumstances', and percentage agreement was calculated. Inter-rater reliability was slightly better for the family group (96%) than for the client group (94%). It is possible that undertaking the interviews provided additional information which was used in the process of analysis to conceptualise statements. As people with schizophrenia do not always follow conventional patterns of language use this may have had more of an impact for the client group.

### **Triangulation**

Banister et al. (1994) suggested that obtaining data from two different positions makes conclusions potentially more valid. Eliciting accounts from both clients and their relatives demonstrated how understanding the course of schizophrenia and its impact on the individual was shaped by subjective experience. In addition, the independent rater discussed with the researcher areas of disagreement and this process provided an additional perspective on the data. These comments and discussions with the researcher's supervisor were used to enrich the emergent model and consider its potential limitations.

### **Validity**

The process of interviewing and analysis was simultaneous. In the last two client and relative interviews, the process of debriefing was used to discuss how emergent categories fitted with participants' experiences. This process confirmed many of the findings, and both relatives went on to suggest changes to service provision when they recognised that aspects of their experience had been shared by others. However, this process also demonstrated that themes can only be used as a general guide for understanding individual experience. Henwood and Pidgeon (1992) suggested that exploring differences can be a useful way of elaborating on the emergent theory.

### **Rhetorical power**

Rhetorical power is a matter of degree, and, ultimately the rhetorical power of the findings are for the reader to decide. The importance of the development of self and the impact of



adolescence was discussed with psychologists working within the field, who commented that the findings made sense in light of clinical experience.

#### 4.3.2 METHODOLOGICAL AND CONCEPTUAL ISSUES

##### Recruitment of participants

The small sample necessarily limits the generalisability of the findings. Participants were those nominated by the Consultant Psychiatrist as people who would be able to discuss their experiences and also had relatives who were in contact with the service and were likely to participate. It is thus possible that clients were those who had strong relationships with their families and thus forming a separate identity was more difficult for them. As participants were involved with a rehabilitation service and had had extensive experience of mental health services it is also possible that ideas about separation and identity had been conveyed by staff. However, the fact that this was meaningful to both clients and relatives may support the validity of the findings, at least for this particular group.

Choosing client participants on the basis of a diagnosis of schizophrenia is problematic and against the advice of some researchers (e.g. Bentall, 1990). However, Bentall suggested selecting a group on the basis of symptomatology to improve validity. The presence of hallucinations and delusions was ensured through use of the HoNoS, and thus the findings provide tentative ideas about the population of people with these symptoms.

## **Conducting the interviews**

Eliciting narratives from people whose thoughts were at times somewhat disordered raised some interesting questions. Decisions about helping clients to structure their thought process inevitably shaped the course of discussions, and it is possible that this impacted on the information elicited.

Secondly, tape recordings based on single encounters risk losing important temporal aspects and also limit personal disclosure (Perakyla, 1997). Ideally a more in-depth study would have been conducted using a longitudinal design to maximise the likelihood of obtaining more personally problematic material. This is particularly relevant when interviewing people with schizophrenia as demands imposed in social interaction may require flexible approaches to the content, structure and duration of the meeting (Perkins and Dilks, 1992). However, time was taken to establish rapport and help clients to feel at ease. Additionally, having worked in the service, staff and clients were relatively familiar with the researcher's presence.

## **Analysis**

Coding the transcripts was more difficult for clients, and probably accounts for the lower inter-rater reliability obtained for client interviews.

Throughout the research process thoughts emerged about possible theories. Inevitably, these thoughts informed and constrained subsequent data collection and analysis

(Huberman and Miles, 1994), although attempts were made to generate alternative constructions throughout the process, and document these in the research diary.

### **The model**

The tentative model that has emerged from the data is necessarily influenced by the researcher's beliefs and ideas. It is thus essential to bear in mind alternative explanations for the data. In considering alternatives, it was useful to consider the different perspectives on the self; in particular those from the social constructionist perspective.

It is possible that the need to develop an identity only occurs after the onset of the 'illness', which is experienced as a biographical disruption much like any other illness (Radley, 1994). Thus the formation of an identity is not underlying 'schizophrenia', but reflects the need to adapt to having an illness and a disability. Bury (1991) on writing about the 'unfolding' nature of chronic illness, proposed that sufferers pass through a series of stages, although there was individual variability in the course and nature of these. The first stage involved seeking help for symptoms; this was noted to depend on their severity and individual perception. It was observed that individuals attempt to 'normalise' the event and it is only when there is interference in everyday tasks that medical help is sought. The second stage involved receiving a diagnosis. Without this the person could not legitimately adopt the sick role and receive help from others. The third stage was characterised by anger, depression and anxiety due to biographical disruption of the individual's life-course. This model would also account for the experiences of clients



and family members, and the parallels with chronic illness are likely to have implications for both direct and indirect work. Karp (1994) described how the process of being diagnosed with depression impacts on the individual's identity, and suggested that with any illness there is a need to evaluate the subjective change in self. Thus this may explain the frequency with which clients and relatives discussed identity issues.

It is also possible that the 'being bad' discussed by both clients and relatives reflects internalised stigma about having mental health problems (Hayward and Bright, 1997).

This is consistent with social constructionist perspectives on development of the self.

Furnham and Rees (1988) examined lay beliefs about schizophrenia, and found that most people thought it meant the patient had a 'split' personality. Beliefs about the person with schizophrenia concerned dangerousness, amorality, egocentricity and a vagrant nature.

Causality was attributed to stress, attentional difficulties, biology, genetics and brain damage. More recently, Rogers and Pilgrim (1997) found that lay people tended to view mental illness as florid psychosis and viewed the word 'mental' in negative terms.

Consequently, it is likely that these negative discourses have an impact on how the person with schizophrenia constructs their sense of self.

#### **4.4 THERAPEUTIC AND SERVICE IMPLICATIONS**

It is essential to note that the findings of the study are of a tentative nature. However, they lead to recommendations being made at two levels. The first is at the level of direct therapeutic work with clients, and the second is as a framework to facilitate staff's

understanding of client behaviour and on which to base constructive service responses.

### **a) Implications for direct therapeutic work**

Focusing on problems with identity may be more meaningful to clients than discussing a diagnosis of schizophrenia. Whilst conducting the interviews it was interesting to observe that although clients did not always agree that they had schizophrenia, they discussed experiences that were consistent with difficulties in the construction of identity. The issue of whether problems with identity/self are causal or a result of 'illness' is complex, but discussions around this could facilitate the introduction of specific interventions. This has implications for compliance, as compliance with medication and other interventions requires a shared conceptualisation of symptomatology and 'illness' (Radley, 1994).

The emphasis on adolescent factors in developing a sense of self has implications for direct psychological work. For example, the factors highlighted by Blos (1979) as central to forming an adult identity could be targeted during assessment and subsequent interventions. Thus work on mastering early trauma, promoting ego continuity and on establishing sexual identity could provide a framework for therapeutic sessions. This structure is important when working with clients with psychosis (Perkins, 1997), and would provide an addition to current techniques used to work directly with delusions and hallucinations (Chadwick, Birchwood and Trower, 1996).

The process of transcribing the tapes also led to ideas about how communication between

therapists and clients could be improved. The transcription process highlighted some of the biases that were operating whilst listening to clients, and demonstrated how the content of conversation is heard through a particular 'lens'. It is suggested that taping an initial assessment, extracting salient themes and returning to clients with the themes written on cards to construct a joint formulation could be a way of enabling client's to be heard and would validate their sense of self. It is acknowledged that this process may be laborious for daily clinical practice. However, this practice may be essential if Clinical Psychologists are to provide meaningful clinical input.

#### **b) Implications for services**

There are several benefits of modelling the impact of psychosis on the self at different stages and how services can assist in the process of rebuilding an identity. First, it provides a model which can be used to train staff and increase knowledge about the subjective experience of psychosis. If, as the model suggests, admission is the point at which the individual can start to develop an adult self through interactions with ward staff, it is essential that staff have the time available to interact with clients as people and not simply as 'patients'. Clients highlighted the benefits of talking and laughing with staff, as well as feeling they were understood. Emphasising that the relationships between clients and staff are fundamental to improvement may help to reduce destructive social distance and help clients to regain their self-worth. By conveying to staff that clients view development of the self as central to their improved well-being, and that this is dependent on interpersonal interactions, staff may not feel the same pressure to 'do' things to the



person. Deegan (1993) noted that 'doing things' to her compounded her feelings of aloneness, hopelessness and lack of identity.

