

**Living with life limiting conditions:
A participatory study of people's
experiences and needs**

A thesis submitted for the degree of Doctor of Philosophy

by

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Abstract

This thesis is focused upon experiences of living with life limiting conditions. It aimed to gain accounts from people who, potentially, had palliative care needs, to highlight a range of experiences of their lives and conditions and to identify what these service user needs might be. Establishing any contribution of involving service users in the research and any social or environmental factors that may shape or influence experiences of living with a life limiting condition were further aims. To this end it was pertinent to consider if the social model of disability could contribute new perspectives to palliative care research.

This qualitative research utilised a participatory approach. Service users were intrinsically involved in the research within the Service User Research Advisory Group (SURAG). My separate study group comprised of twenty-five participants, sixteen women and nine men, aged thirty eight to eighty five years. Fourteen participants had a cancer diagnosis, ten had non-cancer conditions and one participant had both cancer and another non-cancer condition. Ten participants took part in individual face-to-face interviews, twelve in small discussion groups and three were studied purely in a period of participant observation. Thematic analysis was conducted collectively with SURAG members and identified eight different but interconnected themes.

Themes of diagnosis, fear, anger/frustration, grief, relationships, services, difference/individuality and independence/dependence were identified. As well as being a distinct theme in its own right, independent/dependent was in fact a central and overarching theme with a negotiation between independence and dependence being evident across all themes. The theme of services is presented as a theme in its own right. The participatory approach revealed themes unlikely to have been identified by myself as a sole researcher. It also led to service user outcomes being identified and largely positive appraisals of their involvement in the research.

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Acronyms

COPD	Chronic Obstructive Pulmonary Disease is an umbrella term for a number of conditions, including chronic bronchitis and emphysema, all of which make it harder to breathe.
CVA	Cerebral Vascular Accident is the term widely used to explain the event of a blood vessel in the brain bursting, and is also referred to as stroke.
DH	The Department of Health is a Government organisation with responsibility to help improve the health and well being of everyone in England.
DRC	The Disability Rights Commission is an independent body established Act of Parliament to stop discrimination and promote equality of opportunity for disabled people.
GP	General Practitioners are doctors who are not specialists but rather treat all illnesses and are based in the community.
HIV+	Human Immunodeficiency Virus attacks the body's immune system.
LREC	Local Research Ethics Committees are independent of researchers and research funders. They have responsibility for safeguarding the rights, dignity and welfare of people participating in research in the NHS.
ME	Myalgic Encephalomyelitis , also referred to as Chronic Fatigue Syndrome (CFS) , is a complex condition characterised by the symptom of chronic and severe fatigue of unexplained cause.
MND	Motor Neurone Disease is a progressive disease that attacks the upper and lower motor neurones. This leads to weakness and wasting of muscles, causing increasing loss of mobility in the limbs, and difficulties

	with speech, swallowing and breathing.
MS	Multiple Sclerosis is a condition of the central nervous system.
NCPC	National Council for Palliative Care is an independent umbrella organisation for all involved in providing, commissioning and using hospice and palliative care services in England, Wales & Northern Ireland. It promotes the extension and improvement of palliative care services regardless of diagnosis in all health and social care settings and across all sectors to government, national and local policy makers.
NHS	The National Health Service is the publicly financed healthcare system of the UK. It provides the majority of healthcare from general practitioners to accident and emergency departments, long-term healthcare and dentistry.
NICE	The National Institute for Clinical Excellence is an independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health (N.B. Recently renamed National Institute for Health and Clinical Excellence).
NSF	National Service Frameworks are long term strategies for improving specific areas of care. They set national standards and measurable goals within set time frames.
SMD	The Social Model of Disability focuses on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of physical, or other, impairment. The barriers disabled people encounter may include discriminatory health and social support services and the devaluing of disabled people through negative public views.

SURAG	The Service User Research Advisory Group consisted of service users who contributed at all stages of this research project.
UPIAS	The Union of the Physically Impaired Against Segregation was founded in 1972 and has been described as the first disability liberation group in the UK.
WHO	The World Health Organization is the United Nations specialized agency for health. WHO's objective is the attainment by all peoples of the highest possible level of health.

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Authors declaration

I hereby declare that this thesis has not been submitted, either in the same or different form, to this or any other university for a degree.

Signature:..........

Introduction

This thesis has as its focus the accounts and insights of service users with life limiting conditions. This concerns what they need and experience from palliative care and draws on research conducted in one locality in the South of England. The influence of social and environmental factors that shape the experience of living with a life limiting condition is also a part of this focus. The research is based on direct accounts from service users with a range of life limiting conditions and in addition has, as an important and integral part of this, sought to involve a separate group of service users in an advisory capacity within the research process. This Service User Research Advisory Group (SURAG) was formed to both ensure the research stayed in tune with service user concerns, and to ensure the final research outcomes were framed with service user insights clearly to the fore. The SURAG has been intrinsic to the research and has been particularly influential in the data analysis stage of this project.

Palliative care is the field that adds context to this research into life limiting conditions. Whilst much is known about the range of palliative care services available and the need for palliative care services to accommodate service users with conditions other than cancer (Addington-Hall et al, 1998; O'Brien et al, 1998; Field & Addington-Hall, 1999; Addington-Hall, in Payne et al, 2004:94; Murray et al, 2005), there has been far less emphasis upon accessing the views of service users themselves other than in satisfaction type surveys (Fakhoury, 1998; Wilkinson in Bosanquet & Salisbury, 1999:97; Payne et al, 2005:52). There has though, been some focus on service users' needs but this has again been orientated to evaluating existing services (Higginson et al, 1990; Field et al, 1995; Beaver et al, 1999a; Raynes et al, 2000; Seymour et al, 2003).

As there is an awareness that service users with non-cancer conditions require access to some palliative care services, as referred to above, it is important to understand the similarities and differences in experiences and needs between service users with a range of life limiting conditions. Such an understanding may assist in the planning and provision of appropriate services which, to date, have been orientated primarily to service users with a cancer diagnosis. This thesis is attempting to establish if the

experiences of service users with non-cancer conditions are characterised by concerns and needs shared by service users with cancer. Allied to this is whether these service users therefore require access to comparable palliative services and support currently provided mainly for service users with cancer. There is then, a clear comparative element within this thesis.

Having a mixed sample of participants with a range of conditions was an unusual approach in this research, but an approach designed to facilitate insights to the experiences and complexities faced by a wide range of service users in their everyday lives. I also wanted to be open to service user definitions of 'life limiting' as opposed to professionalized definitions in order to be as inclusive as possible. A life limiting condition is conventionally considered to be one where a cure for the condition is not available and normal life expectancy is not thought to be likely. Palliative care however has evolved from primarily focusing upon those who are imminently approaching death to offering input at various stages of an individual's condition. This change has mainly occurred as treatment for many cancers has improved and greater numbers survive. There is now far greater attention to the experiences and needs of survivors of cancer with an ambiguity surrounding what condition may now be considered life limiting.

The research presented in this thesis originated from the practice setting as unanswered questions arose from my experience of working with service users with advanced cancer in a hospice. It was whilst working as a nurse specialist based in a hospice, but working with service users in their own homes as well as nursing and residential homes, that I became aware of the differences in needs, experiences and palliative care service provision between service users with a cancer diagnosis and service users with other serious conditions. I was also aware that service users with non-cancer conditions often raised very similar problems and issues to people with cancer. As I worked with service users over a period of time in which a significant relationship would often be built, I also became aware of the need for some service users to 'have a say' or to be involved to a greater extent in voicing their needs and shaping the things which affected their lives. For some this would mean a greater involvement in the planning and delivery of services that they needed to receive.

My recent professional and clinical experience had been mainly orientated to service users with cancer but previously had been quite varied with experience gained in working with older service users, service users with mental health issues and a range of medical conditions. My interest in conditions other than cancer as part of this research was generated by my previous experience and also by a raised awareness of the palliative care issues faced by these service users brought about by reading (Field & Addington-Hall, 1999; Ahmed et al, 2004; Murray et al, 2005) and hearing of the issues at conferences.

The focus on service user involvement in research equally originated in practice, as outlined above, and also from hearing of the ideas and possibilities during attendance at one conference in particular. Interestingly this was not a palliative care conference and service user involvement was discussed generally, however this led me to consider the relevance of service user involvement to palliative care and to research.

When I first started thinking about the involvement of service users in the research it felt like a revelation and I saw this involvement as fitting with certain principles inherent to palliative care. The philosophy underpinning palliative care has developed along the lines of ensuring a partnership approach between service user, carer and professionals (Faull, in Faull et al, 1998:3). Tenets of mutual respect, honesty, listening, agreeing priorities and goals and a discussion of options are inherent in this philosophy (Twycross, 1995:4). Cicely Saunders was a widely acknowledged leader in the development of hospice and palliative care in the United Kingdom (UK) and her original aims were not only ‘...to be a voice for the voiceless...’, but also to ‘...enable people who were facing the end of their lives...to speak to people outside...’ (Oliviere, 2000:103). Building on from this, the philosophy may be seen not only as a way of listening and learning from service users, but also as a call for engagement with and being led by service users. Indeed, Cicely Saunders’ inspirational encounter with David Tasma, a dying man she met in her role of hospital almoner, was an example of action developing from practice (Du Boulay, 1984:57). It was this relationship, in which service user and professional were able to see the need for improvements in care for people with life limiting conditions and how they could go about changing attitudes and practice, which was one of the precursors to the inception of the modern hospice movement.

Despite this apparent 'fit' to palliative care philosophy, there has been a great deal of scepticism and caution regarding the development of service user involvement initiatives in palliative care practice and research (Small & Rhodes, 2000; Payne, 2002; Gott in Payne et al, 2004:80; Payne et al, 2005). In light of this caution, the service user involvement in this research and the participatory methodology was an unusual approach to take. It sought to establish if some service users with palliative needs are able to, and want the opportunity to have a greater influence in palliative care research. I wanted to try and establish if different outcomes would be forthcoming from this involvement of service users than if the research was conducted conventionally. This was attempted by comparing the experience of involvement in this research with existing literature.

As the influence of social and environmental factors upon the experience of living with life limiting conditions was an important facet of this research, connections were made to the social model of disability. In applying this model the contention is that there are societal impacts that disempower people who have palliative care needs further than their physical impairments. This thesis questions if there is any relevance and usefulness in applying the social model of disability to palliative care. This connection was also an unusual approach to take within palliative care research and will be returned to later in the thesis.

Involvement of service users in the research was achieved via the Service User Research Advisory Group referred to above. The group was actively involved at all stages of the research process and its purpose was clarified in the groups Terms of Reference document (annex D):

“The group was established in November 2002 to share with the researcher the knowledge and experiences of people living with life limiting conditions. To ensure that it remains in tune with their concerns and needs it aims to enable group members to influence the research at all stages of the research process.

The group is not a support group, pressure group or a representative body for people with life limiting conditions but rather an advisory group to

give advice and direction to this research project. Group members will have influence on the outcomes of the research i.e. in terms of action or change supported by the findings of this research”

The SURAG has contributed widely to this research from the reshaping of interview questions, through to the advice given on sensitive data collection, assistance with teaching and importantly, the co-interpretation of data and generation of findings. These contributions are presented in this thesis and in a published account (Cotterell et al, 2006).

Research aims

The aims of the research have been to gain the perceptions of service users with life limiting conditions about the palliative care or other services they receive locally and to establish if it is felt that their palliative care needs have been met. It also sought to capture a picture of life for these service users living with life limiting conditions including any effect on their relationships or of any social influences on their lives. In summary, the aims of this research have been to:

- Gain accounts from people who, potentially, have palliative care needs and to highlight a range of experiences regarding their lives and conditions.
- Establish what service user needs are in terms of support and care services.
- Establish the influence of involving service users in palliative care research, whether there can be a contribution and if so what this may be.
- Highlight any social or environmental factors that may shape or influence experiences of living with a life limiting condition, including whether the social model of disability can contribute anything to palliative care research.

An associated element in this research has been the intention to enable a comparison to be made regarding the first two aims between service users with cancer and service users with other non-cancer, but life limiting conditions.

Structure and content of the thesis

There are then three central elements in my thesis. The first element involves the differing, and similar experiences, of living with a life limiting condition for participants with non-cancer conditions and those with cancer. The second element is the issue of service user involvement and specifically whether service user involvement in palliative care research can be successful. Of particular interest is the nature of this involvement, the process and distinctive outcomes. The third element implicit in this thesis is the perspective offered by utilisation of the social model of disability to this research in the realm of palliative care.

To this end Chapter 1, literature review, examines some of the concepts in these three areas that I draw upon later in the thesis. The traditional remit of palliative care in the UK is highlighted along with challenges to this. It is illustrated how evolving understandings of long-term conditions are contributing to this challenge. I consider the development of service user involvement generally, its ideological base, and go on to examine service user involvement in research along with the scepticism about this involvement in the field of palliative care. This chapter concludes with an examination of the social model of disability and possible connections to palliative care. Chapter 2 addresses underpinning epistemological assumptions, methodological decisions, chosen methods and issues of rigour. This chapter documents the 'doing' of the research, what happened, when and why? The nature of the participatory approach taken is described here along with information about the participants, how data was collected and the collective analysis phase.

Findings are presented in chapters 3 and 4. In Chapter 3 seven different but inter-connecting themes are presented in turn. Three of these themes are directly concerned with emotional aspects of living with life limiting conditions, the reaction to both diagnosis and others' reactions to one self. The impact of diagnosis and changing relationships is described here. How participants strove to maintain a familiar sense of themselves is presented along with challenges to, and attempts to maintain independence. The eighth theme is presented separately in Chapter 4 due to its size and because this theme relates to a separate aim of the research. This chapter and theme describes participants' experience of services. This includes health, social care, private and independent services i.e. hospice services. Participants raised issues

concerned with both actual services and the relationships with staff within these services.

Chapter 5 discusses the research and draws the thesis to a conclusion. Here I draw out key issues that were identified in the findings and place these in the relevant field of inquiry. How this research, with its participatory methodology, and its findings compares to other previous research is discussed here. I consider the challenges and benefits of involving service users within the research process and in particular I consider the collective analysis phase of the research with the differences in interpretation between the SURAG and myself. Finally, in conclusion I reiterate the central concerns and contributions raised in my thesis.

Chapter 1 – Literature Review

1.1 Introduction

This chapter provides an opportunity to consider the concepts and debates that underpin this thesis as well as to clarify the need for the research that it is based upon. In this introduction I begin with a consideration of palliative and hospice care in order to set the scene. In section 1.2 this will be extended to focus on the remit of palliative and hospice care. This will be in terms of the scope of palliative care provision amongst all life-limiting conditions. This section will also consider how understandings of palliative care are changing. Finally, other research conducted with people with similar conditions to those in this research will be highlighted and critically evaluated. Service user involvement has been intrinsic in this research and therefore in section 1.3 a consideration of service user involvement generally will take place. Section 1.4 takes service user involvement further by focusing specifically on involvement in research. Various strategies for the involvement of service users in research will be considered. The final section of this chapter, section 1.5, is concerned with the social model of disability, as this also has been an implicit influence in the development and ongoing completion of this research. The structure of the chapter is displayed in table 1.1.

Table 1.1: Literature review chapter sections

SECTION	TITLE
1.1	Introduction
1.2	Experiencing life limiting conditions
1.3	Service user involvement
1.4	Service user involvement in research
1.5	Social model of disability
1.6	Chapter conclusion

1.1.1 Context: palliative and hospice services

Palliative care is a term that indicates the relief of suffering when curing is no longer an option. The word palliative is derived from the Latin word *palliatus* meaning ‘to cloak’ or ‘to conceal’. In its broadest understanding the central tenet of palliative care is to alleviate or lessen suffering. As perceptions about death and dying have altered over the last several decades so to have terms associated with death, dying and the services provided to support people who are dying. There has been a shift from ‘terminal care’ with its perceived emphasis on care at the time of death or just preceding death towards palliative care with its separate distinctions of ‘the palliative care approach’, ‘specialist palliative care’, ‘palliative medicine’ and more recently ‘supportive care’. It will be useful to define these differing terms.

The National Council for Palliative Care (NCPC) (formerly National Council for Hospice and Specialist Palliative Care Services (NCHSPCS)) has described supportive care as a type of care that:

...helps the patient and their family to cope with their condition and treatment of it - from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.

(NCHSPCS, 2002)

Further to this, supportive care encompasses self help and support; user involvement; information giving; psychological support; social support; rehabilitation; complementary therapies; spiritual support; end of life and bereavement (NICE, 2004a:18). Palliative care is a part of supportive care and is an approach that involves:

...the holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative

care are also applicable earlier in the course of the illness in conjunction with other treatments.

(WHO, 2002)

Principles of palliative care include aims to; provide relief from pain and other distressing symptoms; integrate the psychological and spiritual aspects of patient care; offer a support system to help patients live as actively as possible until death and to help the family to cope during the patient's illness and in their own bereavement; be applied early in the course of illness in conjunction with other therapies intended to prolong life (such as chemotherapy or radiation therapy) (NICE, 2004a:20).

Specialist palliative care services have been described as those services, which have the delivery of palliative care as their core aim. A multidisciplinary palliative care team, consisting of a range of professional staff that has received specialist training, will typically provide these services. Staff will consist of palliative medicine consultants; palliative care nurse specialists, social workers, physiotherapists and occupational therapists among others (NICE, 2004a: 127).

Specialist palliative care will include assessment, advice and care for patients and families in all care settings, including hospitals and care homes and specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams. Intensive co-ordinated home support for patients with complex needs who wish to stay at home is part of the remit. This may involve the specialist palliative care service providing specialist advice alongside the patient's own doctor and district nurse to enable someone to stay in their own home. Many teams also now provide extended specialist palliative nursing, medical, social and emotional support and care in the patient's home, often known as 'hospice at home'. Day care facilities that offer a range of opportunities for assessment and review of patients' needs and enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship forms part of specialist palliative care provision. It also is concerned with advising and supporting all the people involved in a patient's care as well as providing bereavement support services and education and training in palliative care (NCPC, 2005a).

Palliative medicine was established as a discrete specialty by the Royal College of Physicians in 1987 and refers to the practice and study of palliative care made by doctors (Clark & Seymour, 1999:86). This development was not embraced fully by some supporters of hospice and palliative care with fears of a medicalization of dying and a shift from the holistic ethos held dear by many (Biswas, in Clark, 1993:133).

As an organised field of care and support, palliative care has its origins in developments about 40 years ago with work instigated by Cicely Saunders who was the driving force of what is known as ‘the modern hospice movement’. Her endeavours resulted in the establishment of St. Christopher’s Hospice in London in 1967. The concept of ‘hospice’ has however existed for many years prior to these relatively recent developments and records illustrate the existence of hospices in the 19th Century although these were primarily assisting not only people close to the end of life but also people in poverty (For interest see <http://www.helpthehospices.org.uk/hospicecare/index.asp?submenu=3> or <http://www.eolc-observatory.net/>).

The development of modern hospices and the provision of palliative care are synonymous with aiming to both improve the care and treatment offered to dying people and their families as well as understandings about death and dying. Taking a global perspective, the provision of basic palliative care has been said to be applicable to and of potential benefit to 100 million people worldwide and that, despite hospice or palliative care services being available in every continent in around 100 different countries, palliative care is reaching only a small minority of those who need it (Help The Hospices, 2005a). In an attempt to pressurise governments world wide a so called ‘Korea Declaration’ was announced at the 2nd Global Summit on hospice and palliative care which, among other things, called for governments to make access to hospice and palliative care a human right and to include hospice and palliative care in the management of progressive life threatening diseases not purely cancer (Help The Hospices, 2005b).

1.2 Experiencing life limiting conditions

This section will focus on the relationship between palliative care generally and hospices specifically with regard to non-cancer conditions (section 1.2.1) and further, it will consider evolving understandings of how non-cancer and chronic conditions are viewed in both practice and policy (section 1.2.2). In section 1.2.3 other research that has also focused on the conditions in the research presented in this thesis will be considered. One of the drivers of this project was to find out what the normal experience of living with a life limiting condition is and what people need from palliative care services. Research conducted in this field is relevant then in order to facilitate placement of the research in this thesis.

As described previously in the introduction to this thesis, I wanted to ensure a wide range of life limiting conditions were included in the research. To that end participants included people with cancer: chronic obstructive pulmonary disease (COPD), multiple sclerosis (MS), myalgic encephalomyelitis (ME), cerebral vascular accident (CVA), heart failure and human immunodeficiency virus positive (HIV+). It is clear that experiences between people with these conditions will consist of specific issues determined by the nature of particular conditions. However similarities are also clear with these conditions causing common symptoms and other shared issues. I was interested in these differences and similarities between participants with cancer and those with other non-cancer conditions.

That these non-cancer conditions can be described as life limiting conditions is a contested notion particularly for a condition such as ME (Known also as Chronic Fatigue Syndrome). In annex A, a brief summary of all the conditions participants in this research had, can be found. It is highlighted here that ME is a condition that people living with it have struggled to legitimate. It has been discredited as an actual physical condition (Wessely et al, 1998:129) and only recently has it been recognised as a condition in need of medical input. The participant in this research with ME identified herself as experiencing palliative care needs and requested to participate in the research.

Despite little in the literature suggesting that people with ME may require a palliative care service of any description there is evidence of the severity of the condition. In a recent survey of its members for example, the campaign group 'Action for ME' found that 89% of the sample reported being or having been severely affected by the condition. This involved being bed ridden or house bound. Just over 50% reported that they had felt suicidal because of their condition. The situation was worse for those who were the most seriously affected by the condition (Action for ME, 2001). Research involving thirty-three adults with chronic fatigue syndrome confirmed the severity of this condition for them and Anderson et al (2004) highlighted the severe, long-term functional impairment with little improvement over the five-year period of study. This data is based on an identical questionnaire survey at base line and at five years and included questions on quality of life as well as, at five years, a supplementary questionnaire focusing on differences in a wide range of areas. Taylor (2004) highlights that there is no cure for this condition and that the condition affects people in many domains including physical, psychological, social and economic. Others have previously identified the nature of this condition:

These physical, psychological, and social limitations, in conjunction with experiences of social stigma, public misunderstanding about chronic fatigue syndrome, and frequently strained relationships with health care providers, friends, and family members, have led individuals with chronic fatigue syndrome to report consistently low levels of quality of life.

(Anderson and Ferrans, 1997)

There are many ways of describing the different conditions that some people have. Malignant disease is associated with cancer and indicates that it cannot be controlled and that it has spread from the original site to other areas in the body. Non-malignant is a term used to describe conditions that are the opposite of malignant and normally intimates at the seriousness of a condition whilst making clear that the condition is not cancer related. The term non-cancer is also used at times to describe the same thing. Some conditions are known as chronic conditions indicating that the person with such a condition will live with it over some considerable time, normally the remainder of their lives. More recently the term long-term condition has become favourable and

both terms, chronic and long-term condition, can apply to people living with Asthma, Cancer, Cardiovascular Diseases, Chronic Obstructive Pulmonary Disease, Diabetes, Motor Neurone Disease, Multiple Sclerosis, a range of neurological conditions, Parkinson's Disease, and Stroke for example. Any of these conditions can progress to a stage where the person will experience many symptoms or other issues that might reasonably be considered, potentially, to be helped by a palliative care approach. This will be discussed below. Many of these conditions may also be reasonably considered to be life limiting at later stages of the conditions, in that the normal life expectancy of the person is thought to be less than for a person without that condition (Brønnum-Hansen et al, 2004; Sadovnick et al, 1992; Gore et al, 2000).

There has been a debate about the place that hospices and palliative care services have in including people with conditions other than cancer in their remit. This debate has been gathering pace in recent years but despite this, and some policy led recommendations, there has been little change in the practice of hospices with regard including people with non-cancer conditions in their remit. It has been discussed that there is now a challenge to this focus on the diagnosis of cancer within palliative care and it is suggested that funding, difficulty in making an accurate prognosis, education needs of professionals, and limited acceptability of palliative care to people with conditions other than cancer, are all reasons for the slow change in service provision (Addington-Hall, in Payne et al, 2004:94).

1.2.1 Palliative care and non-cancer conditions

The development of the modern hospice movement in the UK has primarily been focused on care for people with the diagnosis of cancer. Indeed this situation has been changing only minimally with latest data suggesting that only 5.3% of new hospice patients in England, Wales and Northern Ireland in the year 2003/2004 had conditions other than cancer (NCPC, 2005b). This association with people who have a diagnosis of cancer was originally due in part to the observed lack of effective ways of dealing with physical pain and other symptoms as well as the social isolation facing dying people (Clark & Seymour, 1999:72). The pioneers of the modern hospice movement particularly noted the ineffectiveness of pain control for example, for people with cancer, and hence this original focus. As hospice and palliative care services evolved, these same pioneers acknowledged the need for the principles and expertise of

palliative care to be extended to people with other non-cancer conditions (Saunders, 1978; Saunders & Baines, 1983). However they suggested it is the person's existing providers of care who should offer this and not necessarily hospices or palliative care services as they stood at this time. Currently, it is acknowledged that only a minority of people receive palliative care services and that the challenge is to enable the expansion of palliative care to all patients with a life-threatening illness (Clark et al, 2005:188; Costello, 2005). As previously, this acknowledgement of the need for palliative care to be available for all no matter diagnosis, has failed to move beyond rhetoric and onto action being taken to redress the imbalance of palliative and hospice provision of services.

It is clear that in terms of policy and rhetoric there is a greater acceptance in palliative care of the need to address the needs of all people with life limiting conditions. However it is also clear that the reality is quite different as highlighted by the data referred to above. One third of the 5.3% non-cancer diagnosed people who accessed hospice and palliative care units were people with conditions of the nervous system (i.e. Motor Neurone Disease and Multiple Sclerosis) and another one third were people with heart conditions or who had had a stroke (NCPC, 2005b). It is anticipated that as people live longer they will live longer with chronic life-limiting conditions (NCPC, 2005c). In order to plan and develop services and provision that includes people with non-cancer diagnoses National Council has recently established policy groups that recognise unmet need exists and which aim to extend palliative care services for people with non-cancer conditions (NCPC, 2005d). Within this rhetoric however lies a waiver that suggests palliative care '*may* already be being delivered as integral parts of other services and referred to by another name' (My emphasis. NCPC, 2005d).

There is now much evidence of these unmet palliative care needs for people with advanced non-cancer conditions (Bosanquet, 1997; Addington-Hall et al, 1998; O'Brien et al, 1998; Dicks, 1999; Field & Addington-Hall, 1999; Kite et al, 1999; Luddington et al, 2001; Ahmed et al, 2004; Murtagh et al, 2004; Murray et al, 2005). Dame Cicely Saunders recently accepted the similar needs of people with these non-cancer conditions (Saunders, 2000). In a review of Health Improvement plans (HImps) it was highlighted that 'there is substantial evidence to suggest that palliative

care provision in England is dependent upon diagnosis rather than need' and that palliative care for non-cancer patients is 'perceived as an 'optional extra' by many health authorities' (Seymour et al, 2002). Further to this, an analysis of policy documents in palliative care identified the pitfall of palliative care and cancer being seen as synonymous, with this symbiotic relationship leading to the 'access difficulties experienced by patients with palliative care needs arising from other diseases' (Matthew et al, 2003).

There are now service developments being advanced to both clarify the needs of people with non-malignant conditions and to investigate palliative care models of working with these different groups of people. The Multiple Sclerosis Society for example has forged links with Kings College London to develop and evaluate a palliative care service for people with multiple sclerosis. This collaborative initiative hopes to identify the areas of palliative care need for people with multiple sclerosis and to identify an effective model of good practice. St. Peter's Hospice in Bristol is developing an approach that includes people with motor neurone disease and other neurological conditions within their remit. The hospice workforce is building up experience and skills in dealing with neurological deterioration. Another hospice, The Joseph Weld Hospice in Dorchester, are involved in an initiative whereby a local consultant neurologist, the hospice palliative care consultant and a palliative care nurse work jointly in a hospice based clinic every three months. The extension of existing service configurations is also taking place internationally. There is evidence of success of a collaborative approach between palliative and medical specialists in an acute hospital setting in Australia in maximising symptom relief and end of life care for people with heart failure (Davidson et al, 2004). There is also evidence that the situation is quite different in America where '15-20% of hospice inpatients had heart failure' (House of Commons Health Committee, 2004:25).

These initiatives are encouraging but infrequent and especially surprising when, several years ago, The National Council for Palliative Care both identified the potential for 'considerable distress in the final months of life' for people with non-malignant conditions, and recommended that 'hospices and specialist palliative care services should recognise that they have a role to play in the care of patients dying from non-malignant diseases' (National Council for Hospice and Specialist Palliative

Care Services, 1998). More recently the Scottish Partnership for Palliative Care brought together evidence from differing disease perspectives in a conference that identified unmet need for people with non-malignant conditions and, as for The National Council for Palliative Care previously, challenged palliative care to make itself ‘truly available to all and to move away from the traditional emphasis on cancer’ (Scottish Partnership for Palliative Care, 2001).

The issue of providing palliative care to all on the basis of need rather than diagnosis has been kept to the fore with recent policy debate and guidance following the House of Commons Health Committee report on palliative care and the Government response in 2004. The Health Committee report recommended the Government undertake a needs analysis of people with non-cancer diagnoses requiring palliative care and highlighted the inequity in service provision between people with cancer and those with non-cancer conditions (House of Commons Health Committee, 2004). The Government response, via the Department of Health (DH), acknowledged the value of investigation into the needs of non-cancer palliative care patients, recognised that ‘...a great deal remains to be done to deliver equitable services...to all who need them...’, but fell short of explaining how this would be achieved other than by saying this was a high priority for the Government (DH, 2004).

1.2.2 Evolving understandings

Whilst there appears to be greater evidence and acceptance of the unmet palliative care needs for some people with non-cancer conditions there also appears to be some indecision about suitable action to take. Challenges for palliative care organisations and services such as hospices, community and hospital based palliative care teams seem to be around concerns of skills, funding, demand, and a variable disease trajectory in non-cancer conditions. Changing understandings of the needs of people with non-cancer conditions certainly appears to be forcing this issue on to the palliative care agenda. Perceived challenges remain however that relate to adapting the current model of palliative care provision to different disease groups than originally intended; acknowledging differences in needs and end of life issues between people with cancer and non-cancer conditions; acknowledging similarities in needs and end of life issues between people with cancer and non-cancer conditions; extending the research and evidence base, both empirical and experiential, regarding

models of service provision that accommodates the broad range of conditions that require palliative care services.

Research has begun into the needs and acceptable service realignments for people with non-cancer conditions with the College of Health, for example, undertaking a pilot study on this subject for people with diabetes and chronic obstructive pulmonary disease. This study identified several points but these were primarily concerned with improving equity of access to services; ensuring availability of treatment and advice by trained professionals; ensuring access to suitable information; and improving primary care services for people with non-cancer chronic conditions (College of Health, 2003). Interestingly in this study, comments by patients and carers identified clear needs for specialist support and advice on issues about their conditions and that this support and advice by professional specialists should be available to them in the context of their own homes in primary care. General practitioners, whilst being seen as professionals with good knowledge of them as a whole, were also considered to have a less than ideal knowledge of their particular condition. Within palliative care it is important to note that the role of local community palliative care teams is to offer specialist advice to patients, liaise with general practitioners and hospital specialists, and to offer current information to patients and their carers.

Organisations for people with long-term conditions are also driving the agenda forward with the Partnership on Long-Term Conditions launching its manifesto for change in 2004. This partnership brings together twenty national organisations including patients, managers and professionals and aims to ‘make the case for a better deal for the 17 million people in the UK living with long-term conditions’ (NHS Confederation, 2004). The range of conditions here includes cancer, stroke, diabetes and multiple sclerosis.

In March 2004 the then Health Secretary, John Reid, launched a programme to establish pilot case-management demonstration sites in which people with chronic conditions would receive co-ordinated patient centred care to promote well being and be enabled to receive care in their own homes (Reid, 2004). One of the motivations here appears to be for expensive hospital admissions to be reduced but also improved services seems to be an aim. Early outcomes appear to be promising but there does

not appear to have been any evaluation from service users themselves (Castlefields Health Centre, 2005). Initiatives such as this and also the Expert Patient Programme, Evercare programmes from America, and the End of Life Care programme from the UK's Modernisation Agency all appear to be grappling with ways in which to facilitate both improved ways of working for people with long-term and chronic conditions, and also ways to make care for these people cost effective in the long term.

The National Service Framework (NSF) for Long-term Conditions (DH, 2005a) has as its focus, improving the lives of people with long-term conditions. It is primarily concerned with people who have neurological conditions (i.e. Multiple Sclerosis, Motor Neurone Disease, Cerebral Palsy, and Parkinson's disease) but it readily accepts that many of its recommendations are transferable to other long-term conditions. This NSF has a 'Quality Requirement' for palliative care in which it outlines the importance of existing palliative care services to work with neurology services and for palliative care to be much more available to people with long-term conditions (DH, 2005a:52).

Understandings about the nature of long-term non-cancer conditions are evolving then, and the ways of providing a more satisfactory service for people with these conditions who have palliative care needs is now gradually being investigated. This is occurring on many different levels with the Government and policy makers contributing to this evolving understanding as well as service user groups and individuals and palliative care organisations themselves. There is now far greater acceptance that some people with non-cancer conditions will require palliative care input at some stage. Perceptions about long-term non-cancer conditions do seem to be changing. The Government appears to be relying on initiatives such as the Gold Standards Framework, The Liverpool Care Pathway for the Dying, and the Preferred Place of Care initiative to extend acceptable palliative care provision to people with all diagnoses. The Gold Standards Framework aims to maximise palliative care in the primary care setting and focuses on the last twelve months of life; The Liverpool Care Pathway for the Dying aims to maximise palliative care in hospitals and care homes within the last 72 hours of life; and the Preferred Place of Care initiative aims to enable people to organise their place of dying in advance. How a more equitable

palliative care service evolves and the satisfaction of this for all people whatever diagnosis will only become apparent over time.

1.2.3 Related research on experiences of life limiting conditions and palliative care

Research identified in this section has been conducted with people with similar conditions to those presented in this thesis. A discussion of particularly relevant research, to the issues raised in this thesis, will be undertaken in section 5.12.

Research from the King's Fund that focused on illness self-management in long-term conditions aimed to gain 'patient' expectations on this subject (Corben & Rosen, 2005). This project emphasised the importance of professionals listening and understanding patient's experience of their conditions as well as challenging the NHS to provide services that fit in with people's lives. Very little information was presented about methodology although findings were derived from relevant literature, interviews with nine people with different long-term conditions and an e-reference group of six people who worked in the area of long-term conditions.

A questionnaire survey was conducted with participants in receipt of palliative care services (mostly patients with a metastatic cancer diagnosis) and participants in receipt of services from a heart failure clinic (mostly patients with a diagnosis of end-stage heart failure) in order to identify their main concerns (Anderson et al, 2001). The questionnaires were developed by a steering group of professionals and the questionnaire consisted of problem orientated questions beginning with the patient's most troublesome problems, their range of problems and then the amount of help they required in activities of daily living. Other questions were about who dealt with their problems and how well these were dealt with and communication between professionals and the adequacy of support given to their carers.

Significant numbers of participants took part in the survey (213 palliative care patients & 66 heart failure patients) and a wide range of data was presented that was mostly focused on the frequency of reported problems along with comparisons between the two groups of participants. It was reported for example that the most troublesome problems for palliative care patients were pain (49%), loss of

independence (30%), and difficulty walking (27%). For patients with heart failure the most troublesome problems were dyspnoea (difficulty breathing, 55%), angina (32%), and tiredness (27%). There was a higher incidence of psychological problems reported for patients with palliative care needs, which are cancer patients in this survey. Action to relieve psychological and social problems was reported to be less in the heart failure group of patients though and palliative care patients had greater professional support. This study concluded that there was unmet need in patients with heart failure and stated that these patients would benefit from palliative care expertise (Anderson et al, 2001).

Other research has compared the challenges involved with meeting the needs of people with cancer and end-stage heart disease (Exley et al, 2005). This qualitative research conducted fifty interviews with patients or carers and also included the perspectives of community health professionals by way of a focus group. The authors concluded that ‘people dying with end-stage cardiorespiratory disease remain the ‘disadvantaged dying’, and that they were less likely to ‘bother’ their GP because of their instilled perception that there is ‘nothing more’ that can be done for them (Exley et al, 2005). It is important to note that in this research participants were drawn from two general practices that were considered to offer ‘good practice’ and to be committed to palliative care. They had well developed mechanisms to identify and support people with chronic conditions. Results may arguably illuminate greater issues for people with respiratory disease in practices less developed towards palliative care provision.

In research that compared the experiences and quality of life between fifty patients with lung cancer and fifty patients with Chronic Obstructive Pulmonary Disease (COPD), it was found that the patients with COPD ‘had symptoms of anxiety and depression to a significantly greater extent than the patients with NSCLC (Non Small Cell Lung Cancer)’ (Gore et al, 2000). The research hypothesised that patients with COPD had equally poor health and similar palliative care needs to the lung cancer sample. Quality of Life tools and semi-structured interviews were utilized in data collection. The study did not go into detail about the nature of the depression amongst COPD patients other than stating that ‘90% of patients with COPD had clinically relevant anxiety or depression’ (Gore et al, 2000). The whole sample was based on

participants over the age of sixty years and it would be interesting to compare these results to a younger sample.

In a research project involving interviews with bereaved carers whose partners had died from either lung cancer or chronic lung disease Edmonds et al (2001) have drawn attention to the differences in service provision between the two groups. Patients with lung cancer had been more likely to receive help from a district nurse and none of the chronic lung disease patients had received any help from a Macmillan or hospice nurse compared with nearly one third of patients with lung cancer having received such help. Treatment of breathlessness, a symptom common in both conditions, was more likely to be treated by a GP for patients with chronic lung disease which may suggest a lack of access to specialist services. This study also reported that more patients with chronic lung diseases needed help with self or personal care compared with patients with lung cancer and that they had this care provided by social services (Edmonds et al, 2001). Having highlighted some differences in service provision between the two groups the research went on to suggest that patients dying of chronic lung disease experience both physical and psychosocial distress at least as severe as patients with lung cancer (Edmonds et al, 2001).

Horne and Payne (2004) conducted semi-structured interviews with twenty patients with heart failure and utilised a grounded theory approach to data analysis. This study was not concerned with identifying the range of problems experienced or the number of problems encountered by participants but rather to identify issues and concerns from the perspectives of participants themselves. Three main themes were identified and seven sub themes. Horne and Payne (2004) highlight 'Can't do', 'Difficulties in Walking', and 'Relying on Others' as their main themes. It is clear that similar issues to those raised in this thesis, as will be seen in the findings chapters, were identified by Horne and Payne (2004). However these similar issues were subsumed in professionally orientated themes and consequently given less of a priority than in the research in this thesis.

Research by Carter et al (2004) was interested in exploring and critiquing Quality of Life tools used as measures of 'good outcomes' for patients with a cancer diagnosis. It was led by hospice professionals with medical backgrounds, utilised face-to-face

interviews, data analysis utilised a qualitative research analysis software package and adhered to a grounded theory approach (Carter et al, 2004). These researchers promoted a theme of ‘taking charge’ as their central theme with issues of adaptation, acceptance, and coping forming key aspects of this theme. They claim that this theme ‘taking charge’, ‘represents an ultimate outcome from a patient perspective’ and that participants were focused on ‘living with a terminal illness’ rather than striving to achieve a so called ‘good death’ (Carter et al, 2004). It is salient to note, in light of the claim for outcomes from patients perspectives, that all ten participants accessed a hospice and their only involvement in the research was as sources of data.

The Carter et al (2004) study built on research previously conducted by some of the same research team, however rather than a focus on people who accessed hospice services the focus was on people with rheumatoid arthritis who accessed a regional rheumatology outpatient clinic (McPherson et al, 2001). Grounded theory methodology was employed in this study of ten women, 90% of whom were in the 30-69 age category, that aimed to establish outcome measures from the perspective of ‘the individual with a disabling condition’ (McPherson et al, 2001). Interestingly, as for the Carter et al (2004) study, a theme of ‘taking charge’ of one’s condition was raised. Both of these studies attempt to identify issues from the perspective of service users and both do so with no involvement of service users in the research process.

Barnett (2005), in her phenomenological study of ten people with moderate to severe COPD, has a particular focus and emphasis on participants’ strategies for coping with their condition. This study identified four main themes that concentrated on physical symptoms, restrictions on everyday activities, emotional trauma and social loss (Barnett, 2005). In a study to understand the supportive and palliative care needs of people with MS, Wollin et al (2006) interviewed service users and their family members and found key issues were around the initial impact of diagnosis, multiple losses, difficulty accessing services and information and sadness. Unhelpfully very little information was given about the methods used in this study.

Some of the differences between conventional and a more collaborative research approach have been illustrated by Munn-Giddings (1993) in her reflection on earlier ethnographic work which she re-examines critically employing an action research

approach. Here it is thought by Munn-Giddings (1993) that this ethnographic research was an ‘arms-length’ research approach that thwarted learning opportunities for those involved, and also made action or outcomes in practice as a result of the research an unlikely occurrence (Munn-Giddings, 1993). Research that is close to practice, or perhaps the lives of service users, is endorsed as offering the potential to enable the examination of research relations. This is expanded upon in section 2.2.7.

Other ethnographic work (Lawton, 1998; 2000) within a hospice highlights this social distance between research and researchers, and the accounts and experiences of service users themselves. Lawton’s (1998) aim was to focus on and contest the notion of hospice as an institution that enforced and maintained understandings of ‘personhood and the hygienic, sanitised, somatically bounded body...’. For Lawton the bounded body is an intact body. Fieldwork, utilising participant observation, concentrated upon participants in terms of their bodily deterioration, their smells, incontinence, vomiting, weeping wounds, bleeding orifices and rupturing tumours. This bodily deterioration was claimed to be linked to a ‘social death’ and people with these bodily problems were suggested to be non-persons and hence their ‘sequestration’ within hospices was said to be explained (Lawton, 1998). Reflection on this research leaves one considering the people who were at the centre of Lawton’s study. Whilst there are passing extracts from participants and two case studies presented in her book the participant seems largely absent other than as a theoretical issue. An outcome of her research has certainly been a challenge for hospices to consider their place in modern society but the focus of her attention appears very specific focusing predominantly on strong and distressing descriptions of end of life incidences with little description of the participants involved, their concerns or perspectives regarding their condition, experience or needs.

A participatory study with a large sample size specifically aimed to access service user perspectives about what they thought of and wanted from specialist palliative care social workers (Croft et al, 2005:20) is an example of a collaborative methodology. This study concentrated on one specific facet of service delivery that of specialist palliative care social work, and sought to highlight what happens in practice, key issues for service users and outcomes of involvement with specialist palliative care social workers. The service user involvement in the research was

facilitated by way of having an advisory group of service users and service user members of a steering group. Service user members of the steering groups were very involved in the project offering their perspectives on both practical (interview schedule development) and 'business' (the general progress of the project) issues. The findings of this project highlight the idea that 'it is neither helpful nor possible to separate the process of practice from its outcomes for service users' (Croft et al, 2005:28). Participants in the research raised issues that were valued to them in terms of their relationships with their social workers and in terms of the practice of their social workers. In the main, participants' experiences were very positive and where negative experiences had occurred these were around issues of access to and management of specialist palliative care social work (Croft et al, 2005:33). Establishing the influence of the service user involvement in this research and its findings is difficult though as no detail is provided regarding service user involvement in analysis or the formation of themes.

Research that had welfare state service users involved and influential at all stages of the project is now turned to (Beresford & Turner in Winter & Munn-Giddings, 2001:163). This involvement included control of the project's funding and the employment of a paid worker. The so-called 'Citizen's Commission' was therefore an example of user-controlled research and clearly service user members of the commission were involved in the analysis of data (Beresford & Turner in Winter & Munn-Giddings, 2001:168). It is also made clear that this involvement in analysis, this user-controlled research, did impact on the findings; 'important new findings do emerge from such research' (Beresford & Turner in Winter & Munn-Giddings, 2001:173). These new findings refer to participants ability to 'offer their own critiques' and their 'own proposals for the future' rather than purely reporting their experiences (Beresford & Turner in Winter & Munn-Giddings, 2001:169). Earlier these authors highlighted that a different and fuller picture emerged because of the participatory nature of the research, because participants knew that they would not be judged and they suggest these factors are reflected in the findings (Beresford & Turner, 1997:140). This different picture can be seen to be concerned with a service user interpretation that supported the dominant discourse of the time regarding

fulfilling an obligation to work but which also highlighted barriers creating dependency and thwarting the right to work.

Research by Morris (1993) has been difficult to categorise because of little information about methodology but there is evidence of it having participatory aspects. The research clearly takes as its starting point, the experience of disabled people themselves and, although its remit is not made explicit, the research was supported by an advisory group, which included people with knowledge and experience of disability.

This research was based upon interviews with fifty disabled people who required varying degrees of personal assistance to fulfil their daily living tasks. Some participants had been in receipt of residential care but the majority had been supported in their own home. This research highlighted much dissatisfaction with health and social care services concerned with both the process and outcomes of these services. Establishing any influence of the participatory approach that seems to have been taken is difficult though as little information is provided about this aspect of the study.

Shaping Our Lives (a national research and development project run by service users) has not only compiled a database of user-led organisations but the organisation is also active in research with service users looking at user-defined outcomes and their measurement, and issues around welfare and social care (Shaping Our Lives, 1998; 2001; 2003a; 2003b). Running through this user-led work it is clear to see many issues to do with relationships between professionals and service users being prioritised. These issues are about respecting service users views, not making judgements or assumptions about service users, and not patronising service users (see Shaping Our Lives, 2003b particularly). Other key issues addressed concern the area of services provided and specifically issues with assistance and support at home, issues of maximising independence, and issues of avoiding fragmented and unreliable services (see Shaping Our Lives, 2003a & 2003b particularly).

An evaluation of services provided by Centres for Independent Living compared these services to services run by non-disabled providers in order to establish any differing

views on the way services are provided (Barnes et al, 2002). Participants in this research ‘were adamant that user-led organizations were far more responsive to their individual needs both in terms of what was on offer and how it was offered’ (Barnes et al, 2001). This research carried out by disabled people raised issues more in keeping with service user priorities and concerns. Financial, political, and local difficulties were identified that may impact on the success and sustainability of Independent Living Centres and these were considered key issues echoed by disabled people themselves.

The supposition with research, such as user-led research, that clearly involves service users is that the research findings will reflect service user concerns and the process will be equal in terms of decision-making for example. This is explored further in section 1.4. Delineating the influence of service users may be more difficult to achieve however.

1.3 Service user involvement

As the involvement of service users has been central to this research consideration needs to be given to this concept. Involvement of service users in research is considered in section 1.4 but here involvement generally is addressed. To begin with it needs to be recognised that there are some points about service user involvement, as both a concept and as a practice, which do not have definitive meanings. What service user involvement is, what it aims to achieve and the term ‘service user’ itself can be contested notions. This section offers a critical overview with the intention of reviewing the literature on service user involvement beginning by looking at definitions and how neutral a term it may or may not be, moving on to explore the current interest in it and then raising notes of caution about service user involvement in palliative care.