Second, the model enables priorities and policies to be more explicit. From the first point of contact with services, attempts should be made to contain the self and start to build a sense of self and identity in a consistent way. This necessitates a co-ordinated approach from ward staff such as that described by Aaltonen and Rakkolainen (1994). Interventions which exacerbate the confusion and fragmentation experienced by clients will ultimately be unhelpful in rebuilding the self. Adshead (1998) noted that practically containment can be offered by empathic listening and by providing information about the hospital, the ward or the experience of psychiatric problems. In addition, Adshead noted that a consistent relationship which facilitates the development of trust is essential. It is of note that these recommendations do not sit easily with a traditional 'through-put' model advocated by the NHS for acute wards (Lavender and Holloway, 1988).

Third, it would appear that the confusion experienced by clients when they are first admitted is shared by relatives. Attempts should be made to provide containment for the client and enable them to start to build an adult identity, but work should also occur with relatives to enable them to feel safe enough to not 'overprotect' the client. Several relatives described their tendency to do this; it is likely that this arises out of the feelings of guilt and helplessness that they described. Previous research has also highlighted this tendency (Lam, 1991). The levels of guilt, regret and self-blame expressed by relatives

were concerning, and it is suggested that staff need to take more time to explain and support relatives throughout the process. Support structures for staff need to be in place so that psychological defence mechanisms used to deal with difficult aspects of mental health work do not have a negative impact on relatives. Rehabilitation services should also recognise that even though relatives have been in contact with services for many years, this does not mean that they understand why their relative is there and may need time to discuss their fears and concerns. This was already occurring for some relatives and was seen as valuable support.

It is also important that continuity and consistency are provided within the community (Lavender and Holloway, 1988). This would require more flexible working arrangements between primary, secondary and tertiary care. Jackson and Farmer (1998) describe a service designed to intervene at an early stage in psychosis. This sort of model could be used to explore ways in which the development of self could be achieved within the community.

#### **4.5 RECOMMENDATIONS FOR FUTURE RESEARCH**

##### **Research on the self and psychosis**

Quantitative methodologies could be employed to test out specific hypotheses with a larger sample. In particular, studies investigating how the second individuation process could be implicated in psychosis would be beneficial. Kroger (1989) described several measures which have been designed to explore issues of separation and individuation in

adolescence. These standardised measures could be used with people with psychosis once they have stabilised on admission wards. Alternatively, there are areas of research which could directly and indirectly explore separation-individuation issues, such as studies of intimacy, relationships with peers and parents, ability to tolerate being alone etc. It would be of benefit to consider whether these factors have any bearing on course and outcome. In addition it would be interesting to investigate whether the second-individuation process in developing countries is made easier through greater community participation. Warner (1994) noted that psychoses have a briefer duration in these countries, and there is a wider network of people to support both the individual and their family.

Second, the benefits of Clozaril were emphasised by both relatives and staff, and it would be interesting to investigate in what ways this impacted on a subjective sense of self. One client commented on the subjective experience of taking Clozaril;

*I'm now on medication, I'm on Clozaril. Its giving me the booster inside my system .I'm now on Clozaril, and my body really seems to calm down. It says to itself I have seen this situation before, and in that respect the Clozaril takes control.*

This could be explored further to gain insight into psychological factors which could be used as an adjunct to the drug, or used with those for whom the medication is unsuitable.

#### Research on staff and client relationship development

There is a need to research the optimal ways in which staff could develop relationships with clients. This work could develop the ideas on attachment described by Adshead (1998), and would seek to take account of clients' differing attachment patterns.



## Research on the experience of family members

There is scope for much research on the impact of psychosis on the family. More studies are needed to investigate the dynamics involved in becoming involved with psychiatric services and how the process can be made easier for families.

## 4.6 CONCLUSION

'Schizophrenia' is a highly complex condition, and a multitude of theories are necessary to understand and assist those affected. Thinking about the construction of the self also requires the use of many abstract concepts, and thus the model outlined can only be one small part of a very large puzzle. It is acknowledged that the ideas generated require empirical testing with quantitative methodologies. However, the findings and implications for practice provide ideas which may increase the likelihood of individuals' experiences being understood in a field which has traditionally dismissed these narratives as madness.

## REFERENCES

- Aaltonen, J. and Rakkolainen, V. (1994). The shared image guiding the treatment process: A precondition for integration of the treatment of schizophrenia. British Journal of Psychiatry, 164 (suppl. 23), 97-102.
- Adshead, G. (1998). Psychiatric staff as attachment figures. British Journal of Psychiatry, 172, 64-69.
- American Psychiatric Association (1994). Diagnostic and Statistical Manual of Mental Disorders. 4th Ed., Washington, A.P.A.
- Anthony, W.A. (1993). Recovery from mental illness: The guiding vision of the mental health system in the 1990's. Innovations and Research, 2 (3), 17-24.
- Appleton, J. (1995). Analysing qualitative interview data: addressing issues of validity and reliability. Journal of Advanced Nursing, 22, 993-997.
- Auerbach, J.S. and Blatt, S.J. (1996). Self representation in severe psychopathology: the role of reflexive self awareness. Psychoanalytic psychology, 13 (3), 297-341.
- Banister, P., Burman, E., Parker, I., Taylor, M. and Tindall, C. (1994). Qualitative methods in Psychology: A research guide. Buckingham: Open University Press.
- Basch, M.F. (1992). The significance of a theory of affect for psychoanalytic technique. In T. Shapiro and R.N. Emde (Eds.). Affect: Psychoanalytic Perspectives, pp291-304. Madison: International Universities Press.
- Bateson, G., Jackson, D., Haley, J. and Weakland, J. (1956). Towards a theory of schizophrenia. Behavioural Science, 1, 251-264.
- Beck, A.T., Emery, G. and Greenberg, R.L. (1985). Anxiety disorders and phobias: a cognitive perspective. New York: Basic Books.
- Beels, C.C., Gutwirth, L., Berkeley, J., Struening, E. (1984). Measurement of social support in schizophrenia. Schizophrenia Bulletin, 10, 399-411.
- Bentall, R.P. (1990). The syndromes and symptoms of psychosis. Or why you can't play 'twenty questions' with the concept of schizophrenia and hope to win. In R.P. Bentall (Ed.). Reconstructing Schizophrenia. London: Routledge.
- Bentall, R.P. (1993). Deconstructing the concept of schizophrenia. Journal of Mental Health, 2, 223-238.

Bentall, R.P., Haddock, G. and Slade, P.D. (1994). Cognitive behaviour therapy for persistent auditory hallucinations: From theory to therapy. Behaviour Therapy, 25 (1), 51-66.

Bentall, R.P., Kinderman, P. and Kaney, S. (1994). The self, attributional processes and abnormal beliefs: Towards a model of persecutory delusions. Behaviour Research and Therapy, 32 (3), 331-341.

Bentall, R.P., Jackson, H.F. and Pilgrim, D. (1988). Abandoning the concept of 'schizophrenia': Some implications of validity arguments for psychological research into psychotic phenomena. British Journal of Clinical Psychology, 27, 156-169.

Bion, W.R. (1957). Differentiate of the psychotic from the non-psychotic personalities. International Journal of Psychoanalysis, 38, 266-75.

Bleuer, E. (1950). Dementia Praecox or the group of Schizophrenias. New York: International University Press (Translated from the German edition, 1911).

Blos, P. (1962). On Adolescence; a psychoanalytic interpretation. New York: Free Press.

Blos, P. (1979). The Adolescent Passage. New York: Free Press.

Boyle, M. (1994). Schizophrenia and the art of the soluble. The Psychologist, 7 (9), 399-404.

Bressi, C. (1996). Introduction. New Trends in Experimental and Clinical Psychiatry, XI (2), 59-64.

Bury, M. (1991). The sociology of chronic illness: a review of research and prospects, Sociology of Health and Illness, 13, 451-468.

Chadwick, Birchwood and Trower (1996). Cognitive therapy for delusions, voices and paranoia. Chichester: Wiley.

Charmaz, K. (1991). Good days, bad days: the self in chronic illness and time. New Brunswick: Rutgers University Press.

Chiesa, M. (1994). At the border between institutionalisation and community psychiatry: Psychodynamic observations of a hospital admission ward. Free Associations, 4 (30, pt 2), 241-263.

Clements, K. and Turpin, G. (1992). Vulnerability models and schizophrenia: the Assessment and prediction of relapse. In: M. Birchwood and N. Tarrier (Eds.). Innovations in the psychological management of schizophrenia. Chichester: Wiley.



Corbin, J. and Strauss, A.L. (1987). Accompaniments of chronic illness: Changes in body, self, biography and biographical time. In: J.A. Roth and P. Conrad (Eds.). Research in the Sociology of Health Care, Vol. 6, The Experience and Management of Chronic Illness. Greenwich, Conn.: JAL Press.

Crow, T.J. (1980). Molecular pathology of schizophrenia: more than one disease process? British Medical Journal, 280, 66-68.

Dallos, R. (1996). Interacting stories: Narratives, Family Beliefs and Therapy. London: Karnac Press.

Davidson, L. (1993). Story telling and schizophrenia: using narrative structure in phenomenological research. The Humanistic Psychologist, 21, 200-220.

Davidson, L. and Strauss, J.S. (1992). Sense of self in recovery from severe mental illness. British Journal of Medical Psychology, 65, 131-145.

Deegan, P. (1993). Recovering our sense of value after being labelled. Journal of Psychosocial Nursing, 31 (4), 7-11.

Department of Health (1991). Building Bridges: A guide to arrangements for inter-agency working for the care and protection of severely mentally ill people. Yorkshire: Department of Health.

DeWaele, M. (1996). A process view of the self. British Journal of Medical Psychology, 69, 299-311.

Eisenberg, N. and Fabes, R.A. (1992). Emotion and its Regulation in Early Development. San Francisco: Jossey-Bass.

Eisenbruch, M. (1990). Classification of natural and supernatural causes of mental distress. Journal of Nervous and Mental Disease, 178, 712-719.

Erikson, E. (1956). The problem of ego identity. Journal of the American Analytic Association, 4, 56-121.

Erikson, E. (1963). Childhood and Society (2nd ed.). New York: Basic Books.

Erikson, E.H. (1959). Identity and the life cycle. Psychological Issues, 1, 18-171.

Erlandson, D.A., Harris, E.L., Skipper, B.L. and Allen, S.D. (1993). Doing Naturalistic Enquiry. London: Sage.

Erwin, E. (1997). Philosophy and Psychotherapy. London: Sage Publications.

Fonagy, P., Steele, M., Steele, H. and Target, M. (1997). Reflective functioning manual (version 4.1). For application to adult attachment interviews.

Foucault, M. (1965). Madness and Civilisation: A History of Insanity in the Age of Reason. New York: Pantheon Books.

Fowler, D., Garety, P. and Kuipers, E. (1995). Cognitive-behaviour therapy for psychosis: Theory and Practice. Chichester: Wiley.

Frosch, J. (1983). The Psychotic Process. New York: International Universities Press.

Furnham, A. and Rees, J. (1988). Lay theories of schizophrenia. International Journal of Social Psychiatry, 34, 212-220.

Gaarder, J. (1995). Sophies World. London: Phoenix

Garety, P. (1985). Delusions: problems in definition and measurement. British Journal of Medical Psychology, 58, 25-34.

Garety, P., Kuipers, L., Fowler, D., Chamberlain, F. and Dunn, G. (1995). Cognitive-behavioural therapy for drug-resistant psychosis. British Journal of Medical Psychology, 67, 259-271.

Glaser, B. and Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine.

Goodman, S.H., Sewell, D.R., Cooley, E.L., et al. (1993). Assessing levels of adaptive functioning: the Role Functioning Scale. Community Mental Health Journal, 29, 119-131.

Goffman, I. (1959). The presentation of self in everyday life. Harmondsworth: Penguin Books.

Harding, N. and Palfrey, C. (1997). The Social Construction of Dementia. London: Jessica Kingsley Publishers.

Hatfield, A.B. (1989). Patients' accounts of stress and coping in schizophrenia. Hospital and Community Psychiatry, 40, 1141-1145.

Hayward, P. and Bright, J.A. (1997). Stigma and mental illness: A review and critique. Journal of Mental Health, 6(4), 345-354.



Henwood, K.L. and Pidgeon, N.F. (1992). Qualitative research and psychological theorising. British Journal of Psychology, 83, 97-111.

Hingley, S.M. (1992). Psychological theories of delusional thinking: In search of integration. British Journal of Medical Psychology, 65, 347-356.

Hingley, S.M. (1997). Psychodynamic perspectives on psychosis and psychotherapy. British Journal of Medical Psychology, 70, 301-324

Hirschberg, W. (1985). Social isolation among schizophrenic outpatients. Social Psychiatry, 20, 171-178.

Huberman, A.M. and Miles, M.B. (1994). Data management and analysis methods. In: M. Miles and A. Huberman (Eds). Qualitative Data; an expanded sourcebook pp428-444.

Hyden, L.C. (1995). In search of an ending: Narrative reconstruction as a moral quest. Journal of Narrative and Life History, 5(1), 67-84.

Hyden, L.C. (1997). Illness and Narrative. Sociology of Health and Illness, 19(1), 48-69.

Jackson, H.F. (1990). Are there biological markers of schizophrenia? In R.P. Bentall (Ed.). Reconstructing Schizophrenia. London: Routledge.

Jackson, C. and Farmer, A. (1998). Early intervention in psychosis. Journal of Mental Health, 7 (2), 157-164.

Kakar, S. (1982). Shamans, Mystics and Doctors. Oxford: University Press.

Karp, D.A. (1994). Living with depression: Illness and identity turning points. Qualitative Health Research, 4(1), 6-30.

Klein, M. (1946). Notes on some schizoid mechanisms. International Journal of Psycho-Analysis, 27, 99-110.

Klein, J. (1987). Our need for others and its roots in infancy. London: Tavistock Publications.

Kraepelin, E. (1905). Lectures on Clinical Psychiatry. London: Balliere Tardall.

Kroger, J. (1989). Identity in adolescence; the balance between self and other. London: Tavistock Publications.

Laing, R.D. (1965). The Divided Self. London: Pelican.



Lake, N. (1997). The social and affiliative needs of people with long-term mental health problems. Unpublished dissertation: South Thames (Salomons) Clinical Psychology Training Course.

Lam, D.H. (1991). Psychosocial family interventions in schizophrenia: a review of empirical studies. Psychological Medicine, 21, 423-441.

Laplanche, J. and Pontalis, J.B. (1988). The language of psychoanalysis. London: Karnac (books) Ltd.

Lavender, A. (in press). Schizophrenia. In M. Power and L. Champion. Adult Psychology Disorders: An introduction. 2nd Ed. London: Falmer Press.

Lavender, A. and Holloway, F. (Eds.). Community Care in Practice: Services for the Continuing Care Client. Chichester: Wiley.

Lehtinen, V. and Vaisanen, E. (1978). Attitudes towards mental illness and utilisation of psychiatric treatment. Social Psychiatry, 13, 63-68.

Leff, J.P. and Vaughn, C.E. (1985). (Eds.). Expressed Emotion in Families. New York: Guildford Press.

Lewis, S. (1995). A search for meaning: Making sense of depression. Journal of Mental Health, 4, 369-382.

MacCarthy, B. and Liddle, P. (1994). The assessment of subjective experience and insight. In T.R.E. Barnes and H.E. Nelson. The assessment of psychosis (pp105-124). London: Chapman and Hall.

Mahler, M. (1971). The study of the separation individuation process and its possible application to borderline phenomenon in the psychoanalytic situation. Psychoanalytic study of the child, 26, 403-425.

Mays, N. and Pope, C. (1996). Rigor and qualitative research. In: N. May and C. Pope (Eds.). Qualitative Research in Health Care. London: BMJ Publishing Group.

McGuffin, P., Farmer, A. and Harvey, I. (1991). A polydiagnostic application of operational criteria in studies of psychotic illness. Archives of General Psychiatry, 48, 764-770.

Miller, P.Mc., Ingram, J.G., Kreitman, N.B., Surtess, P.G. and Sashidarhan, S.P. (1987). Life events and other factors implicated in onset and in remission of psychiatric illness in women. Journal of Affective Disorders, 12, 73-88.

MIND (1989). Major Tranquillisers. London: Mind Publications.

Nuechterlein, K.H. and Dawson, M.E. (1984). A heuristic vulnerability-stress model of schizophrenia episodes. Schizophrenia Bulletin, 10, 300-312.

Nicholson, N. (1995). Qualitative research, psychology and mental health: analysing subjectivity. Journal of Mental Health, 4, 337-345.

Obholzer, A. and Roberts, V.Z. (Eds.). (1994). The Unconscious at Work. London: Routledge.

Overall, J.E. and Gorman, D.R. (1962). The Brief Psychiatric Rating Scale. Psychological Reports, 10, 799-812.

Perakyla, A. (1997). Reliability and validity in research based on tapes and transcripts. In D. Silverman (Ed). Qualitative Research; theory, method and practice. London: Sage Publications.

Perkins, R. (1997). Access to therapy, engagement and adaptation to life with a disability. ( unpublished lecture notes).

Perkins, R. and Dilks, S. (1992). Worlds apart; Working with severely socially disabled people. Journal of Mental Health, 1, 3-17.

Perkins, R. and Moodley, P. (1993). The arrogance of insight? Psychiatric Bulletin, 17, 233-234

Pidgeon, N.F., Turner, B.A., Blockley, D.I. (1991). The use of grounded theory for conceptual analysis in knowledge elicitation. International Journal of Man-Machine Studies, 35, 151-173.