1.3.1 What is involvement and who are service users?

The language of involvement is wide ranging, confusing and at times seemingly contradictory. Over a decade ago it was identified how confusing and ambiguous the concept service user involvement is, and a call for clarification of its meaning was made (Beresford, 1992:16 in Barnes & Wistow, 1992). It is essential to reach a clear

understanding of what is meant by the terms chosen, and what the limits may be with the chosen terms.

1.3.2 Service users

Lindow and Morris (1995:1) give useful definitions that describe a ‘service user’ as a person who needs some kind of support to live in the community and ‘user involvement’ in terms of their participation in decisions which affect how much and what kind of support they receive. Carers, family members, friends and neighbours are also defined as potential service users in their definition and Kelson (1997:2) adds patient representatives and taxpayers to this list.

The difference in language used to describe service user involvement does not seem to be a purely random or innocent occurrence. Each expression may bring with it a certain philosophical or political influence. The sponsor organisation or funders and the group, who are the central focus of the research project will in part, influence the definition used. For example, Lindow and Morris (1995) are particularly commenting on community care and the influence of service user involvement in this field whilst Kelson’s (1997) interest was specifically about service user involvement in the National Health Service (NHS).

The definition of service user is flexible and requires defining in each context that it is employed to describe. It is as broad or narrow as necessary to give focus to the aim of the particular initiative in question. Definitions can however exclude some people or, conversely, include people who might prefer to refer to themselves in other ways and not as a particular service user e.g. a person defined as a mental health service user may define themselves as a survivor. Care needs to be taken in defining service users and this involves being explicit as to those included and those excluded from the definition, as has been achieved by some authors (Baxter et al, 2001:X; Beresford, 2001:509; Royle et al, 2001:2; Hanley et al, 2000:1). The term service user, like consumer described below, may also come bestowed with a sense of passivity conjuring images of the individual being primarily a recipient of services.

Service user is the term used in this writing but the passive, restrictive interpretation mentioned above is not intended here. Rather, I take the term service user to describe

the involvement of people who receive or who are eligible to receive health and social care services and their carers who may be family or close friends.

1.3.3 Consumers

Consumer is another term used to describe people who choose to become involved either in services or research. The suggestion is that service users ‘...are increasingly perceived as consumers or citizens with certain rights or entitlements as a result’ (Robson et al, 1997:1). However, Royle et al (2001:2) use the term consumer to highlight the difference between health professionals and researchers from consumers who do not have a professional role to fulfil. This then, classifies a primary distinction as being that of professionalism. Things are not so straightforward, however, with so-called ‘prosumers’ being seen as inhabiting both professional and consumer positions.

Hanley et al (2000:1), in reference to user involvement in research, point out that we are all potential consumers. However the non-professional consumer often has a ‘...distinct and complementary role to play in the research process’. So then, whilst everyone is potentially a consumer of healthcare, in this case, it seems the key difference is that some people consume services and some provide services. A problem with this term is that as a consumer a person can choose from a range of services and influence the market via their purchasing power. Many people needing to utilize health and social care services do not have the range of choice available to them and it is not usually a case of taking trade elsewhere. There is an important connection here to the ideology that under pins the term consumer and this is described in more detail further below.

There is some leeway here though with direct payments in mind. For the most part though individual service users, although able to take advantage of limited choice and redress in health and social care, cannot tackle wider social exclusion or inequalities of service provision as the providers of care remain controlled by professionals. Within research also, as consumers, people may be seen to have few opportunities to fashion research opportunities or involvement in meaningful ways. The research agenda will fall out of the grasp of consumers who are likely to remain the passive recipients of research activity.

Whilst the term is still in use within health and social care research it is a term that appears to be used less and less with the need to define and be clear about these definitions being taken on board by a broad consensus of people. A case in point is that of the group where the definitions above by Hanley and Royle originated from, Consumers in NHS Research (Renamed Involve in 2003). In previous publications this group, which was established by the NHS's Research and Development Director and charged with taking consumer involvement in research forward, spoke of consumers in a very uncritical way. In a new edition of one of their publications now though the term consumer has been replaced in favour of a more open and democratic explanation that talks of the 'public' and about 'people who use services'. The difficulty of defining people in certain ways is now addressed with recognition that people who use services are often stigmatized and that research can sometimes make this worse (Hanley et al, 2004:ii).

1.3.4 Participation

Participation is another term often cited in relation to service user involvement. It is taken to be concerned with people being involved and taking part in an activity with others about something that actually or potentially could have some impact upon them. It is a very old idea and has been discussed by philosophers and politicians for centuries (Richardson, 1983:1). The term is linked to ideas of participatory democracy, which strives for the enablement of '...people's direct involvement in political, administrative and other processes which affect them' (Croft & Beresford, 1992:27). These ideas bring with them questions about how involved is involved and on whose terms is involvement to be judged? In short, participation is concerned with the interface between the individual and/or groups of individuals and those who hold power. Service providers, charity trustees, research commissioners and/or the state, amongst others, may hold this power.

For some, the position of power holder may not be an obvious or even desired one, but nevertheless, in relation to particular sections of society this is the position they possess. A concern in this thesis and the research that involves service users is this relationship, which is often at question, and in need of examination and equalization.

In her so-called 'Manifesto of an Uppity Crip', Russell (1998:213) discusses the contradictions and vested interests in capitalism, which she feels results in abandonment by the 'corporate state' of disabled people, the sick, the elderly and others. She points to the irony of disabled people following market ideologies '...because the very remedy to disabled people's historical exclusion is a strong government that acts on behalf of social justice inclusion principles', (Russell, 1998:215). Amongst her 'manifesto' recommendations is participatory democracy and the call for democratization at every level and equal ability to participate. The position of a particular section of society, in this example disabled people, is overtly associated to political and governmental policy and action or inaction. A link is made between the situation and potential improvement in this structural situation, and the ability or perhaps right to participate, for Russell, at the highest level.

1.3.5 Citizenship

Another term, citizen, brings other issues to the fore that need careful consideration at an early stage if this is how the people involved are to be referred to and treated. Heater (1999:4) usefully explains the nature of citizenship as evolving from two traditions '...the civic republican style, which places its stress on duties, and the liberal style, which emphasises rights'. It is the liberal style with its focus on citizen's rights that is currently the dominant one he suggests. Heater (1999:7) goes onto suggest that in this style of citizenship the individual is able to go about their private life largely unfettered as they are safeguarded by state-protected rights. However in modern society these rights are supplemented by certain virtues such as a sense of responsibility and civic participation (Heater, 1999:42). Whichever style is thought to be the dominant there seems to be a contemporary broadening of understanding on what it is to be a citizen. It may invoke notions of rights but also of responsibilities and duties, with an emphasis on a sense of community and teamwork, patriotism perhaps, and direct involvement in the community in a civic, social, economic and political sense.

Citizenship is not an uncontested notion however with questions raised about its role in perpetuating oppressive and marginalising practices especially toward those invested with less power or means of self-determination i.e. members of ethnic groups and black people, women, disabled and poor people. As Croft and Beresford

(1992:25) point out though, ideas of citizenship can be used to highlight ‘...people’s exclusions and of giving force to arguments and campaigns for their *involvement*’. As with other terms then, ‘citizen’ needs unpacking and clarification as to its particular meaning in each situation in which it is used. If a person’s citizenship status is measured in terms of their ability and, perhaps more importantly, opportunity to have an active influence in society or to participate at different levels in society, then it can be seen as an inclusive and empowering notion. As will be clear later in this section all terms need to be judged by their use in action to enable power and control to be invested to the many by the few.

The introduction to the aforementioned terms that relate to service user involvement will be of use in achieving an understanding of the ideological stance taken in this research and which is developed throughout this thesis.

1.3.6 The nature of involvement

There are many differing accounts regarding the benefits, as well as the challenges, of promoting service user involvement and some would say that the interest in service user involvement originates in a shifting emphasis in society and government. It is contended, as suggested above, that this emphasis is shifting toward:

...the participatory rights and responsibilities of citizenship and participatory democracy, which aspires to put government in touch with the people, and promotes the social inclusion of those traditionally marginalised within the power structures of society.

(Braye in Kemshall & Littlechild, 2000:9)

The origins and precursors to participation or participatory democracy has been traced by various authors (Croft & Beresford, 1992; Harrison & Mort, 1998) and involves heightening people’s level of independence, human and civil rights and democracy. It also ensures accountability and can be a counterpoise to managerial and professional power. There are overt political implications linked to participation with the concepts of equality and democracy being of central import and this appears to be one of the main distinctions when trying to understand the differences between service user

involvement and participation. However, as with many terms and issues in this area, the meanings are often not made explicit with terms sometimes seemingly used interchangeably. Whilst there may well be a political drive for participation and public involvement in policy issues, it has also been identified that there is a ‘bottom-up’ drive from the service user movement for greater inclusion and participation (Beresford & Croft, 2001). Jenny Morris endorses this in noting the ‘...insistence by historically powerless groups that they want to be involved in decisions which determine the quality of their lives...’ and that they want ‘...their voices heard, to be part of their community rather than set apart from it’ (Morris, 1994:1).

A project conducted by The Mental Health Foundation appears to support the view that service users want to have a say and be involved. The ‘Strategies for Living’ project was a user-led research study looking into how people who used mental health services lived with and managed their mental distress (The Mental Health Foundation, 2000a). In the area of health care this, service user drive for involvement, may be seen in the proliferation of support groups, self-help groups, patient participation groups linked to General Practitioner surgeries, information networks, social groups and more recently internet chat rooms or websites dedicated to sharing of experiences and support. Interestingly, and probably not accidentally, the majority of these groups have risen not out of established health care organisations but rather from individuals themselves who may well have been moved to act in the absence of any other way to become involved or to have a say.

This may well be a satisfactory situation. If people want to organise and come together for support or another purpose that is admirable if it is fulfilling for them. It is easy, however, to objectify these ‘other’ people who have a desire to form a support group for example, but it needs to be recognised that involvement can be an issue for us all. We may though:

...only realise this when something goes wrong, our circumstances change or we come into collision with an official agency. Then we may suddenly see how easily we are excluded and how little we can do about it.

(Beresford & Croft, 1993: xii)

Perhaps then we all have an interest and need to be motivated to increase the likelihood of effective service user involvement in areas we can influence. There may also be a personal as well as an altruistic desire to change things. From a professional position in health or social care, enhancing practice to account for the views and wishes of service users is seen as one measure of 'best practice'. On the face of it this would seem to be the case with practitioners clearly having a desire to assist and respond positively to clients. From the area of social care though, it has been highlighted how unequal power relationships exist between community care organisations and service users (Lindow & Morris, 1995:2) and in the area of palliative care Oliviere (2001) highlights how professionals in this area may present difficulties for service user involvement by declaring that patients need protecting and in not recognising the relevance of service user involvement for patients.

If some practitioners and organisations fail to espouse user involvement then that cannot be said for the government who, in striving for a more 'patient-centred' NHS, recognises the expertise of patients and claims to be striving for 'genuine partnerships' between patients and health professionals so that expert patients can '...actively contribute - from their knowledge and experience – to further improvements in the quality of tomorrow's health service' (DH, 2001a:12). The government has also been stressing the importance of involving service users in the shaping of policy, practice and provision (NHS Executive, 1996; DH, 1999, 2001b). There also seems to be a wider recognition of the role of service users in informing, influencing and participating in health care practice among professionals and managers although a study by Gott et al (2000) which aimed to establish the extent of service user involvement in cancer care, found many inconsistencies among health care managers in their commitment and effort in applying principles of service user involvement into the practice of actually enabling users to influence services and policy. This has been endorsed by evaluated service user initiatives specifically within the thirty-four cancer networks in England (Sitzia et al, 2004).

Commenting on user involvement in voluntary organisations, Robson et al (1997:2) highlight that service user involvement is good practice, helps the organisation to stay 'close to the customer', and that both funders and beneficiaries are likely to expect a commitment to it. This suggests both a carrot and stick approach for the

encouragement of user involvement to occur in these organisations. Kelson (1997:6), focusing on health service users goes further and makes claims for the importance of the service user perspective with regard the planning, delivery and monitoring of services and specifically highlights how this can lead to a better understanding of service user needs and priorities, better relationships between health care organisations and their users and a sense of ownership, partnership and collaboration to exist. It is apparent that the organisation embarking upon a way of implementing service user involvement strategies need to be clear at the outset as to their level of commitment and degree of service user involvement otherwise an unhelpful, unclear attempt at involvement is likely to be the end product.

An organisation may be genuinely committed to service user involvement but the system employed for delivering it in practice may positively discourage involvement and lead any attempt to establish functioning systems, to fizzle out. Unless the approach to involvement is clear and the degree of involvement transparent, difficulties will exist. It has been highlighted that successful involvement is about the individual having some control and responsibility over the degree of involvement (Beresford & Croft, 1993:10). The level of control and responsibility a person has within the experience of involvement is likely to be determined by the type of involvement available. It is wise for all involved to be clear about this from the outset.

1.3.7 Differences of ideology

Kemshall and Littlechild (2000:10) identify four different areas in which service users' participation in social care has developed namely, their own use of a service, strategic planning, the development of user-led services, and in social care research. Whilst it cannot be assumed that the first of these areas is wholly achieved in social or health care, it is the remaining three areas that will be examined in this section. In the area of palliative care Oliviere (2001) seemed to agree that the debate needs to be moved beyond the individual level, questioning whether involvement is needed in more than just clinical decision making and consultation. Oliviere (2001:240) suggests a move from this individual involvement in care towards '...harnessing the collective voice of patients and carers' but it is not clear to what end. Earlier he discusses a model of involvement where '...the collective voice of service users can make a difference to the planning, operation, evolution and evaluation of services' but

his ideas fail to develop a way of enabling people in this area to be any more involved than in what seem to be tokenistic ways (Oliviere, 2001:239). No insights are offered into how palliative care organisations may need to address fundamental values and beliefs if they are to move service user involvement beyond the individual level toward a much more user-led service.

What options may be available then? Several models of involvement exist but there can helpfully be seen to be degrees of involvement along a continuum between a consumerist approach and a democratic approach to involvement. The consumerist approach is broadly concerned with improving services, ensuring the ‘customers’ or ‘consumers’ are satisfied with what is available to them. A democratic approach comes with implicit ideals about participatory democracy, as discussed above, and an integral part of this is concerned with enabling people to have more control and influence on factors that concern them. This then, goes much further than examining issues of enabling people to make decisions about their personal care, although this is important to people, but extends to enhancing the way people can collectively make changes to improve their situation.

A well-known model utilised in service user involvement is Arnstein’s ‘ladder of citizen participation’ (Arnstein, 1969). This ladder begins with ‘manipulation’ and ‘therapy’ both classified as non-participation where the power holders educate or cure and moves to tokenistic aspects of participation like ‘informing’ and ‘consultation’. Moving to the highest rungs of this ladder participation is seen in terms of ‘partnerships’ and ‘delegation’ with ‘user control’ at the top offering people decision-making rights and managerial power. This model is useful as it clearly demonstrates the different levels of involvement and what they can mean to people. With this model in mind, it clearly shows how the idea of consumerist and democratic approaches to involvement can be seen. The democratic approach can be seen to include the top three rungs of Arnstein’s ladder.

It would seem that the democratic approaches to service user involvement are those which could be the most challenging to implement as they are likely to necessitate organisations to review and change their traditional ways of working at the level of policy, practice and ideology. This has been recognised as potentially presenting

existing power holders with a fear of losing control, but it has been usefully highlighted that it is not about taking from one to give to another but, rather, it ‘...is concerned with changing the nature of the relationship between participants’ (Beresford & Croft, 1993:51). Organisations may find it difficult to adapt in ways that make service user involvement more than just a token gesture, especially if one is considering voluntary organisations as they often have a strong tradition of doing things *for* people (Morris, 1994:10). This doing things *for* rather than *with* people is a key idea conjuring images of paternal benevolence on the part of these organisations. Morris (1994:10) goes on to point out though, that many organisations are commonly influenced by issues of social justice and social change and can be influenced by service users. She is focusing particularly on social service organisations and it is open for debate if her positive analysis can be transferred to other organisations in the area of health care.

An important issue is concerned with where control lies. For a genuine democratic participation to exist there needs to be a commitment on behalf of those in positions of power to make participation work for the right reasons. Shaping a service or initiative to be acceptable to the people who need it will involve making real and lasting changes to how the organisation is structured and managed. Without these structural changes effective participation is unlikely to be maintained and an effective challenge to people’s exclusion and oppression is unlikely to occur.

In a discussion of provider-led services in social care Beresford and Croft (2001:299) point out some of the failings of this approach such as placing restrictions on the rights of people, emphasis on social control and a failure to ensure equal access and opportunities. It seems that these failings are linked with aspects discussed above. It is a challenge in health care and palliative care specifically, to facilitate movement from this provider-led approach to a user-led approach. If this challenge is grasped it will necessarily involve service users being active participants in this movement and this is likely to confront pre-existing professional and managerial assumptions about the nature of ‘care’, professional responsibilities and accountability, and the primacy of professional and managerial knowledge. Developing user-led services reflects a service, which is keen to improve its accountability to those for whom it provides the

service (Morris, 1994:57) and organisations need to find ways of sharing this accountability in open and positive ways.

In relation to the research in this thesis it was a more democratic ideological approach that was strived for. Facilitating service user's greater influence in the research with genuine control in decision-making and a changed relationship between researcher and service users was attempted.

1.3.8 Resistance to service user involvement

The full endorsement of service user involvement approaches has been treated with caution in some quarters with suggestions that the acceptance of service user involvement deflects attention from a '...growing disillusionment with political decision-making processes in the UK, and with NHS decision processes specifically' (Harrison & Mort, 1998). Other obstacles accredited to the implementation of service user involvement given by professionals and managers are that service user views are only one side of the argument and that they need to be balanced by the professional view, and that user views are unrepresentative (Harrison & Mort, 1998). It has been contended that service users are perceived as challenging the status quo and consequently the claim of not being representative of all service users is used to neutralise and exclude (Beresford & Campbell, 1994). Rather than being a conscious decision to sabotage involvement though, it may be that an unhelpful criterion has been employed to judge the worthiness of the service user input obtained.

Research into the effect of involvement in voluntary organisations showed that '...users were more interested in services than in management or being on the governing body' (Robson et al, 1997:6). Further concerns raised by providers were that service users were inhibited in meetings by fatigue, stress, by being too emotional, or through ill health were less effective at decision making, poorly literate, had a difficulty in travelling, lacked motivation, or were institutionalised (Robson et al, 1997:6). This range of objections may illustrate misguided attempts at service user involvement, as mentioned above, rather than genuine reasons to reject the notion of involvement. Such objections may also be overcome with persistence and training of both service users and staff. Most organisations will not find service user involvement

implemented quickly or smoothly. Infrastructures will need developing over time in order to support users and facilitate their involvement.

A key incentive for service user involvement is generally considered to be the likelihood of changing things for the better. Involving people in a service at all levels may provide people with tremendous opportunities to shape and change a service they are recipients of or to which they are committed. Forbes & Sashidharan (1997) question whether any involvement can lead to radical change for service users though when user need or expectation may be greater than the service can provide. The suggestion here is that it may be of greater benefit for users to align themselves with other, more politically motivated groups, in order to challenge policy makers (Forbes & Sashidharan, 1997). A further challenge is that the service user voice is in danger of being ‘incorporated’ and silenced by involvement in services and research, particularly those following a consumerist model of involvement where involvement may be seen in terms of a ‘tick-box’ exercise (Forbes & Sashidharan, 1997; Beresford, 2002a). In terms of ideological approaches it may be that the democratic approach to involvement, being explicitly political and which has change and alteration in power structures at its core, offers greater opportunity for genuine sharing of responsibilities and power (Beresford & Croft, 1993:60; Beresford, 2002b). User-led services have developed from this approach, and hence may be seen as enabling of social change and improving the lives of peoples.

Democratic participation or involvement does create overt challenges to organisations as evidence of a shift in the balance of power is expected from service users and this is likely to lead to some conflict or marginalisation of users (Beresford & Croft, 1993:124; Drake in Barton, 1996:160). The research in this thesis was certainly attempting to be far more than a ‘tick-box’, superficial approach to the involvement of service users. The extent of any shift in balance of power will be returned to in section 5.11.

1.3.9 Caution in palliative care

Participation within palliative care cannot be one dimensional due to the difficulty that some people with palliative care needs will encounter in trying to participate. People who are extremely fatigued and debilitated by disease may not be able to

become involved in the same ways as those people who are more physically able. This is not to say, however, that these people do not want to participate and become involved in initiatives that may improve services and care for themselves or others. There may be many reasons for a person with palliative care needs to be involved. These reasons may be; to continue to raise concerns and be involved as they have always been; to be involved as a way to retain a degree of control; an altruistic desire to improve care and/or services for others; in change making initiatives in order to ‘leave their mark’ or as a way of striving and aiming on some reasonably tangible goal.

Until very recently there has been little written about involvement initiatives in palliative care but there are now an increasing number of examples. A report arose out of what was described as a consultation and discussion day for bereaved carers at St. Christopher’s Hospice in London (Thomas, 2003). This day enabled the views and experiences about their partners care in the NHS to be heard and ‘suggestions for improvement’ to be highlighted. An apparent omission though seems to be no clear idea of what happened to these suggestions. The request for this exercise came from the Health Service Ombudsman and so presumably the suggestions were fed back to the Ombudsman but there is no mention of this in the report, nor mention of any changes that occurred because of this work.

Small and Rhodes (2000:1) wrote about service user involvement in palliative care and are directly challenging of it from the outset, raising questions about how far people in the groups included in the study want to be involved in the care they receive, or in the debate about service provision for themselves and others with the same condition. They go on to ask if service user involvement has more interest to politicians and professionals than to service users (Small & Rhodes, 2000:1). Their approach to service user involvement seems to be orientated to a consumerist model of involvement with no evidence as to how service users may have been involved in the research other than in data collection as participants to provide data. In concluding, one of their claims suggests that service users can be expected to be involved and that this is a form of coercion (Small & Rhodes, 2000:216). There does not appear to be any evidence of this, or of other claims, originating from the service users in their study. Alternative views suggest that service users in palliative care can

and do want to have greater involvement (Beresford et al, 2000:12). ‘The Build’ project is an example of how involvement strategies may be constructively carried out in the area of palliative care. This project attempts to enable people with Motor Neurone Disease (MND) to become actively engaged in the planning of the services they receive (Sinha et al, 2002:10).

Other work (Gott et al, 2000), sought to identify the extent of user involvement in cancer care services in one particular region. This study aimed to discover a great deal of information from both health care providers and service user groups about a wide range of issues pertaining to involvement in cancer care within the region under study. The focus was not on individual views or experiences but on areas of organization, process and policy. Whilst being only a local study, some useful points for consideration were made, such as putting strategies in place for involving service users who are not members of user groups and the need to address the difficulties of involving people with cancer who have a poor prognosis (Gott et al, 2000:31).

As Oliviere (2001) highlights, palliative care needs to ‘...overcome the obstacles of the dying and seriously ill participating in service improvement’. An editorial in a palliative care journal also endorses serious consideration of the subject and suggests that we have to rethink our roles and agendas in order to enable people’s participation (Payne, 2002). However there is a clear sceptical tone in many of these contributions with Payne (2002), for example, suggesting that it may be professionals driving this agenda and that service users may not actually want to be involved in activities that will not benefit themselves. Oliviere (2001) also prioritises the many difficulties service users in palliative care face that are likely to make involvement very difficult and others, as described above, warn that involvement could be both burdensome and exploitative (Small & Rhodes, 2000).

More recently Bradburn (in Monroe & Oliviere, 2003:36), whilst generally advocating greater involvement in services and highlighting some examples from practice, suggests involvement couched in consumerist ideology and restricted by the physical limitations of service users. Gott (in Payne et al, 2004:80) whilst linking the need for greater service user involvement in palliative care to the underpinning philosophy of palliative care goes on to recount the especial challenges of achieving

this involvement, as others before her have. It is suggested here that further debate and the development of models of involvement for palliative care specifically are required (Gott in Payne et al, 2004:86). A national scoping exercise that aimed to document service user involvement initiatives in the UK and to give examples of best practice was recently conducted (Payne et al, 2005). The study found that there was an increased activity level of service user involvement in palliative care but that most reports of initiatives were descriptive accounts rather than methodologically robust studies. With regard to direct accounts from service users themselves and health and social care professionals a keenness to engage with the issues was found but it is noted how, in the report author's view, that service user involvement in palliative care is a 'top down' initiative (Payne et al, 2005:50). Familiar reservations are re-rehearsed in the report such as; the unrepresentativeness of service users involved; the possibility of negative effects on service users; the closeness or distance from the direct experience (i.e. is survivor's involvement valid?); the likelihood of well, educated, articulate, English speaking service users being involved in favour of others; the lack of consultative initiatives converting involvement into action (Payne et al, 2005:50).

Amongst academia in palliative care there appears to be considerable consideration of service user involvement with little conversion to practical implications. There is little connection of service user involvement in palliative care to ideological assumptions and repeated rhetoric regarding the challenges of involving service users in this area that conspire to promote a negative impression. This impression is one that may easily restrain constructive attempts to enable service users to have opportunities for involvement. We will come to see that service users involved in the production of this research, members of the SURAG, considered that the involvement of palliative care service users needs to be intrinsic within palliative care services (see section 5.12). An introduction to service user involvement has also been necessary in order to highlight the important differences in involvement initiatives that can also be transferred to the discussion of involvement in research. These differences are in ideology and the meaningfulness of involvement. We will return to these issues in the next section.

1.4 Service user involvement in research

In this section I will reflect on a range of research approaches that have been developed with a broad aim to promote the inclusion of people into the research process, not as subjects or respondents but as, in some way, research partners or researchers in their own right. National Health Service (NHS) Research and Development strategy is now committed to involving service users in the work it undertakes, as active participants (NHS Executive et al, 1998; NHS Executive Trent, 2001; DH, 2001c).

Despite some shared key tenets many variations exist within this inclusive research approach and there is a need to be clear as to the meanings and limitations of these different approaches and to be clear about the possibilities for service users who may choose to become involved in research. The involvement of service users was central to the research presented in this thesis and it is therefore important to consider the many differing approaches in order to be informed as to the approach taken here and described in section 2.3.

In section 1.3 above some principles of participation were described and these can also be extended to the research process and are manifested in ideas of power sharing, with the researcher and researched working together on projects sharing the decision-making. As with all aspects of service user involvement there are differing levels of participation and this will be expanded upon below. Participation in a research project can potentially be great or little and meaningful or meaningless for the service users concerned. Gibbs (1999:8) describes a ‘co-production’ that he hopes will overcome the gap between objective detachment and experiential experiences. There are, however, concerns about participatory research and these will be discussed below.

1.4.1 An evolving participatory research agenda

Participatory research is a much-abused term that requires a careful examination prior to any acceptance of it as a helpful research approach. As with all research approaches or methodologies, its merits vary with the research setting and the researcher. At its best, the process can be liberating, empowering and educational, a collegial

relationship that enables people to participate, to join in, validating their knowledge and experience. At its worse, it can degenerate into a process that co-opts people into an agenda not their own and that consists of meaningless exercises more to do with the researchers objectives and desired outcomes than their own. Whilst participation in the research process, taken at face value, can be seen as desirable it is not an unproblematic approach.

Participatory research and development has a history in rural planning and development in the latter decades of the 20th Century and emerged from a realization that developmental work was largely top-down in nature. It is useful to briefly consider the historical context from which participatory research evolved. This enables an understanding to emerge regarding the original intentions of this approach that will be useful when considering claims made below in section 1.4.2. Chambers (1992; 1983) was especially influential in challenging this trend. The broad aim here was to enable those people who were usually on the receiving end of projects that affected them, to be involved in these interventions. That people resume some control and influence over decisions and plans was the desired result. Participatory development approaches became ‘justified in terms of sustainability, relevance and empowerment’ (Cooke & Kothari, 2001:5). Proponents go further in claiming that participatory approaches to research gain access to lay people’s own knowledge and understandings that have often been ignored (Cornwall in De Koning & Martin, 1996:94). Indeed this reclaimed knowledge is thought to redress the medical knowledge that dominates, and an associated rise in self-esteem and confidence can ensue. An empowering process is said to occur that is described in humanistic terms.

1.4.2 Concerns and doubts

Despite this positive rhetoric of participation though there have been doubts raised, as mentioned above, with regard the level and genuine nature of the involvement people can expect. In discussing this ‘new participatory orthodoxy’ Mosse (1996) raises several tensions to the participatory approach. Highlighted are the tensions between local and outsider knowledge, a suggestion of a covert method for legitimacy founded on the notion rather than the realization of participation, and a primacy of particular local voices at the exclusion of others e.g. women (Mosse, 1996).

Other commentators are much more vitriolic in their challenge to the participation that has largely originated from the realms of rural and agricultural development. Hildyard et al (in Cooke & Kothari, 2001:60) for example, discuss the participatory processes that ‘are reworked to suit the ends of industry and other powerful groupings-notably that of increasing control *over* local people’ (My emphasis). This then suggests that participatory approaches are not without their own fundamental challenges. The claims made for participatory research, in preference to other approaches to research, may better be judged in light of this criticism. Indeed, at least some other research approaches that do not lay claim to involving service users in the research can be seen to be clear on this point rather than taking an unproblematic view or making unfounded claims about participation. Concerns are that an uncritical and unclear participatory research approach may negate debate on issues such as where control lies in a project and about who possesses power and decision-making rights.

Kothari (in Cooke & Kothari, 2001:145) explains how ‘insidious modes of social control’ are not made apparent through the use of participatory approaches. There is a focus on the individual and their actions that can mask wider cultural and social processes. This suggestion was also highlighted by Kemshall and Littlechild (2000:7) who describe how, in their opinion, participation can often be restricted to the micro-level of service users influencing practitioners, and potentially research, at local point of service delivery rather than also influencing and changing things at a policy and service provider level.

The participatory research process, which some argue involves forming collegiate relationships where researchers and service users work as colleagues, often ‘goes no further than contracting people into projects’ (Cornwall & Jewkes, 1995:1669). The potential is therefore not fulfilled and leaves researchers firmly in the position of manager and owner of the project. Croft and Beresford (1992) stated this more explicitly claiming that participation of people in services and welfare has not countered exclusions faced by some people in society. Indeed ‘participatory schemes have mirrored rather than challenged broader oppressions and discriminations’ (Croft and Beresford, 1992:33). This, so called ‘tick box’ approach to the involvement of service users, is far from the approach I attempted to take in this research as will be illustrated in section 2.3.1.

Maguire (1987:51) discussed what she saw as participatory research's tendency to be dominated by men, what she calls an androcentric filter, and of women having less of an opportunity to become involved in such projects and to make use of the benefits of participatory research. Fisher (2002) points out how typically, service users are asked to join in with participatory studies when the 'research issue and the methods have largely been defined beforehand'. In effect then little power, control, choice or decision-making sits with the service users.

Some of the nuances, and at times what can be disguised conflicts, in participatory research are raised in the report of a Canadian participatory project designed to find out about disabled people's lives from their 'standpoints' (Campbell et al, 1998). The authors discuss their intentions of conducting an inclusive study and the problems that equalizing power relations brought. They report in detail about making decisions about the design and other decisions without the involvement of any service users and that equality in research relations was not achieved. Recruitment of service users onto the research team occurred after conducting research interviews with participants and appears to have occurred 'after the event'. These researchers acknowledge that 'participation...does not prevent staff from exercising power...nor does it ensure that research addresses the needs of the researched' (Campbell et al, 1998). This self-critical and reflexive account is refreshing but reinforces the suggestion that participatory research can place a distance between the actual participation/involvement of service users and the ideological and political aspects that underpin such an approach (Beresford, 2002a). Walmsley (2001) agrees that this ideology of participatory research is even unclear, is it rooted in the social model of disability or somewhere else?

Beresford (2002a) has drawn attention to the 'significant similarity' between the consumerist and democratic approaches to service user participation generally and these approaches influence in research. The democratic approach of user participation in research appears to be linked to the aspirations espoused in the emancipatory approach to research. It calls for '...the transformation of research philosophy, social relations...' and is primarily concerned with '...improving people's lives rather than solely with generating knowledge' (Beresford, 2002a). An emancipatory research approach is turned to next.

1.4.3 Emancipatory Research and the Social Model of Disability

The emancipatory research approach that has emerged during the latter part of the 20th Century lays claim to counter the marginalisation of people brought about by traditional positivistic research which is thought to have commonly treated, and in some cases to still treat, those people who are the focus of inquiry as subjects and research as the search for hard, objective truth. Those people involved in research within an emancipatory paradigm question the distinctions made between expert and subject, the assumed passivity of research participants and the claim to ownership of the product of research, among many others. Emancipatory research is often thought of as implicitly linked to and developed from action within the disabled people's movement, and is consequently often referred to as emancipatory disability research (Barnes, 2003; Oliver, 1992).

Mercer (in Barnes et al, 2002:236) explains the position of the emancipatory researcher further and suggests that, in disability research at least, there is a 'necessary partisanship' required whereby the researcher is located in a sympathetic position, with regard the social constraints disabled people live in, within an oppressive society.

Much of the work on developing an emancipatory research paradigm has then been carried forward in the area of disability studies and disability activism. This has a long and complex history to it and is intrinsically linked to the development of a social model of disability (See for example Campbell & Oliver, 1996; Centre for Disability Studies, University of Leeds, <http://WWW.leeds.ac.uk/disability-studies/archive>; British Council Of Disabled People, <http://WWW.bcodp.org.uk>), which is turned to in section 1.5.

1.4.4 Emancipatory disability research

The new way of viewing disability and the issues disabled people face, brought about by the impact of the social model of disability, necessitated a new way of researching the issues and a new form of research relationship that was congruent with the social model. In discussing this relationship between disabled people's organisations, the social model of disability and research, Stone and Priestley (1996) identify that emancipatory research must fulfil certain requirements in order to be congruent in this

field. They suggest that such research must epistemologically be rooted in the social model; it must have a commitment to a social analysis of disablement; it must be relevant politically and to the people who are the focus of the research; the research must reverse existing hierarchies and ensure disabled people are at the centre of the research in terms of control; it must give voice to the personal as political and adopt a plurality of methods for data collection and analysis (Stone & Priestley, 1996).

So, this approach to research can be seen to be a politicized one. It raises issues such as who controls the research? It is a consciousness raising and empowering process that is clearly focused upon challenging the status quo and promoting change for those who are the focus of the research (Oliver, 1992; Zarb, 1992). Some have questioned the desirability of research linked so overtly to a political motive and to claims to enhance the power of service users (Fisher, 2002), whilst others contend that researchers will 'too often cede their claimed independence in order to secure their own professional position' (Mercer in Barnes et al, 2002:236).

In contrast to the rhetoric of conventional participatory research, emancipatory approaches to research require a much clearer and honest explanation of the research process. Barton (1996:4), for example, examines in some detail the position that he, a non-disabled person, takes in relation to disabled people. Oliver (in Barton, 1996:36) speaks of the emancipatory approach to research in terms of ensuring research is relevant to the lives of disabled people and more influential in improving their material circumstances. This is clearly compatible with those efforts of disability activists described in section 1.5 below.

These requirements of emancipatory research would seem to ensure that, in reality, an emancipatory research project is very difficult to achieve and questions have been asked as to its attainability (Barnes, 2001; Gibbs, 2000; Oliver, in Corker & French, 1999; Humphries, 1997; Oliver, in Barnes & Mercer, 1997; Oliver, 1992; Zarb, 1992). Others have questioned the epistemological assumptions of this approach and the ability to equalise research relations (Danieli & Woodhams, 2005). However disagreement is not uniform, with suggestions elsewhere that research operating within an emancipatory domain can be achieved and that researchers should continue to strive for this (Barnes, 2001). Mercer (in Barnes, et al 2002:245) for example, takes

up Oliver's (Oliver in Barnes & Mercer, 1997) contention that emancipatory disability research proves to be 'an impossible dream' by highlighting the fact that any such research should be judged by its capacity to empower the research participants and by challenging disabling social barriers. Barnes (2001) also usefully reminds us that the emancipatory research paradigm should not be seen in terms of individual research projects but rather as a process leading to the fulfilment of emancipatory ideals. Whilst projects need to aim for the ideals of emancipatory research they need to be judged on the cumulative effect they bring to the realisation of emancipatory outcomes. It will be clear in the methods chapter and sections 2.2.7 and 2.3.1 in particular, that the research presented in this thesis has some elements of emancipatory research but that it cannot claim to be wholly emancipatory.

1.4.5 Service user-led research

Service user-led research is broadly considered to be closer to the emancipatory research agenda than many other approaches and it may be seen as an attempt to include the experiences of people who are normally the 'subject' of research, in the research process itself. This engagement within the research process could take various forms but is likely to place the person whose experience is under 'investigation' at the centre of the research with or without professional researchers. Some opinion suggests that service users prefer the term user-controlled research, as the issue of who controls the research is the key point (Turner & Beresford, 2005a: v). In discussion of a user-led project that involved people with learning difficulties Williams (2003) for example, notes that despite some methodological problems, the research had a positive impact upon the people who were involved in it as well as ensuring that all stages of the research remained in tune with their concerns and interpretations.

Faulkner and Thomas (2002) speak of user-led research in the area of mental health service users/survivors as borne out of a frustration with the political resistance to acknowledging service users as experts and their ability to be involved in research.

The Mental Health Foundation, Strategies for Living research team reported on an array of user-led research studies that they facilitated and supported. They describe how user-led research means that service users and survivors select the research areas,

join in with steering groups to monitor and shape the research, design the project and, 'ideally', are the researchers and have control over the funding (Nicholls et al, 2003). Within phase two of this research initiative service users and survivors were consulted in order to establish priorities for the research agenda. This was then acted upon and followed through in the research itself with trained research supporters assisting the service user researchers who were conducting the twelve different projects.

In discussing issues of power between the Strategies for Living research team and user-led project researchers the authors highlight challenges that, even with the best planning, were very problematic. Indeed a number of service user researchers withdrew from their particular projects for a variety of reasons. The Strategies for Living research team report that despite their awareness of potential power imbalances between themselves and attempts to redress these, achieving this was 'a very difficult thing to do' (Nicholls et al, 2003:39). Service user researchers, despite having no control in terms of control of the funding of the project, ultimately had the power to control their research activities and some withdrew this research activity either because they disagreed with the way they were expected to do the research or because of ill health (Nicholls et al, 2003:39). For service users power conflicts can be considered to arise around the key issue of control of the research and especially in terms of project design, management and dissemination (Turner & Beresford, 2005a: 20).

As has been highlighted earlier, there are many different levels of involvement in research. The examples above show a little of what can be achieved when opportunities are given, or taken, by people to direct their own research projects.

1.4.6 Service user involvement in research

There have been parallel demands over recent decades for greater involvement of service users in areas such as policy-setting, planning and delivery of services and more recently asserting that users of health and social care services also be involved in research that affects them. Whilst there may well be a political drive for public involvement in policy issues it has also been identified that there is a 'bottom-up' drive from the service user movement for greater inclusion and participation

(Beresford & Croft, 2001). Jenny Morris endorses this in noting the ‘...insistence by historically powerless groups that they want to be involved in decisions which determine the quality of their lives...’ and that they want ‘...their voices heard, to be part of their community rather than set apart from it’ (Morris, 1994:1).

Different arguments abound as to why involvement in research is important. One is that active involvement in research helps protect the service users who provide data, a concern which has grown in recent years with scandals such as that which occurred at the Alder Hey Children's Hospital, where children's body parts were used for research without the parent's consent (Redfern et al, 2001). Another argument is that active involvement produces better research, research that is more relevant to people's needs, is more reliable and collects more useful information, as well as being more ethical (Hanley 1999). This is a source of some debate and will be discussed further below.

The importance of active involvement in research has now been recognized by the government. As discussed above, in 1995 the Department of Health set up an advisory group now known as INVOLVE. This group has been instrumental in the advancement of active involvement particularly in health research, to the extent that the government, through the 'Research Governance Framework', requires all NHS organizations to ensure that service users are actively involved in research projects and research management wherever possible (DH, 2001d).

The history of this research has, as described above, its roots in the early work in disability research but also in the pioneering work of service users in social and community care. Along with the efforts of disabled people, mental health service users and survivors particularly have delivered radical approaches to research in which they and their organizations, rather than professional academics and researchers, control the research agenda, funding and process. This new model of 'user-led' research within mental health was described above (Beresford & Evans, 1999; Nicholls et al, 2003; Williams, 2003).

However, whilst service users and their organizations have on the whole welcomed the shift towards active involvement in health and social care research, many feel the shift is not moving far enough or quickly enough. Some research funders and research

groups have tried to work with the movement, but it is acknowledged that others have not. One of the reasons given by people who are reluctant to work with service users is that there is no proof that this involvement makes a positive difference to the research. Other reasons are that active involvement is too costly, time-consuming, or simply too difficult. Boote et al (2002) rehearse these and other objections and contend that they are not easily dismissed and go on to call for ‘measures’ and ‘evaluations’ that enable the effect of involvement on research to be developed. These same authors later report on a consensus study and national survey that attempted to do just that (Telford et al, 2004a; 2004b). Eight principles and indicators of successful ‘consumer’ (their term) involvement in research was agreed and the survey of over one thousand lead researchers found only 17% involved consumers, and amongst them only a few indicators were met. Surprisingly no principles were formed to judge if consumers were involved in all stages of the research process and what may indicate that it was genuine involvement, nor to judge outcomes from the research i.e. consumer rated indicators of ‘success’.

A recent initiative, invoNET, led by INVOLVE and Worthing and Southlands Hospitals NHS Trust and launched in March 2006 aims to take forward the evaluation of the effect or influence of service user involvement in research (<http://www.invo.org.uk/invoNET.asp>). This is in the form of a network of service users, researchers and others who are interested in developing this area. A report of phase 1 of a project led by the Cancer Care Research Centre at Stirling University in Scotland exploring what people affected by cancer think about cancer treatment, also included components on service user involvement and its impact (Kearney et al, 2005). This project set up Patient and Carer Advisory Groups across Scotland to work with the researchers on prioritising issues for cancer research. It also highlighted how evaluation of the impact of involving people affected by cancer in research is scarce (Kearney et al, 2005).

Evans and Fisher (in Shaw & Lishman, 1999) discussed principles of service users in research but the principles concerned here were the principles of choice and control. These researchers wanted service users to be in control throughout all research activities, such as analysis and dissemination and seem to be closer to Beresford’s (2002a & 2002b) discussion of service user involvement in research. As well as being

an empowering experience, a requirement of service user involvement in research is to consider how effectively service users are involved in the initial set-up phase, and throughout the research as well as the influence service users have brought to bear on the research. It is concerned to deliver respectful research relations and to remain focused upon service user concerns and suggestions. It is concerned with service users' lives and the direction they see that will bring about acceptable change for themselves or others in a similar situation. Beresford (2003:31) again, points out that such involvement throughout the research process has not however, been widely promoted. There is though, recent reporting of a participatory approach being taken in cancer research with service user co-researchers being active at all stages of the project (Wright et al, 2006). These co-researchers also were included in training alongside the researchers on research methods, data collection and data analysis in order to maximise their research skills (Wright et al, 2006:9).

Walmsley (2003) has suggested that the role of the researcher within research that involves service users is often left unexamined. This is surprising given that, for research shaped by emancipatory and participatory ideals, the actual research relations are clearly seen as important. In a discussion of service user involvement in research it has been described vividly what one of the key things that this approach to research might be about:

The approach...comes from the belief that this experience, often associated with stigma, whose bearers are perceived to be unproductive members of society and weaklings, is useful and productive in terms of enabling other users-and the rest of us-to make sense of it through research.

(Ramon in Ramon, 2003:15)

There is opinion that involving service users in research affects the credibility of the research as the findings represent 'a coming together of different voices, insights and influences' (Relf in Monroe & Oliviere, 2003:100). How this is so needs some exploration, but there is emphasis in recent years that experiential knowledge, that comes from people's unique experience of illness and the services and care they get,

is a key component that sheds valuable light on to research that researchers without this experience can not hope to achieve. This is discussed in section 5.11.8.

1.4.7 Mental health service users/survivors research

Much work has occurred in the area of mental health service users and survivors with regard to involvement in research. A project, for example, conducted by the Mental Health Foundation appears to support the view that service users want to have a say and be involved. The ‘Strategies for Living’ project is a user-led research study looking into how people who used mental health services live with and manage their mental distress (Mental Health Foundation, 2000a). It has produced a wide-ranging set of recommendations for government and service providers to consider and act upon. A further example of service user research comes from a Leeds based women and mental health action group. This group commissioned research into women’s experience of mental health services in Leeds, and a team of women service users conducted the research. The research was based on the belief that women can define their own problems and state what they need and want in terms of support. The women service users were actively involved in every stage of the research process (Foster, 2002:2).

Another user-led research project that was commissioned by the Mental Health Foundation, this time a survey of alternative and complementary treatments and therapies used in mental health. This survey produced evidence of their particular uses and what service users thought of them. The research produced a report, ‘Knowing our minds’, which was able to highlight the value placed on these alternative therapies by service users themselves (Mental Health Foundation, 2000b). The Mental Health Foundation has been involved in many user-led projects but is only one example of an organization that does such work.

As in the area of disability, mental health service users and survivors contribute much to the research base in user-led research. A sign of the increase in service user involvement in research is indicated by the development of a mental health service users’ and survivors’ ‘network’ of researchers. This aims to collate a database of user-led and user-controlled research projects and to facilitate a ‘connecting up’ of users

and survivors with research projects actively engaging users (Strategies for Living Team, 2002:8).

Other initiatives include the Service User Research Enterprise (SURE) based at the Institute of Psychiatry. This is a collaborative project between service user researchers and academics that is committed to service user involvement in all stages of the research process. Service users are employed as researchers and this initiative has an emphasis on users' priorities for research areas (Service User Research Enterprise, 2001/02). University based research departments also contribute in this area with an example being The School of Health and Related Research's (ScHARR) Mental Health Section at the University of Sheffield. Here a maximizing of the role service users and carers play in all their research projects is taking place (School of Health and Related Research, 2004). Despite considerable challenges and with still much development work to go, service user involvement in research within forensic psychiatry is also moving forward (Faulkner & Morris, 2003).

In describing a method, User-Focused Monitoring, for establishing what mental health service users think about the services provided them, Rose (2001:11) describes how service users in a project generated research questions, conducted research interviews, wrote the report and presented results. A staggering number of initiatives are shown to be currently under way within this area and it does not appear to show any signs of abating.

However, despite this groundswell of activity and championing, the 'establishment' of psychiatric system management, administration and clinicians remain very reticent to engage with and/or acknowledge this rising development (Wilson & Beresford in Corker & Shakespeare, 2002:143). This point is supported by other mental health service survivors with Champ (2002) expressing frustration at slow progress in the acceptance of service user involvement in research, and also in the persistence of understandings of mental distress that are still firmly entrenched in the medical model. A redefining of mental distress and experiences considered outside of the 'norm' is one rationale for progression of service user research in the area of mental health but it also shares common aims with the involvement of service users more generally including disabled people's efforts. There are also connections to palliative

care. It was highlighted in section 1.3.9 above how service user involvement in palliative care largely faces a cautious response with people in positions of power failing to enable positive progress to be made.

1.4.8 Service user involvement in research - other areas

Brookes (2001/2) describes how he, as a person with learning difficulties, achieved active involvement in a research project looking at how people with learning difficulties and high support needs can be supported to make choices. As well as contributing research outcomes he gained great value personally due to being an equal on the research team and was spurred to assert that ‘...people with learning difficulties should be more involved in what projects should be about’ (Brookes, 2001:6). Earlier examples from the field of learning difficulties have highlighted how, with the right support, service users in this area can be actively involved in research. Minkes et al (1995) highlight the influence made to the research questions asked, the presentation of the questionnaire and in the dissemination stage of the project but acknowledge that participation in data analysis has not yet been developed. This research approach has been extended with service users with learning difficulties taking on co-researcher roles and developing, planning and conducting research with a researcher as well as co-authoring a paper (March et al, 1997).

More recently, the Department of Health funded ‘Learning Disability Research Initiative’ supported people with learning difficulties to be involved as partners in a research project that aimed to examine the extent of involvement of service users with learning difficulties in twelve separate research studies (DH, 2006a). Service users were involved at all stages of the research and felt that their involvement taught them a great deal about research and despite challenges such as travelling, access difficulties and some distressing interviews, found involvement satisfying. Of particular relevance to the research presented here is the fact that this team of service users undertook data analysis together with researchers in a similar fashion to that described in section 2.4.3 of this thesis (DH, 2006a:33). As well as challenging assumptions about service users with learning difficulties being involved in research as partners, the findings of this project highlighted service user concerns about practical and personal issues of being involved in research.

In a different field, a project to evaluate user panels of frail older people that had been in existence for about three years showed how service users can participate in research at any or all of its stages. The project coordinator wanted to ensure the active participation of older people in order to challenge ageist assumptions about the passivity of old age, to assist with the formation of the interview schedule and to enable panel members to feel at ease in talking to someone nearer their own age. The people participating in the project also conducted the interviews but the project coordinator solely analysed the data (Barnes & Bennett-Emslie, 1997:6). The report outlined the benefits of the user panels in terms of positive appraisals of the service user involvement itself for panel members and some influence of health and social care services. Due to a lack of clarity it is difficult to understand the effect of the service user involvement in this project other than in the formation of interview schedules.

These examples illustrate how, in areas where negative assumptions about desire and ability to be actively involved in research may exist, some service users may choose to become involved given the opportunity. This is of direct relevance to the research presented in this thesis.

With the spiralling interest in service user research and user-led initiatives came the need to try and evaluate these projects and to compile databases of these types of projects in order to judge the extent of this kind of development and to learn from them. The Shaping Our Lives project not only compiled a database of user-led organizations but also is active in research with service users looking at outcomes they want for themselves and their measurement (Turner, 1998:3). Baxter et al (2001) compiled a database of over five hundred literature references to participatory research and in their report include eight case study examples of projects that involve service users. From their investigation of a wide variety of projects and methods, in areas other than health research, they were able to offer a range of helpful recommendations for service user involvement in health related research (Baxter et al, 2001:101).

An example of research that actively involved service users at all stages was a project commissioned by INVOLVE to explore the provision of training that supports the

active involvement in research of the public and users of NHS, public health and social care services. A collaborative team worked on this project including seven people who used mental health services and these people had the title service user researchers (Lockey et al, 2003). The service user researchers were involved in most stages of the project including data collection, had their own training in research methods and used an NHS research department as a base. This research found that there was enormous value in the training initiatives and research involvement to a participant's personal development and confidence. Key elements that were found to enable confidence and enthusiasm to exist for service users taking part in a research project were:

1. Clear aim and purpose. It was not a clear enough goal, 'to contribute'. The training needed to be structured around specific research tasks and real research problems.
2. Involvement in the research process. Service users didn't want to have something 'handed down' but wanted to be involved in creating and developing ideas in which they could become absorbed and take some ownership.
3. Exchange and sharing between people. The sharing of experiences between participants enabled them to feel that they were not alone and this in turn enhanced self-worth. The participants described being more assertive and less reserved. They felt more powerful and in some instances they could illustrate that they had indeed been empowered to make changes happen.
4. Strength of the service users' experience being recognized. The process of listening to and valuing individuals experiences could refine for the individual that their experience, rather than being primarily negative, was a strength that they brought to the research.
5. Time and space for contribution. Enabling service users to make a full contribution to research is likely to take time and it cannot be done under pressure.

6. Safe environment. Confidence to contribute will only develop in a safe environment.

(Lockey et al, 2003:133)

The service user involvement part of this project has been evaluated and reported on in terms of the management and process of involvement rather than in any contribution to outcomes (Faulkner, 2004). The key elements presented above and highlighted as important for the productive involvement of service users in research can be seen to echo with principles raised in this thesis, particularly in sections 2.3, 5.11 and 5.13.4.

1.4.9 Experiential knowledge

The knowledge that originates from service users is suggested to be an alternative knowledge base and one which can contribute to practice in health and social care (Ramon et al, 2004). In discussing the experiential knowledge present in members of self-help groups Borkman (1976) offers a definition that will be useful to consider here:

Experiential knowledge is truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others.

This then highlights that experiential knowledge is knowledge that originates from experience. It might be particularly harnessed in areas where people have had experiences of common interest i.e. experience of particular practice, systems or organisations such as when a group of people are motivated to act in reaction to a poor experience of a particular service or to share their personal experience of their condition. It has been stated that experiential knowledge has two important elements. Firstly, that experiential knowledge arises from personal participation in the phenomenon and incorporates a reflective stance on this experience. The second element concerns the individual's conviction about the validity and trust in this knowledge based on experience of the phenomenon in question (Borkman, 1976).

Beresford hypothesises that it is knowledge that originates from this direct experience that delivers more reliable knowledge and expands:

The greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted.

(Beresford, 2003:22)

For service users then with direct experience of their own condition and their own needs, and in light of the above, knowledge production is not only possible based on this experience but also of central importance as it is a reliable and trustworthy form of knowledge. Others may express caution in such an accepting position though and could draw attention to concerns about the reliability of such knowledge drawn from direct experience. Hollway and Jefferson (2001) for example identify what they term ‘the defended subject’ who unconsciously defends themselves against anxieties caused by information they may provide in a research setting. It is unsurprising that some professionals and researchers, who may be firmly embedded within positivism with its assumptions of objectivity and distance, discredit this form of knowledge. Others may be embedded, methodologically, to resist such knowledge that is claimed to arise from experience. Phenomenologists for example may actively wish to refrain from any potential presuppositions that could sabotage the ‘neutrality’ of research.

Smith et al (2005:77) highlight the difficulty for service users in obtaining credibility for their experiential knowledge and suggest that this knowledge is ‘generally not seen as neutral, objective or distanced from the issues’. This point about competing knowledge claims is not a new one. Beresford and Croft (2001), for example, in discussing disagreements between those promoting service users’ knowledge and those promoting professionals’ knowledge claims within social work, highlight the distance that can arise between both these claims. They go on to call for a ‘two-way rather than one-way process’, that is concerned with the ‘growth and development of practitioners, as well as service users, each learning from the other’ (Beresford and Croft (2001). This call acknowledges the importance of perspectives and the difference in knowledge as well as encouraging a way for professionals and service

users to work and join their knowledge together rather than compete and perpetuate divisions.

Borkman (1976) highlights three differences between experiential and professional knowledge where tensions may arise suggesting that experiential knowledge is pragmatic, orientated to here-and-now action, and that it is holistic. Experiential knowledge can be pragmatic in terms of its emphasis on the knowledge and evidence for change that comes from individuals living the experience; it can be orientated to here-and-now action in terms of learning and changing from experience: and it is holistic in terms of viewing the whole of an experience in all its aspects. She goes on to emphasise that:

The holistic approach of experiential knowledge adds an important element not found in professional knowledge – the cathartic dimension, especially individuals' feelings about and evaluation of themselves and various aspects of their situation.

(Borkman, 1976)

Experiential knowledge raises many questions. Some of these questions may be: Philosophically or epistemologically what is being said? Is it that individuals should not be subjugated by professional knowledge? Is it that individuals can legitimately lay claim to their own unique knowledge base? If so, why might this be of importance? Perhaps this concerns what has happened to people who have been dispossessed of their knowledge and treated unfairly because of it. People who have mental health problems might be seen in this way and it is within the field of psychiatry and psychiatric survivorship specifically where this claim for acceptance of experiential knowledge is clearly well developed (Beresford in Jordan & Lent, 1999:44; Beresford & Wallcraft in Barnes & Mercer, 1997:80; and Campbell, 2005 for a personal account of experience as knowledge).

Tensions between professional knowledge and service users' knowledge are not purely restricted to the area of psychiatric survivorship. Beresford (2000) notes how the knowledge of various groups has been discredited. The knowledge of disabled

people has been discredited because of their perceived incapacity, psychiatric system survivors because of their perceived irrationality and people with learning difficulties because of their perceived intellectual deficiencies. I also question here whether the particular knowledge and viewpoints of people who have life limiting conditions are discredited or at least bypassed due to some form of avoidance or self-protective denial by the healthy. Whilst professionals may find it easy and acceptable to consult people who use palliative care services, perhaps giving primacy and creditability to knowledge that comes from their experience is too difficult for many professionals to accept. Ramon (in Ramon, 2003:16) for example describes service user research as an approach that ‘has been developed as a method of creating new knowledge, hitherto hidden and often described as invalid by professionals’.

Another facet to this knowledge that links with Borkman’s comments above concerning the so called ‘cathartic dimension’, is that for service users the presentation of their own accounts of experiences of services can lead to a ‘better understanding of what these services actually ‘feel like’’ (Winter & Munn-Giddings, 2001:30). Accessing and promoting experiential knowledge then is much more than consultation, it is concerned with impact at a very personal level, how it feels. Put another way, people’s experiential knowledge can ‘contribute to understanding the experience of a condition by telling us how they feel, their attitudes and how they respond to the care services they receive’ (Bradburn in Monroe & Olivier, 2003:28).

The relationship between methodologies based on participatory assumptions and co-operative inquiry is of interest here with Heron (1996:19) suggesting close links with a central proposition that like participatory research, co-operative inquiry also ‘does research *with* people not *on* them or *about* them (original emphasis)’. Co-operative inquiry is linked to action research and has been defined as:

A way of working with other people who have similar concerns and interests to yourself, in order to: (1) understand your world, make sense of your life and develop new and creative ways of looking at things; and (2) learn how to act to change things you may want to change and find out how to do things better.

(Heron & Reason in Reason & Bradbury, 2001:179)

As with action research then, co-operative inquiry is concerned with cycles of reflection and action with an emphasis on change for the individuals or group involved in each particular inquiry group. There is consideration of epistemology and four ways of knowing are proposed; experiential, presentational, propositional, and practical knowing (Heron and Reason in Reason and Bradbury, 2001:183). These four ways of knowing are presented in figure 1.1 below. In this context experiential knowing is said to occur when face-to-face contact is made between people or things and knowing is said to occur through the living of encounters. Following from experiential knowing is presentational knowing which acts as a form of translation of the experiential knowledge into expressed forms. Propositional knowing extends knowledge into the realms of knowing through concepts and theories that are communicated in statements. Practical knowing is said to be concerned with knowledge of skills or competences regarding actually doing something. Congruence is expected between these four ways of knowing.

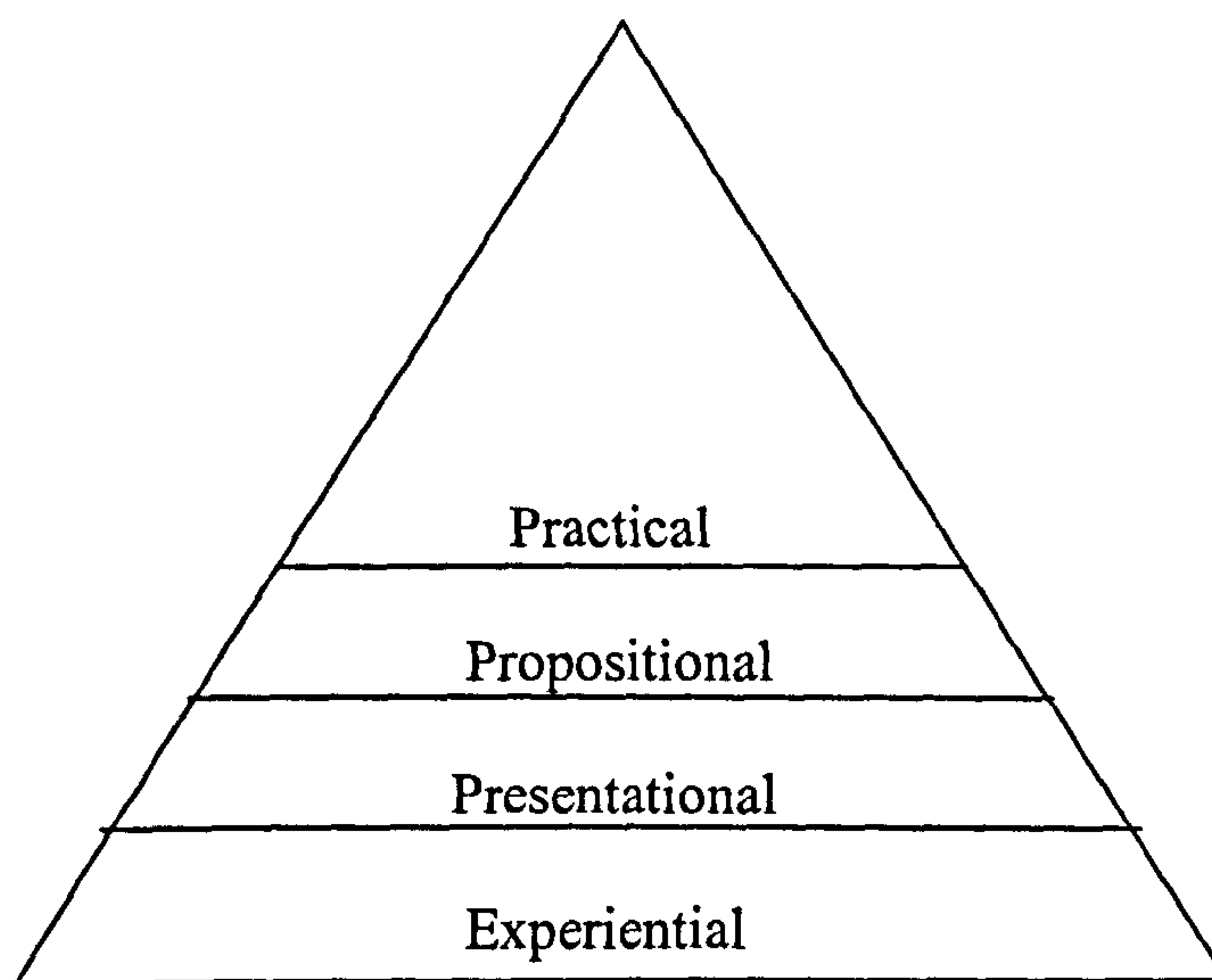


Figure 1.1: The pyramid of fourfold knowing (Heron, 1996:53)

These ways of knowing have also been associated with belief as a precursor to knowledge. For example propositional belief occurs when there is a belief that something is the case; presentational belief concerns the belief in intuitive understandings; practical belief is about a conviction in one's own developing skill; and experiential belief concerns one's own realisation about oneself or one's situation (Heron, 1996:53). In viewing it in this way we can consider that in this research

service user members of the SURAG had developments in all of these phases. Members illustrated belief in what they knew particularly when faced with data from participants that echoed their own experiences; here they also showed intuitive understandings about a whole range of issues and experiences participants spoke of; there was also a clear awareness, for some group members, about their own developing skills; and lastly there was a raised realisation about their own and other's situations.

Co-operative inquiry might be seen as individualistic with attention on individuals within groups to 'change', or to 'face issues' out of the context of their lives and their experiences. However the four ways of knowing schema is an additional tool with which to contemplate the debate of experiential knowledge. In a similar way to co-operative inquiry, Participatory Action Research (PAR) has been described as a 'collective, self-reflective inquiry that participants undertake in social situations, so that they can understand and improve upon the practices in which they participate' (Grbich, 1999:207). Successful outcomes are dependant upon the circumstances of the particular PAR project. Munn-Giddings et al (2005) have illustrated how organisational constraints and undermining can jeopardise the process and outcome for participants, commissioners and research teams. The setting and aim of projects that follow participatory approaches have significant impact on the nature of experiential knowledge formation. In the research by Munn-Giddings et al (2005), due to implicit structural difficulties within the organisations at the centre of the project, many challenges to the success of the PAR project were presented but still participants identified positive outcomes for themselves in terms of strategies for positive change and in generating their own solutions to problems.

Whilst wider structural changes that impact on peoples personal or public lives may be difficult to implement, coming together to work constructively with people who share similar concerns can then lead to changes at different levels. PAR has been traditionally viewed as particularly pertinent within professional practice but more recently has been re-considered in the context of local communities and people's social lives suggesting a wider application in everyday situations where people choose to investigate their own particular circumstances (Kemmis & McTaggart in Denzin & Lincoln, 2005:598).

1.4.10 Section summary

For emancipatory researchers then key concerns are about the relationships that occur in the research project, it's about the locus of power and of social change. It has been suggested however, that in recent years this has become more difficult to achieve due to an increasingly centralized policy setting agenda and there are suggestions that this approach to research remains in a precarious position (Barnes, 2003; Zarb, 2003:1). This concern about a centralized agenda is also applicable in the realms of service user involvement in research. The current political and policy drive for involvement of service users in research could in actual fact work against the ideological intention of most inclusive research. As 'mainstream', traditionally orientated researchers are encouraged (in securing DH funding for projects proof of 'consumer' involvement is needed for example) by central policy initiatives to include service users in their research it is hard not to be cynical and concerned. Expecting researchers to ensure greater involvement of service users in their projects is not likely to persuade them of the merits or even to ensure they necessarily work with service users in constructive ways. Of course some researchers with little previous experience, knowledge or commitment of this approach to research are likely to genuinely engage with this in respectful and considerate ways.

We have seen that the pursuit of participatory research can be problematic if principles outlined in the literature on service user involvement in research are not heeded. Participatory research may fulfil a consumerist agenda whereas research informed by the emancipatory research approach and following key principles of service user involvement in research offer the opportunity for far greater democratic research for service users. It was a democratic participatory approach strived for in the research presented in this thesis and this will be described in section 2.3. In light of this literature it is the relationship between myself and service user members of SURAG that I see as important. In my research I sought to apply principles of sharing control, of maximising service user choices and decision-making in the research and of providing an environment that service users may find empowering and were able to utilise their experiential knowledge. I attempted to offer the use of my motivation and research skills in order to facilitate SURAG members' fulfilment in research terms.

1.5 Social model of disability

The social model of disability (SMD) has been utilised in this research as a way to examine palliative care and life limiting conditions. This connection is unusual and I have not seen this made elsewhere in the literature. There have been connections made between the SMD and various specific conditions i.e. multiple sclerosis (Somerset et al, 2002), impairment (Goodley, 2001; Tremain in Corker & Shakespeare, 2002: 32; Thomas in Swain et al, 2004: 21), ageing (Zarb & Oliver, 1993), mental health (Beresford, 2002c) and as a way of reflecting on death (Murray, 2003). The application of the SMD to palliative care here would though appear to be unique (Barnes, 2006).

I suggest that such an application is warranted in light of the aforementioned connections and the significant debate about the SMD and its tensions with issues of chronic illness and impairment. In terms of chronic illness the emphasis from a SMD perspective is that studies of illness are likely to be individualistic with an orientation to highlighting negative consequences (Barnes & Mercer in Barnes & Mercer, 1996: 13). In terms of impairment the SMD has been charged with diminishing personal aspects of experiencing impairments in order to focus on oppressive structural factors. A related point is that the SMD may assist perceptions of impairment and altered lifestyles that occur later in life. Highlighting the cultural environment that emphasises the purely negative and unwanted aspects of impairments and altered lifestyles is one way of resisting them. This research strove to explore tensions in these areas that may surface in palliative care when utilising the SMD.

In this last section of the chapter I will present a short overview of the social model and make some initial connections to palliative care.

At the outset clarity is required about the origins and claims proposed for what has now become popularly known as the social model of disability. In reviewing early publications focused upon promoting a serious debate on disability issues and in forcing the agenda towards societal change in relation to disabled people, the Union of the Physically Impaired Against Segregation (UPIAS) appear to have been early

pioneers. Their policy statement (UPIAS, 1974/75) clearly identifies disabled people as an oppressed group, particularly in terms of residential homes. Their appraisal of 'segregated institutions' that are the 'ultimate scrap-heaps of this society' is unflinching in its criticism of them and in its call for equal control and choice for disabled people in relation to non-disabled people, in all areas of life (UPIAS, 1974/75:2).

In a discussion of the 'Fundamental Principles of Disability' between the UPIAS and the Disability Alliance clear definitions for impairments and disability were identified by UPIAS:

...we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.

(UPIAS, 1975:14)

This definition has been challenged, recently by way of a feminist critique that seeks to regain the personal and individual experiences of disabled people particularly in terms of impairment and gender that they feel are lessened or side lined by the SMD. This will be discussed further below.

1.5.1 The Social Model of Disability: A short history of its development

The social model of disability has a long history associated with its development and the SMD, as understood today, has evolved over this time and indeed, as will be shown, is continuing to evolve and to be contested (Campbell & Oliver, 1996; Centre for Disability Studies, University of Leeds, <http://WWW.leeds.ac.uk/disability-studies/archive>; British Council Of Disabled People, <http://WWW.bcodp.org.uk>).

These developments have stemmed from what some call a 'social movement' of primarily disabled people, but also movements of mental health service users and survivors, that have emerged since approximately the 1960's and more recently people with learning difficulties. In the realms of the disability movement it is widely acknowledged that Paul Hunt was the primary 'founder' of the movement (Campbell & Oliver, 1996:53). He is responsible for a high profile challenge to the establishment of researchers at the time that captured the imagination and emotions of many people. Hunt was a resident in a Cheshire Home called Le Court in the 1960's and was pivotal in encouraging and enabling other disabled people to challenge the status quo that expected disabled people to be grateful for the institutional services they received. He was responsible for much consciousness raising at the time about the unacceptable situation that many disabled people found themselves in. Hunt was involved in a long and bitter struggle with his particular home over his and other resident's rights to have control over their lives in the home (Hunt, J, 2001).

Hunt was also central to the relationship and critique of research that had disabled people as its focus. Connected to his, and others, challenge to the institutions they resided in was a study commissioned by the Ministry of Health into the participation of residents in 22 of these 'homes' and was conducted between 1966-69 by Eric Miller and Geraldine Gwynne of the Tavistock Institute for Human Relations. This has become a landmark piece of research within disability research mainly due to Hunt's critique of it. The residents anticipated that the researchers would have some sympathy for their situation and aspirations. The report of the research, '*A Life Apart*' (Miller & Gwynne, 1972), concluded that the segregated system was oppressive to the residents. However, it only recommended operational improvements in the institutions rather than the elimination of the system itself, and significantly for residents like Hunt, avoided the recommendation that residents should be more involved in the management of their homes. The residents felt that they had been 'conned' (Hunt, 1981:39).

It is interesting to note in Hunt's paper 'Settling accounts with the parasite people', that the expectation was that these researchers were to be on their side (Hunt, 1981:39; note that Hunt's use of the term parasite refers to what he saw as the parasitic way the researchers fed off the residents to further their own careers). He is

seemingly suggesting what, twenty years later and mentioned above, Mercer calls ‘partisanship’ to be treated as a serious practice in research. There was some basis for the residents to be hopeful that the researchers would reflect their ambitions sympathetically in the research. The researchers were involved with the residents from 1962 and because they were invited by the residents and were from a renowned centre of expertise on group dynamics the residents expected the research to highlight their struggle and for recommendations to ensue that may assist their struggle for control.

Hunt set to highlight how despite their claims of objectivity the researchers actually had preset assumptions and directions to their research which meant that it was ‘profoundly biased and committed against the resident’s interests’ (Hunt, 1981:39. original emphasis). He also focused upon the fact of the researchers’ attempts to focus on the operational aspect of these institutions instead of taking a wider analytic view of how their segregated status could be challenged (Hunt, 1981:40). A direct clash of world views, of understandings and assumptions is obvious, with Hunt firmly identified within the social model of disability and taking Miller and Gwynne to be firmly rooted in the medical model ‘which sees our social disadvantages as caused by our impairments’ (Hunt, 1981:44. original emphasis).

This critique was not only scathing but visionary too. Although the social model of disability and emancipatory research were not clear terms or ideas such as they are today, Hunt had a clear vision that must be ranked as one of the strands that eventually led to the social model and emancipatory research developing into its current form. Hunt went on to form the previously mentioned Union of the Physically Impaired Against Segregation (UPIAS), a disability liberation group. UPIAS promoted an alternative view of disability based upon experiences in institutions, such as it being society that excludes disabled people via the way in which society organizes itself to take no account of them and that society should adapt to include its disabled members and not the other way around (Hunt, J, 2001).

The disabled people’s movement then, developed as a response and a challenge to the existing hegemony of the traditional medical model of care and welfare. Rather than this traditional perspective that placed onus and responsibility on individuals and on

individuals ‘limitations’ and ‘impairments’, the developing ‘social model of disability’ saw explanations of disability clearly lying with society itself. Credit for the development and popularization of the social model is often given to Mike Oliver, the first Professor of Disability Studies in the UK, but he deflects such credit. Indeed the rise of this model is a complex one with many stakeholders. A wide range of organizations have contributed to this impetus of consciousness raising including the British Council Of Disabled People, established in 1981, which claims to be the UK’s national organization for disabled people representing 126 groups run by disabled people in the UK and with a membership of 350,000 disabled people. Disability rights and research have not developed in isolation in the UK however. There have been global struggles but these have primarily been associated with Europe and America (Russell & Malhotra, 2002).

The social model of disability offered an alternative way of viewing disability and disabled people. Instead of disabled people and their impairments being seen as a ‘personal tragedy’ the social model enabled disability to be seen as ‘...culturally produced through the relationship between the mode of production and the central values of the society concerned’ (Oliver, 1990:23). The social model resulted in a consciousness shift in many disabled people as a consequence of people ‘...focusing on disabling environments rather than individual impairments...’ and this ‘...freed up disabled people’s hearts and minds by offering an alternative conceptualisation of the problem’ (Campbell & Oliver, 1996:20). In maturity though, key facets of the SMD have been challenged. Primarily this interface between disability and impairment just mentioned has been the site of disagreement.

1.5.2 Impairment

Whether the dominance of the social model has suppressed discussion of other aspects in the lives of disabled people, such as impairments, has become the focus for significant attention. There have been calls to “bring back impairment” and challenges made that it needs to be located centrally in the debate about what constitutes the SMD. It is contended that theorising impairment does not necessitate a ‘sell out’ to the medical model understanding of disability. It has been framed in these terms:

...our insistence that disadvantage and exclusion are the result of discrimination and prejudice, and our criticisms of the medical model of disability, have made us wary of acknowledging our experiences of impairment. Impairment is safer not mentioned at all.

(Crow in Morris, 1996:209)

Following Crow, and in arguing their case for a sociology of impairment, Hughes and Paterson (1997) agree that debate about the body is silenced as impairment and disability have become annexed by the SMD. These authors go on to highlight what they see as a series of binary opposites produced by this annexation with each binary couple in table 1.2 below (read horizontally) excluding its opposite but including those concepts situated in the vertical column.

Table 1.2: Impairment and disability as binary opposites (Hughes and Paterson, 1997)

The Biological	The Social
Impairment	Disability
The body	Society
Medicine	Politics
Therapy	Emancipation
Pain	Oppression
The medical model	The social model

The key point with regard this proposition is that whilst disabled people may have a politicised social life they also, invariably, experience impairment that is part of their everyday life. There is no Cartesian divide but rather a complex intertwining 'of oppression and affliction' (Hughes and Paterson, 1997).

Impairment is not seen as a site for political struggle by traditionalists of the SMD (namely Oliver & Finkelstein), and yet feminist critiques challenge that in fact, the 'personal is the political' (Stanley & Wise, 1993:66). Here then subjective experience

comes to the foreground and by doing so issues of power, discrimination, and oppression can be examined within the personal sphere. This may be seen as a microanalysis of power and oppression but proponents claim these micro examples connect to the macro i.e. environmental and structural aspects of oppression, which disabled people may face.

In outlining an emancipatory disability research, along with other 'markers' of excellence, Stone & Priestley (1996) claim that such research must give voice to the personal as political. Their work has been given credibility within the sphere of disability studies and appears to be a widely accepted 'how to' guide on conducting effective and worthwhile disability research. It is interesting that these authors should choose to highlight this issue, which on this one point, as mentioned above, challenges the traditionalists of the SMD.

At the outset Oliver (1990: 68), who was previously noted as one of the key influences in the development of the SMD, stated that disabled people have 'preferred to reinterpret their collective experiences in terms of structural notions of discrimination and oppression rather than interpersonal ones of stigma and stigmatisation'. Much earlier though in this same text Oliver (1990:14) appears to completely side step a thorough examination of impairment being quite selective in his descriptions of impairments that may be said to be culturally produced i.e. infectious diseases, accidents at work.

Oliver clearly calls upon structural/Marxist understandings in his consideration of the location of impairment in relation to the SMD. For the conditions he selects it is plausible to suggest cultural and political influences in their production and sustainability. What he completely omits to discuss are impairments that are hereditary in origin, and degenerative life limiting conditions for example.

This is not to suggest that disabled people have not been leading the struggle to be defined on their own terms. Disabled people, disabled activists as well as academics within disability studies have sought to challenge disabling individual and medical understandings of themselves and their lives. Hughes (1999) highlights the rise of the Independent Living Movement as a testament to this spiralling activism (discussed

above) that put disabled people's issues centre stage and has led to policy changes within the UK. Later, Oliver is very clear about what he views is at risk by acknowledging impairment in the SMD when he says:

...that attempting to incorporate personal experiences of impairment into the social model of disability risks diluting our political struggles to overcome the barriers in society we face.

(Oliver in Barton, 2001:152)

In a similar vein, Barnes (in Barton, 1996:57) uses paid work as an illustration and differentiates between impairment and wider cultural representations of disability. For Barnes (in Barton, 1996:57), like Oliver, it is an either/or scenario with material and cultural forces seen as the prime foci of attention, as individual prejudice "is the product of a particular form of social development associated with western capitalism".

A concerted challenge to the prevailing and normative understanding of the SMD has come from Thomas (in Barton, 2001; in Barnes et al, 2002; in Barnes & Mercer, 2004; in Swain et al, 2004). Thomas acknowledges that she shares common epistemological ground with Oliver and colleagues however she points out what she describes as a "too restricted" focus on external social barriers that informs disability (in Swain et al, 2004:25). Thomas refocuses attention instead upon internally constructed disablist exclusions that she terms psycho-emotional dimensions of disability:

Of particular concern here are the impacts and effects of the social behaviours that are enacted between the relatively powerless 'impaired' and the relatively powerful 'non-impaired', for example, in familial relationships, in interactions in communities, and in encounters with health, welfare and educational services. It is about people with impairment being made to feel of lesser value, worthless, unattractive or disgusting.

(Thomas in Swain et al, 2004:25)

In relation to palliative care, valuable connections can be clearly made here and consideration will be given to this in section 1.6 below. Thomas contends that impairments experienced in one's personal life are also subject to prejudice and discrimination although as a consequence of the SMD eclipsing impairment "key dimensions of disability are ignored" (Thomas in Barnes & Mercer, 2004:38) and she goes on to suggest that impairment is the "raw material upon which disability works" (Thomas in Barnes & Mercer, 2004:41).

Morris (1996:13), amongst others influenced by a feminist approach, had previously noted omissions from the social model such as the experience of bodies, impairment and certainly understood the likelihood of criticism from both within disability studies, disability activism and from non-disabled people.

An interesting account of the everyday experience of living with disabilities is given by Titchkosky (2003). Her description and theoretical exploration of living with dyslexia and blindness being akin to negotiation with the 'able-bodied' can be read as a fascinating insight. Of particular interest here though in light of this discussion is her way of dealing with the issue of impairment and disability. Titchkosky (2003:44) suggests that disability is a way of "eliminating subjective experience by making disability into simply the effect of oppressive societal structure". She goes on to suggest that this is an attempt at normalcy by the mainstream and clarifies her own decision to write of both the personal and the political. Writers who have focused on learning difficulties relationship to the SMD also place significance on this 'turn to impairment' (Goodley, 2001). To be clear this means challenging the SMD's insistence that it is purely social structures that are important to recognise and change in favour of including personal accounts about the experience of impairments.

There exists then something of an impasse between the original and Marxist proponents of disability studies and the more recent critical commentators who critique the SMD from several perspectives. One perspective may include palliative care. Small and Rhodes (2000:67) highlight how the SMD has been criticised as being of greater relevance to people with static and slow developing impairments rather than to people who have progressive conditions and impairments. They go on to provide more doubt as to its significance:

For people for whom illness and impairment are more intrusive and likely to assume greater prominence in their lives, the movement's 'social model' and attendant political consciousness may be more difficult to embrace.

(Small & Rhodes, 2000:78)

For Crow (in Morris, 1996:217) 'impairment is problematic for people who experience pain, illness, shortened lifespan or other factors'. A social model of disability, whilst being helpful in aiding consideration of wider social factors that may negatively impact upon people with life limiting conditions, can then create a tension with its traditional relegation of impairment. In its aim of exploring what the SMD may offer palliative care research, the research in this thesis sought to explore and address some of these issues about impairment. It was attempting to establish if both personal and wider societal issues could be given primacy by utilising the SMD. In the findings chapters an indication will be gained of this from the accounts of service users with life limiting conditions and in section 5.13.5 this point will be discussed.

1.6 Chapter conclusion

In summary, this chapter has outlined the nature, remit and development of palliative and hospice care. It has indicated how understandings of non-cancer conditions have been evolving in recent years and how palliative and hospice care services have been challenged to recognise and respond to the unmet palliative care needs of service users with non-cancer conditions which have historically fallen outside of their remit. A wide array of research involving service users with conditions included in this thesis have been drawn upon and critically examined. Some of this research was also conducted utilising participatory approaches. A proportion of the studies compared palliative care needs between participants with cancer and those with one specific non-cancer condition. Generally these comparative studies highlighted similar concerns and needs between the two groups but often with the non-cancer participants receiving less support or palliative service provision. We have seen how much of this research highlighted issues of a physical nature but where some connections could be identified with the research in this thesis the relevant issues were often not prioritised

as central findings. Unfortunately there were many studies where methods were not clearly explained making judgements about the research and how findings were generated, impossible. Studies with a participatory approach also often failed to indicate the full influence of the service user involvement within the study and hence judging if findings were influenced as a result of the service user contribution was also impossible.

Service user involvement generally and service user involvement in research specifically have been critically explored in this chapter. The exploration of definitions, meanings and ideologies is important and directly connects to decisions made about epistemology and methodology in this thesis and specifically presented in chapter 2. The reluctance and scepticism regarding service user involvement in palliative care has been shown and needs to be acknowledged as a contextual issue for this research. The dearth of any ‘evidence’ as to the influence that service user involvement in research may bring has also been highlighted.

Lastly the social model of disability has been examined and tensions within it highlighted. The particular issue causing wide disagreement in this field is that of the focus on more external social factors that shape the experience of ‘disability’ and the relegation of internal personal issues associated with physical impairments that is argued also require acknowledgement and study.

In light of this literature review chapter it will be useful to review the aims of the research presented in this thesis here again. Firstly, it was aimed to gain accounts from people who, potentially, had palliative care needs and to highlight a range of experiences of their lives and conditions. Secondly, to establish what service user needs were in terms of support and care services. Thirdly, to establish the influence of involving service users in palliative care research and this included a consideration of the service user contribution. Of interest was whether this involvement could work in terms of both process and outcomes. Lastly, an aim was to highlight any social or environmental factors that may shape or influence experiences of living with a life limiting condition. To this end it was pertinent to consider if the social model of disability could contribute new perspectives to palliative care research.

This thesis attempts to contribute to the literature in this field in terms of adding to what is known about the experience of living with a life limiting condition and in particular to the evidence about what a wide range of service users' needs are for palliative support and care services. To the best of my knowledge this is the first time such a wide range of conditions has been included in one study and in such depth. The unusual utilisation of both service user involvement in the research itself and of the SMD strove to add alternative dimensions to the research and therefore also to the field.

The involvement of service users in the research was considered to be compatible with central principles in palliative care and was taken forward as a way to explore any influence on research utilising this approach. By clearly presenting how this participatory research was conducted and the process of the service user involvement in it, it was intended that the influence of service users would be more transparent than in some of the current research presented in this literature review. We have seen that there is a resistance to the involvement of service users in palliative care services and research, this research will, in a small way, seek to challenge this resistance. It will also strive to establish what the outcomes of taking this approach will be both in terms of the research findings and in terms of the process of the research or how the research is conducted.

Another intention is that using the perspective of the SMD will enable different societal dimensions to be accessed that have not been fully forthcoming in some of the palliative care research examined in this chapter. This research sought to access not only individual experiences but also collective experiences of life with a life limiting condition and peoples' perceptions of wider societal factors that may also impact on their experience. The usefulness of applying the SMD in palliative care research is therefore examined.

Chapter 2 – Methods

2.1 Introduction

In this chapter I will address issues of epistemology, theoretical influences, methodology and methods that are pertinent to this research. The structure for this chapter aims to be sequential whereby the stages of the research process are dealt with in turn as they occurred in practice. Epistemology and theoretical influences are therefore positioned early in the chapter, as these are considerations that occur at the commencement of a study. The methodology that I chose as appropriate to the epistemological and theoretical influences is dealt with next in section 2.3. It should be noted here that a degree of adaptation occurred at this stage and this will be described in this section. Methods, in terms of data collection and analysis come next and this will include ethical issues pertaining to the research (Section 2.4). Finally I will consider issues of rigour to be considered as part of the critical evaluation of this research. Initially though in this introduction I will outline my early interest in working in a collaborative way and explain why it was that a participatory approach was followed in order to undertake this research. I will also introduce the Service User Research Advisory Group who, it will become apparent, were an integral part of this research. This chapter is divided into the sections shown in table 2.1 below.

Table 2.1: Methods chapter sections

SECTION	TITLE
2.1	Introduction
2.2	Epistemology & theoretical influences
2.3	Methodology
2.4	Methods
2.5	Rigour
2.6	Chapter conclusion

2.1.1 Original plan and motivation

In the introduction to this thesis I described how I became interested to take forward research that was inclusive of service users in a collaborative manner but here I want to outline a little more personal background. This is in order to be explicit about assumptions I held that would impact on the direction of and choices made in this research project.

My professional background is within health care generally and nursing specifically. My career began within psychiatry and I later changed direction to work within palliative care. I was originally motivated by thoughts of making a difference and improving the well being of people with mental health problems. These things resonated with me and it also seemed different and interesting. On reflection I remember being attracted to the idea of being an advocate for people, of tuning in to people's experience and thoughts and of helping them through a difficult time. It seemed challenging and looked like one could really make a difference in people's lives. I held assumptions and ideals that originated in personal experiences and centred on the need for myself and others to be heard and understood. Many years later as a user of social services the ideal to be heard and understood became a need for me in reality, as these opportunities were not available within the 'system' at the time. Although this experience as a user of social services was, and is, transitory and not required from a position of ill health, it has been a small insight into the powerlessness that can accompany the use of services.

My experience of working in palliative care for over a decade has also contributed to my ideals of working collectively. I have had experience in a hospice in-patient unit and a community palliative care team that I went on to manage for a short time.

Working with people who had advanced cancer, I became interested in the difficulty people who are very ill have in getting their ideas and wishes across. I was aware that for some, greater involvement was possible and strived for and that this involvement wasn't just in the personal care required but in a broader way. People had a desire to influence the hospice and to play an active part in it. This was denied them though with very few opportunities to participate and influence practice or the service.

When I became aware of the possibility to be involved in research as a participatory endeavour I saw a connection to both personal ideals and also to ideals in palliative care. Such benefits as valuing people, enabling people to fulfil their potential, listening and treating people with respect and honesty, as well as trying to see things from others perspectives.

2.1.2 The Service User Research Advisory Group (SURAG)

This is intended as brief introduction to the Service User Research Advisory Group and further elaboration will occur in section 2.3.2. In considering undertaking a participatory study I wanted to enable involvement at as early a stage as possible. However, as this research was part of a doctorate, I needed to complete research training at the outset and I also developed my research proposal during this training phase. During this time I talked to many people about my research ideas. On one occasion, during the development of the proposal, I visited another local hospice to talk with some professionals and a group of service users about ideas for the proposal.

At the suggestion of another service user who was to become a member of the SURAG I also arranged a meeting with representatives from various local service user groups to discuss the research aims and questions. This was done though at a time when the Local Research Ethics Committee had already approved the proposal and so there was very little room for substantial change to occur. Only a little service user input to the proposal had occurred. In retrospect I now see this was an oversight on my part as important service user insights may have shaped the proposal differently. However, at the meeting with service user representatives the proposal was welcomed as it was and all felt it a worthy project. The SURAG developed from this meeting and first met well before data collection began.

In forming the SURAG I hoped to achieve a research group that would work together with the project clearly in mind and focused on a common purpose. I aimed to ensure that group members would be clear about their roles and tasks and that all aspects of the research would be collectively considered.

The SURAG was formed to work with myself, the researcher, from the outset in order to share the knowledge and experiences of people living with life limiting conditions

with the researcher. The aim was to ensure that the research remained in tune with service user concerns and needs, and to enable group members to influence the research at all stages of the research process. It aimed to be a democratic group where service user members could genuinely shape and influence the research.

2.2 Epistemology and theoretical influences

Epistemology is concerned with the nature of knowledge, its sources and boundaries. It has to do with the question of gaining knowledge and also with the question of the truth-value associated to this knowledge. It is about what counts as knowledge. The relevance of this quest to unpack our assumptions about knowledge has been described in these terms: 'Epistemology is concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate' (Maynard in Maynard and Purvis, 1994:10). Therefore, a need to explain and justify the epistemological stance that is chosen becomes clear.

This study's methodology is framed by a number of different, but broadly consonant theoretical approaches. I have been influenced by work in feminist theory, critical inquiry, and the emancipatory research paradigm. These theoretical approaches that inform this study all hold a stated position with regard to understanding what is involved in knowing, that is how we know what we know. It is essential that these approaches are appropriate to this study and that they share enough epistemological assumptions that do 'fit' together in a consistent way. The epistemological positions adhered to with each of the approaches that inform this study will be examined here and, in conclusion, their 'fittingness' or adaptation to this study will be discussed.

Firstly though, it is important to discuss epistemology in a wider context than that which will follow for each of the approaches previously mentioned. The three main epistemological positions are objectivism, constructivism and subjectivism.

2.2.1 The main epistemological positions

Objectivism

Objectivism can be characterised as:

...the epistemological view that things exist as *meaningful* entities independently of consciousness and experience, that they have truth and meaning residing in them as objects ('objective' truth and meaning, therefore), and that careful (scientific?) research can attain that objective truth and meaning.

(Crotty, 1998:5)

This epistemological view is what underpins the theoretical perspective of positivism that has predominated in Western thought for centuries with figures such as Plato, Descartes, and Comte, having played a significant part in its historical development. It is out of my remit here to explore this historical development of objectivism and science more broadly. However, central tenets in this 'objective' epistemology concern the unbiased, value neutral position of the researcher. Taking this position claims to eliminate the subjectivity of the researcher and therefore maximise the truth and the credibility of the research and its findings. There is a primacy inherent in this position in which the objective researcher, and other researchers like them, takes on a role as 'the' knower/expert.

For researchers adhering to an objectivist rationale, validity of knowledge generated through research suggests that the research can be replicated by other researchers in very similar situations and always gives the same results. Usher (in Scott and Usher, 1996:13) highlights this as an objectivist epistemological assumption of **determinacy**, whereby a certain truth can be known. He goes on to describe other assumptions of **rationality** whereby there can be no contradictory explanations; **impersonality** whereby objectivity is privileged above subjectivity; **prediction** whereby the research makes knowledge claims that can be generalised and predictions therefore made and; finally, these assumptions are **unreflexive** in terms of the research process (Usher in Scott and Usher, 1996:13).

These assumptions presume that researching social situations and social beings is conducted best following logical and universal rules. Social and cultural dimensions of the research, along with thinking of the research in terms of having historical and political impactors, are of secondary concern to positivist researchers. This position has been summarised; 'objectivist epistemology holds that meaning, and therefore meaningful reality, exists as such apart from the operation of any consciousness' (Crotty, 1998:8).

Constructivism

Marton and Booth (1997:6), in describing Piaget's epistemological position state that his constructivism does '...not assume that knowledge exists "out there", ready made, and that we somehow "take it in" from the environment...' but rather '...knowledge is constructed by the individual through her acts, through her interaction with the environment...'

For constructivists there is no objective truth waiting for us to discover it. Knowledge and meaning is not external to us but is constructed by us and in different ways by different people. The world is made sense of by people's interaction with, and in, the world. For constructionists meaning or knowledge cannot be just 'objective', nor can it be just 'subjective'.

Subjectivism

'In subjectivism, meaning does not come out of an interplay between subject and object but is imposed on the object by the subject' and it is this subject, this individual, who creates meaning from their beliefs or experiences for example and not from '...the object to which it is ascribed' (Crotty, 1998:9).

Subjectivism is a more acceptable epistemological assumption within the realms of a postmodernistic questioning of grand narratives (the widely held and unchallenged assumptions in society i.e. an uncritical acceptance in the abilities and legitimacy of modern medicine or western government), and ways of knowing.

2.2.2 Towards an acceptable epistemological position

The objectivist position is far from the assumptions accepted in this study. This study is concerned with the everyday world of experience which is often changeable, uncertain, and ambiguous. An everyday world in which people interact with and make sense of, in light of their own beliefs, understandings, and values that have been arrived at via personal experience and knowledge and the experience and knowledge gained from their culture. This study is orientated by the constructionist epistemological position and is influenced by a number of theoretical approaches as will be described below. It is important to note that these approaches have been selected because they are compatible with the constructivist position. First though more consideration is required on the nature of knowledge being put forward as central to this study.

In reaching an acceptable knowledge position for this study the challenge is concerned with accessing a partial knowledge or a situated knowledge that may represent the knowledge held by marginalised groups in society. An 'expert' knowledge is not the most important issue here then. This epistemological position moves in the direction of what has been referred to as a post-modern relation to knowledge and understanding. Reason, absolutism, and certainty become challenged by a position that recognises the ambiguity, fragmentation, and relativity that encompasses society broadly and knowledge specifically. I am using the term marginal here to suggest that the voice and knowledge of people with life limiting conditions can easily be seen as of less importance or to be less powerful than other groups of people.

A key understanding in this position is the acknowledgement and importance of difference. A post-modern epistemology acknowledges that many perspectives always influence knowledge. Coming to knowledge will be dependant upon the perspective of the knower. Dialogue is the key for this epistemological approach to be successful. In this epistemological approach I contend that the voice and knowledge of marginalised groups has a place amidst the dominance of conventional groups that often have a more highly perceived 'credible' voice that commands attention and action. This partial knowledge from marginalised groups is no less nor no more than the knowledge from these conventional groups. However, knowledge claims from

marginalised groups of society will face a far greater challenge to be acknowledged as a credible knowledge and to be utilised as a valid knowledge from which to base decisions concerned with changing or improving society. Dialogue, with its listening and responding requirement, can enhance the sharing, acceptance, and understanding of others knowledge.