Radley, A. (1994). Making sense of illness. London: Sage Publications

Rogers, A. and Pilgrim, D. (1997). The contribution of lay knowledge to the understanding and promotion of mental health. Journal of Mental Health, 6 (1), 23-35.

Rosen, H. (1996). Meaning-making narratives: Foundations for constructivist and social constructionist psychotherapies. In: H. Rosen and K.T. Kuehlwein (Eds.). Constructing Realities: Meaning Making Perspectives for Psychotherapists. San Francisco: Jossey Bass Inc.

Sarbin, T.R. (1990). Towards the obsolescence of the schizophrenia hypothesis. Journal of Mind and Behaviour, 11, (3-4), 259-284.

Sass, L.A. (1992). Madness and modernisation: Insanity in the light of modern art, literature and thought. New York: Basic Books.



Seidman, L.J. (1984). Schizophrenia and brain dysfunction: an integration of recent neurodiagnostic findings. Psychological Bulletin, 94, 195-238.

Steiner, J. (1993). Psychic Retreats; pathological organisations in psychotic, neurotic and borderline patients. London: Routledge.

Stern, D.N. (1985). The Interpersonal World of the Infant: A view from Psychoanalysis and Developmental Psychology. New York: Basic Books.

Stevens, R. (1996). Understanding the self. London: Sage Publications.

Strauss, J. (1994). The person with schizophrenia as a person II: Approaches to the subjective and complex. British Journal of Psychiatry, 164 (suppl. 23), 103-107.

Strauss, A. and Corbin, J. (1994). Grounded theory methodology: An overview. In M. Miles and A. Huberman (Eds). Qualitative Data; an expanded sourcebook pp 273-285.

Stevenson, C. and Cooper, N. (1997). Qualitative and quantitative research. The Psychologist, 10 (4), 159-160.

Tomkins, S.S. (1970). Affect as the primary motivational system. In: M.B. Arnold (ed.), Feelings and Emotions: The Loyola Symposium, pp101-110. London: Academic Press

Turpin, G. Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J. and Walsh, S. (1997). Standards for research projects and theses involving qualitative methods: suggested guidelines for trainees and courses. Clinical Psychology Forum, 108, 3-7.

Warner, R. (1994) Recovery from Schizophrenia: Psychiatry and Political Economy. (2nd ed.). Routledge and Kegan Paul.

Weiner, B. (1986). An Attributional theory of Motivation and Emotion. New York: Springer Verlag.

Wexler, M. (1965). Working through in the therapy of schizophrenia. International Journal of Psychoanalysis, 46 (3), 279-286.

White, M. and Epstein, D. (1990). Narrative Means to Therapeutic Ends. London: Norton and Co.

Widdershoven, G.A.M. (1994). Identity and development: a narrative perspective. In H. Bosma, T. Graafsmana, H. Grotevant and D. de Levita (Eds). Identity and development (pp103-117). London: Sage Publications.



Wilson, M. (1996). Asking questions. In R. Sapsford and V. Jupp (Eds). Data collection and analysis (pp94-120). London: Sage Publications.

Wing, J.K., Beevor, A.S., Curtis, R.H., Park, S.B.G., Hadden, S. and Burns, A. (1998). Health of the Nation outcome scales (HoNoS); Research and development. British Journal of Psychiatry, 172, 11-18.

Wood, P.H. (1980). Appreciating the consequence of disease: The classification of impairments, disability and handicaps. The WHO Chronicle, 34, 376-380.

World Health Organisation (1992). The ICD-10 Classification of Mental and Behavioural Disorders. Geneva, WHO.

Young, J. (1990). Cognitive therapy for personality disorders: A schema focused approach. Sarasoot, F.L: Professional Resource Press.

Zani, B. (1995). The mentally ill person and the others: Social representations and interactive strategies. In: I. Markova and R. Farr. Representations of Health, Illness and Handicap (pp145-162). Harwood Academic Publishers GMBLT.

## APPENDICES

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**APPENDIX 1**  
**GLOSSARY OF ANALYTIC TERMS**

**Defence:** A group of operations that aim to decrease or eliminate any change liable to threaten the integrity and stability of the bio-psychological individual and thus the ego\*. The defensive process is expressed in mechanisms and may be partly unconscious (Laplanche and Pontalis, 1988).

**Denial:** A defence mechanism that denies or disavows thoughts, feelings, wishes or needs that cause anxiety (Steiner, 1993).

**Ego:** From the Latin 'I' or 'self'.

In psychoanalytic terms, the ego is one of the three structures Freud proposed that the mind was comprised of; the id, ego and superego. It is a cluster of cognitive and perceptual processes that Freud saw as gradually evolving out of the unconscious structure of the infant's mind, and develops through interactions with the social and physical environment. Much of the egos activity is conscious and thus open to introspection. It can be conceptualised as an executive who acts to maintain psychic balance between the demands of the id and the parental inhibitions and prohibitions of the superego (Laplanche and Pontalis, 1988).

**Fragmentation:** Normal splitting\* can effectively deal with much of the psychic threat facing an individual. However, sometimes this mechanism fails to master all the anxiety, and consequently more extreme defences\* are called upon. In an attempt to free themselves from the experience of a hated and feared reality, the person with psychosis attacks the ego (i.e. the part of themselves concerned with the perception of reality. This leads to fragmentation of both ego and object (Steiner, 1993). Through minute splitting and violent projection of the fragments, Bion (1957) described how this can lead to the



creation of bizarre objects which intensify the persecution of the person through 'mad' experiences.

**Introjection:** This term can be used to denote the transposition of the whole or part of an external object \* to the 'inside' of the individual. The internal representation then takes over the psychological functions of the external objects (Laplanche and Pontalis, 1988).

**Object:** There are several definitions of this word within psychoanalysis. However, in this dissertation the word is used to represent a person, an entity or an ideal. In psychoanalytic literature the word can occur both alone and in many compound forms (e.g. object-relationship) (Laplanche and Pontalis, 1988).

**Projection:** A primitive defence mechanism in which qualities, feelings, wishes or objects\* which the individual refuses to recognise in themselves are expelled from the self and located in another person or thing (Laplanche and Pontalis, 1988).

**Projective identification:** a part of the self is split off and projected onto an object\*, where it is attributed to that object and the fact that it belongs to the self is denied. Thus the resultant relationship is not with a person truly seen as separate, but with the self projected onto another person and related to as if it were someone else.

In itself, this is not a pathological mechanism, and indeed forms the basis of empathic communication. However, it is essential to normal mental functioning to be able to use projective identification in a flexible and reversible way. In many pathological states this reversibility is obstructed and the person is unable to regain parts of the self lost through projective identification, and consequently loses touch with aspects of their personality. At the same time the object is distorted by having attributed to it the split off and denied parts of the self. (Steiner, 1993).

**Reflexive functioning:** the psychological processes underlying the capacity to mentalise about the self and others. It involves both a self-reflexive and an interpersonal component that ideally provides the individual with the ability to distinguish inner from outer reality, pretend from 'real' modes of functioning and intra-personal mental and emotional process from interpersonal communications (Fonagy, Steele, Steele and Target, 1997).

**Splitting:** Klein (1946) considered that this was the most primitive defence\* against anxiety. The object with both erotic and destructive instincts directed towards it splits into a 'good' and a 'bad' object\*. Klein stressed the importance of normal splitting for healthy development. The infant has to organise their chaotic experience, and a primitive structure to the ego is provided by a split into good and bad. If successful, the ego is strengthened to the point where it can tolerate ambivalence, and the split can be decreased and permit the emergence of the depressive position.

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## APPENDIX 3

### CLIENT INTERVIEW SCHEDULE

#### **A. GENERAL INFORMATION**

*I understand that you have had some unusual experiences that have led you to come into contact with our service. I am interested in how you have made sense of these experiences and how these have affected your life. There are no 'right' answers to the following questions; what I am interested in is your opinion and your experiences. I'd like to start the interview by asking some general background information. Could you begin by telling me about your current circumstances.*

##### *Areas to cover*

What experiences are  
Demographic information

#### **B. NARRATIVE ABOUT UNUSUAL EXPERIENCES**

*Q: I would like to find out how you have come to understand the experiences you described. Can you tell me about when these events first started?*

##### *Areas to cover*

Symptoms associated with breakdown  
Salient events around time of initial experiences  
Perceived triggers

#### **C. IMPACT OF TIME**

*Q: Has the way you understand your experiences changed over time?*

##### *Areas to cover*

Fluctuation in attributed meanings  
Fluctuation in perception of experiences  
Beliefs about events related to changes  
Beliefs about the relevance of related events

#### **D. PERCEIVED USEFULNESS OF PROFESSIONAL EXPLANATIONS**

*Q: How did the professionals you saw make sense of your experiences?*

##### *Areas to cover*

Explanatory frameworks used by professionals  
Usefulness of these models in supplementing framework of understanding  
Assessment of/ beliefs about the professional's framework