As Hill Collins (1990:237) suggests, this dynamic of dialogue within and between groups can enable difference to be transcended. There is however an inequality in knowledge production and the acknowledgement of one's knowledge as referred to above. Those with marginalised knowledge will need to struggle for acknowledgement of theirs as a credible knowledge and those traditionally in a privileged epistemological position will need to shift significantly to accept knowledge in different forms, of ways of knowing the world. These ideas are expanded below in the section on Paulo Freire.

Within all the approaches that follow there is a vast range of perspectives and assumptions that make up each approach. Each approach will be utilised by varied academic and research communities that elect the approach, in a wide variety of ways.

Therefore, each approach will have many differences as well as many commonalities drawn out of it by these different interpreters of the approach. There are many facets to feminism, to critical inquiry and to an emancipatory research approach. What is attempted here is to identify and argue for a particular epistemological position that arises from each of the selected approaches; one that will be consonant with the perspective adhered to in this research project.

The choice of each approach as consonant and helpful to this research and thesis is based upon their common aims of challenging research that is conducted on objects and in their aim to bring to voice marginalised groups. Humphries (1997:3) confirms that 'critical, feminist, participatory and anti-racist approaches to research all have this explicit purpose as a fundamental and legitimate premise'. There may be some similarities in the following sections to some of the material presented in the literature review. The specific focus and difference here though is the interest in each of the approaches perspectives on knowledge.

2.2.3 A feminist contribution

In very broad terms most feminist thought will challenge the objectivistic position of traditional science found within positivism, and might also see the development of this 'scientific' epistemology as a means of domination by privileged groups in society. Science, in its objective form, will have its claim of neutrality contested and emphasis will be placed upon the social and historical factors that effect people generally and researchers specifically. Feminism is concerned with mobilising women who share similar concerns as a result of their oppression as women in a patriarchal society.

Feminist research is overtly a political struggle with a central debate being about the significance of being a woman, the place of female experience and gender difference in knowing, and knowledge making. It is often concerned with changing people's situations rather than having a prime focus on understanding their situation. The differences between feminist and positivistic positions may be simply illustrated as shown in table 2.2, with feminism in line with aspects in the post-positivism column.

Table 2.2: Gendered differences of paradigms in science (Hey, 2002)

Positivism	Post-positivism
Objectivity	Subjectivity
Rationality	Emotion
Quantification	Qualitative
Outcomes	Process
Mind/culture	Body/nature
Hierarchical	Multiplicity
Value-free	Value-laden

Harding (in Alcoff & Potter, 1993:49) describes three developments in feminist knowledge positioning; feminist empiricism; feminist standpoints; feminist postmodernism. Feminist empiricism concerned itself with rectifying the male gender bias in science, and challenged this by way of 'adding women in' rather than by

challenging the sexist nature of science itself. Identification of the problems with the omission of women's experience in accounts was now possible.

Feminist Standpoint Theory (FST) went much further and facilitated the privileging of the social experience of women. Here now women's lives were seen in terms of oppression and marginalised knowledge could be brought to the fore. Difficulties with this position became identified though, such as not all women's experiences are the same or even similar. Also, when experiences do seem to be the same women do not draw the same conclusions from them and differences between women such as age, race, and social class is likely to position women differently to each other. Even in sharing a similar experience then, women are likely to have 'differences' between each other that will lead to different interpretations and conclusions about that experience. FST has been defended against these criticisms however, with New (1998) for one proposing that women's knowledge from common experiences can be 'pooled' and collectively analysed. This interest in accessing collective experience whilst acknowledging individual differences is of particular interest to the research presented in this thesis. Here an attempt is made to collectivise and present a range of experiences involved in living with a life limiting condition.

Feminist postmodernism brought about the questioning of what it actually means to know. It enabled the consideration of power positions to be examined and the questioning of truth. Sandra Harding draws on Hill Collins work (discussed below) and promotes a project that:

...requires learning to listen attentively to marginalised people; it requires educating oneself about their histories, achievements, preferred social relations, and hopes for the future; it requires putting one's body on the line for "their" causes until they feel like "our" causes; it requires critical examination of the dominant institutional beliefs and practices that systematically disadvantage them...

(Harding, in Alcoff & Potter, 1993:68)

Harding describes what she calls strong objectivity in which a reflexive position is taken that is aware of the social situation of knowledge generation, how knowledge is produced, and the 'unknowing' of researchers. The unexamined shared assumptions and beliefs between researchers and the researched are at the centre of attention here.

Despite Stanley and Wise (1993:193) proclaiming a 'fractured foundationalist epistemology', their criteria for knowledge production appears to include all the factors a feminist postmodern approach does. These authors also stress the importance of emotion within knowledge production and claim that the 'personal is the political' (Stanley & Wise, 1993:66). This position gives credence to subjective experience and highlights how power can be experienced and examined within personal life.

The preceding discussion may generate questioning as to the necessity or even validity of pursuing so called marginal voices and their knowledge. As was identified by critics of FST, even if it is accepted that a particular group is marginalised, how can quite disparate voices and their knowledge be harnessed and said to constitute knowledge from this group. Isn't it rather many individual voices and many forms of knowledge that arise? Whether it is women, people in black and minority ethnic communities, people who are disabled, or people who are dying, can there really be collective knowledge? Further, can there be a collective knowledge that is generated by people in a particular group and said to represent, in some way, the experience of others in this particular group?

Bar On (in Alcoff & Potter, 1993:96) certainly questions this position and states that 'a socially marginalised group does not have the power to exclude, silence, and command obedience from a dominant group'. The same author goes on to suggest that in giving primacy to the knowledge (epistemic privilege), accounts and experiences of marginalised groups the same values and practices are utilised as by the dominant group (Bar On, in Alcoff & Potter, 1993:96).

This argument appears rather unimaginative. The point surely is not about a particular knowledge, namely a marginalised knowledge, being given greater authority and thereby mimicking the way the dominant knowledge holder behaves. Rather, it concerns marginalised voice and knowledge having an opportunity to have this

neglected knowledge heard at all in a very unequal world. People who have been ignored, misunderstood, or discredited must surely be required to struggle to have their knowledge noticed, let alone accepted. Tanesini (1999:156) is more conciliatory, suggesting that different forms of knowledge be invited, in a participatory way, to be heard in order that all experiences are taken into account. Aspects of this argument are drawn on in this research in which people whose knowledge that has formed as part of their experience has not previously been fully recognised. This knowledge may consist of a range of emotions, personal insights and connections to social forces. This research has attempted to inquire into this area.

2.2.4 An afrocentric feminist contribution

Black feminist thought can be seen to challenge the grand narrative of white, western, male knowledge and power claims. Black women are viewed as being in a subjugated position in relation to the dominant white male society that Black feminists claim exists in western society.

It has been suggested that Black women are 'agents of knowledge' and that this position links with their oppressed 'outsider-within', status (Hill Collins, 1990:233). Agents of knowledge possess a knowledge that originates through living an experience or experiences. It is first hand experience and first hand knowledge. It is asserted that this knowledge that is in the possession of an individual, who is in a marginal position in society, will be discredited by those from the dominant group who have a vested interest in suppressing this knowledge. Hence, the knower is at once an outsider with marginal knowledge and an insider of the society in which they are located.

People find themselves or are placed in groups within society where their knowledge is seen as marginal, as different. There are many such groups who do not adhere, or acquiesce to the dominant knowledge viewpoint. All these groups will have their own different knowledge forms of their experience. They are unique but may well share similarities with other marginal knowers. Hill Collins (1990:236) points out how each group will speak from and share its own partial and situated knowledge. Here, the suggestion is that with partial knowledge accepted, with no one group claiming

dominant knowledge, groups can move to consider the varied world, the common thread that connects us all.

bell hooks (1989:8) highlights the difficulties for even successful black academic women in the United States of America to be heard and acknowledged, as if their perspective and knowledge were inferior to others. She points out that 'the context of silence is varied and multidimensional. Most obvious are the ways racism, sexism, and class exploitation act to suppress and silence. Less obvious are the inner struggles, the efforts made to gain the necessary confidence to write...' (hooks, 1989:8). She describes the effort and process that is required in order to raise self-esteem enough to reach a place from which what one has to say can be thought to be 'good enough' to place in the public domain. She, like Beresford (2003:49), highlights how a history of being marginal, of being unheard, and of being discredited takes a great deal of effort to overcome and to see ones own experience and knowledge as important and equal to others in more dominant groups. This certainly resonates with the experience of some SURAG members who, via their involvement in this research, have rediscovered some of their previous talent and confidence. Some have also reclaimed their voice, their desire to inform others about their experiences and their needs.

2.2.5 A contribution from Freire

The work of Paulo Freire has been an influential one on the development of critical inquiry. His seminal work is *Pedagogy of the Oppressed* (Freire, 1972) and his work has largely been concerned with raising awareness about the empowerment of the oppressed, and this by educational means primarily. He discusses the task of the oppressed, which is concerned with the liberation of themselves and their oppressors. A symbiotic relationship between oppressed and oppressor is suggested by Freire with each dependant upon the other but only the oppressed able to act to change their and their oppressors' situation. As with an emancipatory research approach, Freire talks of action, for him in terms of educational initiatives, *with* not *for* the oppressed.

Knowledge that marginal groups possess can be difficult to release, as people in such a position may feel their knowledge to be unworthy and question their legitimacy in articulating their own knowledge. For Freire, only a critical consciousness of the

knowledge in one's possession can in turn lead to action and transformation (Freire, 1972:40). It can be seen then how Freire's work links to the development of emancipatory research and critical theory with their interest in people's political context, empowerment agendas, and equalisation of the research relationship.

Dialogue becomes the precursor to action and liberation for Freire. Dialogue takes the form of critical thinking with both educator and educated working together equally on their knowledge-raising journey. Humphries et al (2000:9) discuss the links between the work of Freire and feminist knowledge production. Of similar concern to both is the transformation and consciousness raising capacity of knowledge. Whilst Freire's early work may be criticised by feminists for a lack of examination of gendered relations, clear-shared concerns can be seen.

2.2.6 A contribution from critical theory

Critical theory is 'critical' in terms of its stance in challenging claims made by both positivist researchers and also some constructivist researchers, namely interpretivists. It is a critical theory in that it aims to unmask beliefs and practices that restrain freedom, justice and democracy in some way. Critical theory can be seen as having an interest in changing the world in terms of the aforementioned aspects of freedom, justice and democracy. Habermas (1971:308) has identified the knowledge interest involved in critical theory as emancipatory-the unmasking of ideologies that maintain the status quo by restricting the access of marginalised groups to the knowledge that oppress them (See table 2.3).

Table 2.3: Three Domains of Knowledge (Habermas in Tinning, 1992)

Type of Human Interest	Kind of Knowledge	Research Methods
Technical (Prediction)	Instrumental (Causal explanation)	Positivistic Sciences (Empirical-analytic methods)
Practical (Interpretation and understanding)	Practical (Understanding)	Interpretive Research (Hermeneutic methods)
Emancipatory	Emancipation	Critical Social Sciences

(Criticism and liberation)	(Reflection)	(Critical theory methods)
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For Habermas, instrumental knowledge is the concrete, objective, cause-and-effect knowledge derived from empirical scientific methodologies. Practical or communicative action is the interpretative, interpersonal knowledge of society, culture, and human relations generated through language and mutual understanding. It is group-bound or culture-bound and pertains to the social norms within which we live. Emancipatory knowledge is the personal, subjective knowledge of one's self, acquired through critical self-reflection. It leads to personal empowerment. Through emancipatory knowledge, we free ourselves from the constraints of uncritically assimilated assumptions and this can lead to a transformed consciousness.

This connects to Freire's notion of 'conscientisation' although Habermas appears to refer to perspective change at an individual level whilst Freire is overtly political and both the 'oppressed' and the 'oppressors' are involved in consciousness raising as discussed above.

Critical theory is not purely a focus upon individual processes that may dis-empower people then but primarily it is a focus on the causes of powerlessness and oppression. Usher (Usher in Scott and Usher, 1996:23) argues that critical theory refutes the possibility of a '...neutral or disinterested perspective because everyone is socially located and thus the knowledge that is produced will be influenced always by a social interest'.

For critical theorists then, knowledge is not only about finding out about the world, but also about changing it. According to Harvey (1990:3), 'knowledge is a process of moving towards an understanding of the world and of the knowledge which structures our understanding of that world'. Delving beneath the accepted processes and structures that underpin society and shape everyday lives in an inquiring and critical way is the aim of critical theorists.

In their discussion of critical theory Kincheloe and McLaren (in Denzin & Lincoln, 2005:306) highlight how such critical research is '...always evolving, always encountering new ways to irritate dominant forms of power, to provide more evocative and compelling insights'. Critical and emancipatory research can be seen to

hold similar assumptions with regard to the nature of the social world, the positioning of researcher and the researched, the political nature of research and the need to challenge subjective and epistemological assumptions.

The link between a critical research approach and the work of Freire can be seen here as both wish to draw attention upon power relationships within society, expose injustice, and be alive to the fact of false consciousness contributing to this injustice and oppression. The joint endeavour is to challenge this false consciousness, illuminate new ways of knowing and facilitate change. In terms of this research, an attempt has been made to enable issues of living with a life limiting condition to be seen in different ways. This has involved an attempt to explore social structures and social relationships that influence people's lives.

2.2.7 A contribution from the emancipatory research paradigm

An emancipatory research approach has developed out of the social model of disability (SMD), which was outlined in section 1.5. However, there are also clear links with the preceding contributions in feminist works, afrocentric works, critical theorists, and the work of Paulo Freire.

The new way of viewing disability and the issues disabled people faced brought about by the SMD, necessitated a new way of researching the issues and a new form of research relationship that was congruent with the social model. In discussing this relationship between disabled peoples organisations, the SMD and research Stone and Priestley (1996) identify that emancipatory research must fulfil certain requirements in order to be congruent in this field. They suggest that such research must, epistemologically, be rooted in the social model, it must have a commitment to a social analysis of disablement, it must be relevant politically and to the people who are the focus of the research, the research must reverse existing hierarchies and ensure disabled people are at the centre of the research in terms of control, it must give voice to the personal as political and adopt a plurality of methods for data collection and analysis (Stone & Priestley, 1996).

Emancipatory research is primarily concerned with the way research is conducted, so called social relations, and it is concerned with control of the resources available for

research, so called material relations. In talking of his own research strategy Colin Barnes draws attention to the central emancipatory tenets of openness, participation and accountability (Barnes, 1992:121). He goes further to highlight how emancipatory research can be negotiated and this is by taking a critical view of the structures and processes that exist to create disability and by establishing workable dialogues between researcher and disabled people in order to empower the latter (Barnes, 1992:122). Once again, similarities can be clearly seen with the preceding contributions above.

Morris (1992:162) in discussing feminisms contribution to research with disabled people points to the need to move from alienating research to emancipatory research that enables people to take ownership of ‘...the definition of oppression’.

In discussing feminists interest in new ways of thinking and doing research Rosalind Gill suggests that all knowledge production is socially situated, partial, explicitly political and claims that ‘...ethics, values and political commitments suffuse the entire research process’ (Gill in Henwood et al, 1998:39). A feminist perspective on research can be seen then to be compatible with an emancipatory research position. There will of course be differences and contentions, however in broad terms many central assumptions are shared.

2.2.8 Section summary

Having introduced the approaches above I now ask, what of these contributions are helpful to my research and my epistemological position?

The epistemology utilised here is one that is rooted in the lives of people with life limiting conditions, of people whose knowledge is subjugated, under privileged, misinterpreted, and/or oppressed. This knowledge is not part of ‘mainstream’ knowledge in contemporary hospices and palliative care services, as we know them today. The knowledge that can arise from people with life limiting conditions may be seen as a form of wisdom, as highlighting the difference between seeing and knowing. People, who are living with these conditions, including the Service User Research Advisory Group, may be seen as ‘agents of knowledge’ to coin Hill Collins (1990:233) term. This research attempts to go some way in the direction of facilitating

access to the standpoint knowledge and 'truth' of people with life limiting conditions, via the SURAG. My standpoint is of a partisan ally. This is not to suggest that an oppressed knowledge is privileged above others, or that an oppressed knowledge is truer than others. The pursuit of an oppressed knowledge is concerned with rectifying an imbalance, to give voice to this knowledge that is often silenced and given less authority. But what might be an adequate justification that a particular knowledge claim is true?

Beresford (2000:493) points to the knowledge that exists out of the personal and collective direct experience of service users. The SURAG has engaged collectively over time on their own direct experiences and on those who have been research participants. This group of people have faced their own experiences and often seen their own situation in a different light due to sharing their experience and others experiences, within a safe and supported setting. The knowledge that ensues from this group acts as a form of 'conscientisation', of awareness raising that otherwise may not have occurred.

This study aims to be collaborative, grounded in the world of the lives of the people who are the focus of study, to be critical, and reflexive. I propose an epistemology of the dying that is required to be an ethical epistemology; it is concerned with a collective knowledge production generated via dialogue in group contexts. Dialogue and experience is at the fore of an epistemology of the dying. Dialogue here encompasses an ethic of caring in which 'personal expressiveness, emotions and empathy are central to the knowledge validation process' (Hill Collins, 1990:215). Value is placed upon individual uniqueness, a focus upon action-orientated knowledge and as has been suggested, this epistemology will 'draw on their minority group experience...that speaks to the logic and cultures of these communities' (Denzin in Denzin and Lincoln, 1998:339).

2.3 Methodology

The methodology refers to the strategy that shapes the choice and use of the methods employed in the research. The methodology should offer a rationale and explanation for the selection of the methods and the way in which these methods are used and needs to be able to link coherently with the theoretical perspective, which embraces the research.

My research methodology is influenced by a number of different traditions and approaches as described above. The aim throughout is, not only, to understand and give accounts of the social world of the research participants who live with life limiting conditions, but also to take a critical view as to the social processes and influences that shape the social reality of these people. Whilst interpretive approaches have become almost *de rigueur* in qualitative research and particularly in research with people who have health problems this is not wholly reconciled with an epistemological stance influenced by the social model of disability and critical theory.

The quest for *verstehen*, or understanding, is one thing but research that purely describes the individual difficulties, oppressions and distress of people with out any greater contribution or objective to change the situation of those 'studied' has been open to criticism from some quarters (Oliver in Corker and French, 1999:186). Thus investigatory research approaches may not be consistent with the ideals of research underpinned by the social model of disability and emancipation, or for that matter, critical theory with its focus on action and transformation.

Some interpretive researchers have been cognizant of this challenge posed and have repositioned the approach in light of work done in cultural and feminist studies. This repositioning attempts to locate interpretivism in line with thinking that posits that both researcher's and participant's language and action need to be seen as mediated in '...gendered, existential, biographical, and classed ways' resulting in '...self, emotionality, power, ideology, violence, and sexuality...' being brought to the foreground as interpretivist problems (Denzin, 1992:161). Many obstacles remain unresolved in the domain of the interpretivist such as the distancing of the researcher

from those 'researched' which may lead to a privileging of the researchers views, and the interpretive authority and control of the researcher (Schwandt in Denzin & Lincoln, 1994:131).

The sum of my considerations on methodology has led me to work with the idea of a participatory approach as the guiding strategy for this research in which service users were included in most phases of the research. Service user involvement in the research is the central element in this participatory study.

Early in the research I had explored the idea of a critical ethnographic and participative dual approach to which end a period of participant observation followed in a hospice day centre. I later reconsidered the participant observation aspect as being difficult to reconcile with a participative methodology that genuinely attempts to be inclusive of service users. This reconsideration took place over time. Initially I was aware of the potential for this approach to be non-participatory but I was also convinced that I could adapt ethnography and in particular the style of participant observation to suit my participatory ideals. I therefore tried this for myself after careful consideration, discussion and planning. During the period of participant observation though, I became aware that this approach was not consistent with the inclusiveness of the project. I continually doubted both the value of the period of observation in research terms and the sincerity of the approach.

My field diary kept for the duration of the participant observation period clearly shows my awareness of the artificiality of my presence in the day centre. My concern is illustrated by one particular entry made following my fourth period of observation when I was reflecting on my presence in the day centre as neither a service user nor staff member. I questioned myself, 'is this method disempowering? Am I an alien who has landed in their midst'? The inequalities began to outweigh any advantages I had envisioned or any ability I had felt I possessed to counter this difference in power. The limitations or restrictions of this participant observation method of data collection have been documented previously in terms of striving for inclusive research relations (Davis, 2000; Wright & Nelson, 1995: 59; Munn-Giddings, 1993). Consequently no data from this period have been utilised in the analysis stage, however holding a group discussion, with the service users who were attending the day centre at the time,

completed the period of participant observation. This does form a part of the data that has been analysed as part of the research. An account of my consideration of a critical ethnography that I had thought would be compatible with a participatory approach is given in annex B. A reflection on this period of participant observation is also presented in this same annex.

In the next section I focus on the methodology that has been the over arching one for this study, participatory research. Prior to this though it may be helpful to see the research presented as a brief timeline so that an understanding about the order in which the research occurred can be seen. This is presented below in table 2.4.

Table 2.4: Research timeline

Date	Activity
July 2002	Local Research Ethics Committee approval
August 2002	Consultative meeting with service users of a hospice
September 2002	Consultative/planning meeting with representatives from a range of local service user organisations
November 2002	First meeting of the SURAG
January 2003	First group discussion
February to October 2003	Nine face-to-face interviews conducted
July to November 2003	Period of participant observation
November 2003	Second group discussion
March 2004	Third group discussion
May 2004	Last face-to-face interview. Completion of data collection phase
June 2004 to January 2005	Period in which ten collective data analysis sessions took place with the SURAG
January to March 2005	Period in which five theme generation sessions took place with the SURAG
April 2005	SURAG meeting to re-categorise my initial themes in line with the new themes

2.3.1 A participatory research approach

Participatory research has been discussed in the previous chapter, literature review, in terms of its development and claims. Here I will describe the approach of participatory research utilised in this project. This needs to be clear as the approach utilised can mean very different things for the service users involved and to service user's influence upon a project. In this research the participation of service users has been achieved by the work of the SURAG and this group will be described further below. As the participatory approach evolved over time some discussion and reflection on process is included in this section. For clarity I consider it more appropriate to offer some explanation about the evolving participatory approach here, rather than separated into a later section of the discussion chapter.

In considering key elements of a participatory research approach (as outlined in sections 1.4.1; 1.4.2; 1.4.10) it can be seen how a similarity exists that links participatory research to action research, to participatory action research, to co-operative inquiry, to participatory reflective inquiry, to feminist participatory research, and to other specific approaches. I would argue that this link stems from the position and values of a generic participatory research. It is clear that it is not just the type of activities that mark a participatory research project from others but also the values implicit to it. Mullender et al (1993/4) take the view that research needs to address considerations of values just as practice has and calls for participatory forms of research that can include the active contribution of people in the research and which can be empowering in many different ways.

It has been noted how participatory research does not parade an orthodox methodological position for in truth a '...creative and very wide variety of approaches have been used' (Hall, 1992). A participatory approach will aim to generate knowledge and analyse accounts in a collective way. Utilising an effective participatory research approach places a central concern upon relationships within the research process, relationships that engender trust and meaningful understandings between those involved in the research. These research relations promote a joint critical reflective approach from where to view the research, its stages, and its emerging outcomes. Participatory research places a focus upon power in the form of power exerted and managed between professional researcher and lay or co-

researchers. Equalisation of power in these relationships is strived for and partly manifested by a sharing of decision-making regarding the research. Northway et al (2001), for example, contend that a participatory research approach aims to challenge the 'marginalisation and powerlessness' implicit in other research methodologies.

Maguire (1987) highlighted how lay partners in her project benefited by learning and understanding more about their situation as well as by sharing in decision-making and control of the research. She refers to the values of this type of research referred to above when she says, 'a deep and abiding belief in people's capacity to grow, change, and create underlies this democratization of research' (Maguire, 1987:39).

As I described at the beginning of this chapter, I regret that it was only belatedly that I engaged with service users at the design stage of the research. It should be acknowledged though that there was not a discrete group of people or organizations with whom to approach for input on research design. Indeed this may illustrate that some difficulty exists for local communities and/or small-organized gatherings of people to identify or act upon researchable issues that may be of importance to them. An allied point is the difficulty for researchers who may be amenable to conduct collaborative projects. The research issues of concern in this project are not ones that have been presented in a collective voice, as those people living with life-limiting conditions do not readily organise in groups dedicated to pursuing improvements in their lives or tackling inequalities that may exist. For people living with cancer and some other conditions there are support or educational groups but these often appear to be orientated to supporting people to live with the condition rather than challenge existing short falls in provision or research.

Given this, the issue of sharing control of the research process may be more problematic. How can people, who may well share a concern about their life situation, stake a claim to a researcher's project? If someone outside of their direct experience initiated the research, a researcher, how can the people invited to join in share its aims?

This issue has some relevance to this research as members of the SURAG began their involvement after the proposal was accepted and was therefore largely unalterable. On

a teaching assignment about participatory research early into the research with two SURAG members at a University, a student asked a very pertinent question aimed at one member of the group. The question was, "who owns the research"? The immediate response was "Its Phil's baby". Straight away I felt surprised and somewhat disappointed. Later, on talking it through further, both members confirmed that they saw the research as mine. They spoke of feeling they have a good say in the project and one of them compared this project as 'better' than some other research she had been aware of. She explained this, as "it feels right". She went on to say that she was much more comfortable with this project as views of service users are heard and acted on, and that we are doing the research together. Nevertheless, for sometime I was hurt.

Later, on reflection, I realised that it was predominately myself for which the project meant so much. I was impassioned by it. It was not just the fact that this is an academic endeavour that impassioned me, but I wanted this small project to make a difference, to lead to action at some level. I was partisan. I knew members of the group also felt similarly to me on this but it was also myself who organised the SURAG meetings, wrote the agendas (always inviting further agenda items from members), wrote the minutes, and kept the group updated on the project. Members of the SURAG were active in the group and have said how the group and the research had changed them but some members do see it as "Phil's group", despite my protest and desire to extend ownership.

Enabling the participation of service users in research is concerned with voice. Enabling so called 'reality from the margins' (Hooks, 2000:ix) to be voiced. Participatory approaches to research accept as a given that certain members of society have less opportunities than others to be 'self-reliant, self-assertive, and self-determinative, as well as self-sufficient' (Park et al, 1993:2). It aims to redress this state of affairs, to enable people to become more aware and more critical, and to enhance people's opportunities to examine and "...understand the social forces in operation and gain strength in collective action" (Park et al, 1993:3). It is through dialogue with others in the SURAG that members of the group come to see the problems facing them, the feelings regarding their situations and the situations of others like them with, I think a fresh and critical gaze.

In conclusion, a participatory research approach appears to have been a valid one to take and an approach that has enabled the involvement of service users. How effective this involvement has been will be considered in detail in sections 5.11 and 5.13.4 of the discussion chapter.

2.3.2 The Service User Research Advisory Group

The Service User Research Advisory Group (SURAG) was formed to work with me from the outset in order to share the knowledge and experiences of people living with life limiting conditions with me and contribute, as equal partners, in the research. The aim was to ensure that the research remained in tune with service users concerns and needs, and to enable group members to influence the research at all stages of the research process. It aimed to be a democratic group where service user members could genuinely shape and influence the research. Further consideration of the work and impact of the group takes place in section 5.11 of the discussion chapter.

The group was active at most stages of the research process, for example making decisions on the reframing of questions, through to assisting with how research information was collected, and making sense of the information, to teaching and writing about what we have done. This joining together to carry out research is particularly unusual in palliative care. Table 2.4 above indicates how some service users were consulted in the early design stage about project issues but there was no involvement of any service users in protocol development or other early design work. This point is returned to in section 5.11.7 of the discussion chapter.

The group has consisted of nine people in all, over the time span of the research (See annex C for a membership list). I co-ordinated and facilitated the group and was in attendance at all but one of the 32 meetings. The ethos was democratic and this was relayed into practice. Unfortunately four members have died during the course of the research and another two members chose to leave, one through ill health and the other in order to focus on other activities. Five group members were involved from inception of the group through until data analysis was complete. Two of these original members died following completion of the data analysis stage of the research with one of these two members having seen the final research report that was completed in November 2005.

2.3.2.1 Forming the group

Many people locally were contacted about the research and the SURAG in order to both recruit to the group and to recruit research participants. This first contact with people about the research was in the form of an introductory letter outlining the research and asking for volunteers to get involved. Also included with this letter was a newsletter that gave more in-depth information. In all, over 300 letters and newsletters were circulated to local service user and support groups, religious groups, hospital consultants, specialist nurses, community district nurses, and general practitioners, as well as to social service and mental health organisations and individuals. The intention here was to let as wide a range of people know about the research as possible as well as prompting these people to discuss the research with service users they knew.

The aim was to have about eight members in the SURAG and therefore the first service users who expressed an interest in the research met with me and were asked if they would like to join the SURAG *or* be interviewed as a research participant. Once eight people had been recruited to the SURAG subsequent service users were asked to take part in interviews or small group discussions. The first meeting of the SURAG took place in November 2002 and the first interviews with research participants began in January 2003.

Prior to the first SURAG meeting I spoke with all the people who were to become members individually. This was to explain about the research and a little about the role of the group whilst acknowledging that it would develop over time depending on the influence of members themselves. Nine people, eight service users and myself attended the first meeting of the SURAG. Four service users of this original group knew each other a little due to attending the same hospice day centre and the other four service users knew no one at all in the group when we first began. Until meeting these people to discuss the SURAG and the research I had not known any of the service users. Of the eight service users four had a diagnosis of cancer, three had Chronic Obstructive Pulmonary Disease (COPD) with one of these people also having diabetes, and one person had been a carer of a partner who died of cancer. Two members were men and six women. One member was involved in a Patient Forum group within a local Cancer Network and another was vice-chair (later to become

chair) of West Sussex Disability Network, a service user run representation and consultation organisation with nearly one thousand members. This person was also a lay representative on a Research Governance and Approval Committee in the same Acute Trust that I was employed by and subsequently invited another SURAG member to join this committee at a later date. The majority of members had no experience of working together as service users on any type of project and none of the members had previously been involved in a research project.

2.3.2.2 Work of the group

The SURAG drew up their own Terms of Reference document, which explicitly set out their individual and group roles and remit (see annex E). This document was slightly refined over time as the group developed. The group was involved in the continual management of the research in regular meetings (thirty-two meetings in thirty-eight months). The group contributed in many ways. For example the group helped with the phrasing of interview questions; gave insights based on their own experiences about participants responses; raised important points about the research data as we reviewed it; commented and advised on the researcher's style and level of sensitivity to participants; was very involved in making sense of all the data (data analysis); has been involved with teaching about the research and how we have done the research which included making a video that was shown at a conference (Cotterell, Cowdrey & Paine, 2003; Cowdrey & Paine, 2004; Cotterell & Paine, 2005). A paper from one conference presentation is part of the online resource from this particular conference and the final research report is also available as a written document (Cotterell et al, 2005) and as an online resource on the Sussex Research Consortium website (see http://www.sxrc.nhs.uk/consortium_activity/0258.htm).

The collective analysis stage of the research was a particularly challenging phase of our working together and involved going through all the typed sheets of interview and discussion group information. When we put all the information together the pile was over four inches deep and contained over 140,000 words!

2.3.3 Ethics, governance and methodological issues

As research information was collected from NHS patients' approval was obtained from a Local Research Ethics Committee (LREC) in June 2002. Worthing and

Southlands Hospitals NHS Trust acted as the Research Sponsor for the research. Their role was to ensure that the requirements of the Research Governance Framework were met. This included ensuring that the research was safe for patients and the public, that it reached a common standard of quality, and that it was conducted properly. Research Governance approval was granted by The Sussex NHS Research Consortium for the majority of data collection and separate Social Services Research Governance approval was also obtained in order to carry out a group discussion within a social service run day centre.

All participants were provided with full information about the research before they agreed to take part, both in written and verbal form. This information explained what they would be involved in and that they could withdraw at any stage with no repercussions. Written consent was also obtained from participants before they participated in the research. Any information that participants gave that would make them identifiable or that might identify another person, were not included in the analysis or any other writing. This was to ensure participants remained anonymous. In talking about participants here I do not mean SURAG members but rather participants who were involved as interviewees.

All research evidence such as cassette tapes and anonymised interview and discussion group typed sheets (transcripts) were locked in a secure archive cabinet in the Research Department, Worthing Hospital.

I wanted to ensure, as far as possible, that participants did not feel distressed due to their involvement in the research. I was aware that talking about personal aspects concerning their condition and how people have treated them could raise areas of concern. To minimise any distress I ensured that all participants understood the nature of the research and their part in it. As well as the written information about it they had a copy of the questions to be asked and opportunity to talk with me about the research and the research questions. I also had a support system in place whereby a local hospice agreed to provide emotional support to participants if necessary.

Participants often reported positively about receiving the questions in advance and of having the opportunity to reflect on them. They also often reported a determination to

have a say, to tell me about their experiences. When the interviews or discussion groups were conducted participants were reminded they could stop or pause at any stage. No participant did this although some interviews were conducted at a slow pace to give time for responses, enable participants to take a break and to form their thoughts. At the conclusion of one-to-one interviews and discussion groups participants were asked for their thoughts about it and invariably stated they were happy to have been involved and to have been asked for their opinions. Many participants added that they hoped the research information would be used positively to inform organisations and services about their needs.

All participants were sent a letter of thanks following their involvement and a copy of the summary of the interview or discussion group in diagrammatic form. This led to correspondence or telephone contact in a few cases with participants discussing their research information further and in some instances offering to assist at a later stage if required. Some participants wanted further copies of the diagrammatic summary in order to pass on to family, friends and GP's as a way of illustrating their situation to them. No distress was reported when this contact was made following data collection.

It is important to note that by the end of the data collection stage ten of the twenty-five participants had died. Also four of the nine members of the SURAG had died during the course of the project. This indicates both how seriously ill people who participated were and the need for thoughtful research practice to occur.

There is rightly a great deal of concern in palliative care about research with people who have life limiting conditions, particularly those approaching the end of life (Aranda, 1995; Johnson & Plant in De Raeve, 1996:93; Beaver et al, 1999b; Seymour & Ingleton, 1999; Casarett & Karlawish, 2000; Seymour et al, 2005). Conducting this research in a thoughtful, sensitive and ethical manner was of high importance because of the type of issues familiar to palliative care researchers. A difficult balance between over protection and enabling safe participation was successfully negotiated.

2.4 Methods

Initially I had envisaged recruiting 20 to 30 adult participants with a range of life limiting conditions in order to gain perceptions of palliative care from these different perspectives. I wanted to include a wide range of conditions both cancer and other non-cancer conditions. I also wanted to be as inclusive as possible in terms of the definition of life limiting. I could have set rigid criteria and requested medical opinions or conducted physical tests in order to judge the severity of a person's condition. However I was also aware of the difficulty of accurately making these judgements and I was also keen to enable participants themselves to judge whether they considered their condition to be classified in this way. I was aware of the difficulty some people with non-cancer conditions had in accessing care or support and I did not want to add to these difficulties in terms of making access to research participation very difficult (The list of conditions participants had can be found in annex A).

As described in section 2.3.2.1 above, an extensive mail out occurred in the locality of the study in order to enable as many potential participants to have the opportunity to be involved. As well as recruiting to the SURAG, 25 participants were recruited to the study from both this initial mail-out of research information and from a subsequent one a little later. Personal contact was also made with a range of professionals and service user groups locally. I presented the research at some user group meetings and made initial contact with several future participants in this way. Anonymised personal biographies for all the participants can be found in annex E. Tables 2.5 and 2.6 below show information about the participants that took part in the research.

Table 2.5: Participant information

Characteristic	N (%)
Female	16 (64%)
Male	9 (36%)
Cancer diagnosis	14 (56%)
Non-cancer diagnosis	10 (40%)

Mixed - cancer & non-cancer diagnosis	1 (4%)
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Table 2.6: Participant ages

Characteristic	Age (years)
Age range	38 to 85
Mean average age – all participants	65
Mean average age – participants with cancer	71
Mean average age – non-cancer participants	56

It is clear from these tables that more women than men took part in this research and more participants had a cancer diagnosis. On average, it is clear that participants with a non-cancer diagnosis were younger than those participants with cancer. There was a range of conditions and types of cancers included in the research. Table 2.7 shows the different diagnoses participants with non-cancer conditions had and table 2.8 shows the different cancer types participants with a cancer diagnosis had.

Table 2.7 : Participants non-cancer diagnosis

Diagnosis	N
Stroke	1
COPD	1
MS	2
HIV+	2
ME	1
Sub-arachnoid haemorrhage	1
COPD and Heart Failure	1
Cryptogenic Fibrosing Alveolitis	1
Total	10

Table 2.8: Participants with cancer. Cancer type

Type	N
Lung	1
Multiple Myeloma	2
Bladder with pelvic secondaries	1
Oesophagus	2
Non-Hodgkins Lymphoma	2
Bowel with liver secondaries	2
Glioma	1
Unknown primary with bone secondaries	1
Ovary	1
Basal Cell Cancer	1
Total	14

One person had a diagnosis of both breast cancer and respiratory disease.

2.4.1 Health and social care services available for participants

Along with personal information concerning participants an awareness of wider contextual issues is necessary. Due to one of the research aims being concerned with experiences of health and social care services it is important to reflect on those services available for participants at the time this research was conducted. A brief overview of these services follows.

2.4.1.1 Acute service provision

This was provided locally by one NHS hospital Trust on two hospital sites. This Trust provided acute hospital services for approximately 200,000 people at the time the research was undertaken and provided a range of services such as medicine, medicine for the elderly, general surgery, maternity, paediatrics and accident and emergency.

The Trust had achieved a two-star rating from the Healthcare Commission during the year in which data collection occurred. The Healthcare Commission had a statutory

responsibility to annually assess the performance of NHS Trusts on a number of factors and to issue ratings based on this assessment. The two-star rating reflects that the Trust was considered to be 'mostly' achieving high levels of performance and failed to achieve the top three-star rating due to under performing in the area of financial management. In this same assessment exercise across the UK 40% of Acute Trusts achieved the highest three-star ratings, 36% achieved two-star, 18% one-star and 6% no-star ratings. The Acute NHS Trust that participants in this research commented on was therefore an average performing Trust compared to others and utilising this form of measurement.

2.4.1.2 Primary care service provision

Primary care is the term for services provided by people normally seen when people first have a health problem. This might be a General Practitioner (GP), a district nurse, dentist or an optician for example. Local Primary Care Trusts (PCT) manage all of these services. The main primary care service referred to by participants in this research was the service provided by GPs. As in all areas of the UK there was a mixture of large and small GP practices that participants had access to. Some practices consisted of two or three GPs working from the practice with their support staff and others consisted of larger teams of GPs with a wider range of support staff and facilities.

2.4.1.3 Social care service provision

Social care is a term that refers to a wide range of services provided by both local authorities and the independent sector. Local authorities with social service responsibilities have a statutory responsibility to ensure the social care needs of people are met. In terms of this research, the services predominately utilised by participants was a day centre and assistance at home, which is known as home care.

The day centre provided day services for adults in the local area and could accommodate up to 100 people each day. The day centre was focused primarily on adults with physical impairments. At the time that participants participated in a small discussion group the day centre was considered to be under threat of closure as a local consultation process was under way with a remit to reduce financial expenditure across social care services. Home care was provided directly by a combination of

social service home carers and contracted out home carers from independent or private providers. The independent home care providers were approved by social services and this combination of service provision was similar to those provided elsewhere in the UK.

2.4.1.4 Palliative care service provision

The sole provider of specialist palliative care in the locality the research was undertaken was one adult hospice. This hospice provided services such as in-patient facilities (for up to 15 service users), day centre facilities (for up to 15 service users daily), community nurses offering specialist advice to people in their own homes and a social and welfare team who provided advice, support and counselling. As well as social workers and nurses other professionals available included doctors, a physiotherapist, chaplain and complementary therapists. This range of services and staff were typical across UK hospices. Another common characteristic was that this hospice restricted its remit to two conditions, cancer and motor neurone disease. Again this was typical compared to other hospices in the UK. There were also two palliative care specialist nurses based in the local acute hospital who advised and supported patients and staff. These nurses were supported by a hospital consultant doctor one half day weekly.

The above information, on the health and social care services available locally at the time the research was conducted, has presented a contextual insight into local provision of services. In summary, it is clear that the services available locally were not exceptional but rather, were quite typical of services provided across the UK. In the next section considering the methods taken to carry out the research there will be some degree of reflection on how and why this occurred. Whilst critical evaluation is primarily addressed in the discussion chapter there are some occasions in this section where this occurs. From section 2.4.3 to the end of this section the process of how analysis evolved is described and it is here that some evaluation occurs when it is central to how the method developed in practice.

2.4.2 Data collection

Methods of data collection that were consistent with the methodology and epistemological stance were sought. I therefore wanted data collection to concur with values inherent to the emancipatory and participatory research approaches. Data collection was required to be conducted in an open and honest way. This was achieved by thorough explanation of the research and its aims and by giving participants a very good idea of the areas of interest in the research. All participants received a copy of the questions to be asked at interview or group discussion well in advance of their interview or group discussion and then had the opportunity to ask any questions. Table 2.9 below shows the questions used in both interviews and group discussions. The questions were developed through informal discussion with service users in a hospice setting and with representatives from local user groups. This occurred prior to the forming of the SURAG.

Table 2.9: Question schedule

No.	Question
1	Can you tell me about your condition, from the time you first had it to now?
2	What has it been like, living with your condition?
3	How do people around you, treat you now you have your condition? (Family, friends, work, neighbours, health workers & social care staff etc)
4	What are the major things, if any, you need help with in relation to your condition?
5	What involvement do you have with people who help or advise you about your condition? (For example hospitals, general practitioner, district nurse, hospice, day centre or other organisations)
6	What do you think about these services?
7	Are there things that you would like some help with that you don't currently

	receive?
8	Is your level of control and choice over things affected now you have your condition?
9	Would you like to have a say in what services are available to you?
10	Do you think that people understand what it is like, living with your condition?
11	Do you need support? (Physically, emotionally or other)
12	What support do you get?

Data collection conducted adhering to a participatory approach also requires that participants feel that their participation is, as far as possible, in their own control and that they can make their own decisions regarding involvement. Informed consent was achieved by giving information as described above as well as a Participant Information Sheet, Lay Summary and newsletter that explained the background, aims and role of the SURAG in lay terms (The Participant Information Sheet can be seen in annex F). Being influenced by emancipatory and participatory approaches extended into direct research contact with participants as well. How the data collection was achieved was important. Such issues are known as the social relations of research (Oliver, 1992). The methods of data collection are now explained in turn.

2.4.2.1 Individual face-to-face interviews

Ten participants took part in individual face-to-face interviews. The interviews lasted between forty minutes and an hour and half. Each interview was tape recorded and transcribed verbatim. Initial summaries were made and returned to participants following typed transcriptions and initial analyses being made.

It has been highlighted how easy it is to be over-controlling in the interview setting and how being too structured can give the impression of not being in attendance with

the participant (Gillham, 2000:3). This rigidity is far from the emancipatory style I wanted to achieve. My aim was to genuinely be present with participants and show my interest in what they had to say. Whilst keeping the research focus and aims in mind, along with an awareness to draw out issues of importance to the research, a certain flexibility was incorporated into the interviews that reflected interest and concern in what the participants were relaying. Burgess (1982:108) recognises that ‘...researchers need to have understanding and sympathy for the informant’s point of view’ and they need to carefully follow participant’s responses and during the interview decide upon the direction it needs to take allowing participants to ‘...talk in their own terms.’ Hence a balance is arrived at of addressing areas that are the main foci of the research and the areas that are important for the participant to convey to the researcher. Oliver (1990:8) criticises how research participants can find the experience of interviews as isolating due to the interviewer presenting themselves as the expert and questions being framed in unfamiliar and disabling ways. The suggestion here is that the research participant can be left feeling that their experience of disability, or I would also suggest living with a life limiting condition, is an individual experience with no mediation present from external forces.

As part of my attempt to follow an emancipatory model I adapted an approach outlined by Barnes (1992), namely a three-stage strategy for interviewing. The strategy aims to enable potential participants to make informed decisions about their involvement prior to an interview taking place and gives participants an opportunity to add further comments when the tapes have been transcribed and returned to the participant. My way of managing interviews was to give participants plenty of warning about when the interview would take place and time to read the type of questions and areas that was going to be covered. Participants have commented on having seen the questions and have found it helpful in order to prepare themselves. I facilitated an open dialogic style of interviewing and was flexible in going with the participants’ direction for a period of time until I judged a need to refocus onto the aims of the study. Prompts that aimed to enable participants’ to elaborate on their responses supplemented the questions. Interviews, and therefore transcripts, consequently gave the impression of being un-structured. Whilst I intentionally tried to keep interviews conversational I always returned to the interview questions and also to previously mentioned points for elaboration if required.

Following interviews I sent a card to participants thanking them and inviting them to contact me if any issues raised in the interview were troubling them or were in need of any support. When I had transcribed the taped interview I completed an initial analysis summary of the themes generated in the interview and presented this in diagrammatic form with, normally, one theme per page along with supporting comments from the transcript for that theme. This initial summary was then sent to the participant along with an invitation to comment on the content. Several participants did respond to this either verbally or in writing. I revisited some participants who wanted to talk through some of their comments or to clarify certain issues. These clarifications were altered in line with their comments. My aim has been to equalise the social relations that exist in the research interview encounter.

It can be seen that Gillham's (2000) concerns are addressed by taking note of Oliver's (1990) and Barne's (1992) suggestions and making the interviews more equal and respectful. Beginning interviews with open-ended questions enabled participants to focus on key issues and experiences as they identified them. I made it explicit to participants, both at first contact and at the commencement of interviews, that I was interested in their experiences of their conditions and also of services. I also made it clear that the object was to learn from them in order to both profile their experiences and also to try and bring about changes where they were required.

I note, from my critical reflections journal, a questioning about my style of transcribing. As a matter of course I transcribed the taped interviews verbatim and ensured that I included all comments and utterances made by both the participant and myself. This made the transcript look fragmented but my inclination was to present the content of the interview as accurately as possible. In viewing the transcript it can be seen how the dialogue had a to and fro structure with many encouraging and clarifying comments introduced by myself. This, of course, could make the interview very disjointed and hesitant but in fact it did not, as dialogue was steady and plentiful. As I said in my research journal after one episode of transcribing:

I feel that interviews are nearly conversational although I lead with the preset questions. I am happy to offer participants some scope for talking about issues/events that are important to them. I try not to be overly rigid but

nevertheless I still need to cover all the questions. I suppose I am trying to carry through the emancipatory tenets of the method into the interviews. I note that I say many short conversation enhancers in the interviews like, right, yeah, umm. The transcript is littered with these comments.

My aim was to make the interview transcript as transparent as possible in order to show, not how objective I was, but rather how successful or not I was in facilitating an open, dialogic and free flowing interview whilst still eliciting responses to all planned questions (See annex G for an extract of transcript from one interview).