## **E. BELIEFS ABOUT EXPERIENCES**

*Q: Why do you think this happened to you?*

### *Areas to cover*

Causal belief systems (e.g. religion/ family beliefs) - current and past  
Ideas about mental health and wellbeing  
Ideas about impact of significant relationships - current and past  
Other explanatory frameworks e.g. diet / recreational drug use etc

## **F. IMPACT ON SENSE OF SELF**

*Q: Have these experiences changed how you think and feel about yourself and your life?*

### *Areas to cover*

Self-esteem  
Sense of self (as both 'actor' and self monitor)  
Impact of experiences on life: friendships, work, living arrangements, interests and abilities

## **G. CHANGE IN RELATIONSHIPS WITH OTHER PEOPLE**

*Q: Do you think that having these experiences/beliefs has changed how other people see you?*

### *Areas to cover*

Identify main people (prompt: e.g. neighbour/family friend)  
How beliefs are perceived by these people  
How feel are perceived by society/ general public

## **H. DEBRIEFING**

*Q: Could you tell me how you feel having completed the interview?*

*Q: What was it like talking to me about these issues?*

*Q: Has taking part raised any particular issues for you?*

*Q: Finally, I would like to ask you whether there was anything that was not covered in the interview that you would like to talk about now?*

### **To be read out after each interview: -**

*Thank you for taking part in this interview. It will help me to come to a better understanding of how people make sense of their emotional experiences and what things are helpful in this process.*

*If any issues arise out of this research or if you have any questions that you were unable to ask today, then please contact me on (01892) 507667. If I am not available then please leave a message and I will return your call as soon as possible.*

## APPENDIX 4

### THE RELATIVES' INTERVIEW

#### **A. GENERAL INFORMATION**

*Q: I am interested in how you have made sense of the mental health problems your relative has had and how these have affected their life. There are no 'right' answers to the following questions; what I am interested in is your opinion and your experiences. I'd like to start the interview by asking some general background information. Could you begin by telling me about your current circumstances.*

##### *Areas to cover*

What perceive mental health problems to be  
Demographic information

#### **B. NARRATIVE ABOUT EXPERIENCES**

*Q: I am wanting to find out how you have come to understand your relative's mental health problems. Can you describe events from the first moment you realised they had problems?*

##### *Areas to cover*

Symptoms associated with breakdown  
Salient events around time of initial breakdown  
Perceived triggers

#### **C. IMPACT OF TIME**

*Q: Has the way you understand their experiences changed over time?*

##### *Areas to cover*

Fluctuation in attributed meanings  
Fluctuation in perception of experiences  
Beliefs about events related to changes  
Beliefs about the relevance of related events

#### **D. PERCEIVED USEFULNESS OF PROFESSIONAL EXPLANATIONS**

*Q: How did the professionals you saw make sense of your relative's experiences?*

##### *Areas to cover*

Explanatory frameworks used by professionals  
Usefulness of these models in supplementing framework of understanding  
Assessment of/ beliefs about the professional's framework



## **E. BELIEFS ABOUT EXPERIENCES**

*Q: Why do you think this happened to your relative?*

### *Areas to cover*

Causal belief systems (e.g. religion/ family beliefs) - current and past

Ideas about mental health and wellbeing

Ideas about impact of significant relationships - current and past

Other explanatory frameworks e.g. diet / recreational drug use etc

## **F. IMPACT ON PERCEPTION OF RELATIVE**

*Q: Do you consider that your relative is the same person as before their problems?*

### *Areas to cover*

Change in perception of relative in relation to:

Self-esteem

Sense of self (as both 'actor' and self monitor)

Impact of experiences on relative's life: friendships, work, living arrangements, interests and abilities

## **G. CHANGE IN RELATIONSHIPS WITH OTHER PEOPLE**

*Q: Do you think that having these experiences has changed how other people see your relative?*

### *Areas to cover*

Identify main people (prompt; e.g. neighbour/family friend)

How beliefs are received by these people

How feel they are perceived by society/ general public

## **H. DEBRIEFING**

*Q: Could you tell me how you feel having completed the interview?*

*Q: What was it like talking to me about these issues?*

*Q: Has taking part raised any particular issues for you?*

*Q: Finally, I would like to ask you whether there was anything that was not covered in the interview that you would like to talk about now?*

### **To be read out after each interview: -**

*Thank you for taking part in this interview. It will help me to come to a better understanding of how people make sense of their relative's emotional experiences and what things are helpful in this process.*

Approval from Local Ethics Committee

Our Ref: JC/jlr/97.96.18

7 January 1998

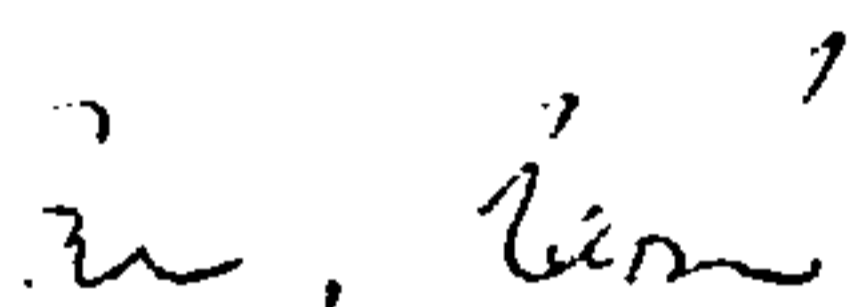
Ms Sarah Barker

Dear Ms Barker,

**Re: Making sense of a diagnosis of schizophrenia - 97.96.18**

Thank you for your letter of 14 December, enclosing the amended consent forms. This is satisfactory and I am now happy to give ethical approval for the study to proceed. I have signed the patient information sheet.

Yours sincerely



Canon Ian Ainsworth-Smith  
Acting-Chair  
Local Research Ethics Committee

**Please Note:** All research should be conducted in accordance with the guidelines of the Ethical Committee and the Committee should be informed:

- (a) when the project is complete.
- (b) what stage the project is at one year from today's date.
- (c) if any alterations are made to the treatment or protocol which might have affected ethical approval being granted.
- (d) all investigators whose projects have been approved by this Committee are required to report at once any adverse experience affecting subjects in the study.

## APPENDIX 6

### PATIENT INFORMATION SHEET

‘Making sense of mental health problems’

#### INTRODUCTION

This study is being carried out by Sarah Barker, Psychologist in Clinical Training, and supervised by Dr Tony Lavender who is a Clinical Psychologist with extensive experience in working with people experiencing mental health problems. I am also receiving advice from Dr Rachel Perkins who is a Consultant Psychologist and the Clinical Director of a rehabilitation team.

#### WHAT IS THIS STUDY ABOUT?

I am interested in how you have made sense of the mental health problems you have and how these have affected your life. I am also interested in how your view compares to what other people think.

#### WHAT WILL HAPPEN DURING THE STUDY?

This study will involve an interview.

The interview will be audiotaped so that I can listen to what you are saying rather than taking notes.

The interview should last no longer than 45 minutes.

#### WHAT IS THE PURPOSE OF DOING THIS RESEARCH?

By paying more attention to the way you have made sense of your experience it is hoped that we can gain a better understanding of what is useful in understanding mental health problems.

#### WHAT IF I REFUSE TO TAKE PART OR STOP HALFWAY THROUGH?

That is fine; your treatment will not be affected in any way.

#### WHAT ABOUT CONFIDENTIALITY?

All material will be held in confidence and will be used for research purposes only. Audio tapes will only be listened to by me and my supervisor. They will then be erased. Your views will be written up, but no one will be able to tell who was interviewed.

You do not have to take part in this study and can stop the interview at any time; it is your right to do so. This will not affect the service you receive in any way.



**WHO SHOULD I CONTACT IF I HAVE ANY CONCERNS?**

After the interview if you want further information, or if anything is unclear, you can contact me at Salomons Centre (Tel: 01892 515152 ext. 7667)

**The Local Research Ethics Committee has approved the above statement.**

Signed by the Chair of that Committee.....

Date.....Index number of protocol

## APPENDIX 7

### RELATIVES INFORMATION SHEET

‘Making sense of mental health problems’

#### INTRODUCTION

This study is being carried out by Sarah Barker, Psychologist in Clinical Training, and supervised by Dr Tony Lavender who is a Clinical Psychologist with extensive experience in working with people experiencing mental health problems. I am also receiving advice from Dr Rachel Perkins who is a Consultant Psychologist and the Clinical Director of a rehabilitation team.

#### WHAT IS THIS STUDY ABOUT?

I am interested in how you have made sense of the mental health problems your relative has and how these have affected their life.

#### WHAT WILL HAPPEN DURING THE STUDY?

This study will involve an interview.

The interview will be audiotaped so that I can listen to what you are saying rather than taking notes.