2.4.2.2 Small discussion groups

Twelve participants in all took part in three separate discussion groups. These discussion groups lasted between one hour and an hour and a half. As for interviews each discussion group was tape recorded and transcribed. Initial summaries were made and returned to participants following typed transcriptions and initial analyses being made. Such a method of data collection was hoped to be an appropriate way of gathering data that endorses a participatory methodological position.

My ideas for data collection in groups evolved over time. My initial planning was in terms of utilising focus groups. I wondered if this method might offer participants a greater sense of control over the process and also engender peer support. Focus groups are traditionally considered to be the prevail of market researchers and have been used as a method for collectively examining specific issues or for debating particular questions and priorities. On thinking through and planning a group more thoroughly I became aware, however, that it was not a traditional focus group forum I was looking to replicate but something that engendered greater discussion and comment between participants about their particular experiences and thoughts. I wanted it to be quite free ranging and non-formulaic.

I came to call the group a small discussion group and I wanted the method to be semi-structured as an individual interview might be. There is support for the compatibility of group research with participatory ideals with suggestions that research in a group can ‘...shift the balance of power in favour of the participants’ (Barbour & Kitzinger, 1999:18). My experience of the small discussion groups confirms this as participants

were able to discuss issues with each other, agree with each other and also to disagree, they supported each other by showing signs of understanding, verbally and non-verbally, and they spoke freely. Both, within the group and afterwards, the group members stated their comfort in talking with each other and showed that they could express a position different to each other.

In discussing the positive uses of focus groups within qualitative research Morgan (1998:12) suggests that participants in a focus group want to understand each other, their differences and commonalities, and it is this exploration that can lead to interesting interpretive insights being raised. I had hoped that participants would feel able to compare their experiences and offer their own interpretations that could be invaluable to all participants.

I felt that how the group was established was important and that this would probably influence the process and perhaps also the outcome of the discussion group. Members of the SURAG and myself spent time discussing the potential and challenges of the groups. They had considered the use of discussion groups to be a useful way to collect research data from participants. SURAG members thought that people involved in a discussion group would need to be selected carefully as not everyone would feel comfortable talking about themselves in public. They would also need to know what was intended i.e. how long it would take, what sort of questions would be asked and that they didn't have to answer everything. Holding discussion groups at the hospice was thought appropriate.

I addressed these issues by careful selection of the participants and by giving full explanation to them as well as a written explanatory leaflet one week in advance that explained the process of the group and gave examples of the questions to be asked. This gave participants time to focus on the subject area, time to think through their responses and time to decide if they really wanted to join in. I also planned to give participants a copy of the transcript of the taped discussion group if they wanted this, which they all did, and to give them a summary of the interview with initial analytic thoughts. Comments they had about this were feed back into the analysis stage. The planning of groups as a data collection method has been seen as especially important in the area of palliative care (Hudson, 2003).

Robson (1993:241) highlights how group interviews are attractive in certain research contexts, for example when the research involves studying an established group. Indeed, feedback from participants in the group interviews revealed a unanimous belief that the group worked well because all participants knew each other to a certain extent. One participant in particular felt they would have said less if the group consisted of complete strangers. This person agreed that if they all had something in common like a life limiting condition, then this would be less of a problem. Other challenges are raised for utilising this method of data collection such as the potential difficulty to follow up views of individual participants, and that some participants may dominate the group restricting others from offering their views (Robson, 1993:241). This was not the case however in these groups with a quite equal level of participation occurring between participants.

A further interesting issue is that during one of the group discussions one participant spoke of the degree of agreement perceived to exist in the group. I reflected whether this was due to genuine similarities amongst the participants or could be due to participants feeling they cannot disagree or offer alternative opinions, a so-called 'group-think'. However in reviewing transcripts from the discussion groups it is clear that participants spoke with conviction and did in fact offer some differing accounts. One example is when a participant had been talking of their fear when diagnosed with cancer and I asked if this had been the experience of others. Straight away one participant talked of their relief at being diagnosed as this came after a long period of their symptoms being discredited and diagnosis of cancer meant they were not imagining their physical symptoms. The issue of group participants conforming and offering only comments they feel the facilitator or other participants want to hear is considered unlikely by Morgan (1993:7), as the whole group interview is set up and conducted on the basis of finding out as much as possible about the participant's experiences and feelings. Differences of experience are clearly the aim and I feel were highlighted.

Fontana and Frey (in Denzin & Lincoln, 1994:364) however, suggest that '...emerging group culture may interfere with individual expression ...' and 'group-think' is a possible outcome. This would seem more likely if one person dominates

the group and the researcher needs to address this possibility at the outset. Responses from the entire group are needed to ensure the fullest possible coverage of the topic and so quieter members may need encouragement to participate with the facilitator balancing the directive interviewer role with the role of moderator.

Four people participated in the first discussion group, three women and one man. They all attended the day hospice on the same day each week and so were reasonably acquainted with each other. The staff in the day hospice approached them initially to see if they would be interested to participate and to find out more from myself. I spoke to them all, gave them written information about the research and the group discussion and I then contacted them three days later to see if they wanted to participate. The group discussion took place one week after our first meeting. The participants were aged from early sixties to early seventy years of age and they had been attending the day hospice together for two to four months. The women had been attending for the longest period of time and were quite familiar with each other.

The second discussion group in the day hospice followed on from the period of participant observation (described in annex B) and six people participated in this, four women and two men. These participants were recruited, as I had known them during this phase of the research. Only one person in this discussion group was unfamiliar to the others having attended the day hospice on just one occasion prior to the group.

The third discussion group with two woman participants took place in a social services day centre and it was a member of the SURAG who suggested accessing this centre in order to include a wider range of participants. I had hoped to recruit more participants to this group but on the arranged day of the discussion the other participants had not attended the centre. Subsequent offers to participate were not accepted. The manager of the centre had assisted me in the identification of possible participants and the organisation of the group.

McLafferty (2004) highlights the importance of positive group dynamics and interaction in order to enhance data collection, which would seem to support the participation of people in a group who are known to each other in some way. This

certainly appears to have facilitated smooth and non-threatening discussion groups in this research.

2.4.3 Data analysis

This section on data analysis is a substantial section as it reflects a prolonged and complex phase of the research in which members of the SURAG were centrally involved. Due to this involvement, the participatory methodology taken and the epistemological influences in which service user's knowledge is given voice, this section is particularly important.

The approach taken for analysis of data in this study has been selected to reflect, and coherently link, to the epistemology that underlies this study. This compatibility will become clear during this section along with the process of data analysis that occurred over some quite considerable time. I will also reflect upon this process and consider the challenges and benefits of conducting collective analysis in this particular context.

2.4.3.1 Collective analysis: Linking the plan to the literature

In discussing analysis in collaborative action research Miles and Huberman (1994:9) describe analytic tasks including the 'unpacking (of) taken-for-granted views and detecting invisible but oppressive structures'. One of the main rationales for taking a collective stance in data analysis is to assist in this 'unpacking' of data and views. Collective analysis assumes that analysis of data is aided, more likely to be genuine, and more likely to reflect the 'oppressive structures' people face, if people with the same sort of concerns, issues, and experiences as participants, are involved in the understanding of the data.

The same authors go on to describe three interconnected flows of activity in data analysis; data reduction; data display; conclusion drawing/verification. Data reduction involves the transforming of data from field notes and transcripts into a more simplified and abstracted form. Data display refers to the organising and compressing of data into information that is accessible and compact that enables researchers to see what is happening without having to examine masses of 'raw' data. The activity of conclusion drawing and verification is concerned with decisions about what the data means, its regularities, patterns, and explanations along with verifying these same

conclusions (Miles & Huberman, 1994:10). To some degree, the initial summary 'bubbles' already produced from each participant's transcripts in my initial analysis has been a type of data reduction and a way of displaying large amounts of data in a reasonable and manageable way. The planned collective data analysis moves us on to conclusion drawing and verification phase that Miles and Huberman (1994:10) identify.

The literature on this collective approach to data analysis is limited, although a collaborative approach to data analysis has been taken by Beresford and Turner (1997:33) in their work with the Citizens Commission, and Van Manen (1997:100) outlined ideas for collaborative data analysis by way of a research seminar group. However, whilst the former was designed to include service users in the analysis stage, the latter appears to be suggesting the involvement of colleagues or professionals rather than service users or people who are the focus of the research.

The main field for any commentary on ideas of collective or collaborative data analysis is within mental health and learning difficulties literature. Minkes et al (1995) suggest that involving people with learning difficulties in data analysis is thus far ineffective. As part of his doctoral research examining the nature of self-advocacy for people with learning difficulties Goodley (1998:420) raises an unanswered question about who it is who actually owns the analysis and who it is who has the final say on what is included or not, even within research with a more participatory design. Within the field of mental health research Rose (2001) describes efforts to include service users in data analysis who are members of groups responsible for helping in the evaluation of mental health services. Further involvement at this stage is described in the report of the 'TRUE' project that aimed to explore the provision of training for service users wanting to be involved in research. Service users worked as researchers on this project and were involved at all stages of the research process including data analysis. Involvement in analysis was in terms of individuals reading transcripts followed by small group discussion of interpretations (Lockey et al, 2003).

Another perspective on data analysis that is in keeping with a desire for a collective analysis comes from Winter and Munn-Giddings (2001). Coming from the assumptions of action researchers they insist the focus for this approach to research,

and therefore to analysis also, is upon learning and implementing change rather than on description and pure interpretation (Winter & Munn-Giddings, 2001:235). There are similar aims between the type of analysis these authors describe and the analysis I strived for here. For example they discuss the need to 'develop new ideas'. That is thoughts about the subject that weren't apparent prior to the research and data analysis occurring (Winter & Munn-Giddings, 2001:235). It is clear that the SURAG members desired change and a new way of viewing and understanding their own and research participant's situations and experiences. That is not all though, they wished to highlight new ways of doing things, they wanted improvement, and these aims were not to be met by maintaining the status quo or by merely confirming previously held thoughts.

It is the collective, co-sharing approach that enables interpretations to remain rooted in the experience of participants that I strived for. Beresford (2003:53) develops and expands on this type of connection between people's direct experience and their own interpretations of these experiences, indeed going further and linking this to the development of their own knowledge.

2.4.3.2 Introducing the collective analysis phase

Analysis was both a discrete stage in this study and embedded within the data collection stage. How this was achieved during the course of the study is of relevance, as is the way analysis was conducted both individually by myself, and collectively by the service users in the SURAG. This group, its makeup, remit and role is described in section 2.3.2 of this chapter. To ensure accurate recording of both the content and process of the embedded data analysis over a lengthy period of time, several methods were used and this can be seen as a three staged approach (See table 2.10 below).

Firstly, as data was collected over time from participants I undertook an initial analysis and presented this diagrammatically (See annex H for an example of one such sheet from the participant Hazel). Each participant would have several diagrammatic sheets illustrating different categories. These initial analytic ideas were shared with the SURAG at the regular meetings held and all these meetings were minuted and a contemporaneous write-up made. This write-up included group discussion and comment about the initial analysis. Secondly, I kept a 'Research

Journal' document in which I kept account of the content of all research related contact including the SURAG meetings and any participant contact. The accounts from the SURAG meetings included further elaboration of the group's contribution with regard any data analysis discussed. Thirdly, I kept a critical reflections document in which I kept track of influences upon me over time during my research and PhD, theoretical as well as emotional. This formed a way of both collecting reflexive notes and of developing ideas and accounting for their progress. Within this document, which began in February 2002, SURAG member's insights about data analysis are recorded. Such insights include both supportive and critical reflections on participant transcripts and initial analysis.

Table 2.10: Stages in the embedded data analysis

Stage	Description
1	Researchers initial analysis presented diagrammatically with SURAG members commentary
2	Research journal accounts of both participant and SURAG members analytic responses (including validating statements)
3	Critical reflections account of challenging SURAG analytic contributions

Data analysis was certainly embedded in the data collection stage of the study then, both individually myself and collectively with members of the SURAG. The SURAG first met in November 2002 and at the third meeting of the group in February 2003 the first discussion about data collected, in January and February 2003, took place. The main attention at this stage was on the process of data collection but service user members of the SURAG also readily engaged with the information presented in relation to their own experiences and in a way that attempted to make sense of this data. In advance of the next meeting in April 2003, group members were presented with initial data analysis that I had completed on a transcript from an individual interview. During this meeting the group commented and added their perspective on

this analysis, which largely involved an endorsement of the participants coping strategies and experience of relationships since being diagnosed with a life limiting condition.

However, some aspects of this reflection can be seen as a level of analysis. For example, when discussing this participant's ways of coping with their condition group members endorsed their pragmatic way of just 'getting on with it' but went further to explore what the participant was saying in terms of fatalism. They were able to consider aspects of this participant's fatalism from what they had said and felt that the participant was not simply passively accepting their situation nor simply focusing purely on the depressing nature of living with a life limiting condition. Rather SURAG members were identifying a positive act involved in 'getting on with it'. They were identifying a way of living whilst living differently, a way of living whilst aware of the seriousness of ones situation.

The discrete collective data analysis stage with the SURAG commenced in June 2004 and was completed in early January 2005 (See table 2.11 below). Each of these group analysis sessions were tape-recorded, notes made on a flip chart, and an interpretation sheet completed from this (See annex I for an example of one sheet). These sheets are not verbatim accounts but an overall account of the key components taken from a combination of the flip chart notes and the tape-recorded meeting. In all there were thirteen transcripts, which included both individual interviews and group discussions (Twenty-two participants in all. Three participants took part in the participant observation phase only), and these were examined one by one. Consequently there were thirteen interpretation sheets completed.

Table 2.11: Discrete data analysis stage - content

Analysis session no.	Date	Description
Session 1	June 2004	Participant 7 'Chris' and his partner 'Clare'

Session 2	June 2004	Participant 7 'Chris' and his partner 'Clare'
Session 3	July 2004	Participant 13 'Jess'; Participant 5 'Simon'; Group Discussion 01.03
Session 4	July 2004	Participant 13 'Jess'
Session 5	August 2004	Participant 11 'Mel'; Participant 12 'Sheila'
Session 6	September 2004	Participant 15 'John'; Participant 18 'Hazel'
Session 7	October 2004	Participant 24 'Edith'; Participant 17 'Becky'
Session 8	November 2004	Group Discussion 11.03
Session 9	December 2004	Participant 34 'Delia'
Session 10	January 2005	Group Discussion 03.04

2.4.3.3 Personal reflections on collective data analysis

At times I became frustrated by the time this stage was taking. At several of these afternoon sessions I planned to look at two or three transcripts but in reality we often looked at far fewer. I spoke about this with the group and it was generally felt that there were two reasons for this. Firstly, group members felt, as we did more of them that they were looking in greater detail at the transcripts compared to the first sessions. Secondly, that some of the transcripts were very dense. Dense in terms of the content that, at times, was difficult to digest due to the way participants spoke, repeated themselves or raised difficult experiences. Without exception, at different

times each SURAG member struggled with some of the content of data in the transcripts. Often this was due to a resonance with their own experience and/or that they felt angry or sad for participants. Whilst I felt frustrated at our seemingly slow progress with data analysis, I was always conscious of the difficult task facing group members. On reflection it felt better to continue at a slower pace than speed up or take short cuts and potentially forfeit the quality of material we were accumulating. Following a particular meeting with my PhD supervisors early in data analysis I returned to the group and discussed the possibility of analysing a sample of transcripts. I knew the answer before asking. The group felt strongly that all transcripts needed to be entered into analysis. They didn't want to break the momentum of this process or exclude particular transcripts from it.

There may have been issues of training that could have been more fully pursued at this stage. This is highlighted in section 5.11.7 of the discussion chapter.

In the original analysis plan I had intended to create themes from the write up of the discrete collective data analysis stage myself. I had envisaged that it would be reasonably clear what themes were emerging from these collective sessions and that I could extract them from the write-ups of these sessions (the interpretation sheets) and at a later date show them to the members of the SURAG for discussion and then confirmation. I did not do this however as having conducted the first sessions and reviewing the interpretation sheets it became clear that the group needed to be involved in confirming and agreeing what themes needed to be drawn out of these session write-ups. If I had completed this stage alone it would have missed the point of collaborating together on this study. It also became obvious after the first group analysis sessions that it was far from clear what the resultant themes would be. There was still further work to do before themes could be identified confidently and reliably.

This was disappointing as I was aware of time going by and I had a desire to complete data analysis and the generation of themes by the end of 2004. Having worked with the SURAG for two years at this stage though, I had little hesitation but to extend this part of our work together. I took a pragmatic approach and decided to let it happen at its own pace. It was not all in my control and I recognised this. It had a momentum of its own. Perhaps this momentum comes when working with others. I felt the research

had become 'ours' and not 'mine'. For the most part I was very happy with this as it felt like a shared responsibility to take the research forward, and it was also reassuring to have advisers and supporters to hand. Less frequently, I felt this frustration at my perception of a 'slow paced' research project. I was also very aware of my desire and need to progress with thesis writing but did not always have as much energy for this as I would have liked. The research and in particular the analysis, was taking a lot of time and energy.

At this time I was also preoccupied with personal doubts about the research and the potential research findings. I was aware of other research that was involving service users as co-researchers or advisers and comparing this with our research and how the SURAG had been working. I was thoughtful as to how I would have done this study differently now with the knowledge I had gained over the previous few years. This also coincided with presenting our research at the INVOLVE conference and hearing examples of other collaborative research. I worried about the group's lack of research training and about not planning ahead and organising funding that would have enabled the SURAG members to be paid for their time and involvement. I also worried about the quality of our analysis. When we were in the middle of our analysis sessions I was reviewing all the interpretation sheets we had done and for a while I couldn't see how we were going to generate themes from them. At times the interpretation sheets seemed very broad with SURAG members discussing issues more generally rather than focusing on direct interpretations from participant transcripts.

Subsequently I had opportunities to take time and reflect on what we achieved as a group. With regard the analysis of data I can now see the uniqueness of it. When we completed sessions orientated to the generation of themes (Please see the next section) I was also able to see the long process of data analysis reaching an end point. All the time and effort that had gone into the interpretation sheets I saw as worthwhile when we started seeing the themes take shape. Undoubtedly this stage could have been conducted differently but we would not have what we have, rich interpretation from the perspectives of service users and themes that were generated through a thoughtful and considerate process.

2.4.3.4 First theme generation session

Following on from the ten analysis sessions, we held sessions designed to collectively extract themes from the typed interpretation sheets. In the previous stage we took one transcript at a time and analysed it together, which led to the interpretation sheets being formed. In this next stage we took each interpretation sheet in turn and proceeded to decide what themes could be gained from these sheets. We reviewed five such sheets in the first session. This session was tape-recorded. Here is an extract about this first session from my research journal:

All SURAG members joined in and contributed about all of these sheets. Members suggested different themes and we had some debate about these. As we built up the number of themes, different things from the interpretation sheets were added to what was considered the right theme. We had some acknowledgement that some themes could be collapsed/merged and that this can be done at a future meeting after we see what we have at the end of this process.

I was worried once or twice when (name of SURAG member) suggested various themes by saying things like “I think pain must be a theme for people living with a life limiting condition”. I pointed out that the themes need to come from the data or things that are generated by the data. As it happened, later there were items from the data that could fall into the themes this person suggested.

I went on further to consider how I had introduced this part of the analysis:

I do worry that I have been too prescriptive about the analysis and generation of themes in terms of identifying items that only can be tracked back to the data. Several people commented about this and at times went through the transcript in question to ensure that the participant had in fact, said a particular comment. I have previously spoken with everyone about themes coming from the data and this has become quite a literal take.

I do believe that researchers can have the capacity to generate themes that sum up, or illustrate issues or points that participants may not have actually verbalised but rather intimated. Or it may be that a particular theme is such that describes very well what seems to be raised but not said by participants. This is difficult really. Perhaps I have over done the 'be careful' pep talk. On the other hand I didn't want spurious things identified from the data. Now I might have set up this phase in a distorted way. I hope that after this initial, generation of themes, phase we can look at what we have and think creatively about the themes and check the transcripts and interpretation sheets. It seems to me that we are identifying patterns from the participants and final theme decisions can be agreed later.

This session had been preceded by some input from myself about thematic analysis and the process I suggested we follow for this stage (See annex J). The group accepted this proposal. I also led a discussion about the principles of service user involvement in data analysis (See annex K). Another extract from my research journal highlights how this discussion went:

We talked through these sheets and had a lengthy discussion about them...there was a surprising level of discussion I felt. Everyone was keen to discuss the process of how we are to generate themes from the interpretations we have done and there was also a lengthy discussion about assumptions, value judgements, neutrality and bias, and the role of the group in pulling out themes. I described how themes might be generated and we brain stormed and I did a simple diagram (Using ideas from the group) on the flip chart to illustrate how this might look as themes and sub-themes:

Fear of the future

Loneliness-----

Isolation

?

Services-----

?

Positive

Others reactions-----

Negative

Everyone said they found this helpful.

2.4.3.5 Considering theme generation from my own initial analysis

During the time that the SURAG were generating themes I decided to re-consider the analysis I conducted following the data being collected (See annex H for an example of this early analysis) to establish what my theme generation would look like. I wanted to decide if the themes that I focused upon were very different to those the SURAG were beginning to build. I structured my themes around the original questions asked at data collection. Themes that came easily to me were LIVING WITH A LIFE LIMITING CONDITION, SERVICES (with sub-themes of positive and negative), BEING DIAGNOSED, IDENTITY (with sub-themes of difference, understanding and future) and RELATIONSHIPS. At the time I noted that the themes being formed from SURAG members focused far more on emotions and reactions i.e. FEAR, GRIEF, and ANGER/FRUSTRATION.

The path we took was chosen with the intention of making the analysis as inclusive of the SURAG members as possible. This was always foremost in my mind and decision-making. During this collective analytic process it was very much a case of learning and adapting as we went along, as there was little literature to draw upon and guide us with this phase of the research.

2.4.3.6 Possibilities for collective analysis

There are few examples documenting attempts at, and the results of, collective data analysis. Where there are examples there is often little detail about the process that was taken to ensure a collective analysis occurred. Rhodes et al (2002) for example, highlighted that one of the values of working with a service user advisory group was the fact of such a group indicating what they thought of the researcher's original interpretations of data. This was achieved by presenting the initial analysis to the group. Little was documented here though of how this occurred, nor was it

documented what effect service user's comments had on the data analysis or the researchers themselves.

A citizen commission made up of service users aiming to report what they had to say about the welfare state utilised a two-stage approach to analysing their data. This participatory research study firstly called upon the paid worker on the study, a service user, to start the process of analysing all the information. This person identified key issues and these were then discussed in a meeting of the commission. These discussions formed the basis for the commission's proposals and recommendations (Beresford & Turner, 1997).

In discussing emancipatory disability research, Mercer (in Barnes & Mercer, 2004:128) points out how proponents have often side stepped full elaboration of methodology in favour of methods, staying 'onside' politically, and hence attempts to 'collectivise data analysis (even in a small advisory group) were rare'. This is viewed as an important omission which, in order to advance a collaborative and service user sensitive project, needs to be remedied. How knowledge production is influenced by a collective collaborative methodology is an important point. Many qualitative studies highlight how participants have been given the end product of interview data in some form as an attempt at participant validation of data or inclusion, however far fewer accounts have been documented about how participants or other service user representatives have influenced the research process generally and the analysis of data specifically.

One of the key issues for this research has been the attempt to maximise the involvement of the members of the SURAG in all stages of the research but specifically, and of interest here in this section, to involve members meaningfully in the analysis of research data. This way of conducting analysis has sought to include rather than exclude and to that end unwieldy and complex analytical strategies have been avoided. The distance between SURAG members, the data, and their interpretations has been kept to a minimum. By this I mean that members experience, and knowledge that this experience has brought, has been seen as integral to their analysis of research data. This experience and knowledge could be bypassed by adopting a technical or complex analytic strategy. The epistemological assumptions

inherent in this research and explained in section 2.2 of this chapter highlight the need for knowledge rooted in the lives and experiences of people with life limiting conditions to be placed in the foreground. This knowledge has been attempted to be placed in the foreground during data analysis as described in the account of how analysis was achieved above.

A further aim has been to include differing interpretations and this has been attempted by using a collective approach to data analysis with people who have life limiting conditions being at the centre of this approach. This is in keeping with aims in the emancipatory research approach whereby collectivising the commonalities of experiences is given primacy (Stone & Priestley, 1996).

All SURAG members related transcripts to their own experiences and to this end a degree of validation has been achieved. I have captured many examples of SURAG members echoing the experiences, issues, and concerns that participants relayed during the course of data collection. Members generally showed great empathy with participants and mostly endorsed participant's accounts. There were though, examples of criticism and judgement making towards certain aspects that some participants discussed. Some things just didn't resonate with members and attempts were made to explain these occasional differences with their own experience and perception. There were one or two instances when I felt quite uncomfortable with the criticism levelled at a participant. There were various reasons for my uncomfortable feelings. Firstly, I felt the judgements to be unfounded and that they did not reflect what I new from having met the participant. Secondly, I new both for personal and professional reasons that one should strive to avoid making value judgements and criticism of research participants. It didn't seem ethical or professional. Thirdly, it didn't seem possible to make these judgements from the data we had. I discussed my opinion about this with the group as issues arose and my point about remaining focused on the data in front of us and trying not to speculate was always accepted. Group members appeared to be able to acknowledge this point quite readily when it was highlighted to them (These issues are discussed in section 5.11).

When I was preparing the data analysis stage of the research I had identified and adapted a framework that I thought would be helpful for the group and the analysis

stage. When I discussed this with SURAG members they gave favourable agreement to using it. Whilst I had wanted to enable the SURAG members to utilise their experience in analysis I also was aware that we needed to accommodate the everyday events and issues of participants along with wider and insightful interpretations. I thought the framework would allow us to focus on the task at hand whilst offering flexibility to gain these insightful and more intuitive interpretations. I had not though considered that the group might judge and personally criticise participants. I do not consider this a flaw of the framework used however but rather I see this as a lack of research training in the group that I had not anticipated.

2.4.3.7 Critically reflective thinking: an interpretive framework

As discussed above, a way of making sense of data was sought that would maximise the interpretations offered by members of the SURAG. A form of reflective analysis was utilised in order to offer shape and direction to the collective analysis we wanted to conduct. The intention was not to offer a rigid model or staged process but to have at our disposal prompts, which encouraged us all to take a critical or an alternative view of the data.

Hart (1995) proposes five 'interpretive modes' that were formulated during deliberations about her own research which considered how teachers could maximise pupils learning through broadening teachers own understandings of their pupils perspective and widening their interpretive frame. This was considered to be achieved by taking account of a wide array of information pertaining to pupils learning or more pertinently, a pupil's difficulty with learning. Whilst these interpretive modes were developed in the context of advancing educational practice, their critical orientation can be helpful in the domain of research and particularly helpful within a methodology that strives for an emancipatory and socially encompassing interpretation. As will be described below, the framework encourages broad engagement with the data from a variety of perspectives. It overtly addresses the emotional aspect of data analysis at a personal level and also encourages researchers to view the experience from the perspective of the participant. This particular point connects well with service users being directly involved in data analysis as direct involvement is achieved and perhaps also greater understanding of participant's experiences and perspectives.

These 'interpretive modes' have been further developed (Hart, 2000) and an adapted form has been presented by action researchers who utilise a framework based on the modes, to analyse research data (Winter & Munn-Giddings, 2001:249). This adapted framework (See annex L) has been further modified and used in this research and therefore a short explanation will be given of the key items that underpin this framework. In explaining these modes further I will adapt them to the situation of research, research participants, and interpretation of research data, however the model originates from Hart (1995).

Firstly, the *interconnective* mode of thinking, accepts participants responses for what they are but goes on to link them to the environment, the situation that the participant occupies i.e. a participants account of loneliness and being misunderstood associated with living with a life limiting condition might be seen in terms of their own and others perception of their newly fashioned place in society. Secondly, the *oppositional* mode of thinking, challenges the grounds on which perceptions are based by raising an alternative view i.e. this participants feeling of loneliness and misunderstanding is appropriate in terms of their life limiting condition. This mode assists in allowing us to acknowledge existing norms and expectations we may hold and to challenge them.

The third mode, the *decentred* mode, necessitates the researcher to 'step outside' their own frame of reference and try to construct the experience from the others point of view. This may involve acknowledging the context in which participants are in and appreciating their accounts within this context i.e. a participant's loneliness might be seen as both a response to living with a life limiting condition but also perhaps as a way to negotiate their relationship with those around them who have their own expectations and fears. Acknowledging the response of loneliness solely in terms of an acceptable response to having a life limiting condition may originate within ones own frame of reference but the alternative interpretation allows openness to participant's perspectives.

Fourthly, the *affective* mode acknowledges that ones own emotional responses need to be considered as they may have influence upon our interpretations of participant's data. This mode asks the question; to what extent are our interpretations based within the frame of our own hopes, fears and desires? I.e. for myself as researcher, have my

prior assumptions regarding epistemology and viewing the research from a critical and social model of disability stance, affected my interpretations? From the point of service user members of the SURAG, has their desire to be seen and heard as individuals with life limiting conditions themselves played a part in their interpretations of data? We might also helpfully reflect on the effect on interpretation of emotional response in ourselves that originate from very emotional and frank accounts from participants. Lastly, the *hypothetical* mode acknowledges the requirement in interpretation to be open-minded and to allow different and perhaps competing understandings to emerge. This interpretive mode of thinking reminds us of a certain unknowness to participant's accounts. Interpretations of these accounts may take time to become clear and it may be that we, as researchers, need to further learn from the accounts of participants.

Whilst these modes and the adapted framework fit with the intentions of research and particularly with research that has service users involved, as this project does, it hasn't been totally straight forward. Some members of the SURAG utilised the framework more than others. These members structured their interpretations in terms of the framework and in analysis sessions they would typically raise a point from the transcript and offer the link to one of the framework questions. For example, when we were conducting an interpretation session for Participant 11 'Mel', a point was raised from the transcript about the participant loosing her friends once diagnosed with her condition and the SURAG member raising this point immediately referred us to question 3 of the framework (what does this tell you about relationships with others?) so that I could make note of this.

Conversely, others often did not make a link to the questions in the framework when interpreting data in transcripts. This was mainly the men in the group. Whilst the men proceeded similarly to the women members of the SURAG, they tended to raise issues and points from the transcripts that concerned themselves and things that 'are remarkable' as one of them said. Nevertheless, utilising this framework has been more helpful than unhelpful.

2.5 Rigour

The need for rigour has been widely debated within qualitative research with conflicting advice on both the need for rigour at all and on how to ensure a research study achieves rigour. At its most basic rigour can be understood as a way of ensuring research has been conducted in such a way as to adhere to principles that are reliable and clear to the interested onlooker and that fulfil the expectations of the research and academic communities. However this is a highly contested area in which some qualitative researchers at one end of the spectrum may advise adhering to a 'scientific' and formulaic set of measures and at the other end others who may propose an 'anything goes' view towards rigour. Silverman (2000:175) has however cautioned against the latter view and asserts that without reliable methods and valid conclusions 'research descends into a bedlam where the only battles that are won are by those who shout the loudest'. As the reader of this thesis will need to judge how plausible or believable the research that it is based upon is, I will outline some of the debate on rigour.

There are various perspectives on the issues of rigour in qualitative research and some of the earliest attempts to counter positivist claims of rigour and to fashion an alternative but robust criteria for rigour in qualitative research were developed by Guba and Lincoln (1985; 1989). Initially criteria were outlined around key questions which researchers should measure studies against:

- How truthful are the particular findings of the study? By what criteria can we judge them?
- How applicable are these findings to another setting or group of people?
- How can we be reasonably sure that the findings would be replicated if the study were conducted with the same participants in the same context?
- How can we be sure that the findings are reflective of the subjects and the inquiry itself rather than the product of the researcher's biases or prejudices?

(Guba & Lincoln, 1985:290)

This was further developed into a proposal of equivalent criteria to that accepted as standard in conventional, positivist influenced research i.e. internal validity, external validity, reliability, and objectivity. The alternative measure for robust rigour, the so called parallel criteria, was formed around the idea of 'trustworthiness' within which four concepts were proposed as an alternative and more appropriate criterion of rigour in qualitative research (see table 2.12 below).

Table 2.12: Parallel criteria of rigour (Guba & Lincoln, 1989:233)

Conventional criterion of rigour	Parallel criterion of rigour
Internal validity	Credibility
External validity	Transferability
Reliability	Dependability
Objectivity	Confirmability

A short explanation of these four criteria of rigour will be given in turn that highlights the proposed significance of them to qualitative studies:

Credibility (Internal Validity)

The accuracy of a qualitative study is typically participant-orientated rather than researcher-defined. Rather than claiming the truth of research to be based on a presumed 'reality out there' the focus is moved to the match between the 'realities' of the research participant and the 'realities' represented by the researcher/s. Several techniques are suggested to elaborate this including peer debriefing and member checks.

Transferability (External Validity)

This criterion refers to the degree of 'fit' that the findings have in similar contexts outside the study situation. To enable this to occur the qualitative researcher is required to provide as complete a description as possible of the time, place, context, and culture in which the study took place.

Dependability (Reliability)

It is suggested here that dependability exists when the 'decision trail' left by the researcher is clear and logical. It needs to be both tracked and trackable by other researchers or readers of the study. During interpretation for example each explicit detail about how themes were derived should be open to scrutiny and capable of being tracked back to the data from which they arose.

Confirmability (Objectivity)

Confirmability is concerned with 'assuring that data, interpretations...are rooted in contexts and persons apart from the evaluator and not simply figments of the evaluator's imagination'.

(Guba & Lincoln, 1989:236 to 243)

These alternative criteria have been criticised though as being too positivist and therefore not alternative enough (Seale, 1999:46; Sparkes, 2001). A full critique of this position will not take place here, as it is a philosophical and methodological discussion that is not the purpose or the focus here. However it is salient to highlight that Sparkes (2001) recognizes that whilst there can be no 'recipes or rigid formulas' that 'proves' validity, qualitative researchers need to construct 'a multitude of criteria for judging both the process and products of qualitative research'. Multiple criteria consist of a range of ways whereby research can be judged and I suggest that ideas of rigour here are now far from conventional understandings, rather, together they may be termed a 'critical rigour'. I will now outline some of the key principles that together may constitute the markers of this critical rigour.

One may judge the authenticity of research and consider how engaged the reader becomes with the lives and emotions of those described; the research may convincingly convey that the events and experiences relayed did occur and were felt in ways proposed by the researcher; the research may be judged on the impact it has on the emotion and intellect of the reader; the research may also be 'believable' which does not necessarily mean that the reader will believe all that is stated but that the reader can accept that the issues raised and the experiences relayed 'seem to have happened' (Sparkes, 2001).

Another way of assessing credibility within qualitative studies, especially collaborative studies, may be to utilise what is known as critical change criteria. Patton (2002:548) for example proposes consequential validity as a way to assess 'who benefits and who is harmed by an inquiry, measurement, or method'. The outcomes of a project for participants, service user researchers, and the interested public are the things of importance using this criterion. So in seeking rigour there may be a shift of focus from the researchers actions that may require an explicit 'audit trail' of the influences and actions of the researcher (Koch, 1994), towards an understanding of rigour as the judgement of research findings based on 'the usefulness of the research product' (Koch & Harrington, 1998). The research project shows engagement with the multiple perspectives of the differing voices within it along with the necessity for others to engage with it in either agreement or disagreement. The faithfulness and fullness of this presentation of differing perspectives has been suggested to be related to validity (Winter & Munn-Giddings, 2001:21).

With this research in mind it is clear that the voice of participants has been strongly heard in the wide range of accounts relayed in both of the findings chapters (chapters 3 and 4). Within each theme it is apparent that different emphases are at play but that collectively they support the theme within which they are located. It is for the reader to judge the 'believability' of the findings of this research however the genuine emotion in the accounts relayed is self-evident. Participants have sincerely offered accounts of their lives and members of the SURAG, people with direct experience of life limiting conditions themselves, have been integral to the interpretation of these accounts. This closeness between direct experience and its interpretation has been suggested to maximise the reliability of the knowledge produced by research (Beresford, 2003:33). Central to this proposition is the hypothesis that it is not fixed criteria, qualitative or quantitative, that is required by which to judge the rigour or validity of research but rather that it is this closeness of interpretation to experience that leads to more helpful and useful knowledge as well as being 'more likely to support the empowerment of the people that it relates to' (Beresford, 2003:53).

From a Black feminist perspective similar suggestions for the validity of interpretation based on direct experience is made, 'concrete experience as a criterion

for credibility frequently is invoked by Black women when making knowledge claims' (Hill Collins, 1990:209). The level of involvement of service user members of SURAG in the data analysis phase of this research was presented earlier in this chapter and the similarities and differences in interpretations between myself and SURAG members is discussed in section 5.10 of the discussion chapter. In this section issues of personal development and empowerment of these service users is also highlighted. Whilst it is certainly not claimed here that there is but one reality, or that the reality has been highlighted here, it is claimed that validity linked to the nature of analysis and data interpretation that involved service users with direct experience of the issues under focus here has been achieved.

The attention to interpretation based on a closeness to direct experience as a form of validity as discussed above can also be seen to be associated to other distinct claims for knowledge and validity that have originated from the fields of feminist and disability studies. The claim for 'strong objectivity' which stresses the limitations or even impossibilities of objectivity in the positivist understanding of the term promotes a 'strong reflexivity' which proposes knowledge as socially situated within the experiences of individuals (Harding in Alcoff & Potter, 1993:69 to 73). Other feminist writers highlight similar issues regarding validity and also concentrate on the power of dialogue, ethics of research, and empowerment as important issues in judging validity in research (Humphries et al in Truman et al, 2000:13; Gill, in Henwood et al, 1998:39; Stanley & Wise, 1993:66). In a wide-ranging critique of the problems associated with validity in qualitative research, Oakley (2000:72) concludes that it is the awareness of, and action to minimize error in research that is the distinguishing mark of 'good' research.

Within the field of disability studies, criterion of rigour in research have developed alongside principles of good research conduct as a response to what in the past has been seen as disabling research practice. An example of what has been described as a disabling research project was described in section 1.5.1 of the literature review and Hunt (1981) was strident in his claims of these researchers being biased and self-interested. Emancipatory disability research developed over time from then and key indicators have since been promoted by which research should be judged. These criteria or indicators include an examination of the 'research relations' between those

who 'do' research and those who are 'being' researched with an emphasis on a far greater collaborative relationship with researchers engaging in an emancipatory project with those 'being' researched (Stone & Priestley, 1996).

The ability to move from the gathering and presentation of individual experiences towards a collective understanding that resonates with those who are the foci of study and wider communities have also been highlighted (Barnes, 2001). This resonance with the wider community refers to the highlighting of disabling consequences of society (Barnes, 2001). Further to this, that the experiential knowledge from groups at the centre of study is prioritised (Oliver in Corker & French, 1999:191) and that those involved in research are empowered (Mercer in Barnes et al, 2002:245) are both considered key principles with which to judge emancipatory research. Whilst this research has not claimed to be an emancipatory project it is claimed that many criteria of validity of the aforementioned critical rigour are achieved. This will be clear from discussion in sections 5.10, 5.11, and 5.12 of the discussion chapter in particular.

2.6 Chapter conclusion

This chapter has presented how this research was conducted and outlined in detail the influences that informed it and the decisions that were made to achieve this participatory study. Early in this chapter my personal interest in this area and my motivation for being involved in research in this area was explained. There is a clear link between issues raised in practice and this research. The active involvement of service users was one of the aims of this research and within this chapter many issues concerning the involvement of service users in research have been explored.

As highlighted in section 2.2.2 I considered that there were certain key elements required to reach an acceptable epistemological position. Such a position is acceptable in terms of the values implicit in this research. This position primarily involves ensuring that the experience and knowledge of service users with life limiting conditions is central to the research. Several different research approaches have been drawn upon in order to illustrate what the nature of knowledge is in terms of this research. Knowledge that reflects the particular perspectives of service users with life

limiting conditions was strived for. I accepted that service users living with life limiting conditions could know differently. That is they would have access to a knowledge based on their experiences of having a life limiting condition that myself, as a researcher and non-service user did not. An aim was to highlight collective experiences and knowledge whilst acknowledging individual differences in this experience and knowledge.

In terms of methodology, I was concerned with finding a way that avoided distancing the research and its findings from the experiences of service users with life limiting conditions. The methodology needed to accommodate openness and inclusiveness in the process of 'doing' the research and this was strived for through the active participation of service users throughout the project. The Service User Research Advisory Group was central methodologically and the group was intrinsically involved within the method, particularly in data analysis and the generation of themes. As well as describing the methods of data collection utilised in this research and the ethical dimensions, this chapter considered issues of rigour and particularly how this research may be critically viewed in terms of rigour.

Chapter 3 – Findings: Experiencing life limiting conditions

3.1 Introduction

In this chapter and the next the focus is on the findings from the research. There are eight themes in all of which seven are presented in this chapter. Themes are presented individually and have also been divided into sub-themes when appropriate for reasons of clarity. This chapter is divided into the sections shown in table 3.1 below.

Table 3.1: Findings chapter 3 sections

SECTION	TITLE
3.1	Introduction
3.2	Diagnosis
3.3	Fear
3.4	Anger/Frustration
3.5	Grief
3.6	Relationships
3.7	Difference/Individuality
3.8	Independent/Dependent
3.9	Chapter conclusion

Prior to introducing the themes a brief summary of the participants is presented alphabetically in table 3.2 below. This can be referred to when reading the findings chapters and will assist in understanding a little contextual information about the participants. All names are pseudonyms and more detail about participants can be found in annex E.

Table 3.2: Participant demographic information

Name	Gender	Age	Condition	Cited services	Brief biography
Becky	Female	44	HIV+	Acute	Diagnosed for 12 years.

				hospital, primary care & palliative care.	Occasional paid work. Lived with partner.
Bert	Male	85	Bowel Cancer with liver secondaries	Acute hospital & palliative care.	Diagnosed over one year. Had previously had a mild stroke. Lived with partner. Died suddenly during observation phase of the research.
Bessie	Female	78	Basal Cell Carcinoma	Acute hospital, social care & palliative care.	Diagnosed for six years. Had 11 operations on site of the cancer. Attended day hospice for first time on day she took part in a small group discussion. Lived with partner. Died in hospice two months after her research involvement.
Chris	Male	66	Stroke	Social services home care & acute hospital.	Stroke occurred 2 ^{1/2} years previously. Required help with all daily activities. Lived with partner.
Delia	Female	76	Cryptogenic Fibrosing Alveolitis	Acute hospital, primary care & social care.	Diagnosed for two years. Required oxygen periodically. She lived alone.
Edith	Female	79	Breast Cancer with appendix secondary & radiation induced lung damage	Acute hospital & primary care.	Diagnosed for twenty years and more recently had pulmonary embolisms and lymphoedema. Required oxygen 15 hours daily. Lived with partner.
Fiona	Female	61	Bladder Cancer with pelvic secondaries	Acute hospital & palliative care.	Diagnosed for three years. Had attended day hospice for four months. Lived alone. Died in a nursing home three months after her research involvement.
Greg	Male	67	Bowel Cancer with	Acute hospital &	Diagnosed for six months. Had attended day hospice for three

			liver secondaries	palliative care.	months & had been an in-patient also. Lived with partner. Died at home two months after his research involvement.
Harry	Male	68	Unknown primary with bone secondaries	Acute hospital & palliative care.	Diagnosed over one year. Lived with partner. Had attended day hospice for two months. Died in hospice four weeks after his research involvement.
Hazel	Female	58	ME	Acute hospital, primary care & social care.	Diagnosed for seven years. Lived alone in an adapted house.
Jess	Female	50	MS	Acute hospital, primary care & social care.	Diagnosed for over 12 years. She was wheelchair dependent and on the 'Direct Payments' scheme. Lived alone.
John	Male	38	HIV+	Acute hospital, primary care & palliative care.	Diagnosed for 14 years. Had AIDS defining illnesses. Lived with partner.
Lily	Female	84	Cancer of the ovary with bowel secondaries	Acute hospital, social care & palliative care.	Diagnosed 18 months. Had surgery twice. Lived in private residential home. Had attended day hospice for three months. Died in nursing home three weeks after her research involvement.
Maisie	Female	77	Non-Hodgkins Lymphoma	Acute hospital, primary care, social care & palliative care.	Diagnosed for 13 years with recurrence one year ago. Had received chemotherapy & radiotherapy. Had attended day hospice for four months. Lived alone. Died in hospital two months after her research involvement.

Malcolm	Male	79	Non-Hodgkins Lymphoma	Acute hospital, social care & palliative care.	Diagnosed for 10 months. Had received chemotherapy. Had attended day hospice for two months. Lived alone.
May	Female	69	Cancer of the Oesophagus	Acute hospital & palliative care.	Diagnosed for nine months. Had received chemotherapy & radiotherapy. Had attended day hospice for four months and had been an in-patient in hospice. Lived alone. Died in hospice eight months after her research involvement.
Mel	Female	53	COPD	Primary care.	Diagnosed for four years. Advised to stop paid work. Lived alone.
Pete	Male	48	Glioma	Acute hospital & palliative care.	Diagnosed over one year. Lived with partner. Died seven months after his research involvement.
Ralph	Male	74	Cancer of the Oesophagus	Acute hospital & palliative care.	Diagnosed within last twelve months. Had a stent (tube) inserted into his oesophagus to help him swallow. Had attended day hospice for three months. Lived with partner. Died in hospice two months after his research involvement.
Sheila	Female	62	COPD & Heart Failure	Acute hospital & primary care.	Diagnosed within last 10 years. Stopped paid work soon after diagnosis. Required oxygen 15 hours daily. Lived with friend/unpaid carer.
Simon	Male	75	Lung cancer	Day hospice & acute hospital.	Diagnosed for two years. Had attended day hospice for six months. Lived with partner.
Sylvia	Female	55	MS	Social care.	Diagnosed for eight years. She was wheelchair dependent and on the 'Direct Payments' scheme. Lived alone.

Val	Female	69	Multiple Myeloma	Acute hospital, primary care & palliative care.	Diagnosed for two years. Had received chemotherapy. Had attended day hospice for four months. Lived with partner.
Wendy	Female	57	Subarachnoid Haemorrhage	Acute hospital & social care.	Diagnosed for 14 years. She had severe weakness down one side of her body and speech difficulties. Lived alone.

Themes are not presented in any hierarchy of importance nor in terms of the number of times participants may have discussed particular issues. The order of themes is not meant to signify any sequential process that individuals 'should' move through. The themes arose from participants in this research and have not been arbitrarily arrived at.

The order in which the themes are presented has been chosen because it represents the structure of actual interviews or group discussions, in terms of what was discussed at different stages during the interviews or group discussions. Participants were always asked to begin with an explanation of their diagnosis, when they were diagnosed, and what had happened from diagnosis to the present time.

Following the theme of diagnosis the themes of fear, anger/frustration, and grief could be in a different order, however participants spoke of these emotions throughout their interviews or group discussions but mainly towards the beginning. This was probably due to early questions being about their condition and their life with their particular condition. The themes of relationships and services also occurred at this point when questions were directed to these issues. The themes of difference/individuality and independent/dependent arose from discussion that occurred throughout the interviews and group discussions but tended to occur at later points in the particular interview or group discussion.

The themes presented here are themes identified, agreed and accepted by both the Service User Research Advisory Group and myself and constitute the main findings

of this research. The themes are now presented as in the order of table 3.1 but it should be acknowledged that despite the themes being discrete there are interconnections between them and some overlapping of issues at times. Please note that the theme of services is substantial and relates specifically to one of the aims of this research and therefore has been organised in a chapter of its own. The findings about perceptions of services are presented in chapter four. Figure 3.1 below outlines the key components and/or sub-themes representing them. Sub-themes are highlighted in bold but the main aim here has been to present key issues that themes consisted of in an easy illustrative form.

Theme 1: Diagnosis	Theme 2: Fear
<p>Personal impact</p> <ul style="list-style-type: none"> • Trauma of diagnosis • Diagnosis as legitimacy <p>Impact on others</p> <ul style="list-style-type: none"> • Sharing knowledge of diagnosis • Managing reactions <p>Wider impact</p> <ul style="list-style-type: none"> • Effect on life • Changing life perceptions 	<p>Initial Fears</p> <ul style="list-style-type: none"> • Struggling with uncertainty • Fearing the future <p>Day to Day Fears</p> <ul style="list-style-type: none"> • A fearful present reality • Privatness of fear
Theme 3: Anger/Frustration	Theme 4: Grief
<p>Personal Impact</p> <ul style="list-style-type: none"> • Lack of control/powerlessness • Frustrating restrictions <p>External Impact</p> <ul style="list-style-type: none"> • Frustrating condition/treatment • Others reactions/responses 	<p>Functional Losses</p> <ul style="list-style-type: none"> • Loss of physical ability/loss of work • Loss of control over daily life <p>Abstract Losses</p> <ul style="list-style-type: none"> • Loss of aspects of life • Changing perspectives on life
Theme 5: Relationships	Theme 6: Services
<ul style="list-style-type: none"> • Variability of reactions to diagnosis • Life restrictions/changing relations • Social withdrawal • Withdrawal of others • Relationships tensions/assumptions 	<ul style="list-style-type: none"> • Some beneficial services • Many unsatisfactory services • Some valued staff attitudes • Many unsatisfactory staff attitudes • Differences in care/support provision
Theme 7: Difference/Individuality	Theme 8: Independent/Dependent

<ul style="list-style-type: none"> • Seen and treated differently • Striving to be accepted for one self • Requiring care/support • Maintenance of self-esteem • Negotiation of others perceptions • Controlling stigmatization 	<ul style="list-style-type: none"> • Increasing dependence/others influence • Maximising independence/control of self • Negotiate assumptions of impairment • Focus on achievements
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Figure 3.1: Themes and key components arising from data (with sub-themes in bold)

3.2 Diagnosis

The theme diagnosis consists of three sub-themes, ‘personal impact’, ‘impact on others’, and ‘wider impact’. Participants spoke about their diagnosis in terms of how the diagnosis was relayed to them, the impact on themselves, their family and friends, and in terms of wider implications and concerns.

3.2.1 Personal impact

The shock and surprise of diagnosis was clearly relayed by participants. This was similar no matter which condition participants had. This may partly be due to the suddenness of the onset of symptoms but also to a sense of inviolacy. John illustrated this attitude:

There was a great belief in it won’t be me.

He went on to talk about the day he found out his diagnosis:

People have said to me did, did you think you knew. No I don’t think I knew, right up until the Doctor rang me and said she needed to see me and then I knew exactly what was going on and I said to Ron ‘you need to come down to the Doctors with me’...it was just a medical. We were going through the formalities of remortgaging really... it wasn’t anything particularly important. We were both shocked.

The route to diagnosis was different for Becky who discovered an ex partner was very ill with AIDS and got herself tested straight away with the inner belief that she was going to test positive:

It was just intuition. Everyone kept saying to me ‘oh you don’t know, you don’t know’... but I just knew, I just had a feeling, it was like ‘yeah, you know, that’s going to be it’...But even still didn’t lessen the shock. That bit (getting the diagnosis) was the worst possible thing that, that I could imagine.

Becky clearly spoke of the horrendous first few months after diagnosis when she had endless rounds of hospital appointments and tests and became very depressed:

I did the classic denial thing, ‘well I’m okay I’m fine it’s not going to affect me’...that lasted for a few weeks and then I crashed. I had major depression. I thought I’m going to be dead by the time I’m forty and that’s all I could see.

She had good reason to be depressed at this time, before combination drug therapy, as she was told to expect to live between five and ten years. She went on however to describe herself as naturally an optimist who made a clear decision early in the course of her HIV+:

I’m not just going to sit back and be a victim.

This was very difficult though when she was seeing others around her in hospital and outpatients who were very ill indeed:

I was seeing a lot of people...who’d lost loads of weight and were literally at deaths door and I thought no. No, I’m not going to do that.

Becky had been diagnosed with HIV+ nearly twelve years before the interview and she reflected on this:

I've adjusted over the years, as I've had to change. And my health has sort of gone a bit up and down...The secret is adjusting as best as you can and not giving up.

Hazel highlighted the suddenness of the onset of her symptoms when she was aged fifty years:

I had been feeling a bit tired...I woke up one day and I had a pounding headache...I went back to bed and that was it I couldn't get up again. It was just total wipeout, my body felt as though it had given up completely. It was as sudden as that.

She went on to describe the level of fatigue she felt from the start of her symptoms:

It felt as though I'd run a marathon the previous day, I'd got a really bad hangover, and a dose of flu...altogether.

Hazel also described the particular difficulties she encountered in getting her condition diagnosed, how her General Practitioner had prescribed medication for depression, conducted blood tests that didn't establish what was wrong, and how when she was seen by a hospital consultant she was diagnosed with menopausal depression. Hazel was angry at what she saw as a dismissive attitude but was taken seriously two weeks later by the same consultant and was admitted to hospital where she spent the next four weeks. She described the process of gaining her diagnosis:

They did all sorts of things like muscle tests and...cos my muscles...I couldn't do anything...my muscles were so weak. Lifting a cup of drink up to my lips was two handed and a real effort...brushing my teeth was a real effort, brushing my hair, I couldn't lift my hands up above my head...I couldn't sit on a toilet I had to be supported....it really just felt as if my body had...had totally given up.

Hazel was eventually seen by a neurologist who considered the diagnosis of CFS but the consultant who was in charge of her care felt differently:

The consultant I was under was one of these people who didn't believe in it as a proper illness. He was quite determined there was something else wrong with me. In the end I became so miserable there because the hospital atmosphere was the last thing I needed, the noise, the light...the nurses thought there was nothing wrong with me.

Following her daughter's intervention Hazel was discharged home with a provisional diagnosis of CFS but her problems continued:

I lost my job and my cottage was tied to the job so I had to find more accommodation. For about three months I just sort of stayed like that. Quite suddenly I went into urinary retention...I was packed back to hospital and that time I was there for nearly four months and I had MRI scans on the whole of my body, I had CAT scans and you name it I had it. I saw the same neurologist again and in the end he said well there is nothing I can pin point, it is CFS.

Hazel described how it took seven months to be given her diagnosis. She had contacted the ME association herself in a search for some kind of diagnostic test and literature about it. She described CFS as a broad term but found the term ME to more accurately describe her condition in line with World Health Organisation guidelines. The actual name of her condition was an issue between her and the medical team treating her:

They're very reluctant to call it ME but the second or third time he did call it ME (Neurologist)...encephalomyelitis literally means inflammation of the brain and the doctors are insisting there is no inflammation of the brain, although the brain is affected it's not inflamed which is why they won't call it Myalgic Encephalomyelitis.

More recently Hazel was still encountering issues with the legitimacy of her condition when she needed to see a different hospital doctor and she describes a letter this doctor sent to her General Practitioner:

For the diagnosis he hadn't put ME or CFS he'd put general malaise, this is after the government has recognised ME.

This struggle to obtain a diagnosis and for it to be considered legitimate led Hazel to reflect on her situation:

There were times when I was first ill when I thought I wished to goodness I'd got something like cancer because I thought well, then I'll die from it. Also I mean people will accept cancer. You know, if you've got cancer you're ill. Whereas if you've got ME a lot of people still think its yuppie flu.

Jess's experience with multiple sclerosis was to have not only a prompt diagnosis, but for her condition to deteriorate quickly:

I was diagnosed as being MS and I was in a wheelchair within about six weeks.

Other participants discussed the personal impact of diagnosis in greater detail and the potential cost of decisions that are taken at a time when they are still shocked by their diagnosis. Fiona recounted her experience:

I was diagnosed with bladder cancer...I had a big operation, a complete cystectomy because they thought that would be the best cure.

She later regretted this decision though:

The tumour is back in the same place. So there's nothing else they can do. I regret my decision. I wish I hadn't done anything because I've hated living with the stoma and all the inconvenience, the degradation. Horrible.

Fiona was not tolerating living in the way she was:

So I do regret that. But that's hindsight. This is just a sheer waste of time. I wish I could go now. I have no fear of dying and I wish I could go now...I

don't have a family. All of my family are dead as well. I have nothing that keeps me here.

May also discussed her initial reaction to her diagnosis, which followed her having an endoscopy for suspected gallstones:

When I came round from the anaesthetic they said "I'm afraid we've got some bad news for you", you go hot and cold, coz you know what is coming, it is going to be something horrible. "You have a tumour in your gullet" and I just went icy cold, just couldn't believe it...it frightened me to death. I was absolutely petrified. My one thought was that I didn't want to die. I've got so much to live for - my family and whatever - and that's all I could think of.

This account from May and others that preceded it give an indication of the personal impact that faced participants at this time. Impact was emotional and involved issues of mortality but was also concerned with some of the consequences of diagnosis that had influences beyond the individual level.

3.2.2 Impact on others

Participants here told us of negative reactions to their diagnosis by the people around them and of an inability to accept the diagnosis. John described the effect on his partner:

...obviously Ron had to relay his fears as well because he was also fearful for himself because he had to be tested there and then and he didn't know,

John also spoke of his mothers' reaction to being told of his HIV+ diagnosis:

She had a very bad reaction to it. She physically moved away from me and said it's your own bloody fault, I told you this sort of lifestyle would get you into trouble and now it's been proved, and we fell out. I hadn't spoken to her for over a year after that until I apologised...I didn't want to apologise to her...for upsetting her. I knew that if I ever wanted to have a relationship with her again I had to apologise and do all the running.

He also spoke of the impact the news had on his sister:

...when she did find out...she was very upset, and she actually found a counsellor and had counselling over it cos she didn't understand how she could...how it would happen...what would happen in the future. She thought I don't want a phone call saying John's gone.

Becky has also had to deal with the reaction of others around her as her and their perception of the imminence of dying has changed over time:

In the early days when I first told people it was very much a case of 'oh my god, how long have you got to live'? As time's gone on and as they've seen that I'm still quite well and with what's been happening with the medication and I talk to them and they ask me how I'm getting on and I think they're much more reassured.

For Becky though an important decision has been who to actually tell about her HIV+ diagnosis:

The difficult thing is who to tell and how you deal with telling those people and their reactions...I've told some members of my family but not all of them. Some of my friends know some don't. It's really hard.

She went on to explain her rationale for telling or not telling:

Sometimes it's for my benefit, because I feel I couldn't cope with how they might react...but also it's for their benefit because I'm not sure if they could cope with it and also do they really need to know? On the other hand it is a huge relief when I am with people who know...I can be totally myself. The other thing is the, how would they react...stigma wise, prejudice, that kind of thing?

3.2.3 Wider impact

Participants spoke of much wider, and perhaps unexpected, reactions and implications that accompanied their diagnosis. John for example spoke about how he came to leave work when he was diagnosed:

I went in and spoke to my boss and told her what had happened and said I can't come back and they said no you can if you want and I said no, I'm not coming back, I don't feel safe here.

Later he spoke about how he found another job but after a period of HIV+ health related problems:

...they found reason to fire me...I don't think they really did know how to deal with it. I think they decided it's easier if he's not here and they found a way round it. I fought over it...I went to two tribunals over it...in the end I gave up. I couldn't... you know this was six months, seven months after I'd left work. I couldn't lead.... I couldn't get up every day constantly thinking about work, would I, would I fight for this, would I fight for that? I had to let it go.

He went on to talk of the implications of this with regard to paid work:

I spent two years not working after that. We lost our house because my insurance company wouldn't pay. I felt very guilty about that. I did find it difficult. I never got past the first interview stage anywhere. When you get to first interview stage you have the first interview, then they ask you to give a medical report and I couldn't hide it.

John also had the awareness of how serious a condition he had, reinforced early on:

I remember when I found out, after about six months after I found out I had a friend in London who I went to see and we went to a house of one of his friends that I had spoken to before and there were about twenty people that were HIV positive and their partners or friends. And we talked about different

things and it was very, it was sociable...talking about things and six years ago the nineteenth person died. I was the only one left.

Hazel relayed some of the difficulties of securing a diagnosis of ME:

I have been ill seven and a half years and I was fortunate in a way that I was so ill right from the start that in fact I got a diagnosis within six months...but a lot of people with ME don't get a diagnosis for sort of.... five, ten fifteen, twenty years.

Hazel went on to reflect on being newly diagnosed:

It's been like a living hell it really has because (pause) I mean it's slightly better now but seven years ago nobody would recognise it as an illness...I knew I was physically ill.

Like Hazel, Becky spent some time in the interview reflecting on the course of her condition. Following some traumatic years after diagnosis she now seemed able to focus on living. She ensured she strictly adhered to her combination drug regime but was very aware of how different it can be:

As long as you look after yourself and you're aware of your limitations you can carry on and, with the drugs now, as long as they work for you.

Unfortunately there are still a lot of people that drugs don't work for, and there are still a lot of people out there who...who are very ill. I'm lucky.

Becky was also able to gain a lot of knowledge about her condition and go on to be very involved in teaching others about HIV+:

For the last eight years or so I've done a lot of community speaking, involved with Positively Women...

In this way she seemed able to challenge some of the more negative and frightening aspects of her condition. She had spoken of being very depressed for significant periods of time and it can be seen as a real reverse for her to be able to raise public awareness and perceptions about HIV+. Some participants discussed difficulties or delays in being diagnosed. Malcolm for example relayed his experience:

I had a tumour in my groin...I called it a lump... they didn't do a biopsy... there was some evidence, I had rashes and all sorts (doctor said) come back next year. When I got into the blood section (haematology)...the doctor said if he could have got to me earlier he could probably have got rid of the tumours, which of course are still there. I kept telling them about it and they kept looking at the blooming thing.

There were similarities with Val's experience:

I've got multiple myeloma stage three. I'd been under (Hospital) for four years with rheumatoid arthritis. I kept onto them about the pain because it didn't seem to me to be arthritic...one of these blood tests had shown something up...I went and had that bone marrow thing and they picked it up straight away.

Other participants spoke of their condition being very advanced at diagnosis. Lily is an example of this:

I started with ovarian cancer...which had obviously been there for some considerable time, but I wasn't ill. They told me it was metastatic...then they said there's nothing we can do just refer you to the hospice.

Both Val and Lily seemed philosophical about this in their discussion of the difficulties of diagnosis:

I think cancer is an incredibly difficult thing to diagnose...Oh apparently it is, and it's...what's the word I want, it masks other things, which is what has been happening.

For others though there was anger and regret at the delay in diagnosis as Delia illustrates:

I was diagnosed in the October...it was the February or the March I went to see (GP)...I said I do get out of breath...she said I can find nothing wrong, I think it's in your head...if it had have been diagnosed earlier it...they might have been able to help. I think there must be a way of diagnosing these things earlier.

For Delia there was also anger at the assumptions people make when a person has a condition that affects their breathing even if it is a non-cancer condition:

People automatically think 'oh you've got cancer because you've been smoking'. And it's nothing to do with that at all.

3.3 Fear

Participants raised this theme of fear in different ways. The theme of fear consists of two sub-themes, 'initial fears' and 'day-to-day fears'. For some, fear was raised in discussion of their reaction to the diagnosis of their condition and the realisation of what this meant. For others, different fears were raised that related to their day-to-day experience of their condition.

3.3.1 Initial fears

The fear experienced at the time of diagnosis was highlighted in the last section in which the theme of diagnosis was explained. We heard how frightened May was at diagnosis and how her first thoughts were about dying. For Val though, fear was present before diagnosis as she explains:

I thought I was going mad. I really thought it was some neurotic woman going on and on. And when they told me it was a huge relief. I wasn't going round the twist.

For Val it seems that doubts about her mental health were almost worse than a diagnosis of cancer itself. Other participants discussed the dying process, fears around this and a personal need for religious faith as illustrated by Mel:

I know where I'm going when I die although, you know, the actual dying process is not a very nice thought, but um no I just know that my life is in God's hands and he, he you know, he knows, he knows when and where and etc so er you know.

Participants who had been referred to the hospice and who were attending the day centre there reflected on their reaction to referral. Here May describes her initial thoughts:

When they first said the word Hospice I sort of got that hot and cold feeling. In my first day over here that fear was dispelled completely. The word Hospice, sort of the old feeling...where you go to die, you go in and you're never going to come out.

May further illustrated her change in opinion about the hospice and her fear of it a little later. She had been describing being an inpatient at the hospice and witnessing the deterioration and death of a friend in the same ward as herself:

It did take away some of the fear for me. I witnessed her in that week going downhill, you know, getting ready to depart as it were and it did take away some of the fear for me. I sort of thought well she was so beautiful in the last few days and she was cared for - you couldn't wish for better care, it was absolutely marvellous.

Reflecting on her experience of the hospice May concluded:

It does take some of the scary bits out of, of having cancer. You know, I think you learn to live with it better.

Val continued this discussion:

I had an awful feeling...about cancer and going kicking and screaming at the end, and here (hospice) has taken that away.

Simon also echoed this initial fear:

The word Hospice struck terror in me. Not knowing. I thought I was going to be put in here, slung in a bed to d...daft I know. The word hospice you think Oh oh.

For these participants it seems that the initial fear of the hospice, and perhaps death, were effectively reduced by their experiences. Participants did not restrict discussion of fear to personal impacts though. John for example highlighted the fear his partner experienced:

He was also fearful for himself because he had to be tested there and then and he didn't know.

John also discussed a fear that was associated to other people, a fear of passing the virus on to others due to the nature of his paid work:

I honestly didn't know a great deal about it. I decided I couldn't go back to work.

He also feared for aspects of his future related to paid employment:

I'm going to live in poverty for the rest of my life.

Delia also found her fear to be associated with others around her and future orientated things:

I don't know how long it can last...it is terminal. I've so much to live for. I want so many things. I want to see my granddaughter established...I want to

see...I don't see my grandson who lives in Spain, very much. I want to see my daughters have a good life.

She had asked her general practitioner directly about her future but this did little to help her with planning:

I said 'I'm going to ask you a question, I want an honest answer, how long have I got'? And she said 'we don't know with this', and that was it you see, you don't know.

Sheila, who had a diagnosis of COPD and heart failure, also acknowledged a fear associated with an uncertain future. At the time of the interview a friend acted as an unpaid carer for her but she had concerns:

You're so dependent on a carer...I'm sixty two, things are going to be very different as the years go by I expect...I mean I've been like this since my early fifties...I can do far less than I could then, so I must be getting worse... you don't know what's going to happen in the future...I worry about, if anything happens to Jane yeah I must admit. I think how would I manage? So I do worry about that side of things...it does play on my mind a little bit without taking over.

Fearing a future that may not exist was also described by Becky who also described how she deals with this:

Long term, looking ahead...I don't do that...I can't control that, I still can't let myself believe I suppose...that it's going to be there. So in other words a bit of you blocks sort of thinking too much.

It is apparent that these fears were similar across the different participants in this research. These fears were not confined to participants with cancer but occurred across the range of conditions in this research.

3.3.2 Day-to-day fears

Chris's partner and unpaid carer discussed the changes in her home since Chris needed to have social service carers visit each day. For them there was a tension between having carers in their home as a matter of necessity and the dissatisfaction of having carers in the home alone with Chris who was totally dependent upon others. Often the carers were unknown to them causing more concern:

I would at least at least like to see the person who I'm leaving my husband with. Chris gets very frightened and panicky with strangers. I'm just not the sort of person to go out and leave my home in charge of a person I've never seen.

Chris's partner also described her awareness of Chris's reliance on her:

I am frightened of getting ill...I don't know what I'd do.

There seems to be a dimension here about a lack of control both physically and socially. Edith addressed a more personal fear:

I'm frightened of loosing the use of my legs. I'm not using them very much...
(Because of breathlessness).

For Delia there were fears raised because of her breathing difficulties as well. Whilst she had a fear of stopping breathing during her sleep, she also wanted some advance indication that she was dying:

I've always said I don't want to wake up dead. If I can't breathe I do wake up and have some oxygen. I'd rather wake up than be dead. I want war...I want warning.

For John there are aspects that remain unspoken to others:

There are times...I won't let it go...you're holding upset and worry and stress and fear...you're holding them all in. I...know how I feel...I don't try to go down there.

Simon identified fear in others due to his cancer diagnosis:

You get very, very few seems to think it's contagious and...I can see them almost visibly standing back.

3.4 Anger/Frustration

This theme consists of two closely related emotions. Anger was less often discussed in a direct way but participants described their frustration with aspects of their conditions and lives that, at times, appeared as anger. This theme has been divided into sub-themes of anger/frustration that is experienced to do with aspects of participant's personal lives, 'personal impact', and to do with participant's relation with others, 'external impact'.

3.4.1 Personal impact

Jess gives a clear account of how personally frustrating living with her condition is. She had been talking about paid carers and the humiliation of having intimate care provided for her and so this anger/frustration encompasses both sub-themes:

Some carers are rougher than others. Some carers just don't actually, they do their job and they don't realise the emotions behind it and that is one of the things that you just sort of...tolerate, but I don't think you ever come to terms with it. If you accepted it too much you wouldn't fight the MS. The tiredness of MS. So you have to sort of accept the fact that it's something that happens and there's nothing you can do about it.

The sense of being out of control of one's most personal needs and the necessity of relying on others comes across here. Talk of carers becomes merged with talk of

living with the condition and the frustration that both these things can lead to. Jess also described the frustration she felt regarding loss of dignity:

It's tiring emotionally cos you are out of control. You're having your bottom washed...and one minute you're sitting there and the next minute somebody is underneath.

Mel had been talking about how she needs to drain the fluid from her lungs:

I suppose it's something that just becomes a part of you and some days you think "oh I don't want to put up with this anymore" (laughs), and I don't want to have to do physio every morning and every evening.

She went on to comment on the impact of this on her:

Just occasionally you get a bit bitter and twisted and think its like having a bit of a weight round your neck. But then that's life, you have to put up with these things.

Sheila described a catalogue of events that, over time, led to certain 'restrictions'. The events were described in such a way as to convey a perception of everything going wrong, of distressing and debilitating events occurring one after the other and of the difficulty of pulling herself up following these events. She reflected on how it used to be and how it is now:

I was able to go out then and do gardening, sweeping up the drives, washing the windows and paintwork, doing ironing, hovering, going out down the town, going out in the evenings, I can't do any of that...it's finished...gradually things have been chopped out of what I can do less and less and less and less.

A sense of frustration was conveyed by this inability to do the everyday tasks that used to be taken for granted:

I couldn't go out and wash the windows. I couldn't do any of that. I couldn't wash my car, I can't do the hovering. I can just about do a bit of washing up...Sometimes I've just got to stop...I've just got to stop and get my, get the air back.

Edith also expressed these similar frustrations and the negative effect on her:

I can't do anything that I used to do, I'm just what I call a load sitting here doing nothing.

Hazel spoke of the many everyday difficulties she faces and the variability in how she felt and the frustrations associated with this:

I could transfer from a bed to a chair...sometimes on my own, sometimes with one person's help...the exhaustion...it's not like any ordinary kind of tiredness...like coming round from an anaesthetic...I couldn't think straight. I could write it all over my wall...frustration about everything.

For John, thinking of the future and the changes in plans was particularly frustrating as was what he felt people were saying about him because he wasn't working and at the time they didn't know he was unwell with HIV+:

It was frustrating because I expected to have a good working life and get a lot out of it and I had a lot of dreams myself of what I wanted to do...and you have to get over that that's whipped away from you...You have to realise that you're not immortal, you know, don't start planning pensions...and things like that.

Sylvia spoke of her frustration with her dependency on others. She had been reflecting on the dreams and fantasies she had prior to developing MS with regard her children's wedding:

You have this mental picture in your head about when your sons or your children get married...my son Steve, he got married a couple of years ago. Well

in my head I've thought for years 'oh blimey I'll be the life and soul' and flitting from one guest to the other and...I just had to stay where I was put.

Wendy adds that she was frustrated at being unable to look after her grandchildren:

I just used to look after the kids. But now I can't.

Sylvia also spoke of frustration with people's attitudes to you:

When I'm out and I'm in my wheelchair and you see somebody you know and the person pushing you knows them they talk above you...they do not talk to you. They seem to think that because you're in a wheelchair you're an imbecile.

Sylvia went on to describe frustration at everyday things that she can no longer do:

I mean that used to drive me crackers...Because something's fallen on the floor...There was no way I can bend over and pick it (up). No way I can dust or Hoover.

Wendy discussed the home care she received and she echoed Sylvia's frustration with the little but important everyday things she can no longer do:

I can't do the bra (laughs). You know it's so frustrating.

Sylvia discussed how she tries to not have homecare in the evening but how this is a struggle for her:

Well at the moment I can still do it and I am fighting against having...
'Twilight' in.

'Twilight' is the evening homecare service Sylvia was referring to. Both Sylvia and Wendy appeared to be conveying a struggle with frustrating limitations and their aim

to maintain dignity and independence. Delia also spoke of the many everyday tasks she could no longer do and the frustration she felt at this:

I can't walk...if I walk I can't breathe...I find it difficult to tie my shoelaces up...otherwise I'm out of breath. It's just the breathing...it curtails your life completely.

3.4.2 External impact

For Edith there was anger about lung damage she received following radiotherapy treatment for breast cancer. Her anger wasn't just about having lung damage but about the long process to have this damage acknowledged and apologised for. There is a frustration and anger towards 'the system' and the manager's explanations and handling of the situation:

They did say they'd damaged my lungs...I had a letter saying that it was the radiotherapy but I've never pushed it any further cos I think if you feel bad enough you can't push for compensation anyway...but I found the attitude very off hand. Not a sorry or anything like that it was just one of those things...I don't mind that as long as they admitted it was their fault. They did in the end. I said I just want somebody to say what happened.

Becky expressed a frustration towards her HIV+ condition itself, how it made her feel, and the medication regime that was now part of her daily life in order to survive. She had been talking about long depressive episodes following her diagnosis and of a frustration about how to feel better:

Those were very hard times. Very difficult to get through...it goes on for so long. A year of just...feeling awful. Feeling awful in yourself and you don't know why...and you don't know what to do to make yourself better. It's really frustrating, so hopefully that's not going to happen again.

Maisie spoke of being in hospital when undergoing chemotherapy for her lymphoma. She describes being very unwell because of the chemotherapy, of being in a side room with no visitors, and after three weeks she needed to leave:

I said to him “I’ve got to go home, I’ve got to go somewhere I can’t stay here. I want a bit of loving care and that delicate food that I can eat”. So I went into a Nursing Home for two weeks, which I paid for...and then I got pneumonia. So I was back in (Hospital) (laughs). so they carried on with the chemo.

Chris’s partner Clare spoke of attitudes to them both since Chris had his stroke:

Chris...had a good job...and we had a bit more respect but now we’re just that old couple who...”Oh, he’s bedridden, incontinent”...this is how they talk about you.

Clare went on to describe frustration at not being understood:

They (carers) don’t seem to think that people are wholly trapped in their own homes.

May talked of her reaction following diagnosis in terms of her focus for living:

I’ve got so much to live for - my family and whatever - and that’s all I could think of...all these questions go through your head. Why is it happening to me? What have I done?

In this next extract May goes on to talk of her attitude towards cancer and dealing with it. She shows her determination when faced with an immovable situation:

And then it settled down and I went to see Mr. Khan again and he was absolutely marvellous. I have accepted that I have to live with it. I like to think my faith has got stronger. My religious faith, which I have found a real help...every day I get up and I say “right thank you Lord for another day”. And I live that day. It’s no use thinking about tomorrow or next week or what’s going to happen next year...I find I can cope with it by doing it from day to day.

3.5 Grief

This theme is illustrative of the many losses someone with a life limiting condition can face. The theme of grief includes the sub-themes of ‘functional losses’ and ‘abstract losses’. There is a particular interconnection with the previous theme of anger/frustration here.

3.5.1 Functional losses

In identifying many losses Jess acknowledged that a part of her still focuses on those things she can no longer do:

You still perceive yourself as...being able to do all the things, dance, swim, never in a wheelchair. Sometimes you go down steps in a dream and think this can't be quite right. I can't do that can I? I think you get very frustrated especially...with my hands and that makes you more emotional. Because you're dependant on people and that brings you're emotions out.

On very practical terms John spoke of his struggle to retain employment after he was diagnosed with HIV+ and his eventual decision to stop pursuing his right to work. This account draws on issues that have been raised in a different context in previous themes for John. However here the emphasis of his account is different and is considered to illustrate an aspect of loss. An insight is gained here of the energy that is required of individuals to challenge organisations:

I went to two tribunals over it...in the end I gave up... there was too many things going on and I couldn't...I couldn't get up every day constantly thinking about work, would I, would I fight for this, would I fight for that? I had to let it go.

John also described the consequence of unemployment and the losses this brought:

I spent two years not working after that, I was signing on. We lost our house...my insurance company wouldn't pay. I felt very guilty about that...it took a long time to get used to that.

Hazels experience had some similarities to Johns with her condition leading to her inability to work, loss of accommodation and multiple changes to lifestyle:

I lost my job and my cottage was tied to the job...so I lost that...so I had to find more accommodation...I live entirely on benefits now.

The grief of the situation Hazel found herself in was described in interview:

I did have periods...when I was very depressed and thought well there must be something else wrong with me or it's all my fault that I'm not getting better like...other people seem to. I was depressed...because I was so physically...to suddenly be knocked down like that I just couldn't understand it...couldn't cope with it.

Edith also encountered sadness and regret to do with her conditions effect on her life:

We've always danced well at least four times a week, we used to go on holiday...now I can't get on a coach...then I had the pulmonary embolism and I haven't done anything since then.

The effort of daily life also took its toll on Mel who sometimes felt like giving up:

Some days you think 'oh I don't want to put up with this anymore'. Everything is an effort...like walking through mud.

Like John and Hazel, Becky discussed work, the loss of it and she saw the possible implications:

When I had to give up work, you can't pay the mortgage...benefit doesn't really pay your mortgage. So had I been on my own I would have ended up on

income support, living in a flat somewhere that I didn't have any control over. I wouldn't be able to choose where I wanted to live...and that adds a great deal of stress if you're worrying about money.

Following discussion about loss of physical abilities Val identified the dynamic aspect of life where things have to change and people have to adapt to new situations:

It's very hard when you've always been independent. Very hard...to accept that you've got to learn everything all over again.

In response to Val, Bessie added:

You've got to change your whole life.

3.5.2 Abstract losses

Fiona had been talking about her cancer, treatment, and the reoccurrence of her cancer of the bladder (Outlined in the theme 'diagnosis' above) and went on to talk about the profound effect this news had on her:

I have enough problems with the stoma and all the rest of it, you know. No more thank you very much. It's too much and I don't want to hang on to this life any more either. Can I go now please? My way of looking at it.

Sheila talked of the impact of her condition on her daily life, on everyday things and summed it up by saying:

You suddenly see your life, parts of your life being cut. You're not dying or, well you're not sort of being told you've got a year to live or something. You're just being told "right you can never go on holidays abroad...you can't go dancing, swimming, there's so many things you can't do anymore. It's almost like being put in a prison only it's not obviously. I suppose restrictions; restriction I suppose is the best way to describe it, it's very restricting.

Later Sheila suggested that the majority of people have no idea what it is like to live with a condition such as hers and went on to describe a situation where more was expected of her than she could achieve, because of her breathlessness. An assumption was made about her physical ability and she was left gasping for air with the other person unsure as to what her problem was. Sheila voiced regret about this situation, this loss, and described her way of managing this loss:

I'm not bitter or anything because you know worse things can happen to you but um yeah I mean I, I do think "oh I wish I could do that" or "I wish that was me" or...But um, you can't dwell on those things really cos you would get depressed.

In one of the group discussions Malcolm, Maisie, Bessie, Lily, and Val had been discussing various losses of liberty, choices, and independence when Bessie said:

There comes a time where you just can't, don't you...?

This was responded to in discussion by Maisie:

You just can't, you can't cope.

Val then asked a rhetorical question:

Don't you find you sort of re-evaluate your life?

Next Val described the things that she had changed since her diagnosis of multiple myeloma, in part because of her awareness that her partner needed to know these things prior to her death. Delia also described how she had needed to adapt in light of the losses her condition had brought to her. She had been talking about friends who had withdrawn from her since diagnosis and how others 'jolly me along', when she said:

I do get black days. When the black dogs on me.

For Delia the ‘black dog’ was a term used to describe her depression. For Sylvia it was clear that others close to her were also very affected by her diagnosis and debility although attempts were made to hide this:

(Daughter-in-law talking about Sylvia’s son) told me many a time that he’ll cry, you know because of the frustration that he can’t do anything. My Paul he wouldn’t even talk about it for the first six months.

Sylvia went on to discuss the loss she felt over the changed relationship with her grandchildren. The loss of spontaneity:

I’ve got a two year old granddaughter and I’ve got a six month old grandson...and you can’t pick them up yourself and cuddle them. They have to put the babe on my lap.

Sylvia went on to describe the loss of not being able to do the things she used to do and what resulted from this:

I did lose several friends. Well they just got...because I can’t do what I did do when we were out and I would get up and dance and stuff like that, they just don’t want to know you now.

For Clare there was acknowledgement of the loss of parts of Chris since his stroke:

He does nothing for himself...our whole life has changed.

Further to this Clare spoke from her perspective as an unpaid full time carer:

I can’t do anything spontaneously...you get pushed about more, people think they can do what they like with you because you are very vulnerable, you’ve got no position any more and you need them and they know you need them...therefore they treat you badly I think.

3.6 Relationships

All participants spoke about the effect their particular condition had had on relationships. Participants spoke of relationships with family members, friends, colleagues, and people encountered in particular settings. It was clear that participants had observed differences in relationships following the diagnosis of their condition and some of these differences were clear changes in people's reactions to them whilst others were more subtle changes in social interaction. For some, the reaction to receiving their diagnosis was extreme amongst friends. Hazel for example points out the variability amongst friends and the abrupt way some of them reacted:

They have varied terrifically. I've got sort of a few core friends who have been wonderful, who have been really supportive and have stayed friends but others, I mean some of them...somebody I've known twenty years just dropped me like a hot brick six weeks into the illness. They came to see me and they did admit that I was much worse than they had expected, and I think they just found it impossible to handle.

Hazel also identified a point about what some friendships are based upon. For her, some friendships were based on joint activities that when she was unable to keep up affected the friendships:

Perhaps we didn't have so much in common as it were and I couldn't participate in that so we'd lost that sort of link.

Other friends were more forthright in their opinions and assumptions:

One (friend) told me I was letting my family down and everybody down by not pulling myself together and getting on with it.

There seems to have been a difference between friends who knew her prior to developing ME and those friendships made after diagnosis, with Hazel suggesting an idea about friends made since her diagnosis:

They've only known me like this, which makes it easier for them to accept me as I am.

She also outlined a very different relationship with family and friends, one in which friends have other roles to fulfil in ways different to before diagnosis:

There are days when I think oh the weathers nice I'd like to go for a walk... so you know I try and rope friends in to do that and things like all my paperwork, paying my bills that sort of thing again I get friends and my daughter to do all my official things.

Hazel spoke of her good relationship with her daughter and also described how at times she found people exhausting and therefore withdrew from people herself. Mel raised a different kind of relationship that can be affected. The relationship with work colleagues was affected for Mel who was confident in her decision to stop work as she was feeling so ill but other aspects of this were problematic:

You miss sort of going to work, you miss the social interaction with people and well yeah self esteem is all part of it isn't it?...in some ways you cut yourself off I suppose.

As for Hazel there was some thought that you made decisions that enforced a kind of social withdrawal. Another aspect for Mel involved her considering what others might think of her. She spoke about her friendships:

That hasn't been very, very good really (pause) people thinking that, you know, it's all in my mind, the illness, being ill. Putting it on.

As for Hazel, Mel suggests that because of an inability to perform her usual social functions due to tiredness some friends judged her negatively:

I don't think they appreciate what we have to cope with. Some people are just uncaring aren't they really? They want their needs met and um...(Pause) I

suppose I'm used to caring for others and I suppose it doesn't always get reciprocated.

For Mel and her 'core' group of friends news of her condition brought lasting changes to the group which subsequently became divided:

One of these friends, I must admit she was a very close friend but she is not anymore, but she told other, other friends of mine that she 'oh I suppose as I'm her closest friend I'll be the one that will have to look after her'. She is still friendly with all my friends so it has all been, it's all been very, very difficult. It sort of like split the group in a way um (long pause) er (sighs) it was, it was sort of like two sides.

Other participants echoed these accounts about the challenges to friendships, which follow them becoming unwell. Chris's partner Clare spoke of their friends that had fallen by the wayside:

They've all dropped by the way except a few cos you can no longer go out. Chris is not the same person. They've got their lives to carry on in the main stream of life haven't they?

In talking of relationships in a group discussion Ralph reflected on his friends:

Probably some people don't like to come because they don't know what to talk about.

Val responded to this with a question before thinking through the answer for herself:

Do you think it's a bit like bereavement? Some people are just embarrassed. So they keep away because they just don't know what to say. They don't like you or them to dwell on it. So they skip over it, if you know what I mean. I suppose it's 'there but for the grace of God' sort of thing.

Relationships with members of family were also affected following diagnosis of the participant's particular condition. John described his consideration of whom to tell about his HIV+ diagnosis:

My sister and I are very close and I didn't want to tell her until I was used to the idea.

He did however visit his mother and tell her straight away:

She had a very bad reaction to it. She physically moved away from me and said 'it's your own bloody fault I told you this sort of lifestyle would get you into trouble and now it's been proved' and we fell out. I hadn't spoken to her for over a year after that until I apologised.

John did tell his sister at a later date who feared that he was about to die and needed counselling herself at that point. The relationship with his mother was eventually salvaged and he spoke of how she was to become very supportive of him. John went on to talk of his relationship with his partner:

I think HIV is a relationship destroyer. Ron, my partner, has been the first to admit that if something ever happens to me he will never live with somebody else who is positive. He said 'I've seen too much damage and I don't want to go through it again' and it...to be honest it is more than most people can cope with.

Whilst acknowledging the difficulty of being the one with the condition John also reflected on how it must be for the partner involved:

It can be character destroying and I'm sure it must be for him sometimes.

The presence of a partner was important though for John. He thought it was important to have someone who knew how he felt when others did not and to whom he could speak of his feelings. Since diagnosis and stopping work John felt there was a greater difficulty in making friends:

Most friends I made at work...I tend not to have very many close friends...I don't want the pressure of friendship.

The importance of having people around who are understanding and accepting was also evident from Edith's discussion about her relationships. The maintenance of relationships with family and friends was very important to her and she went to efforts to present herself in ways she thought would be acceptable to people. For example when asked how she is she would answer positively and in good humour:

I'll say I'm fine you know...(Laughs). It makes people comfortable. They don't have to say 'oh what's wrong'...I think it's the way you treat them.

Concern about the negative reactions of others was also discussed by Becky who had experience of this with boy friends over a long period of time:

(I) decided sort of at the outset to be upfront and honest (about HIV+ status in intimate relationships). And it was just total rejection you know? When that's happened two or three times, that really hurts. They don't see you, they see the illness.

These reactions had a profound effect on Becky:

It made me feel really (pause) dirty because of the way I contracted it, through having sex...That all became tied up and it's like...it's all to do with sex. I'm a diseased person. Who would want to have sex with me? Because you might get something horrible. After a couple of attempts I said no more men I'm not interested.

Later, when least expecting it, she went on to meet the man who was to become her husband and deal with the intimate side of their relationship in order to protect him from HIV. They dealt with this together. Like John, Becky has had to consider whom to tell about her condition and who not to tell:

I've had different reasons for telling or not telling different people but sometimes it's for my benefit, because I feel I couldn't cope with how they might react...but also it's for their benefit because I'm not sure if they could cope with it and also do they really need to know?

Becky spoke of some people having prejudices about HIV and feeling stigmatised. These factors were taken into consideration when deciding whether to tell the truth to people or not. Some very close members of her family did not know of her HIV+ condition and she described a delicate balancing act in making this decision and in maintaining the secret. She acknowledged the effect this had on friends and family that did know who also had to keep her secret. There was also a cost to sharing this information in some relationships and not others for herself:

It is a huge relief when I am with people who know, I don't have that, I can be totally myself.

Becky had found groups she belonged to, helpful. She had found a support group useful at one stage and a women's group for women who are HIV+ was helpful:

It's just really good because we talk about problems, difficulties you know, people have talked about medication difficulties and side effects and illnesses and...all sorts of stuff...and you can do it in a safe environment with other people who know what you're talking about.

For other participants having a partner was also seen as very important and raised in group discussion. Bessie highlighted how:

There's a big difference being on your own.

Malcolm added:

In getting emotional support. The silence is deafening.

The same discussion led to Greg reflecting on friends who had struggled with their relationship since his diagnosis with cancer:

People...literally have hidden from me... they don't know what to say to you... they're embarrassed.

He went on to explain the effect of this avoidance on him:

It leaves you feeling...as though you don't belong, as if they think they're going to catch something off you.

Other participants in this group discussion, like Maisie, valued friends who were helpful:

Some people I find are very, very supportive...I've had the most wonderful set of friends.

Despite having a supportive family Delia found herself let down by some friends and one in particular. :

I have one particular friend who has so disappointed me. My family I think are a bit disappointed too because they thought she would be the one person that would support me. But I've had nothing like that...it used to upset me terribly...it destroyed my faith in human nature a little bit.

Sylvia also experienced difficulties of a similar nature:

I did lose several friends...they just don't want to know.

She noted that the change in her physical ability, and therefore what she was able to do with friends had changed causing some friends to loose contact. During this group discussion both Sylvia and Wendy discussed their partners changing attitudes to them following the development of their respective conditions:

Because of our problem, we both lost partners...they don't want to know...he just couldn't handle the running around etc. Or just a coward.

Both Sylvia and Wendy's partners left them and for Sylvia her MS diagnosis brought tensions into her relationship with her son as well:

The eldest one (son) of the two, he still can't accept it even now. He still thinks that Mum should be up and doing as she always did. He hasn't got a lot of patience with me. But the other son's alright.

Both also thought more widely about the effect of having their conditions and spoke of the 'baggage' that comes with it. They both spoke of the delays and obstacles involved in getting what you need. A certain way of being treated:

I do find that when you are disabled nobody really wants to hurry to help you.

Wendy particularly spoke of her feelings of loneliness at home and was pleased to be able to attend a local day centre where:

There's lots of people here that we talk to...we talk about everything don't we? We've all got a disability.

In interview, as well as acknowledging that her friends had been supportive, Sheila endorsed the advantage of having a partner at home:

All the time you've got somebody good and reliable then you've got some control and some order.

For Jess, how people respond to her because of her level of impairment was important:

I hate it when people want to self-motivate me. I find that derogatory, as they seem to think they've got to encourage me to fight the tiredness. It makes me worse because then I get stubborn and cussed.

How family members respond to her and what she expects of family members was also important to her:

You want to make sure that your mother and your sister aren't thinking, 'Oh my God I've got to go over there and do some work'.

Jess was striving to be independent which at times was difficult to achieve:

I don't take peoples attitude...some people talk rubbish...I haven't got time for rubbish.

She was clear as to what she would accept and what she wouldn't. Relationships for Jess needed to be equal and not founded on sympathy or obligation.

3.7 Difference/Individuality

This theme refers to participant's sense of difference, of being different to others or treated differently to people without their particular condition. It also refers to seeing and experiencing life differently. Whilst being concerned with issues of difference, the theme also says a great deal about individual participants themselves, their sense of who they are, their uniqueness, and perhaps a redefined individuality.

For Sheila there was a difficulty in acknowledging the reality of the condition and the change in herself and this difficulty in appreciating changes wasn't solely for her friends and family but for Sheila herself:

To start with there was a not an awareness, even some of my family and friends didn't really appreciate it cos you're...that it's a condition, not now so much but at the start because you still look quite well and because you've not got a broken leg or...maybe something like you've had a stroke or something, people aren't sympathetic because you look so well and you're still walking around and I think they think what's the fuss about?

Sheila then talked of her delay in recognising the changes in herself:

It was me that...didn't understand as well that much for that matter right at the beginning because I did think I could do this that and the other.

Sheila went on to talk about the implications of having her condition, being breathless, being unable to do things as before diagnosis, and being seen differently because of this breathlessness and inability to perform everyday tasks effortlessly as before. Observing others who can still perform these everyday tasks effortlessly was hard:

I do think 'oh I wish I could do that or I wish that was me' or...but you can't dwell on those things really cos you would get depressed.

Edith shared this awareness of the changes her condition had brought:

It's the whole impact on my life...All the work everything cooking, washing, cleaning all is done by my husband.

At one point in her interview Jess had been talking about the changes in people after being diagnosed with MS and how people treat her. There was a sense of not being seen for herself in what she was saying, of people assuming certain things because of her MS:

I think some carers and some people within the medical profession have a (pause) idea of what MS is like and a pre planned attitude...and they say 'oh you've got MS so I'll treat you like that'.

Jess described some people's view of MS as being associated with laziness. Some of her carers assumed she was lazy and tried to encourage her to do things for herself, such as housework, when in fact she didn't have the energy to do these things and just wanted the carers to get on and complete them. She went on to say this:

You ask them to do something, they'll turn around and say 'oh no you can do that yourself' and go.

She described being seen in such a way and challenging this assumption as an ongoing process:

That is something that you have to sort of keep battling with to make sure they realise that they're here for one hour a day and you're actually doing it yourself twenty three hours a day.

Jess, on rare occasions, had had carers tell her that they are not her servant. This was one end of the range of responses she had experienced and she felt this happened because with a condition such as MS she was not seen as ill:

Whereas people with cancer or other conditions...diabetes, it's more concrete. People have to suddenly realise that you can't feed yourself yet in ten minutes time you might be able to feed yourself, and it's very hard to comprehend.

Jess had an understanding of how people could come to these assumptions about her due to the variable nature of impairment in MS. Jess though kept her sense of self-intact:

I'm still the same person I always was. You put up with the wheelchair and get on with it, but you still perceive yourself as being able to do all the things, dance, swim, never in a wheelchair. I don't think you change your perception of yourself.

She went on to describe how MS is different for each person:

MS is exceptionally individual.

She highlighted how everybody has different symptoms and different reactions to MS but returned to the point of how she is seen by others:

I think some people see er...are wary of er the wheelchair. And er I'm wary of 'oh don't get involved she'll er...you'll get caught and you'll have to do

things'. People aren't keen or whatever, they don't want to be involved cos um to them it looks as though er...somehow they could be made use of.