The interview should last no longer than 45 minutes.

#### WHAT IS THE PURPOSE OF DOING THIS RESEARCH?

By paying more attention to the way you have made sense of your relative’s experience it is hoped that we can gain a better understanding of what is useful in understanding mental health problems.

#### WHAT IF I REFUSE TO TAKE PART OR STOP HALFWAY THROUGH?

That is fine; your relative’s treatment will not be affected in any way.

#### WHAT ABOUT CONFIDENTIALITY?

All material will be held in confidence and will be used for research purposes only. Audio tapes will only be listened to by me and my supervisor. They will then be erased. Your views will be written up, but no one will be able to tell who was interviewed.

You do not have to take part in this study and can stop the interview at any time; it is your right to do so. This will not affect the service your relative receives in any way.

**WHO SHOULD I CONTACT IF I HAVE ANY CONCERNS?**

After the interview if you want further information, or if anything is unclear, you can contact me at Salomons Centre (Tel: 01892 507667)

**The Local Research Ethics Committee has approved the above statement.**

Signed by the Chair of that Committee.....

Date.....Index number of protocol



**APPENDIX 8**

**CLIENT CONSENT FORM**

Sarah Barker  
Psychologist in Clinical Training

Tel: (01892) 507667

I have read and understood the patient information sheet which describes this research and I have been given a copy of this to keep. The nature, purpose and possible consequences of taking part in this research project have been explained to me and my queries have been satisfactorily answered. I understand that the interview will be audiotaped. I have had enough time to consider and decide whether I wish to take part.

I understand that I am entering this project of my own free will, that I may withdraw from this study without giving any reasons, and the future management of my care will not be affected.

Signed.....

Name (printed).....

Date.....

**APPENDIX 9**

**RELATIVES' CONSENT FORM**

Sarah Barker  
Psychologist in Clinical Training

Tel: (01892) 507667

I have read and understood the relative information sheet which describes this research and I have been given a copy of this to keep. The nature, purpose and possible consequences of taking part in this research project have been explained to me and my queries have been satisfactorily answered. I understand that the interview will be audiotaped. I have had enough time to consider and decide whether I wish to take part.

I understand that I am entering this project of my own free will, that I may withdraw from this study without giving any reasons, and the future management of my relative's care will not be affected.

Signed.....

Name (printed).....

Date.....

## APPENDIX10

### RESEARCH DIARY

1/7/97

Am currently preparing a research dissertation proposal. Both before and during training I have been drawn to working with clients with severe and enduring mental health problems, and I have decided that this area interests me and would consequently be a good place to start. Tony Lavender has agreed to supervise the research. I am pleased about this as his clear thinking complements my sometimes tangential thought process! He suggested starting a research diary as I am contemplating qualitative research.

Currently, I am in the middle of an elective placement on psychiatric rehabilitation. Despite having worked in rehab before, I had underestimated the level of anxiety I would initially feel when I met with clients. Over the course of the placement I have been able to understand and cope with this better, and feel I have gained some insight into what it is like to have a diagnosis of schizophrenia. The placement is stimulating and I enjoy the conversations with clients and staff. My placement supervisor has been influential in my growing interest in social constructionism. My previous clinical work has been strongly influenced by developmental perspectives, and I wonder where this fits with work with this client group.

6/8/97

Have been introduced to Nicola Morant by a colleague at work as he thought we had similar ideas about mental health and social constructionism. Nicola completed a Ph.D. about professional explanations of mental health problems, and it is interesting to talk to someone who is also into constructionism. She suggests the use of a narrative approach to research how clients have made sense of their life, and provides some useful ideas for the interview schedule. She also agrees to help with the qualitative analysis which is a big relief!

3/10/97

The end of the research week. This has elevated anxiety levels again, although I am pleased that my proposal has been accepted in full.

10/11/97

Meet with the Psychologists at the rehab team to discuss their comments on my interview schedules. They have provided some really useful comments which I have used to amend the interview. Make some changes and submit my application to ethics.

5/12/98

Receive provisional ethical approval; just have to make small amendments about taping the interviews which is a relief.



5/2/98

Conducted pilot interviews today with a family I had worked with on placement. Found myself thinking about Chadwick, Birchwood and Trower's comments on paranoia and the self when talking with the client. Did his persecutory feelings result from threats to the construction of his sense of self? With the client it seemed that it was harder for him to structure the narrative in a coherent way. I think having a clearer view of the process will help me to better facilitate the client interviews. Felt uncomfortable using the term 'mental health problems'; particularly with the client as he doesn't think he has any. With the relative the narrative was a lot more spontaneous, which was a relief!

6/2/98

Have seminars on psychosis. Interesting discussions around self-reflection and the ability to mentalise. Think about people with psychosis being viewed as unpredictable; is this related to an inability to mentalise/think about the self and thus one's sense of self is dependent on others? Do staff perpetuate client's inability to reflect by being 'macho', or does this style of being in some way help? Is it something about not achieving mental autonomy? Could useful interventions actively encourage people to reflect on each others mental states?

I have found academic debate about this client group interesting, and on my placement found this a useful way of coping with anxiety. However, I also consider that a lot of the academic literature in this area pathologises clients, and enables clinicians to distance themselves from the strong emotions that are elicited during face to face work. Attempt to inject a social constructionist perspective during seminars!

Also had supervision. Discussed the pilot interviews and thought about them in terms of reflexive functioning.

25/2/98

Meet with the Consultant to identify names of possible participants. Things seem to be getting going now and the project seems more feasible.

1/3/98

Read a book which discussed the sociology of the body. The idea is that one's identity and one's body are inextricably linked, as a physical presence is necessary to engage in a dialogue with others. The body thus provides a model for the self that is constructed through interaction with others. Think back to clients and recall that they felt parts of their body were underdeveloped/not their own/ not present. Wonder how this relates to their sense of self. Does this suggest an over-reliance on other people to obtain a sense of self?

19/3/98

About to go to conduct the first interview. Feel very anxious about this; I'm worried the client will get worse following the interview process. He's been doing really well recently and I'd hate to feel responsible for his relapse.



Return after the interview. Feel overwhelmed with what I was told. Not that its that different from clinical interviews, but the pace seems faster and asking about sense of self seems to access important beliefs.

24/3/98

Have arranged three interviews today; one with a relative and two with clients. Arrive for the first client's one. Talk to the staff initially and they warn me the client is upset about his finances and this may dominate the interview. He is very eager to talk about his experiences, and I hurriedly set the tape recorder up.

During the interview I start to feel very anxious. He talks about his boxing prowess and how he is able to defend himself. He then talks about how women have the power to completely take men over, and as a women I must know about the power I have. I change the conversation to discuss the television, but very nearly terminated the interview. However, the interview probably only lasts 40 minutes as I do not feel wholly comfortable sitting in his room discussing the inordinate amount of power women have! After the interview I return to the staff to collect demographic data. Agree to return later in the day when the second client will have returned from their day centre.

Conduct the interview with the mother of the first client I interviewed last week. She is Italian and mouths certain words; wonder what the transcription will be like! This interview feels a lot easier than those with clients. However, I am struck by the feeling of responsibility she has and how much guilt is around.

Return for the second client interview. Staff warn me that he is thought disordered and has a tendency to go off at a tangent. He has written a book and is keen to stress that his mental illness has nothing to do with personality. He reads initially from the loose pages of the book, before abandoning this and talking to me. The interview is not as structured as the first two, but a lot of interesting material emerges. Particularly struck by how it appears that he has no sense of self, and instead his self is dependent on other people. Notice how in the first interview too, when asked if having a mental health problem means he is a different person, he responds that his mother treats him the same. (i.e. again sense of self highly dependent on others). He also mentions that his father was not strong enough for the job. He then attempts to make sense of his life and the universe.

Later in the day find my head is spinning with the material gathered. Wake in the night with the interviews salient in my head. Entering into their world feels scary, and I think of my friends to help me cope; there is something quite systematic about this process and I wonder if this is important. Wonder whether this is something akin to what happens; the anxiety I feel is very powerful and I have to reflect on my own self; who am I?! Contemplate object relations theory; but wish I didn't have to as its the middle of the night! Find deconstructionism is not always helpful, and go back to temporarily thinking about more pathological models to reassure myself that the anxiety I feel will not lead me to go mad! The joy of Clinical Training!



26/3/98

Transcribe some of the tapes. The material does not seem as scary now, and I wonder what felt so powerful in the interviews. Contemplate transference and countertransference. Also wonder if one of the clients was right and there is no meaning or sense to their world! Phone Tony and ask for an earlier supervision session. Unfortunately there is no time before the date we'd scheduled. Tony offers to listen to the tapes on the way to a meeting which feels helpful.