Jess was very aware that family and friends could all too easily take on caring and helping roles for her but she wanted to resist this and just be a daughter, a sister, a friend. She did not want people to feel they had to help her, which is why she had paid carers. For Jess there was significance in the motivation carers had to do their job. She felt some were in the job for money and convenience but others had other motivations as well and it was these carers who, Jess felt, were more able to see her for herself:

Some people ignore the money. You find carers that have experiences of disability or disability within their family er are often very good carers. As long as they can accept it within their family...they make very good carers on the whole.

This experience Jess suggests is what enables certain carers to see beyond disability and impairment to the person that is there. Jess described needing to maintain herself and to resist being governed by others:

You have to do, to keep maintaining your own sort of self-esteem.

Although some carers may have thought she was lazy or labelled her in other ways, Jess was sure she needed to keep hold of the truth of herself:

You know your own sort of value.

She went on to describe a balancing act between challenging assumptions and having a 'don't let them put you down....' attitude and not being 'belligerent'. She described a reflective take on her situation where she has to judge whether to challenge someone's attitude to her that she feels is unwarranted or let it go and put the interaction down to being overly sensitive because she is tired. This weighing up of how people are seeing and treating her caused Jess to comment:

It's good and it's bad but... it's me.

Jess went on to talk about transport issues and her perception that in some other countries 'you are not a second class citizen, you are not different'. Jess had been explaining that she was trying to get out into society, that she wanted to work alongside non-disabled people and not in segregated 'disabled' work environments. I summarised this and she replied:

Exactly what I'm trying to do, not being housebound and treating you as the problem... We need to get people out and about.

Someone had told Jess of a different experience for disabled people:

She went to America and she found that her husband wasn't treated as a second class citizen but they found that, she thought the ethos over there had changed from Vietnam and that wheelchair users were heroes. They had to treat them as humans therefore they couldn't exclude them.

I asked Jess how she feels she is treated in this country:

I don't take notice of how people treat you... It's to do with me. It's their problem not mine... I think as I get older and as I get tired people's attitudes will affect me more.

Jess showed great awareness of how she is perceived by others and great determination to hold onto her individuality. Simon also talked of how other people saw him since his diagnosis with cancer. He had been talking about others attitude to him changing in that it was like they thought they could catch his cancer and he perceived them 'standing back' from him. He certainly didn't want people's sympathy but he did appear to still want to be seen as himself and to be understood in his new situation, with cancer, when he said:

One thing that I've always said, you can't feel another person's pain. Not unless you've had it.

Still talking about those people who 'stand back' from him Simon went on:

They don't know whether to say I'm sorry or say serves you right (laughs) you know. No I am very philosophical about everything. Take me as they like. Take me as they find me.

Simon indicates his determination to be himself. During a group discussion I had asked if anyone saw himself or herself in a different way following diagnosis. May had been talking about having had a very good year prior to her diagnosis and went on to say:

And then when I was diagnosed with it - yes I do feel different. I try not to, because I know I'm the same person, not as quite as complete as I was but I'm still the same person, still the same age.

May elaborated on this feeling of difference:

Things that are small really don't matter. Much easier to cope with. Because, whereas before, you perhaps fuss over something or worry about something, now you think it's so tiny compared with the problem.

The discussion then moved onto planning for one's own death and preparing finances and practical things for family that will be left behind. In a hiatus in the discussion Val moved the discussion onto viewing life differently and commented:

Do you find you get very conflicting emotions though? Sometimes, you know, people go on and on about something which is so completely 'so what'? And then you get cross. You think 'oh what on earth are you making such an issue about it'.

Fiona agreed adding:

Yeah, yeah, things like they've got ten pairs of shoes – and I think what a waste of your time you know, people are starving, people are dying and you're going on about shoes. It isn't until life hits you hard. That is only when you stop and take...stock isn't it? Otherwise we all end up wanting pairs of shoes

and the latest fashions and a holiday in Bermuda and so on, you don't stop to...you don't think it...when you're young you never stop unless life hits you hard. And when it does hit you then...well you take stock and you change. You see life completely different don't you?

An allied issue to this reprioritisation was raised by Mel who had been talking of giving up work and how people had not understood her need for time off due to her ill health. At this time before she was diagnosed she felt that there was disbelief amongst friends that she was actually unwell:

Friendships...that hasn't been very, very good really (pause), people thinking that you know it's all in my mind, the illness, being ill. Putting it on.

At a later stage Mel discussed continuing problems with friends failing to acknowledge her current situation:

I don't think they appreciate what we have to cope with.

Mel seemed to feel that there was an invisibility surrounding her condition and this was reflected in her comments when we were talking about services she didn't receive:

You could almost feel as though 'well I've got the diagnosis now but nobody'... (Sighs) you're just sort of like left to get on with it on your own really. So from that perspective it's not very good.

Mel felt unsupported and described her life and living with her condition in these terms:

It is a lonely walk.

She certainly didn't want to be a nuisance to people, including her GP and social worker, but on the other hand felt that due to her condition more support should be available:

The GPs can't, they can only try and sustain you they can't cure you or can't really do anything for you. I don't know I just get this feeling but...Oh I don't know. It's just the whole health service you know you, you sometimes are made to feel you are just, you're just a nuisance.

Mel's suggestion is not only of a lack of interest but of invisibility. Who she is, or who she has become, appears to remain unseen to friends and professionals. Hazel also talked of this difficulty in describing her condition and in helping others to understand. She had been talking about her early symptoms of ME, tiredness in particular, when she highlighted the difficulty of explaining it:

The exhaustion did...it's not like any ordinary kind of tiredness, it's very hard to explain but it...it's more (pause) I've described it before as like coming round from an anaesthetic.

Again there were similarities with what Mel had spoken of, in terms of actually being believed about the problems she was experiencing. Her hospital consultant is an example of this:

He was quite determined there was something else wrong with me.

There seems to be an issue to do with legitimacy here and of a struggle to assert one self. Hazel spoke of this difficulty in getting medical professionals to agree that she had a 'real' condition despite bodies like the World Health Organisation recognising ME as a neurological condition:

It's slightly better now but seven years ago nobody would recognise it as an illness. I knew I was physically ill.

Hazel further illustrates the difficulty of asserting one's own wishes when she was considering what sort of control she has over her life:

There was a time when I felt I had no control over my life at all...I just felt that everything was sort of almost spiralling out of control...um (long pause) you know it's easier now...but certainly there are times when I think um everybody else has more say over what happens to me than I do.

Hazel returned to the issue of others understanding her:

I think more people understand now than before certainly...but until you've experienced it you've just no idea. It's something that unless you've experienced it, it's very hard to really comprehend what it's like.

For John there was a conscious decision taken about what he presented of himself and to whom. He describes an ability to divorce himself from some settings:

When I go to hospital I'm the other John, so I go to hospital and they dig and prod and do all the tests and do whatever they need to do and that's fine. Really, I don't have any, I don't get embarrassed about any problem I have. I can talk about anything.

And whilst able to express himself fully with his partner, he identifies a reluctance to fully let others know what living with HIV+ is really like:

When I'm out of the hospital I'm back to me and myself again...even when I'm not very well people will say to me how are you and like everyone else I should probably just say fine, I'm fine. But the person you live with knows you're not...and that's where you get to express it and get, you know, you can actually say the things you feel like, 'I can't keep going on like this' and 'I can't cope like this'.

It is not necessarily in order to protect others that John prevents himself letting people into his thoughts and fears, but rather as a way of protecting himself:

I don't think I want to hear myself say it...cos then I actually know what, how I feel, whereas I just don't try to go down there and when I'm not very well obviously I spend quite a bit of time at home and if I'm not well or if I get upset that's fine cos I'm on my own and I can just plod along and cope with it and it's fine and, you know, when Ron comes home I'm fine again and if I'm not he knows the difference.

As other participants have discussed, John talked of the lack of understanding amongst people to do with his condition and its effect on him:

It's not just physical illnesses like um bad chests and pneumonias um and things like that, it's also the tiredness um and sometimes it's lack of understanding. Some people don't realise that you can get extremely tired and there are times that you don't want to face people. I mean it's difficult to explain to somebody. I tend not to have very many close friends and I think the reason for that is that I don't need, I don't want the pressure of friendship.

He talked in terms of the expectations of friends and his need for his own space, to take each day as he finds it and if he doesn't feel well to rest without people asking questions that are difficult to answer. John attributes this need for his own space to the difference he felt when young and he knew he was gay. He said he became used to his own company. John was regularly reminded of his HIV+ condition due to hospital appointments to check the level of virus in his blood:

I am very aware of my (HIV) status all the time.

He was aware of the level of virus in his blood and well able to judge what this meant. However this was a private thing:

I don't discuss it with many people. If I have a good visit and my CT4 count is high, which is what...I'm aiming to...then I ring my Mum and tell my Mum because I know she'll be pleased. And I tell Ron. If it's a bad one I don't tell my Mum, I only tell Ron.

Sharing knowledge of himself was a process of selection for John and much information about the condition part of himself was not shared with anyone. Having a condition such as HIV+ played a big part in the life of someone like John and adaptation is called for to accommodate the changing person. Wendy also seemed to speak of aspects of this relearning and reshaping of life. She had been talking about how she felt that she had very little control or choice in her life when she outlined her current position:

I just feel normal...and wise and patient. Well patient...every time...wait a while and I thought right five minutes and waiting and waiting and waiting. Forever. I have to learn to wait. To be patient.

This patience was a new thing for Wendy who felt that she never was good at being patient. She had needed to adapt to her new position and she illustrated this by showing her ability to wait for carers. Sylvia agreed with Wendy but also illustrated the difficulty of adapting in this way:

I am not so impatient. I used to do everything at ninety-five miles an hour plus and I do find that ever so hard that I can't now. Now I've had to calm down...it's horrible. I still try and rush things.

Sylvia spoke at length about her changed life situation, her need for carers several times a day, and everything they did for her. It was clear that this was a big part of who she had become. A sense of resignation was present for both Wendy and Sylvia. When asked to sum up living with their conditions Wendy stated:

You just have to.

And Sylvia quickly added:

You've got no option. But I hate it.

She went on to talk about losing friends as she became less and less able to participate in things with friends:

It is very lonely.

For both resignation was mixed with regret and frustration about this new world they were inhabiting. In considering how much other people understood what it is like to live with MS Sylvia said:

You just can't imagine it.

She went on to say:

I do find that...people are intolerant of you.

This led Wendy to add:

That's why I said I'm invisible.

For both of them it was clear to see the changes in themselves that they felt had taken place. For Wendy there was a sense of being invisible and Becky illustrated how she actively tried to negotiate people's reactions to her now that she had HIV+. She tried to shape the social world around her by withholding information about her condition:

I do struggle...the difficult thing is, who to tell. And how you deal with telling those people and their reactions...I've told some members of my family but not all of them.

This negotiation continued to be a struggle for Becky who, in some ways, had learned to live with her condition, and in another way had to continually judge what to say about her condition and to whom. Becky described this as:

It's quite difficult...delicate balancing act.

As well as the difficulty of managing knowledge of her condition in people around her Becky spoke of managing everyday issues, of trying to exert some control on situations that are unpredictable, as when she has plans to do something and she is

unexpectedly unwell and can't fulfil the plan. There are issues of determination and Becky shows pragmatism in terms of everyday tasks:

You've just got to be flexible and be able to rearrange stuff.

The condition is not a static one and therefore neither can the person be. Becky illustrates this further when she offers an account of how her perception of her condition had changed over time:

In the early days, (HIV) to me was a terminal illness, it was like cancer.

As treatments altered and advanced she needed to adapt to a different position though:

Basically, bottom line I was going to die sooner rather than later. But that has gradually changed as times gone by.

Becky had lived far longer than she initially was told and thought she would. Later Becky spoke of another area that had been a challenge to her personally, that of others understandings of her. This is connected to her thoughts about telling people about her condition in the first place but is about her ideas of how others perceived her:

I think they see the outward person and to all intents and purposes you look exactly the same as everybody else...so there's nothing wrong with you, how come you're drossing about on benefits.

She highlighted though:

But what they don't appreciate is, they don't see you day to day.

And if they were to see her then:

I think until they actually see you when you're feeling ill you know or if you're having a bad day or a bad week or whatever they don't understand.

Becky felt this was more the case for less common conditions like HIV+ where people do not come across people with the conditions so often compared to something like cancer. She could see that people may find it hard to understand but felt that in a way people easily take an unsubstantiated position:

People don't understand and in a way why should they...
but people are very quick to judge.

Becky clearly illustrates the way it is easy to be seen as different and also highlighted the way in which she has attempted to define her own individuality:

You've kind of got to put it in its place cos for a long time it *was* my life...
(Original emphasis).

She described how HIV+ defined who she was but now Becky was more able to say:

This is me and oh yeah, by the way I've got HIV.

In a group discussion Maisie and Malcolm had been discussing their inability to carry out everyday roles that they did before diagnosis and their lack of functional ability (i.e. difficulty to walk) when Val stated:

It's very hard when you've always been independent. Very hard...to accept that you've got to learn everything all over again.

Bessie then added:

You've got to change your whole life haven't you?

The discussion was focused on the changes that were enforced upon them, their adaptation to a new way of living. In her interview Delia also discussed such changes that she was enforced to make:

If I'm ironing, I will do perhaps quarter of an hour and then sit down and then do some more later...because I can't breathe properly.

In thinking about choices Delia felt these were restricted:

My choices are very, very few and very few really but I mean I know my capabilities.

However she described altering in order to accommodate this situation. Again, as described above, changing and adapting in order to reshape expectations and the reality of daily life is highlighted. Clare, talking about her partner, again highlights a challenge to the individual in light of diagnosis with a life limiting condition:

Chris is not the same person.

She goes on to describe how they both are treated differently now her partner has a stroke:

You're used to being the *controllers* (Original emphasis) and suddenly you're the vulnerable needy people.

Later Clare elaborated on the changes that were experienced by them both:

Your own character and whole way of life is completely changed.

3.8 Independent/Dependent

Participants spoke of a tension between their attempts at maintaining independence and of a pull towards being dependent. In this section independence is taken to mean being free from the influence or control of others, the ability to act for oneself.

Dependent is taken to mean relying on a person or something like a service for care or support, being influenced by others. Jess for example illustrates the borderline between independence and dependence. She had been talking about arranging her

own personal assistance via the direct payment scheme which was a way of maintaining her independence but outlined a problem with this when she was particularly ill:

You become sort of dependant and they take over a bit (carers) because you're not really well enough to be in control and fight for what you want.

Jess, who arranged her own carers under the direct payment scheme, described not being well enough to change her carers in line with new requirements on her part. For Jess there was also a fine line in acceptability within the care she needed. She resisted paternalistic carer's attempts to motivate her, taking great offence to their apparent assumptions:

I hate it when people want to self motivate me, cos I feel as though I know when I'm tired and I know when I.

She described this approach in these terms:

I find that derogatory as they seem to think they've got to... (Pause) encourage me to fight the tiredness.

The effect of being seen and treated in a way that has MS as the biggest part of her was described by Jess:

I hate it when people want to self motivate me, cos I feel as though I know when I'm tired. I find that derogatory as they seem to think they've got to... (Pause) encourage me to fight the tiredness. And it makes me worse because then I get stubborn and cussed...you wouldn't like it. I'm just best left to my own devices.

For Jess this was a breach of her independence and her need to define her own way of managing her situation and her condition. In fact Jess found the whole concept of paid care a strange one and identified it as a cultural characteristic:

The concept that I find er hard to comprehend is paid care. It's very unusual but that's the English way of doing things. We pay for our loved ones to be looked after. I find it's not an idea that's very easy to understand, paid care... It doesn't always work and it depends whether or not the carer is doing it for the money. They're doing that job and they don't particularly want to do it... it's the job they can do today and not tomorrow.

To Jess it felt like some carers just turned up and were purely doing a job. If they didn't want to turn up for various reasons then they didn't and another person would be sent from the agency. Jess manoeuvred between this reliance on paid care and a pull to dependence and her determination to be seen as an individual and independent. She spoke of her experience of this manoeuvring:

I like to be independent. I don't like the MS tag. Sort of a label because it does give people preconceived ideas. I remember in one hospital... I remember sitting on the bed once and I had to transfer from my bed onto the wheelchair and obviously they couldn't lift and handle and I have a hoist and normally do it myself, I said I would do it eventually when I had enough air...It took me two hours, I just sat and waited and eventually the Nurse come in and said afterwards 'well if it was me I wouldn't have wasted all that effort' and I said 'well you could have done it earlier on'. But they don't comprehend that you can't (do things quickly)...don't understand how one minute you can, one minute you can't.

Hospital admissions were sometimes required for quite minor ailments like a twisted ankle or a chest infection. These relatively minor ailments though, meant Jess couldn't do what she needed to for herself at home and hence hospitalisation followed. Independence was challenged then in all sorts of ways. Jess went on to talk about paid work and difficulties she experienced with this. She felt that transport to enable her, and others in similar situations, to get to work places was a big problem. Jess chose to work one day a week in a school just down the road from where she lived. This cost her £5 a trip that she paid for out of her mobility allowance but she preferred to do this rather than sit around her home every day. She explained that:

For the last eighteen years my biggest problem of not working is transport. I could have worked and not been a parasite ha, ha.

Jess felt strongly about this and saw getting out of the house into society as very important:

I'm trying...not being housebound and treating you as the problem.
We need to get people out and about.

She added:

People who are wheelchair users can't just be stuck away at home...they have the right to go out on a Saturday, to have children, be out and about everyday of the week...live a normal life.

I then asked if she thought perceptions of disabled people had changed more recently:

I think we've got a long way to go still but I think there's a huge difference to what it must have been like.

This led to a wider discussion of how people with impairments are treated in this country:

I don't take notice of how people treat you. It's to do with me. It's their problem not mine, but I mean...I think as I get older and as I get tired people's attitudes will affect me more.

Jess went on to talk about having had a particularly difficult last six to twelve months and the necessity to keep struggling on and work through difficulties when she said:

I find it harder and harder to take it. The carers will say that as well...that I don't like being cared for, and you've got to look at it from their point of view as well, that you don't like the care, but you mustn't take it out on the carers.

Jess spoke about her impairments:

Recently I lost the power in my arms...I had to be fed...that I didn't think I'd ever be able to cope with. Now I can't wash and dress myself. Once the carers put me in (shower chair) I can actually wash myself...but that's exhausting.

And the impact of these impairments:

Because you're dependant on people...that brings your emotions out.

In talking of her relationship with family Val also referred to the tension between independence and dependence:

My husband...can only deal with it by almost pretending it's not happening, so I feel I've got to be strong for him and so that seems to undermine me. I realise then I'm not as strong as I kid myself.

Val went on to discuss her emotional reaction to these situations and the influence that, at times, is exerted on her. Shortly following Val's comments the group discussion that she was part of went on to discuss how much time they might have to live, and Fiona spoke about taking some control and organising things for when she dies:

So as not to leave a mess for the person that's going to sort out when you're not there...knows exactly what to do. My stepmother's got a list of people to ring and to let know. I've written my...I've paid for my funeral; I know the service that I want. All those things. And all my money I've put it all together sort of thing so there's no...she won't have to mess...the solicitor won't have to mess about. There's a list of everything. And that doesn't...isn't sad to me, it is so that I don't leave a mess for her who is going to have to sort it out.

Val added in agreement:

Oh no it's a feeling of accomplishment.

Fiona went on to describe how strongly she felt about this:

I've destroyed all my photographs - I don't want people going through my photographs. I thought about that. Photographs of my children and my life. I just don't want them to know and I have destroyed everything. I spoke to my stepmother about it first. She was quite in agreement. I don't want someone coming into the house...that's got no feeling. I don't want them touching photographs of my life.

Taking control of events that will happen after one's death was also discussed by Ralph in response to Fiona:

I even rang the Pension people to see how much money my wife would get. She couldn't believe it, the girl in Scotland or wherever it was, Newcastle. With this eh SERPS thing, she's entitled to all of that because of the time we're talking about. So I asked how much would she get actually get? I said well I'm only asking.

For these participants taking control in discernable ways was an opportunity to exert their independence in actions. For Mel though, taking control seemed less of a possibility when she relayed the challenge to her independence created by her condition. She was speaking of the effect her Chronic Obstructive Pulmonary Disease had upon her:

Breathless, tired, fatigued at times and everything is an effort but some days are better than others. Some days it's like walking through mud. I have days when I can be really ill, when I can sort of hardly walk from one, well just from one chair to the next.

As well as her condition impacting upon her physical independence it also impacted upon her socially:

I had to give up my job in 98 because the...(Name of hospital) said you really can't go on working. It was a bit of a relief in a way. In other ways your life is totally changed.

This affected her financial independence as well as her ability to access social interaction and to maintain her self-esteem. Like for Val, Mel found her condition causing tension upon her relationships, which in turn affected her ability to be fully independent. She had been describing how a friend had 'dropped her' when she became unwell:

She told other, other friends of mine that she 'oh I suppose as I'm her closest friend I'll be the one that will have to look after her'.

Decisions about her friendship were taken out of Mel's hands and she had to adapt to the enforced changes this led to. Simon also spoke of the effect of others on him and his attempts to retain independence. He had been talking about how some people avoided him following his cancer diagnosis:

Some people go 'oh dear, oh dear, oh dear' and you can see it's...'ooh out the way' (laughs) but...I walk out the way. As soon as they start mumbling, I don't want to know.

He then spoke about how he felt it was impossible for others to understand what he had been through. Simon described his attitude of expecting others to accept him as he is, not wanting people's sympathy and his independent nature. Simon highlighted how this desire to retain independence can be challenged in a variety of ways. There was a time when he was first diagnosed when his partner kept certain information from him that can be seen to have been a challenge to his independence:

They discovered that it was in the right lung (cancer). With the emphysema, I didn't realise this was between the specialist and my wife, that he didn't want to operate because the condition of lung...they would take away one side of the lung and put me in a wheelchair. And my wife said please don't do that to him.

Another aspect of independence concerns the ability to do things for oneself. For Simon the lung cancer meant that walking and many other activities were very limited due to a lack of oxygen. He ended up relying on his partner to drive him everywhere although they did find a solution to this that increased his independence:

Walking does me. It eh...my wife's bought me a little electric scooter so I scuttle about around the village if I want to.

Simon spoke clearly of his inability to be active and the negative effect of this for himself and his partner who tried to protect him by restricting the things he did. This was a particular source of tension between Simon and his partner:

I can't be active any more, if I do the washing up it kills me, but I want to do it and I feel such an idiot and I'm told "sit down, no, no, no I'll do that", I said leave it and I'll do it, you know, rows at home because, you know, I want to, you know I feel as though I want to do it all the time.

Adapting to greater dependence was problematic for Simon in light of his previous belief:

I was a full believer in looking after yourself. Um not to rely on anybody that you don't have to.

John highlighted a different but related point when he was speaking about his low points with his HIV+ condition. He had been in hospital, very unwell and feeling isolated, when he came to the conclusion that he had to live for others as much as for himself:

I've got things to live for still...you have to search for whatever you've got to live for.

Johns illustrates a reprioritisation and a determination to live, to take control as much as he can, and to be positive. He had been speaking of friends who had died of AIDS

and who had, selfishly he thought, declined to take medication and John reflected on dealing with his own HIV+:

A lot of people get depressed over things like this, and I used to but I don't so much now cos I think part of that is that I know full well that I can only solve the problems that are solvable...there are plenty of problems that are not, that I can't solve...and there's no point in wasting my time getting upset about them and depressed about them, it's, it's a waste...you know there's no nirvana...life is about problem solving...There's no point in...hanging around.

Sheila also tried to focus only on her present problems. She had been talking about how her condition was progressing and how that in some ways she sees herself as worse than previously but in some other ways she sees herself as improved. She said:

You don't know what's going to happen in the future.

She envisaged needing to move into a flat and needing greater external help. With this she felt a greater sense of being trapped would occur, of being limited and dependent on friends. This is an area that Sheila said she tried not to dwell on. Hazel also reflected on her bodily impairments and increasing sense of dependence this brought:

I was just lying there in hospital; I mean none of them knew what to do with me. None of them knew how to treat me, I mean and by that time I needed two people to even get off the bed onto a chair.

Hazel highlights here how much of a physical effort life had become for her and how reliant on others she had become. She went on to reflect on the progress of her condition and the difference in her life when she said:

I think I was very fortunate, well I still am in that I have always been happy in my own company...so you know periods spent on my own, I was, I was at peace.

She considered that ME would be even more difficult to deal with if she had been a gregarious type of person. Hazel went onto talk about the level of control and choice she felt she had in her life when she spoke about the events leading up to moving into her adapted home. This was an example given by Hazel of how others had influence over her:

When I moved here, it was left to everybody else to decide whether this house was suitable for me, I was the last person to have a say in it.

This caused problems for her not only in the loss of independence but in practical ways:

Their idea of a disabled person is of one set person, somebody who is in a wheelchair and nothing else gets taken into account...not all disabled people are the same.

Hazel pointed out she needed more than purely wheelchair access to her home and toilet. She needed peacefulness and the ability to lie down easily without waiting for help to do so. Edith also spoke about having a choice in things that concern her. For her the warden in her retirement flat was an important person and having some say in the selection of this person was something she had considered:

I do think that that we should have a choice...when they're choosing a warden. I think residents should be allowed to say who they want...if they want to pick two or three and then give us a choice out of those.

Edith later addresses the need to have people around whom she was comfortable with and felt secure with. However whoever is involved, the warden in this instance for Edith, one needs to get along with them. For Edith this meant avoiding upsetting the warden and even with other people, Edith suggests there is a need to be conciliatory and shape herself to accommodate other's perceived needs. In discussing her disappointment with the lymphoedema service she described herself:

I'm a very independent person.

Rather than attend what she saw as an unsatisfactory clinic she had organised her partner to massage her swollen arm. They were both self-reliant and have refused to be dependent on others. Because of Edith's conditions her partner now completes all domestic and personal caring. Becky spoke of her very difficult times with depression after she was diagnosed with HIV+ and described how she found it difficult to know what to do to help herself. She needed to see the bigger picture in order to plan her future:

I think probably every day things, sort of the nitty gritty of every day life I've got control over. But probably the bigger picture, like planning for the future and things like that I...no. So long term sort of looking ahead I...no, I, I don't do that...cos I can't control that.

Despite this though Becky did want to be informed about her condition:

I like to know what I'm dealing with, I like to know what the potential side effects are...I like to be responsible for my treatment with the doctor.

She also reflected on the many losses she was acutely aware of following diagnosis and how she dealt with this:

That was really tough and I, I got to the stage when I thought well I can either sit here and wait to die, or I can actually do something with the rest of my life (Laughs). So I decided to get on with it and try and live life as normal as possible and that's what I've done ever since.

There are similarities here with John's attitude described above. In a group discussion, Maisie had been talking about her efforts to relearn to walk following the spinal cord compression she had when cancer went to the bones in her spine. The cancer had pinched the nerves that control the functioning of the legs. Val commented how hard it was to adjust to such a loss of independence and to relearn daily activities. Others in the group discussion joined in this discussion and Lily said:

I was never still I was here there and everywhere...Now I can't do anything...

It comes hard.

Bessie also commented on the effect of her condition on her life:

It's taken a certain quality of life from me.

Malcolm followed Bessie and added:

Yeah we would all agree with that I think. I was really very active...
it's all just gone.

Later Lily spoke about what her loss of independence had led to:

I've gone into a home, cos I found I, I just I just could not cope.

In an individual interview Delia also spoke about what her condition had taken from her in terms of independence to complete daily activities on her own. Things not normally thought about, like tying your shoelaces or Hoovering, had become areas of great difficulty for her. These limitations led to a dependency on others:

I would never have thought that I'd have to ask someone to make my bed. It just curtails your life completely really.

As other participants have identified a process of relearning appears to take place:

My children bought (a battery operated buggy) for me. I was having to be helped so much and it's so awkward, I hate people rushing around helping me.

Despite many examples of loss of independence because of her breathing difficulties Delia also spoke about how she manages these limitations so that she is not completely made to be dependent on others. She spoke of interspersing activities with regular rest breaks, and of completing attainable things like reading a book or doing tapestry. Her aim was clear:

I've always been independent I think um I'm determined to do it on my own basically but I have terrific backup from my family.

But overall this loss of independence had hit Delia hard:

I do resent it...because I've been so active all my life you see...I've never, never sat around. Everything was so busy. Which I loved. And now I, I end up like this.

Delia also considered the choices she can now make in life and said that her choices are very few but that:

I suppose I choose not to do things basically because I know my capabilities.

Wendy and Sylvia had been talking about the social services day centre they attended. They identified many positive things about this attendance including the fact of the day centre increasing their confidence and offering social interaction that was, otherwise lacking. On a practical note the fact of having meals provided was also a big advantage as it relieved one other aspect of daily life. This was particularly important for Wendy who ate little at home on her own:

It's one less that we have to worry about isn't it? It's really difficult all alone to eat.

3.9 Chapter conclusion

From the accounts presented in this chapter a clear impression of what it is like for participants experiencing life limiting conditions has been given. The period around diagnosis was of great significance for participants in terms of their own reaction to ill health and diagnosis as well as in terms of the impact of others around them at this time.

Three themes that highlight emotional aspects of living with a life limiting condition have been identified. The themes Fear, Anger/Frustration and Grief clearly illustrate individual and personal reactions to diagnosis, impairment and life with a life limiting condition. These themes also give an indication as to how other people, services, professionals and factors like paid work intertwine with these emotions.

This attention to the influence of others was presented as a theme in its own right. The theme of Relationships highlights a range of points about the relationships participants had been involved in. There is a connection here to the next theme, Difference/Individuality. Perceptions of difference were influenced by particular relationships as well as participants' own awareness of others' judgements or assumptions made about them and their condition. Within this there were also accounts indicating an importance associated with establishing individuality.

The last theme in this first findings chapter was Independent/Dependent. This theme relayed accounts from participants concerned with challenges to independence and participants' efforts to maintain independence. This theme transpired to be of central importance in this research and to have significance through all themes. This is discussed in chapter 5.

As well as indicating personal aspects of living with life limiting conditions it has also been evident within all these themes how participants have been influenced by environmental or social and attitudinal factors. Friends and family who have sometimes displayed discomfort, callousness and ignorance about their conditions have clearly shaped participants' experiences. Environmentally, the work place and the impact of health and social care services and their staff also clearly impacted on participant's experience of their conditions. This will be highlighted more directly in chapter 4.

The agreement on themes between participants with different conditions is quite striking in this chapter. In only one theme, anger/frustration was the voice of participants with cancer less evident than those with other conditions. Other differences to be noted involved participants with cancer, rather than those with non-cancer conditions, highlighting issues about the embarrassment of friends, after death

planning and fear reduction through hospice contact. Apart from these points accounts were very consistent whether from participants with cancer or participants with non-cancer conditions.

Chapter 4 – Findings: Services

4.1 Introduction

Services

All participants spoke of the different services that they had experience of or of services that they thought they needed access to. Some participants spoke in depth about particular services. This theme consists of five sub-themes; ‘acute service provision’, which refers to hospital services; ‘primary care service provision’, which refers to health care delivered in the community; ‘social service provision’, which refers to social care delivered in any setting; ‘palliative care service provision’, which refers to care delivered in hospices primarily; ‘other services’, which refers to services or aspects of care provision that fall outside of the previous themes. Sub-themes are sometimes further categorised where appropriate, in terms of participants’ experiences of staff and of the service itself. This chapter is divided into the sections shown in table 4.1 below.

Table 4.1: Findings chapter 4 sections

SECTION	TITLE
4.1	Introduction
4.2	Acute service provision
4.3	Primary care service provision
4.4	Social care service provision
4.5	Palliative care service provision
4.6	Other services
4.7	Chapter conclusion

4.2 Acute service provision

Many participants spoke of their various experiences of care and treatment they had received in hospital.

4.2.1 Experiences with staff

Interactions with staff were often described as well and it was clear that the relationship participants had with hospital staff was important to them. Unsatisfactory encounters brought great disappointment to participants like Hazel who found her consultant unsympathetic and insensitive:

Consultant at (hospital) diagnosed menopausal depression...he put me on anti depressants again, sent me off home.

This initial response was to slowly change though:

I had another appointment to see him two weeks later, by which time I was even weaker and he admitted he thought that perhaps there was something physically wrong.

Problems with gaining legitimacy in terms of her ME diagnosis continued for Hazel though:

The hospital doctors, ugh...when I've been in hospital I've been told my illness is self perpetuating...remarks I got from doctors there were just unbelievable. They would say...have you seen a psychiatrist recently? Some of the nurses are as bad if not worse.

Hazel was both angry and incredulous with her treatment by staff:

It makes me livid. I think...would I really, if it was all in the mind, would I really have been like this for seven and a half years?

Accounts of experiences with hospital staff was also given by Edith who described an out patient appointment in the breast clinic at her local hospital where she attended every six months. This appointment was with a doctor she hadn't seen before:

I don't think I have the same treatment as I did before...the first time I saw him he had the wrong notes, but he doesn't seem to take any interest.

Edith went further:

The other one I had (Consultant) was caring...but this one...just treats it as a joke...doesn't take an interest.

Other doctors and staff in this breast clinic treated her differently though:

The nurses are very good they always come up and talk to me.

Edith had also experienced some difficulty in radiotherapy when having treatment for breast cancer with staff that, she felt, didn't protect her enough:

They (radiographers) were so busy arguing about which way I should lay and how I should lay I don't think they put anything on me. They normally cover the parts that don't want radiotherapy. I think the things were left off and I think this is how they burnt me you know.

For Edith, this omission led to serious consequences:

They burnt my lungs. They went too deep, it burnt my back...(Resulting in) a lot of lung damage.

In contrast, Simon found that the input of a specialist nurse in lung cancer at the local hospital was helpful:

She's excellent. She goes out of her way to try and help in any way that she can. I think she's one of the prime movers in, through her and (Name of doctor) the specialist, instigated my coming here in the first place (Hospice).

In a group discussion participants had been talking about the variability between their GPs with regard to getting appointments to see them or for the GP to come and see them at home. The difficulty with weekend availability of GPs was discussed and in response to May's comment about her GP Val talked of the need she has for consistency and communication between professionals:

I've got no faith in my GPs whatsoever. Every time I've said anything to him, he's said...see your consultant. And then you see the trouble with consultants, well no it's not trouble it's their job, the rheumatology bloke is only interested in the rheumatology side of it, the haematology is only interested in the...you're up a gum tree before you start. And then the rheumatology fella says 'Well I can't do anything for your rheumatism because the main thing is the bones' and it's so, oh well.

In a different group discussion Malcolm also referred to communication issues between healthcare professionals. When he told one doctor about the lump in his groin nothing was done because he wasn't being seen for that problem:

They didn't communicate with each other...I don't know ...what they thought or didn't think.

In the same group discussion participants had been sharing accounts about the problems they had encountered when being discharged home from hospital when Maisie commented that:

The social worker at Westbury Hospital was a dead loss.

Despite having some good experiences of hospital doctors Delia was disappointed with her hospital consultant:

Mr. Hagley (Consultant Physician), I didn't think very much of him...he was very arrogant, and treated you out of hand. (One) day he wanted to look at me on his own, he pushed my...he said you can go out there and pushed my daughter...I did not appreciate being handled by that man.

Sheila too felt dissatisfied with her hospital consultant:

One of the old school...you don't need to know anything. It's as though you're on the back burner as far as (Hospital consultant) is concerned.

Other hospital staff, including doctors, were more considerate with some specialist staff being particularly helpful:

Respiratory nurses are excellent.

Becky also had experience of some helpful staff:

The pharmacist is very, very helpful (at HIV unit). When I changed onto the latest combination...she spent 1^{1/2} hours with me and my husband, talking us through the different possibilities.

The hospital consultant she saw was also highly regarded by her:

Always open to listen to any query or difficulty I might have.

In terms of specialist help for her HIV+ things were positive as well:

They're very good like that...they understand more about the emotional aspect of it, and that you worry.

4.2.2 Experience of services

Participants also gave accounts of experiences with particular hospital services. Edith found the hospital lymphoedema service to be lacking. She needed this service because of the lymphoedema she had in one arm following her mastectomy for breast cancer. Edith's arm and shoulder was very swollen and she had very little use in this arm. Gaining appointments with the person providing this service was problematic for her though:

I'm not very happy with the lymphoedema. I'm not very happy with the treatment on that really.

Edith clearly thought her lung damage was a direct result of the radiotherapy she had received for breast cancer but pointed out that she never saw anyone specifically for

this problem. Speaking in January, Fiona also talked of her experience of the hospital lymphoedema service:

There is one nurse at Westbury Hospital who deals with lymphoedema. She does 20 hours and so, that's rubbish. The waiting list is...now she's seeing people in June. I mean, I'm, I'm in such pain and in such a mess I mean you can see the size of my legs. I need to see somebody, like many other people probably, need to see somebody today or tomorrow not June. Mind you I may not be here in June.

Chris's partner Clare spoke of their experience of their local hospital when Chris was admitted having had a stroke. She recollected how dirty the ward was with blood stained dressings on the floor and how one of the nursing assistants had lost their temper with Chris. She was particularly upset though about aspects of care:

One of the things that I found absolutely awful is that there is absolutely no dignity so that people who can't move or help themselves have absolutely no dignity or modesty allowed in hospitals.

Clare was referring to how Chris's bottom half was not covered when she visited him and did not have the awareness himself to ensure he was 'respectable'. Clare made her point to the hospital management and was even offered a job ensuring these kinds of standards were met. Chris needed items of equipment on his discharge home from hospital and Clare commented on helpful hospital departments:

The occupational therapists, I think they were good. They've supplied this bed and the and the mattress and...the hoist...the sling was cutting Chris and I mentioned it to the girl called Laura who got all this organised and within six weeks we had a lovely sheepskin one which was lovely only by asking.

John felt his experience of hospital inpatient care was coloured by his HIV+ condition and staff's anxieties about this:

It's more a lack of dignity and respect. The nurses tend not to want to come into my room (fearing infection)...(partner) will come in and see me at eight before work...and then he'll come back at five after work and I'm still there with the same drip in the morning, I haven't had anything to eat or anything because the nurses have just ignored and left me behind.

This experience was about four years prior to his interview when he was in hospital with pneumonia and he felt that the staff just didn't have the necessary training or understanding of HIV+. John also highlighted difficulties he had experienced with going to hospital onto an open ward where privacy was difficult to achieve:

I don't know who I'm going to see there. When you're not very well you don't want an adverse reaction, you don't want people pointing fingers.

In discussion of services Val remembered the time of her chemotherapy in her local hospitals cancer care ward:

The...ward at Westbury, I can't speak highly enough of. They're absolutely marvellous.

May joined in this discussion and spoke of her experience in another hospitals cancer care ward:

It's a marvellous ward, absolutely marvellous. I had three separate weeks in there and you get personal attention, you get a nurse supplied to you for however many days it is and that nurse keeps an eye on you all day...they were marvellous to me. I shall never forget their kindness and the attention. They simply coaxed me back to health again, literally, with their kindness and they couldn't do enough for you, whatever you wanted it was there, you know.

Fiona made a more general point about her experience in her local hospital in response to Ralph who had been describing his families support at the time of his diagnosis:

I found it hard when I'd been in Westbury Hospital and they had been disorganised and it's me fighting them. Because I've got nobody to stand up for me, I haven't got a husband or a son.

Being on her own with little support her hospital experience felt like a battle:

Fighting them. And they're all busy...you are alone standing up for your rights is very, very draining. You've got to battle by yourself and you're not feeling right. That is very hard.

Delia had different but still negative experiences of her local hospital. She was describing to me how her dentist wanted her to go to hospital for dental treatment but she had refused because she didn't want to return to the hospital:

I had awful treatment in Parklands when I had my knee done, and I would never go to Westbury Hospital again. I found Parklands when I had my knee done particularly dirty and uncaring. I went to Westbury...last year, I had cellulitis of this leg. I waited from half past seven until ten to four in the morning before I was taken to the ward, without oxygen.

She explained further:

I was taken to the new part of the Hospital which is very good and I couldn't fault the nursing at all there for four days and then they took me to the old part and that was absolutely horrendous. I was so pleased I didn't have a wound because I don't think I would have come out alive. I have never seen as much dirt in all my life.

The care wasn't what she would have expected:

I was supposed to be having these intravenous injections every six hours. And they were never on time. The staff were very uncaring. I thought this isn't nursing as I've known it in the past.

Delia felt the resources weren't there for the hospitals and the staff in them to provide the best of care but still held staff in high regard despite some of her experiences:

The doctors and nurses, all these brilliant people get so little help. When I was in Parklands Hospital the nurses were terribly busy.

Becky also felt there were fundamental problems with health care provision and had been discussing difficulties she had in trying to get hospital doctors to see her as more than the one thing she was seeing them for:

Sometimes there's a lack of joined up thinking...that's probably the case throughout the NHS no matter what you're dealing with (laughs). They tend to look at things in isolation. There is a complete lack of communication between different departments...I think that's very much a general NHS failure. You feel like you're just coming up against a brick wall sometimes. You're trying to get them to think a bit outside their box...and say 'well, we appreciate that this is part of the bigger thing for you'.

4.3 Primary care service provision

4.3.1 Experiences with staff

Many participants spoke of relationships with General Practitioner's (GP) and a range of views were expressed about these relationships. John for instance commented about the knowledge base of his GP:

Sometimes he's (GP) cut out of the loop...he admitted that he knows a little about a lot and quite often I need to know I need to know...a lot about a little.

Being 'cut out of the loop' refers to John's relationship and input with specialists for his HIV+. Often John would communicate directly with a clinical nurse specialist in HIV/AIDS. At times this person would direct him to his GP, at other times he would be offered advice or brought to out patients clinic to see his consultant.

Communication issues also interfered with the relationship with his GP:

There are times that he doesn't express himself very well, his people skills are diabolical at times. We've fallen out a lot at times because he tries to take over different treatments...he's even written to the hospital and told the dermatologist there not to see me...sometimes it makes it awkward, I don't want to go to the GP.

This has led John and his partner to consider ways of dealing with this, at times, unsatisfactory situation:

We've discussed a few times about leaving him and going somewhere else, but at the end of the day he knows my medical history better than anyone.

Another issue in this decision-making is that John felt that, despite certain limitations, his GP acknowledged that John knew a lot about his own condition and would listen to his thoughts and sometimes prescribe certain medication without seeing him because he trusted his opinion. John was also able to acknowledge that it must be difficult for his GP, not being totally aware of all the problems he encounters and what all the hospital specialists are doing. John had seen another GP in the practice who told him of his diagnosis. He reflected on this encounter as shocking but supportive:

(Name of GP) said 'I'm sorry John but I have got some news for you and it's not very nice' and I said do you do you mind if I get Ron she said of course not and I called him in and she told us what was wrong and she was very good...she led me into it slowly, over an hour she spoke to me.

For Mel such support was perceived as an elusive reality:

You don't get any support at all...you just have to get on with it yourself. I don't think there is the support there at all because there's not enough resources is there really?

Considering where she might get support from she went on to consider the role of her GP:

I don't think GP's have got time

Mel felt that she even made some small medical decisions, as the GP didn't always see her when she had a chest infection. Rather her GP would prescribe antibiotics having spoken to her on the phone and without examining her. Instead of perceiving this as offering some autonomy it was problematic for her:

Well sometimes you'd like somebody else...you know I'm not a doctor, somebody else should be making these decisions you know.

Mel moved on to consider that GPs are limited in what they can do for her but nevertheless was left feeling dissatisfied:

The whole health service...you are sometimes made to feel you are just a nuisance.

Hazel though spoke of a positive first interaction with her GP:

My GP was brilliant to start with.

Her GP took immediate action, signed her off work, prescribed medication and referred her to the hospital. Hazel went on to describe her perception of her GPs current attitude to her:

My GP, (pause) I think she's as frustrated as I am...there's virtually nothing she can do for me, I mean she can obviously, I mean she does my prescriptions and that sort of thing for relief for the symptoms...I think it would be fair to say now that I know more about ME than she does.

For Delia there was also gratitude to her GP:

Dr...(GP name) has been very supportive.

Her GP had tried to facilitate placement in local hospices for her but with no success:

When I was feeling very low (GP name) suggested that I went to (Hospice 1 name) for a week for respite...they didn't want me because I'm not a cancer sufferer basically...they couldn't deal with my condition.

Feedback from her GP showed determination to help:

(GP name) said we didn't get on too well...she said I think you'd like it at (Hospice 2 name)...she didn't hear from them and I didn't... so obviously they don't deal with...

This rejection was particularly bitter for Delia as she had a good friend with cancer who received care from one of the hospices and she had heard good things about it:

I think the Macmillan Nurses are absolutely brilliant. A friend of mine...he couldn't say enough about the nurses (Hospice 2)...he's come home to die...but he has found them brilliant there.

Sheila also had a positive account of her GP to offer:

My GP is very good...she explained everything.

Sheila saw herself as fortunate to have this positive relationship with her GP. John spoke positively of his relationship with a clinical nurse specialist in HIV+/AIDS who was based in the community:

I can ring the Clinical Nurse Specialist at any time and get information straight away.

District nurses were not referred to very much by participants. This may be due to the nature of the issues facing participants in this research. John talked of district nurses who kept an eye on him every few weeks when he came out of hospital and Hazel highlighted positive experiences with nurses that visited her at home:

They've been excellent. They've been lovely. But then...some of them have been coming to me for six years.

Hazel highlighted difficulties she faced due to professionals not knowing a great deal about her condition and also not listening to her own insights about how the condition affected her:

My GP got a physio to come out to me who just didn't have the first idea about ME and it was a disaster cos it just made me worse, she wouldn't listen.

This was related more generally to how she felt many people treated her:

This is the thing that really annoys me more than anything else is that nobody would listen to what I was saying. I knew what my body could do, I knew what I was capable of but they all had their own ideas of what I ought to be doing.

Maisie had received a different service from physiotherapists:

Through perseverance...the physiotherapists were marvellous...
I did manage to walk again.

However returning home from hospital she was disappointed by a lack of help:

When I came out of hospital...I didn't have any support from the nurse, the doctor, social worker. If it hadn't been for my neighbour...I could have laid down and died.

Becky's community HIV specialist nurse was an important resource for her and had been helpful on some practical issues:

If I've got a problem I will speak to Jane. I think Jane's brilliant, she's very, very supportive...she's very easy to talk to which is important.

She also attended a group for women with HIV+. She described this as informal but helpful:

Jane facilitates part of it, she'll give us any information...or any news or developments...then she might leave and we'll chat...it's really good because we talk about problems, difficulties, medication difficulties, side effects and illnesses...and you can do it in a safe environment with other people who know what you're talking about. It's really supportive.

Becky had also had good input from her GP:

My GP here is actually quite good. I ummed and ahed whether to actually tell him...he was actually very good...he actually spent time talking to me...I was surprised.

4.3.2 Experience of services

John reported problems obtaining dental services because of his HIV+ condition:

Dentist I've had a lot of problems with. I've had to go to hospital for dentist because obviously I had to tell my dentist straight away what was wrong and he said to me...I don't want to see you again' and he refused to see me.

Edith also had experienced problems accessing a dentist locally because of her difficulties walking and breathing:

I've been trying to find a dentist, that hasn't got steps and stairs.