Been thinking about the development of sense of self and went to the library to get more information on this. Read about the second individuation process that occurs during adolescence. Wonder whether this is what is so difficult for people with schizophrenia. Also wonder what it is that distinguishes those who go on to rehab services. Is there some aspect of the developmental phase that is impossible to resolve due to family pressures, early trauma etc.? If this is the case would it be possible to target these people at an earlier stage with psychological interventions? Also wonder about the possibility of increasing the links with primary care.

6/4/98

Just returned from completing two more interviews. Feel a bit low. My thoughts on identity and adolescence and clients having to cope with not having a subjective sense of self are OK in the research world. However, I've just interviewed two people for whom this has had such an enormous impact on their life and resulted in no friends, difficult to find work etc. Still struggle with my perceived imbalance in the research process. Trying to think how the research could have a practical application and thus be of some use. Finding it hard to make the phone calls to the parents, although rationally I perceive these as easier than the client ones.

Generally feeling very confused about all the theories and how it all fits together. Know that there must be a multifaceted approach, but can't hold all the relevant bits in my head! The introduction section keeps shifting and evolving as I try to relate my thinking to its structure. Find I'm now asking existential questions as I write the dissertation!

7/4/98

Continue to struggle to write introduction. Writing about the self and how it develops; why did I choose such a vast topic! One of the clients I interviewed yesterday had a struggle between being youthful and adolescent and getting older; again consider where developmental theories fit in terms of psychosis.

11/4/98

Someone in the pub described a colleague for whom 'daydreams' had been taking up more and more of their reality. Wondered what it was that led this 'daydream/delusion' to increasingly dominate their world. Their colleague had self diagnosed themselves as having schizophrenia, but had not approached their GP and was continuing to work. Thought about Spitzer's work on delusional beliefs and wondered whether it is more of a



continuum than a discrete difference. Wondered what would encourage people to recognise the increasingly different reality they were immersed in and whether could target specific psychological help before a breakdown. Don't think I agree with the 'lack of insight' argument as within the narratives there seems to be awareness, albeit different from the usual reality.

15/4/98

Went to discuss preliminary analysis. Felt a lot more relieved once it had been explained to me; grounded theory seemed less of an abstract mystery! Had sent a couple of transcripts for Nicola to peruse. Was struck by how she had also initially thought the speech was very disjointed and 'a load of rubbish' but on closer inspection she had also seen themes and awareness of difficult issues. The parallel with recovering from other illnesses was discussed; i.e. the before, during and living with it aspects.

16/4/98

Another relative interview. I talk to the mother whilst the father sits in the corner saying very little. She describes how upsetting the process was, and how it is like a living death. Wonder whether if it is ever possible for relatives to fully resolve their loss, and how important it is for psychologists to acknowledge how difficult it must be for your child to develop schizophrenia.

27/4/98

Two more relative interviews today. I'm stuck by how pathologised families are in the literature and find I'm increasingly thinking how hard it is for families. Have been reading about models of chronic illness and wonder whether some of families who have someone with a more physical illness would also have high EE and be more prone to relapse.

After the interviews go and meet another trainee in the pub. He wanted to debate social constructionism with me after he read a paper where the author had deconstructed everything and became 'mad' himself. I appreciated his concern!

18/5/98

Someone on the course has lent me 'On the Road' by Jack Kerouac. This is the book that one of the participants identified strongly with, and I'm curious to know whether this will provide any additional insights as I'm analysing the data. Maybe its also a work avoidance strategy that enables me to sit in the sun and con myself that I'm working!

5/5/98

Another relative interview. It has been many years since her child was diagnosed, but she is still very tearful about the whole process and is angry about the services she received; particularly in the early years. She acknowledges how painful it is to think about the process, but wants to make suggestions so that services are improved for others. Discuss the codes that have emerged from previous interviews and this seems to validate her experience. Then go to interview another client, but she is feeling too tired so I



arrange to return at a later date after discussing the research and clarifying that I can contact her relative.

28/5/98

Interview two clients. During the interviews I am amazed at how clients continually emphasise the importance of growing up, separating and developing. Wonder if I am leading them in any way, but on transcribing the tapes this doesn't seem to be the case. Also continue to contemplate models of chronic illness, although I recognise that this seems to fit better with the accounts of relatives rather than clients.

1/6/98

Another relative interview. She is very keen to discuss her experiences, but questions how valuable her comments will be. This seems to be a general theme; relatives saying that they think they haven't been much help. Notice that this seems to parallel their beliefs about the whole process; they feel useless. Also go to interview a client but staff had forgotten to remind her I was coming and she has gone out. Arrange to go another day.

6/6/98

Getting 'submerged' in the data as the book on grounded theory suggests. Note how it is interesting that many of the questions about change are answered from the point of breakdown. This fits with ideas about biographical disruption. However, I am shocked to notice that I tend to classify client's feelings and emotions in terms of pathological labels. Family members are thus seen as 'sad' whereas clients are 'depressed'. Have rectified this, but also wonder what other biases I haven't spotted. Initially have a tendency to try and 'formulate' what is occurring, but after talking to a colleague at work realise that I have to put my formulations on hold and conceptualise at a more micro level. This is different from the usual psychological process, and takes a bit of getting used to.

10/6/98

The last client interview! This person described how they had gained confidence over the years and were a lot more outgoing now. They were starting to really integrate with the community and this seemed a really hopeful interview to end on. Discussed the seeming importance of forming an identity, and she acknowledged that this was really important but she still needed others around her. Then interviewed her relative, who also described how much she had improved, but how it had been a long and difficult process and she wondered what she could have done differently. A lot of the change was attributed to the environment and supportive staff. Discuss the codes and categories that had emerged. She thinks that gaining confidence was important for her daughter, and wonders whether she overprotected her as a child.

18/6/98

Am writing the draft results section, and notice how between clients and family members I am still labelling similar experiences for families and clients in different ways.

However, am also struck by how similar the process is from both perspectives, and am excited by the strong themes about development of a sense of self.

23/6/98

Reflect upon the whole process of the research. Feel that I have learnt as much from this research as from my elective placement in rehab. I feel I have gained a lot of 'insight' into the clients world and that of their family, and the stuff on sense of self seems central to the process. Wonder how medication enables clients to feel more cohesive? Discuss this with Tony who suggests the potential to do research with Clozaril on how it impacts on the clients subjective sense of self.

24/6/98

The last interview! Due to holiday arrangements relatives had been unable to meet earlier. However, the discussion is very interesting and parallels a lot of other relatives' experiences. When I discuss the findings with them they emphasise that psychiatric hospitals are not the optimal environment due to the chaos that abounds. Transcribe the tape and thankfully return the tape recorder!

26/6/98

Meet with Tony and discuss the results. Describe my tentative ideas about identity, adolescence and the self and attempt to also construct a model of relatives' experiences. However, as this was not the focus of the interviews the resultant theory is a bit thin and decide to stick with clients' experiences.

30/6/98

My friend helpfully agrees to do the inter-rater reliability study. This highlights how Clinical training influences the process of coding, although agreement is high.

3/7/98

Meet with Tony again and show him the model that is emerging from the data. Frantically writing discussion, amending introduction etc etc etc!



## APPENDIX 11

### LIST OF CODES AND CATEGORIES PRODUCED

This appendix summarises the codes and categories obtained from the narratives told by participants. The number in brackets refers to the number of participants who gave a response that could be included within that particular code and category. The structure follows that of the results section; four distinct time periods from the first psychotic episode until the present, with an expanded section on current functioning to address the thoughts on services and professionals, views on causal factors, and perceived impact of the experiences on sense of self and relationships.

### EVENTS PRECEEDING THE FIRST PSYCHOTIC EPISODE

<b>CLIENTS</b>	<b>RELATIVES</b>
<b>Previous character (9)</b>	<b>Previous character (8)</b>
Being normal (3)	Being good (4)
Having relationships with opposite sex (2)	Being friendly (2)
Wanting to be different (1)	Hyperactivity (2)
Being religious (3)	
	<b>Difficult relationships (5)</b>
<b>Feeling unhappy (6)</b>	With family members (2)
Low self esteem (2)	With girlfriend/boyfriend (2)
Unhappy with situation (4)	With peers (1)
<b>Loss or change in social network (3)</b>	<b>Too many demands (2)</b>
Marriage of close friend (1)	Academic (1)
Redundancy (1)	Situational (2)
Death (1)	
	<b>Change in character (6)</b>
<b>Difficult relationships (1)</b>	Challenging boundaries (3)
With girlfriend/boyfriend (1)	Change in self (2)
	Low self-esteem (1)
<b>Drug taking (2)</b>	
	<b>Anxiety (3)</b>
	Somatic symptoms (2)
	Obsessions and compulsions (1)
	<b>Change in brain functioning (1)</b>
	<b>Parental love and protection (6)</b>
	Willingness to give (3)
	Worrying (1)
	Advising on relationships (2)
	<b>The family foundation (1)</b>

## EVENTS AT THE TIME OF THE FIRST PSYCHOTIC EPISODE

### CLIENTS

**Perceptual changes (6)**  
Hearing voices (3)  
Religious experiences (3)

**Endings (3)**  
Of the world (2)  
Of self (1)

**Aggression (3)**  
From others (1)  
To property (1)  
Verbal (1)

**Avoidance (2)**  
Of others (2)

**Emotions (6)**  
Fear of others (1)  
Fearful of experience (2)  
Feeling watched (1)  
Feeling calmer (1)  
Feeling special (1)

**Others reponses (4)**  
Offers of help (1)  
Lack of understanding (1)  
Being sent away (1)  
Perceived as different (1)

### RELATIVES

**Behavioural change**  
Hearing voices (5)  
Feeling persecuted (2)  
Recognition changes (2)  
Behavioural change (2)

**Observably ill**  
Looking white (3)  
Unrecognisable (1)  
Shaking (1)

**Avoidance**  
Of professionals (1)  
Of other people (3)  
Of treatments (1)

**Professional involvement**  
GP (2)  
urgency (2)  
Police (1)  
Neurology (1)  
Prision service (2)

**Initial attributions**  
stupidity (1)  
trying to impress (1)  
being lazy (1)  
testing boudaries (2)

**Emotions**  
Fearful for the person (5)  
Fearful of the person (3)  
Despondency (3)  
Guilt (1)  
Love (1)

**The process**  
gradual onset (1)  
Lack of understanding/knowledge (6)  
Immersion (3)

## EVENTS AT THE TIME OF ADMISSION

### **CLIENTS**

#### **Subjective experience (4)**

Feeling ill (2)  
Mental struggle (2)

#### **Process of admission (6)**

Voluntary (2)  
Involuntary (4)

#### **Emotions when admitted (10)**

Fear (2)  
Upset (3)  
Confusion (3)  
Anger (1)  
Feeling distant (1)

#### **Experiences of hospital (3)**

Distress of others (1)  
Unsafe (1)  
Medication (1)

#### **Explanations received (10)**

Medical (3)  
In terms of symptoms (3)  
Diffuse explanations (2)  
Worked out by self (2)

### **RELATIVES**

#### **Positive staff involvement (4)**

Containing (3)  
Hopefulness (1)  
Compassion (1)

#### **Negative staff involvement (8)**

Lack of support (3)  
Incompetence (2)  
Hopelessness (1)  
Asking intrusive questions (1)  
Not listening (2)  
Lack of choice (1)

#### **Explanations received (5)**

Medical (1)  
Blaming the family (1)  
Lack of explanation (4)

#### **Disagreement with advice (4)**

#### **Their emotions (4)**

Distress (3)  
Depression (1)

#### **Reflections on client's behaviour (3)**

Avoiding the family (1)  
In another world (1)  
Not themselves (1)

#### **Questioning benefits of treatments (3)**

Medication (2)  
ECT (1)



## CURRENT SITUATION

### The impact on life

#### CLIENTS

**Disability (12)**  
Loss (2)  
Making a new start (2)  
Having to make an effort (3)  
Frustration (2)  
Impact on life opportunities (3)

**Experience of symptoms (10)**  
Feeling confused by voices (3)  
Change to more positive voices (2)  
Negative voices (1)  
Constancy (1)  
Fluctuation (1)  
Uniqueness (2)

#### RELATIVES

**Thoughts about clients' ability to control behaviour (8)**  
Unpredictable (1)  
Uncontrollable (2)  
Controllable (2)  
Uses illness for own gain (2)  
Projection (1)

**Thoughts about impact on attention (5)**  
Thinking too much (1)  
Being distracted (3)  
Forgetfulness (1)

**Observably anxious (3)**  
Pacing (2)  
Sleep disturbance (1)

**The balance between protection and autonomy (3)**  
Acceptance of dependency needs (1)  
Need for protection (2)

## Current emotions

### CLIENTS

**Relief (8)**  
Relief; things could have been worse (3)  
Relief at getting better (5)  
**Calm (2)**  
About the prospect of death (2)

### RELATIVES

#### Own emotions

**Sadness (5)**  
Regret (4)  
Loss (1)  
**Anger (8)**  
Anger at client (3)  
Anger at authorities (1)  
Frustration (3)  
At being blamed (1)  
**Fear (1)**  
of relapse (1)

**Resignation (3)**

#### Perception of client emotions

**Sadness (3)**  
**Fear (1)**  
**Loneliness (3)**  
**Constancy (1)**  
**Suspicion (1)**

## Thoughts on services and professional support

### CLIENTS

**Positive staff involvement (4)**  
Friendliness (2)  
Understanding (1)  
Reassurance (1)

**Negative staff involvement (2)**  
Untrustworthy due to power imbalance (1)  
Unrelaxed (1)

**Different realities (6)**  
Questioning label (3)  
Questioning value of advice (2)  
Not being believed (1)

### RELATIVES

**Positive staff involvement (4)**  
Practice (3)  
Advice (1)

**Medication (7)**  
Benefits of (4)  
Side effects (2)  
Dependent upon (1)

**Help of voluntary groups (1)**  
**Community care (1)**  
**Suggestions (2)**  
More support for relatives (1)  
More consultation (1)

### Ways of coping

#### **CLIENTS**

**Medication (7)**  
Benefits of (4)  
Side effects (2)  
Dependent upon (1)

**Cognitive methods (3)**  
Distraction (2)  
Challenging thoughts (1)

#### **RELATIVES**

**Development of practical strategies (7)**  
Being honest (2)  
Calming techniques (1)  
Modifying own response (4)

**Ways of coping with own emotions (12)**  
Rationalising (4)  
Repression (3)  
Infantilising (1)  
Increase in self reliance (1)  
Talking to other parents (1)  
Religion (2)

### The impact of time

#### **CLIENTS**

**Increased understanding (2)**  
Of symptomatology (1)  
From family members (1)

**Better emotional coping (1)**

#### **RELATIVES**

**Increased understanding (7)**  
Of schizophrenia (3)  
Of the client (1)  
Continued difficulty with (2)  
Dawning realisation (1)

**Change in symptomatology (4)**  
Got better (2)  
Got worse (2)

**Development of negative family relationships (1)**



## Why they think it happened to them

### CLIENTS

**Predisposition (1)**  
**Birth (1)**  
**Childhood factors (2)**  
Illness (1)  
Childhood foundation (1)  
**Adolescent factors (10)**  
Being bad (3)  
External pressure (1)  
Taking drugs (2)  
Not recognising inter-relationships (1)  
Death (1)  
Strong emotions (2)

**Not knowing (2)**

### RELATIVES

**Fate/chance (4)**  
**Predisposition (5)**  
Dormant factors (2)  
DNA (1)  
'Eccentric' relatives (2)  
**Premorbid personality (7)**  
Sensitive (4)  
A worrier (2)  
Inflexible (1)

**Antenatal (2)**  
Virus (1)  
Trauma at conception (1)

**Trauma at birth (1)**

**Childhood factors (13)**  
Injections (2)  
Epilepsy (1)  
Head injury (1)  
Virus (1)  
Attention problems (1)  
Questions about parenting (3)  
Disrupted education (1)  
Lack of social network (3)

**Adolescent factors (11)**  
Taking drugs (3)  
Menstruation (1)  
General adolescence (1)  
Work (1)  
Sexual activity (1)  
Change in location (1)  
Change in social network (2)  
Change in brain chemistry (1)

**Multiple factors (3)**  
**Badness is illness (1)**  
**Continued to question (1)**

### Impact on sense of self

#### CLIENTS

Developing the self (7)  
Forming an identity (3)  
Growing older (3)  
Separating from parents (1)

#### RELATIVES

Duality (4)

Change in observable functioning (9)  
Dependency (2)  
Lost social skills (1)  
Different personality (2)  
Lost self-esteem (2)  
Gained self-esteem (2)

Coming through (4)  
Uncertainty (1)  
Separation (2)  
Guilt (1)  
Need for client to develop own identity (3)

### Change in relationships with other people

#### CLIENTS

Loss of friends (3)

Reasons for avoidance (6)  
Hard to communicate (2)  
Hard to have relationships (1)  
Stigma (2)  
Effort involved in making new friends (1)

Better relationships with others (6)  
Mother (4)  
Others (2)

Importance of relationships (4)  
In defining oneself (3)  
Issues of loneliness (3)

#### RELATIVES

Separate from society (8)  
Avoidance by client (1)  
Avoidance by others (4)  
Segregation (3)

Treated differently (6)  
Blamed more (3)  
Stigma (2)  
Conversation censored (1)

Positives (6)  
Accepted (3)  
Not a visible disability (2)  
Tolerance by others (1)

Hopes for future intimate relationships (2)