Having tried many dentists but experiencing many access issues she eventually was referred to the community dental services. Chris's partner Clare spoke of her disappointment with community physiotherapy services:

I wish there was a little bit more Physio cos I think that people who are bed ridden and Chris doesn't get any Physio only what I pay for...he's been in plaster for six to eight weeks. Taken into hospital because his hand clenched

up and these nails they went all black and grew into his palm, although I tried to open them and I cleaned it with Wet Wipes and cotton buds and tried to blow it dry with a hair dryer and everything...It eventually got so that he couldn't open his hand without absolutely killing him. And so he was taken in and had his tendons cut.

4.4 Social care service provision

4.4.1 Experiences with staff

Chris's partner Clare described her perception of social service carers:

My carers are lovely who come in.

She then went on to speak of the management of the carers in a more critical way:

A lot of people who have come like Social Services, not the home carers themselves but the management of the care, they come to assess your needs as if you're some sort of dog they're going to put in Battersea Dogs Home.

For Hazel there were similar issues to do with the management of carers and the routinization of caring services:

The morning call is for breakfast, wash and dress...well I find it too much to do all those three things in one go. The seniors can't understand why I can't...they'll say 'well it's only a three quarter of an hour call' and I'll try and explain that three quarters of an hour is too long for me to be doing any activity. There's not enough flexibility in the system.

Hazel seemed to be struggling to get her needs understood by the home care managers and there appeared to be intransigence, which led to no change in practice being implemented:

Two of the seniors came round (from homecare)...to fill in some form...and asked how the service could be improved...and I did say all this...they turn round and said 'well it's not always that easy to organise'.

Hazel went on to discuss her carers and her need for consistency:

The thing that's made such a difference is that I've got regular carers now, who know me. If I see a stranger coming (Homecare)... that makes *such* a difference (Original emphasis).

She felt that having different carers had a negative effect on her because they don't really know you. On the occasions when carers she didn't know and who didn't know her visited, there was often a clash of understandings:

One of the home care girl's talk's non-stop...although I've said to her sometimes you know I've got an awful headache...doesn't make a great deal of difference.

Another carer presented similar problems for Hazel:

There's one (Home carer)...came in absolutely shouting at the top of her voice...been to elderly people who were all deaf.

Hazel summed up the issue for her:

They don't think of you as a separate individual most of the time.

This perception of professionals involved in her health and social care was reinforced by a social worker who she felt failed to see her as an individual:

I had a super Social Worker...she left and I got this other one who is pleasant, but wouldn't listen to me...She felt she knew what I needed, even though she'd had no contact with ME.

Two participants had experience of employing carers under the direct payment scheme. This scheme is intended to offer individuals who have been assessed as needing social care input to take the control and have the choice in terms of the carers they have to fulfil their daily support needs. Local social services departments devolve the money they would spend on an individual to that person who is then responsible for hiring their own carers/personal assistants, and for paying them. Up until September 2002 West Sussex had 165 people receiving direct payments. Sylvia spoke positively about how direct payments were working for herself:

I'm very lucky because I have homecare...seven days a week in the morning to shower and dress me... I'm on direct payment. And I have a girl four hours on the Monday and a couple on Wednesday evening to do my housework and bits and pieces and sit and natter and have a cup of tea. And then I have two social girls, one Friday evening and one Saturday afternoon.

She went on to explain some of the other things her carers do for and with her:

The one (On) Friday evening, we tend to sit and play scrabble and I love that. And then the Saturday afternoon one...sort of do whatever, if I want to go down the town she'll come with me. Very good, very good.

Sylvia pointed out that employing carers yourself under direct payments, means that you can ask them to do household chores and more socially orientated tasks for you whereas Homecare staff are not allowed to do this. Later in the group discussion that she took part in Sylvia was asked about her thoughts on having a voice to influence services, what did she feel about this:

I think really and truly it is important they know all that...they're so good anyway the girls. But they're just doing a job. I must admit the ones I've got are absolutely brilliant. But I think it would do for the higher uppers to know how we feel.

Asked what she would pass on to the 'higher uppers' she spoke about the importance of the continuity of carers and the tolerance carers need:

Tolerance to a degree because if my carer's away and you've got another one stepping in...they don't know you so well and I'm always conscious that they're watching the time and I'm feeling hurried. And of course that throws me out something awful. It makes me a million times worse.

Wendy responded to Sylvia and went on with this point:

And time...as you said you're flustered and (they) said 'what you going to do now' and I thought...I mean I can't speak at all, I can't think...I think it's just time...watch...watching the clock.

For Wendy the issue of feeling rushed by carers was an important one and she also highlighted how carers do not always complete the tasks required but hurry off before they can be reminded. She did also acknowledge the quality of some home care staff:

Home Help...she's really nice...communicate...and she helps a lot...knows exactly what to get, food wise. She knows me.

Like Sylvia, Jess was on the direct payment scheme. She described how a care plan is completed and funds allocated in order for her to employ staff to fulfil the care plan.

She went on:

I have more choice. Carers come in four times a day...and help with shopping...and can accompany me out places.

Despite greater choice though there were some drawbacks:

But what people find is that you're given the money then social services don't want to help you...so you have to go out and find new people...basically that's the hardest bit...especially when you've come out of hospital desperately ill.

The fact of having to set up your care package when coming out of hospital was something Jess found particularly difficult:

You need somebody to actually be able to get the help for you...but then that's not independent living.

She also found it an issue obtaining the right staff:

It's hard to find people who are good. Most are wary about doing work as heavy as I am now.

Jess explained, not heavier in weight but in a one-hour visit to her at home there are many duties to do:

I pay for an hour and I need an hours care.

Jess also commented on her experience of the attitudes of some carers:

'Can you hurry up and get out of bed cause I've got six more people to do'.
Somebody said that to me once. That's the way I've been treated.

In a group discussion Lily commented on her experiences of home care, which seems to raise questions about planning at the level of individual needs:

You never get the same person twice (from home care) you never know what time they're coming. Some of them just want to sit and talk.

4.4.2 Experience of services

For Wendy and Sylvia attendance at a social services day centre was very helpful. Wendy brought up the day centre when the discussion was focusing upon the services received:

Everybody at the Day Centre, I'm just so lucky... I think its support isn't it?
And mixing with the people.

Both Wendy and Sylvia spoke of the many things the centre had to offer them including many activities, lunch provided in a sociable atmosphere, but also they both

spoke of the day centre as a source of company that helped to combat their loneliness. Wendy particularly spoke of this aspect:

Mum died... and support...when you're lonely, all alone. I can't stand...all alone living and pacing around. I don't care for eat...but now we have proper meals (At day centre).

Sylvia added:

Well I'd hate it if we didn't have...to come here.

Simon had a different experience of a social service day centre. Initially it was really enjoyable and he was learning new skills but then things changed, tutors left, meal prices rose, and in the end he took the decision to leave:

Because of pure mismanagement we lost all our volunteer tutors. Every one of them. There was nobody to teach anything...upset everyone on the staff, and all the volunteers, one by one, they said 'oh it's not worth it'. I left. I did miss going down there when I packed it in.

He went on to comment about social services home care and the difficulty of obtaining domestic or more practical help as they have strict criteria and do not provide this. Sylvia spoke of difficulties obtaining a new wheelchair:

I'm forever phoning wheelchair services. I'd like an electric wheelchair; this one makes my backside ache to hell, the seat's so hard plus I can't get out of it. They say that they've got a big long list. Left a message on the answer phone yesterday, nobody came back...

Wendy had experienced problems in being fitted for a leg splint:

(Name of GP) wrote a letter to the hospital to get a splint (To support foot as has foot drop). I rang up the Neurogym...I wait...come down to the hospital... It's a long way. It's too large...have to ask (For another) prescription...last

Friday I got a splint...this one is so big it hurts when you're walking. But the problem is the hassle...and I'm so annoyed...I just flipped in the Neurogym.

Chris's partner Clare had been discussing how life had changed so very much since Chris had his stroke and how life now lacked any spontaneity when she also commented about social services and the financial assessment of them:

And then the all the intrusiveness of it all, of Social Services trying to do an assessment and this review, our means, mine as well. My private bank accounts and I've always I worked for twenty eight and a half years, they had to know how much I'd got and see my bank accounts as well as Chris's which I think is very intrusive.

Clare spoke of how recently they were told they didn't have to pay anymore because Chris had a medical condition and the NHS now funded his care. Clare had already taken action however:

In the meantime I thought blow, the Social Services are taking the money from me so just spent my savings. I thought I worked for that, we have never smoked or drunk, this was going to be our little holiday money, our little nest egg to go on holiday trips.

Maisie spoke of her attitude to home carers:

They just want the money; a lot of them are youngsters and they just want the money.

Bessie joined in this discussion and added:

They seem to work in a muddle.

For Lily the problem was rooted to a particular cause:

There's nobody supervising them...they're sent out from these agencies...the agencies don't know what they do.

Malcolm though had experienced a different service from carers supplied by the hospital:

The hospital service (Hospital at home), is very good, very dependable.

Delia gave her account of her first dealing with social services:

Social Services who have been quite useless.

However this did improve after they did provide her with useful equipment only to be disappointed again at a later date:

I said I wanted to be assessed and they said they were very busy at the moment. I am so disappointed in Social Services I wouldn't ask them again for anything.

Jess explained how because she was on the direct payments scheme she hadn't got a social worker and a social worker was needed in order to be referred to a social services day centre. On reflection though she felt:

I'm not going to a day centre just to sit with MS people...sit and do nothing. I like to be independent. I don't like the MS tag.

4.5 Palliative care service provision

All the participants with cancer in this research had some involvement with their local hospice and some had also had some involvement with other personnel, usually at the hospital, with a remit for palliative care. It is therefore unsurprising that much was discussed about the hospice and the hospice's day centre. Simon for example was full of praise for the hospice day centre:

There's always something new going on, always something to keep you occupied - if you want it - you can do whatever you want to do. If you want to sit and do you crossword all day long, read the paper or do whatever you want, there's no embargo on any, you do exactly whatever you want to do. And, er, as I say we're looked after well, the food is great, everything about it is...I can't praise it enough.

He went on to mention a less practical aspect that he considered to be a positive of attending the day centre:

You see we're all in the same boat here Phil. You've got a very common ground haven't you?

When discussing the hospice day centre further Simon highlighted an insight about the culture of the centre:

I mean never once in there have I heard anybody talk about their illness. That seems an unwritten taboo. You don't think about it, there's so much other things to think about, everybody's got different interests. Why talk about it, makes you morbid.

I pointed out how this may seem surprising when experience of cancer is surely one of the common links between everyone in the centre:

See, no, no never hear about it. Never hear about it. You don't want to keep being reminded of it anyway. We don't want to come in and sob on each other's shoulders, no way. Come out to have a fun day (Long pause).

Simon also described an acute awareness and consideration for the success and security of the hospice. He was very aware of the trying financial position the hospice was in at that time and expressed a commitment to have less, in terms of day trips or events in the day hospice, if that would save some money for the hospice. Simon was perhaps more aware than others of the financial constraints as he had been asked to speak to the local press about the hospice. He also commented on the issue of having

more of a voice within the hospice. This seemed to be allied to a sense of ownership and pride in the hospice:

One thing, I don't know whether it's right to say this but we don't, many from the Management come down and talk to us about things...it would be nice for management to come down, if they've got the time, to spend an hour and talk to us, just chat to us in general about how things are going. We want to know. We care about it. And from our point of view, us to them. And only by talking to them, only sending messages upstairs... (Laughs).

Simon's relationship with the hospice predated his own involvement, as a close relative had been cared for and died in the hospice one year prior to Simon's interview. This was perceived as a positive experience:

He was very, very ill when he came in and, I was struck then by the very, very quiet efficiency that was going on all around. The work was being done but you'd think nobody was doing anything but it was all being done. Very quiet efficiency. And they were lovely.

He described the effect of this on him in more detail:

I saw him lying in the bed...I thought what's going to happen to me...stick me up in the corner and that's it you're gone (Laughs). It was nothing like that at all. Nothing like that at all. I was totally wrong. That changed my...when I found out he was being looked after but I still had the dread of the word Hospice. Still had the dread for it. (Long pause) Fear of the unknown that's all it is.

Two group discussions were held with two sets of participants who attended the hospice day centre ten months apart and these led to a great deal of discussion about the day centre and the hospice more generally. In one group discussion Fiona, like Simon, commented on the commonality between day centre attendees that suggested a sense of community:

We're all in the same boat aren't we?

Later in the same group discussion there was further talk about the day centre, Fiona repeated that 'we are all in the same boat', and May added more about what seems to be that sense of belonging:

You're all ill; you're all on your way out aren't you? You've got the support of the medical team and everything if you need it.

Again, like Simon had said in his interview, it was highlighted by Val how cancer is not the main focus in the day centre:

We don't dwell on it as a group do we?

Fiona agreed with another rhetorical question:

I think we laugh more than we do other things don't we?

The discussion went onto day centre attendees sometimes having 'bad days' and that this is accepted when Val commented on what seems to be a coping mechanism to do with sharing similar experiences:

And that they're coping, I suppose, so that if they can cope, you can cope.

Discussion led on to be more focused on the hospice generally and what referral to the hospice meant. Fiona had been talking about problems with treatment in the hospital when Val said that she felt a lot better since she was referred to the hospice. She explained:

My fear was always...not for myself, don't get me wrong I'm no hero, but you've got a horror of being an absolute pain to somebody and you know here, that the Hospice is there for you when you come to that time. And that is a big relief.

Fiona agreed:

You feel that support behind you, don't you?

This was added to by May:

Anything that happens to you, you know, they will, if necessary, have you in to recuperate or try to sort it out for you.

Val again described her relief about referral to the hospice;

They know exactly what they're doing and you know you're in good hands.

This discussion became more serious when May recalled her inpatient stay in the hospice and its effect upon her:

It's completely taken away the fear if the time comes when you've got to face up to that sort of thing, I would be quite happy to come back in here and, and cope with it in here.

A relationship she formed with a fellow inpatient had a particular impact on her. She had become friends with this person and May was still an inpatient when this person died:

I thought, well if that ever happened to me, if it happens again and I get into this situation I would definitely be happy coming in here and being cared for.

Val also knew this person:

A couple of days before she died...she looked *so* peaceful.

It took away all that... (Original emphasis).

Val later talked again of advantages to being 'a hospice patient':

I think once you're under the Hospice, I think they listen to you...

This was in terms of other doctors like GPs and hospital doctors. Ralph picked up on this point:

Yes, you've only got to say (Name of hospice) on a prescription and it's immediate.

Ralph also felt that the community nurses from the hospice could facilitate obtaining a prescription from the GP surgery much quicker. Val added:

I suppose they've got more clout you see, haven't they? Let's be honest.

There was also some desire to share the work of the hospice with others:

I'm very quick to sing praises if anybody asks me about it. Because I think it's good that people know, you know, the immense work that they do here.

There was discussion about how these participants were actually referred to the hospice and they felt that others might not be so fortunate in getting referred and therefore not have the same service provided. It was unanimously felt in this group discussion that being associated with the hospice had particular advantages, such as help and support at the end of a telephone as Fiona pointed out:

If you are in a tizz about something you've got a, you know, a dedicated nurse or whoever, you can ring.

Having described her appreciation of the contact to someone at the hospice Fiona was more critical of another hospice service:

There used to be somebody here for lymphoedema in the hospice but it seems to have been got rid of. Obviously money, you know. Back to the same old thing. I have come up against that.

For Ralph a positive experience of the hospice was presented in a practical way when he described a physical pain he had the day before the group discussion. A community nurse from the hospice had contacted him when he was in pain and gave him advice:

I said 'I've got this terrific pain, I can't stand up' and then she said 'Well you're taking the codeine and...paracetamol as well' and I said 'Well no I'm not coz I thought that was the alternative'. So I started taking that again and within an hour I was fine. And last evening I had a meal. All happened within about three hours. It changed.

Ralph had previously also had a helpful encounter with a palliative care nurse at his local hospital:

The good thing I found was waiting to see the palliative nurse at Westbury Hospital, we waited half an hour but it was worth seeing her after the diagnosis because that immediately put me onto (Hospice) books.

This was added to by Fiona:

I too was on their books and when I went home they followed me up and all the rest of it, which was very good.

Ralph was also impressed by this nurse's influence and ability to make things happen:

She also got me home too on the day when they said I wouldn't be able to go home. Coz I couldn't eat the food. She saw what they were trying to give me and she said 'Leave it to me. I'll go and talk to the doctor' and about ten minutes...she came back and said, 'you're going home' she said. 'You're not going to eat any more of that'. She was very good actually.

In another group discussion Greg added his perception of the hospice. Following discussion about referral to the hospice Greg stated:

I have to admit the Hospice have been the best.

In this group discussion Malcolm also thought highly of the hospice:

Very good, very good. And the thing is, most people have the same, well more or less...sort of problems.

Gregg enlarged on this and this discussion had similarities to Simons above:

You can talk openly about it can't you?

Val identified another aspect of this sense of belonging that was described by participants in the other group discussion with participants from the hospice day centre:

We're all sympathetic to each other because you know where you're going.

As well as a sense of community, of belonging due to the shared experience of having cancer in common, this group discussion also felt that there was an acknowledgement of the skills available within the hospice. Lily stated:

The doctors themselves acknowledge that the hospice know more than they do... (About palliative care).

She elaborated:

From the medication point of view, they know far more than the doctors...in here.

Val added:

The GPs say that.

Bessie illustrated this point from her recent experience:

The other week I came in here (Hospice) for a week because I was so exhausted...they'd put me on a load of tablets, which I couldn't sort out. So I came in here for a week to get re-medicated. I'm on five now and I went home.

Gregg recalled what his oncologist had said when referring him to the hospice:

My oncologist said 'I can't do anything more for you, I'll pass you over to the hospice where they know more than I do'. At least there's somewhere where we can get help, get something done.

Maisie found that the hospice offered reassurance to friends and several participants spoke of the sense of relief knowing that a hospice community nurse could be contacted. Gregg spoke directly of this sense of security for both himself and his family:

It gives everybody else a sense of relief that they can say right...you've done so and so, I can phone this number and get a reply straight away.

Val added:

Someone to turn to isn't it?

Lily explained from her experience:

From the relation's point of view they feel, they can ring here too. My daughter in law and my son on occasions have phoned here, to (Community nurse name) to find out a bit more about what the condition is you know?

Bessie also joined in about this:

I think you need most of all...you can reel it off, connection and support. Connection and a good support...somebody that's reliable.

Lily seemed to sum it up for others:

Well they are the specialists aren't they?

Other hospices were spoken about as well. John and Becky spoke of a hospice especially for people with HIV+/AIDS. John commented that it was out of his geographical area though and some of the difficulties this raised:

The (Hospice name) is out of my catchment area and because of the way its run...my consultant had to make sure that the budget was there for it.

Funding for access to the hospice had changed over time and it had become much more difficult to obtain the funds required although John acknowledged that he had never been refused placement there. John was clear about what the hospice could provide for him:

It's not just when you're ill it's also when you need a break and you need the time on your own. They understand everything, the food's better...they can do special diets...which is much easier than the hospital dealing with that.

He then went into more detail about what the hospice offered him and compared this to his experience of hospitals:

They go through things, do you need any religious understanding and do you want to talk to anybody. There's a lot of palliative care...I've tried aromatherapy massage and complementary medicines not available in hospitals (and it) makes you feel a bit more positive that they actually understand more...and you're surrounded by people who you don't need to discuss what's wrong because they know because they're in the same position as you. If I want to talk to somebody about a fear, or I'm upset, or I'm tired or sometimes you want to just chat, in a hospice immediately your nurse or whoever's around will come in and chat to you and they'll spend an hour or so with you. There's no nurse has got time to talk to you in hospital.

He wasn't always so sure about the hospice though as he recalled how he felt when first referred:

I felt, initially, that hospices were places to die...it takes a lot of getting used to that it's not like that at all.

Becky recalled how she had gone into this hospice the last time she had changed her combination therapy:

I was booked in for two weeks. I only stayed five days (laughs) because I found it incredibly depressing...people in there because they're ill. I felt I was put there under false pretences; I was taking up a bed that maybe somebody who was really ill could have used.

She went on to talk about hospices more generally:

I've always assumed for myself that when the time came I would actually be in a hospice...not realising that hospices have this narrow criteria. I think I would rather be somewhere like a hospice than a hospital, because of their expertise and it's more personal...that's all they deal with.

For Becky there was a thought about her condition and being treated differently in hospital because of this.

4.6 Other services

Some participants spoke about different groups they were involved in. Usually these groups were of a supportive nature for people in a similar situation to themselves. Sheila was involved with a group designed for people with breathing difficulties. She discussed an exercise they did whereby they produced a helpful guide for other people with breathing conditions that highlighted useful tips:

The pooling of ideas can often produce some good results, people's thoughts and ideas or what they feel about what they need...so often in this country it seems to me that decisions are taken without having any knowledge really of what's on the ground or... (What) the recipient really wants.

Sheila went on to make a point about the difference in services for people with impairments in different areas specifically about the lack of disabled parking in certain areas that makes life so much more difficult for you if you cannot walk far due to breathing difficulties. John discussed his involvement in a self-help group that helped him, but it also held a more salutary reminder for him:

There were about twenty people that were HIV positive and their partners or friends...and we talked about different things and it was very, it was sociable...and six years ago the nineteenth person died.

John also spoke of a similar issue to that which Sheila had raised. John made the point that consultation exercises need to lead to real improvements for people. He had been involved in one consultation:

Its one thing being listened to when you're expressing your views; it's quite another thing for them to be acted upon. You need to know that you haven't wasted your time. It was useful to us because it was a sounding board for us to say what was missing.

Chris's partner Clare spoke of receiving respite for Chris in a local nursing home that was intended to be regularly for two weeks with six weeks at home. The first time this was put in place there was unintended consequences however and he didn't continue with this arrangement:

He came out with bedsores, it was just a nightmare and...I wouldn't want my dog or cat to be in the situation that Chris was in, in there, I mean he wasn't communicated with in any way, he was just left.

In place of this respite social services were to provide a carer for two hours a week in order for Clare to get out for a short break. This was also problematic on occasions:

The other day when I said to them which of you is staying it was neither of them and it was the name of a girl that I'd never heard of let alone didn't know her, never set eyes on her. Well in every home you've got valuables and

private things...I would at least like to see the person who I'm leaving my husband with. I was expected to go...and come back...and not even see the person who has sat with my husband for two hours. And Chris gets very frightened and panicky with strangers.

Hazel spoke of a nursing home experience that was very different to that previously highlighted by Clare. Her experience was of a private Christian nursing home that offered, so called, 'holistic care'. As well as doctors and nurses they had other staff available, such as counsellors, physiotherapists and a chaplain. She tried to go there twice a year if she could. In order to have one or two week periods of care there Hazel would use her savings and sometimes be given money contributions by friends and family. This appeared to be the one place where Hazel felt understood, accepted and as if she was improving in some way:

I have improved very, very slightly each time I've been there. It's an absolute lifeline.

One aspect that made this experience a good one for her was the flexibility it offered:

I can ring the bell and somebody will come...I haven't got to worry about meals...I haven't got to think ...it's eight o' clock I've got to get up...I can have my breakfast and then an hour later I can have a wash...then an hour later I can get dressed. They respect the fact that if...I don't feel I can get out of bed at 9 o'clock they won't pressure me to do it.

Another important point for Hazel about what made this nursing home such a lifeline was to do with communication and valuing:

They have experience of ME. They accept me for what I am and how I am. They treat you like a whole person. It makes me feel that I am a whole person even though there's so much I can't do, I'm still me, there's still a lot to me.

For Jess, an issue that had been difficult was obtaining physiotherapy services:

Very hard to get physio for conditions like MS...usual comment is you're too tired for it...which is a good cop out. I got private physio...eventually from being in a wheelchair to being able to walk with sticks for 10-15 minutes.

4.7 Chapter conclusion

It is clear from this chapter that participants offered many examples about their needs and experiences in terms of a range of health and social care services. Across all services participants' accounts clearly highlighted expectations for genuine and sincere relationships with staff that they came into contact with. Attaining these expectations was variable with mixed accounts about all services and staff. Positive experiences were evident although detrimental influences on participants due to services or staff were also clearly evident.

Accounts about acute services highlighted issues about not being taken seriously in encounters with some hospital staff and for one participant an alleged incident that could be termed malpractice led to serious and enduring ill health. Lack of communication between hospital departments and brusque or arrogant attitudes were identified as being particularly unsatisfactory. Staff members who took an interest and engaged in effective communication with participants were highly valued. Restrictive and thoughtless hospital services were identified and contrasted with some accounts of hospital services that offered a high standard of support and treatment which were considered invaluable. At its worse hospital services could make participants feel as though a battle had to be fought in order to receive what was needed. At its best hospital services could foster positive experiences such as respect and control.

In primary care GPs were often discussed and the common perception was of GPs having very little time to spend with participants that sometimes translated into a perception that they did not care. There were examples counter to this, however, and this involved the GP being perceived as working with the participant in what could be described as a partnership relationship. Certain primary care staff members were singled out as effective and in these accounts aspects of the relationship with these individuals appeared to be important.

The social service homecare service received a great deal of consideration with participants often reporting a lack of understanding of their needs on the part of both the carers themselves and their managers. A lack of awareness of individual and variable needs was clearly evident. Relationships with individual carers were important but there were often unsatisfactory relationships and many accounts highlighted undesirable attitudes amongst some carers. There were exceptions however with some carers being respectful, helpful and aware of participants' individual needs. A particular social services run day centre was highly valued by those participants who attended.

It was only those participants with a cancer diagnosis who could comment on the hospice service as this was only accessible by service users with this diagnosis at the time the research took place. Participants were largely consistent in relaying accounts that highly commended the hospice. Despite the initial fear of the hospice highlighted in section 3.3 of the previous chapter, participants were unanimously reassured and satisfied with their experience of the hospice and its staff. Personal experience of attending the hospice day centre or inpatient unit appeared to be the basis for this reassurance and praise of the hospice. Participants identified evidence of respectful relationships with staff, effective management of disease orientated problems, skilled interventions and an unexpected opportunity for genuine social support. This support was importantly considered to be for participants' families as well as for themselves. Rather than a focus on dying, priorities in the hospice appeared to be focused upon living as fully as possible.

The abandonment of a lymphoedema service and a lack of management profile were the only unfavourable accounts. Palliative care nurses in the local hospital were also singled out as effective with these nurses seen as influential advocates for participants. There were similar positive accounts of a separate hospice out of the immediate geographical area for service users with an HIV+ diagnosis. Again issues about having individual needs acknowledged and catered for were seen as an important achievement here.

It is clear from this chapter that there are common issues for participants that run across services. Members of the SURAG have highlighted key issues that should be

taken forward by service providers as shown in section 5.12 of the discussion chapter. Attention to the accounts in this chapter highlights that these issues are in the areas of the relationships between service users and professionals, choice and voice.

Across all themes presented in both findings chapters it is clear that there are similarities and differences in experiences and needs between participants with cancer and participants with non-cancer conditions. Tables 4.2 and 4.3 below give a summary of these similarities and differences.

Table 4.2: Similarities in experiences and needs

Similarities between participants with cancer and non-cancer conditions	
1	The highlighting of emotional aspects of participants' experience of living with life limiting conditions was common across all conditions.
2	All participants highlighted that some relationships were affected negatively since diagnosis with their condition.
3	All participants struggled with maximising their independence, choice and control regarding personal issues but also with their ability to influence health and social care services and staff.
4	All participants experienced life differently and also struggled with a sense of being treated differently since diagnosis.
5	There were similarities in the need for diagnosis to be made, the impact diagnosis had on participants and on family and friends.
6	There were similarities on the range of losses, frustrations and restrictions participants felt were present in their lives.
7	All participants gave many accounts of services and shared many experiences of poor services or relationships with a variety of professionals. Effective

	relationships with professionals were of high importance to all participants.
8	All participants encountered the stigmatising effects of living with a life limiting condition to some degree.

Table 4.3: Differences in experiences and needs

Differences between participants with cancer and non-cancer conditions	
1	Participants with non-cancer conditions widely indicated that they felt unsupported and relayed their difficulties in getting their needs identified and acted upon. However participants with a cancer diagnosis who could access a hospice relayed far fewer concerns on this point.
2	Participants with non-cancer conditions were more likely to identify a struggle to obtain the services and support they felt they required compared to participants who had a cancer diagnosis.
3	Participants with cancer placed value on accessing a hospice and its day centre facility. Participants with non-cancer conditions were unable to access this resource.
4	Participants with non-cancer conditions identified a desire to support and be supported by others in a similar situation but this was mainly achieved only by participants with cancer who accessed a hospice day centre.
5	There is clear unmet need for participants with non-cancer conditions and clear service provision differences between participants with cancer and those with non-cancer conditions.
6	It was primarily participants with cancer who reported friends being embarrassed and not knowing what to say to them.

7	It was mainly participants with cancer who spoke about planning and arranging for their deaths and protecting or helping their families after they had died.
8	Participants with cancer had fears of dying allayed by their contact with and experience of care and support in a hospice.
9	It was mainly, but not solely, participants with cancer who initially saw their diagnosis as a death sentence.

Chapter 5 – Discussion

5.1 Introduction

The focus of this chapter is to reflect and to critique the main sections and major findings that comprise this thesis. Further to this data will be theorised, findings linked to previous research, the influence of the SURAG and the unique contribution of this research will be considered. This chapter is divided into several sections as shown in table 5.1 below.

Table 5.1: Discussion chapter sections

SECTION	TITLE
5.1	Introduction
5.2-5.9	Themes
5.10	Reflection on agreements and differences in data interpretation and findings generation
5.11	Service user involvement in the research process
5.12	The placement of this research within the field
5.13	Thesis conclusion

Initially, each of the eight themes that were presented in the findings chapters will briefly be discussed in turn. Here the themes will be considered and relevant research drawn on as appropriate. It should be noted that despite the themes being presented as discrete items there is much interconnection between themes within each participants' accounts. Two sections will then consider specific aspects of the research methodology. In coming to decisions about findings there were common agreements and some differences in interpretation of data between the Service User Research Advisory Group and myself. A discussion of these differences in interpretation takes place in section 5.10. In section 5.11 I consider the impact of the Service User Research Advisory Group and the value added by enabling a group of service users with life limiting conditions to collaborate on this research project.

This discussion takes place as this participatory working is unusual in palliative care research and therefore it is important to learn from the experience.

Next, a discussion will take place of the particular contribution of this research in comparison to other research within the same or similar fields (section 5.12). Here a comparison to other research with service users' opinions of palliative care needs and provision as well as comparison to a wider pool of service user research and their findings will also take place.

The aim of this research was to:

- Gain accounts from people who, potentially, have palliative care needs and to highlight a range of experiences of their lives and conditions.
- Establish what service user needs are in terms of support and care services.
- Establish the influence of involving service users in palliative care research, whether there can be a contribution and if so what this may be.
- Highlight any social or environmental factors that may shape or influence experiences of living with a life limiting condition, including whether the social model of disability can contribute anything to palliative care research.

The focus has been on people with life limiting conditions and it is pertinent to remember that to some degree, participants were self-identifying. Research information was given to interested people that clearly described the aim and remit of the research and discussed various conditions potential to be considered as life limiting. Therefore participants acknowledged this life limiting classification for themselves. Professional discourse may resist such a classification for some of the conditions presented in this thesis but it is interesting to note that some people with conditions such as Multiple Sclerosis, Chronic Obstructive Pulmonary Disease and Myalgic Encephalomyelitis may choose to define themselves otherwise. This research has enabled accounts to be prioritised from participants' own lives and experiences on

their own terms. Gaining accounts from people with both malignant and non-malignant conditions was hoped to highlight differences and similarities between experiences of these conditions. Reflection on these aims and concluding remarks will take place in section 5.13.

This qualitative research, utilising a critical and participatory methodology, has facilitated a great deal of in-depth information about experiences and views of participants. With the help of the Service User Research Advisory Group (SURAG) the thesis is rich with the direct experience and views of people who live with life limiting conditions. The SURAG has enabled a knowledge to be generated that originates from people with life limiting conditions themselves.

It may be easy to assume that the first four themes in findings chapter 3 (diagnosis, fear, anger/frustration, and grief) are primarily cognitive coping responses or strategies and that they are strategies to protect individuals against the reality of facing their own mortality or to assist them in adapting, adjusting, accepting, and/or in some other way to accommodate their particular changed position in life. There may indeed be aspects from participant's accounts that could be highlighted in this way. However this focus in previous research on coping strategies has been suggested to be an individualistic interpretation allied to the medical model's attempt to 'classify patients according to their emotional reactions to cancer' (Mathieson & Stam, 1995).

Instead of a specific focus on individuals 'managing' their situation by way of 'internal cognitive control', so called personal strategies, the approach taken here has enabled a focus upon the social context that may perpetuate so called 'disabling environments' to also be brought into view (Campbell & Oliver, 1996:20). The research here provides a clear insight into the everyday lives and experiences of participants with life limiting conditions and the negotiation that participants are required to make both for themselves and in response to others around them. These four themes, as well as the others, need to be understood in terms of the social impact that can occur on top of people's existing impairments. The social model of disability, as described in chapters 1 and 2, is central to the understandings presented in this thesis. This theoretical position has been one of the positions that has guided my understanding and also the SURAG members' understanding of the data.

Data were collected at one particular moment in time. Prospective data were not collected which may account for the fact that the themes are more orientated to the impact and response to participants' conditions rather than how they adapted over time. It is also interesting to consider any links between participants' accounts and their biographies. In what ways might their accounts of living with their particular condition be affected by their particular situations? (Please see annex E for a description of participant biographies).

5.1.1 Participants' social context in relation to their accounts in data collection

Participants' accounts that were given primacy in the preceding findings chapters can, here at the outset of this discussion chapter, be usefully considered in light of their biographies. In comparing participant biographies with their accounts in the findings chapters, some connections can be made. This relationship between participants' biographies or situations and their accounts of their experiences is a complex issue. The intention in this short section though is to offer some indication and acknowledgement of how participants' previous experiences may have affected their contributions during data collection. Some examples are presented here to illustrate this linkage.

Firstly, Fiona described her readiness to die in both section 3.2 of the findings chapter (Diagnosis) and in section 3.5 (Grief). From her biography we see that she had been diagnosed with bladder cancer for three years at the time of her interview and in the year immediately prior to her interview she had been diagnosed as having secondaries. She also lived alone and described how both her children had died and that she only had one family member remaining alive. This may also shed some light on her comments in section 3.7 (Difference/Individuality) when she spoke about life hitting her hard and how when this occurred life was experienced very differently.

Simon's fatalistic and pragmatic attitude to his cancer and situation as outlined in his biography helps to make sense of his comments in section 3.8 (Independent/Dependent) when he spoke of his impatience with others who may express sympathy to him and his belief in looking after himself.

In her biography we see that Jess, who was diagnosed with MS, had requested to have a colostomy and an ileostomy formed during the year prior to her interview so that she didn't have to wait for carers to visit in order to go to the toilet. In the theme of 'Services' in chapter 4, Jess offers vivid accounts of her experiences and feelings about home care. We hear of her poor treatment by some carers and again in section 3.8 (Independent/Dependent) we hear accounts of carers' intolerance and impatience with her. This may go some way to explain her rationale for requesting that a colostomy and an ileostomy be formed. She was now able to be a little more independent and self-reliant.

We see in Hazel's biography that she had taken the initiative and contacted me about the research and getting involved in it. She clearly thought that she and others with ME could have palliative care needs. This seizing the initiative had also manifested itself when Hazel was at the stage of trying to obtain a diagnosis as we can see from section 3.2 (Diagnosis). Hazel offers her account of this process and her need to represent herself and to push for the identification of the correct diagnosis, which went against medical opinion at the time.

The final example I will draw on here to illustrate the connection between participant biographies and accounts given at interview is that of Chris and his partner and unpaid carer Clare. From Chris's biography we can see that Clare identified her motivation for the involvement of her and Chris's experience in the research as a way to let others know what it is like to be in their situation. Perhaps what Clare was attempting to counter was the sort of attitudes she identified in section 3.4 (Anger/Frustration). Here we see how the attitudes of others made her feel as if they were both 'written off'. Also in chapter 4 (Services), it is highlighted how someone who is very dependent and vulnerable can easily be mistreated in both hospital and nursing home environments.

Links or connections between participants' lives, the contexts in which they live, and their accounts of their experiences in this research are quite evident then. It is accepted here that people's lives, including their experience of having a life limiting condition, interconnect with and influence their understandings of their situations. However, whilst this personal perspective has been highlighted in this research, what

is also clear is how personal situations are influenced by the social world around people, a social world that in this research clearly has influence upon people and their lives. Participants' earlier biographies and personal values will have influenced their accounts of living with life limiting conditions but importantly it should be acknowledged that social forces will also have influence upon participants' lives.

We will now move to the discussion of each of the eight themes in turn. For an illustrative representation of the themes please refer to figure 3.1 in chapter three.

5.2 Diagnosis

We have seen that the period around diagnosis of participants' conditions was very traumatic. We heard how shocked participants were by the diagnosis of their conditions, how unexpected and suddenly this happened. For some there was a real struggle to obtain a diagnosis but gaining diagnosis was seen as important in order to know what they were facing and in order to start appropriate treatment. This delay and difficulty in obtaining a diagnosis has previously been identified in research conducted by the National Cancer Alliance (1998:9) with people who have a cancer diagnosis for example. For people with multiple sclerosis similar difficulties have also been highlighted (Small & Rhodes, 2000:98), whilst in a study with people who had rheumatoid arthritis there were mixed feelings of wanting confirmation of diagnosis but also of a realistic acceptance that little could be achieved medically for their condition (Bury, 1982).

Diagnosis in the research for this thesis was also seen as a means of legitimising the change participants were experiencing and which was all too clear for family and friends to observe. This has similarly been highlighted in ME/CFS research (Ware & Kleinman, 1992). We saw how early in participants particular conditions a drastic effect was felt in their bodies. Often a total change in functioning ensued and sometimes significant decisions were required in a short space of time. Participants struggled with whom to tell about their condition and how much information to give; managing others' reactions to their diagnosis; making decisions about continuing or stopping paid employment; obtaining adequate and relevant information about the

condition; and facing fears about debilitation and death. Gaining diagnosis was certainly perceived as life changing. Not only in terms of how others now responded and acted towards them but also in terms of participants' own perceptions of many aspects of their lives. The process of gaining a diagnosis has been described as representing a 'major status passage' (Small & Rhodes, 2000:137) in which how the diagnosis is conveyed has an important impact upon individuals' perception of their condition and their capacity to maintain some sense of control over it. The research in this thesis also highlighted emotional responses to diagnosis in which participant's relayed how they went 'icy-cold' when given their diagnosis. Fearing mortality and desiring life and living were clear responses.

5.3 Fear

Within the theme of fear we heard about uncertainty and things that remain unknown. Participants spoke about trying to grasp what was happening to them and what the future may hold. Fears were apparent initially following diagnosis that reflected participants' thoughts about dying, perhaps imminently. We also heard about participants adapting over a period of time to thoughts of dying and of their fears changing. The reducing fear following referral to a hospice is an example of this and may be considered as a secondary role of hospices. Some participants gained some reassurance when they saw others who were very ill and noted how it was for them, how they were cared for. We also heard of fear encountered on a daily basis. A quite pragmatic fear about requiring to plan for death, plan for greater dependency, of having to give up or renegotiate independence, and of having to keep fear to oneself.

For those participants who were referred to a hospice there were enhanced fears about the nearness of death as the hospice was associated with death. This point was also identified in other research with people with cancer who accessed hospices (Seymour et al, 2003). Indeed Field (1996) has highlighted that cancer is particularly a 'feared death' because diagnosis is often unexpected, can occur at any age, and once diagnosed the terminal phase is predictable and associated with pain. McNamara (2001:36) also stresses that 'fear...is an emotion common to the cancer patient and at some point they inevitably realise the true root of this fear'. The root of this fear is

suggested to be the knowledge of approaching death. Some of Field's (1996) claims may well be challenged nearly ten years on as pain control has advanced and treatment options have improved. This research though has illustrated clearly that people with conditions other than cancer also face many similar fears (See section 3.3). Establishing this from a range of conditions is unusual within the life limiting and palliative care literature.

Participants with Chronic Obstructive Pulmonary Disease in Barnett's (2005) research also raised the issue of fear in terms of their breathlessness and the fear of dying during a panic attack. The identification of fear in this context though is mainly focused on feelings of anxiety and panic to do with the experience of breathlessness. In the research presented here fear was far more wide ranging touching on many different areas including physical, social and emotional areas. It was not restricted to individual fears but wider influences were apparent. John for example feared contact with others: acknowledged his partners' fear and feared for an uncertain future. Delia and Sheila both had fears for the future also and speculated how their conditions would impact on their relations with others. Simon feared others' perception of him as 'contagious'. A dimension of fear associated with being physically and emotionally out of control was evident in this research.

5.4 Anger/Frustration

Anger and frustration as a theme connects to feelings of a lack of control, and participants' frustrations about the care they received. There was also a sense of humiliation raised by some participants. We heard of participants' sense of powerlessness in the face of their conditions and with the care and support they received. On the whole there was a resignation about this position but this was often tempered with an urge and determination to maintain independence and dignity. Accounts gave a great sense of the 'everydayness' of participants' conditions, which included the repetitive, day in day out, demoralising, frustrating, and unchanging position participants found themselves in. There was also a sense of controlling this negativity from some participants with a sort of pragmatic shrug. For some there was anger about the unrelenting and all too visible progression of their condition as well as

anger and frustration about the enforced changes both physically and socially. Deterioration was by stages, but this brought great changes to participants' lives. These changes had a profound impact on participants and their self-image.

This theme has also raised the issue of anger focused on some participants' perceived lack of a future, a theft of dreams and fantasies. The clear frailty and impermanence of life, as well as the enforced difference to the world of the well was highlighted by this theme. Similarities can be seen here with the so called 'biographical disruption' proposed by Bury (1982) whereby it is suggested that individuals deal with the impact of illness by adjusting or giving up their previously held visions of their future. Previous work has also identified this process in terms of a biographical accommodation in which people with a chronic illness not only have an awareness of physical impact but also can move to control and balance their lives despite illness (Corbin & Strauss, 1987:250). Charmaz (1997:76) has proposed that as the person with a chronic condition becomes more and more immersed in the condition then 'they must *reconstruct* their lives upon illness' (original emphasis). Anger and frustration in this research had a wider focus however beyond the internal experience. There was anger about harmful treatment, the isolation of illness and treatment and an acute anger at the altered perception of one self that others hold.

Other research (Barnett, 2005), into the experience of moderate to severe COPD, has raised the point of how frustrating it is to live with this condition. This reference is a passing one however included under a theme entitled 'emotional trauma of coping with COPD'. There is a substantial difference in weighting about this part of living with a life limiting condition with the research here delving into some depth about anger and frustration. The research presented in this thesis offers a far greater emphasis on this area and is a particular contribution in the field. Ryan (1996) identified frustration over activity restrictions and dependency on others as a theme in research with people who had rheumatoid arthritis. Research with service users who had cardiac (heart) failure also identified the daily frustrations of living with a progressive condition (Murray et al, 2002). One participant for example commented "You can't do what you did before, things you took for granted are now an impossible dream" (Murray et al, 2002). There are aspects from the research findings presented in this thesis that resonate with this point, however experiences like frustration in

Murray et al's (2002) research are, as with Barnett's (2005), somewhat hidden under the broad theme 'living with illness'.

This veiling of anger and frustration is also apparent in research that focused on people with 'terminal' cancer and that focused on what these people considered as areas of priority in their lives (Carter et al, 2004). The frustration experienced of lacking energy to complete everyday activities is stated but this 'personal/intrinsic factors' theme is a very small part of the presented findings (Carter et al, 2004). Conversely personal impacts of living with a life limiting condition are prioritised highly in the research presented here. This may be in some part due to the service user involvement in the research and this is a particularly unusual focus in the literature.

5.5 Grief

Participants gave accounts of the many losses they had experienced and the deep sorrowfulness that many felt. Participants also spoke of the physical changes their particular conditions brought, namely fatigue, and the loss of energy they experienced to continue with life in their usual way. The continued physical effort and struggle clearly brought with it many feelings such as regret, sadness, powerlessness, and hopelessness. For many these feelings were not purely in response to physical changes but were also in response to social changes such as the change in relationships with some friends and family members.

Participants also spoke about grappling with guilt wondering if having their condition was their fault, being puzzled about their continuing ill health and also struggling to understand their new situation. Regret was experienced at the loss of their previous life but this was tempered by the perception of a need to adapt and to move with their newfound situation. Unusually in this field there were indications of positive aspects being strived for. There was though always a temptation present to give up due to the daily effort required to adjust. This situation was likened to being in prison with a lifetime sentence enforced. Grief was also felt in the realms of personal friendships that had changed in light of the participant's diagnosis. Loss was not only experienced in the physical domain of functional ability but in social and emotional domains also.

The presence of social and emotional support and the ability to express emotion in a supportive environment has been suggested to be related to greater coping in people with a cancer diagnosis (Zakowski et al, 2003). The impact of losing social contact and emotional support is therefore significant. The external impact of conditions was clearly relayed in this research with Hazel, John and Becky for example describing the effect of the loss of employment and Sylvia and Clare clearly relaying the impact of their conditions on relationships with people close to them.

In a study comparing experiences of patients with lung cancer and patients with Chronic Obstructive Pulmonary Disease (COPD) the occurrence of depression was high amongst the sample with COPD (Gore et al, 2000). This study was very different to the research presented in this thesis and sought to establish, through the use of psychological and physiological scales and measures, the extent of problems experienced by patients. Whilst not producing first hand accounts the authors claim to demonstrate the unmet need for patients with COPD generally and highlighted the high emotional impact of this condition.

Other research, with people with heart failure, also raised issues about the functional or physical losses they had experienced due to their heart failure. This research also identified how participants had experienced a loss of friends, and loss of a future (Horne & Payne, 2004). Further research with people who had advanced COPD also highlighted loss as a central theme (Seamark et al, 2004). There are striking similarities between some of the accounts in this research and the research described in this thesis. For example Seamark et al (2004) quotes a participant, Donald, as saying "It hits you and when it hits you it do hit you, believe me that's the hard task of it" in relation to the losses that COPD brings. In the research in this thesis we heard an account from Sheila, also a person with COPD, about the impact of her condition on her life "You suddenly see your life, parts of your life being cut...It's almost like being put in a prison only it's not obviously. I suppose restrictions, restriction I suppose is the best way to describe it, it's very restricting". An idea of the impact and day-in day-out consequence of this condition is highlighted in both of these accounts. In the research in this thesis such losses were not restricted to people with COPD. There were many similar accounts relayed by participants with all the different

conditions included. This commonality of experience across different conditions is rarely explored in the literature.

5.6 Relationships

Changes in relationships that participants experienced formed a theme as accounts described a wide range of responses to participants' diagnosis and ongoing lives with their conditions. Participants told accounts of how, as restrictions were enforced upon them by their condition, some friends dropped away and this concurs with Barnes and Mercers (in Barnes & Mercer, 1996:14) claim that chronic illness not only affects daily living but social relationships as well. Some responses from friends were extreme and unexpected. Some participants felt they were being seen for their condition and their impairments rather than for themselves and wished they could be accepted for the person they are. These changes in relationships led to a degree of social withdrawal for many participants. The changes in relationships that may be the result of assumptions and negative labelling might be said to be stigmatising and Field (in Field & Taylor, 1997:139) highlights how 'people with highly visible impairments or disabilities are more likely to experience stigmatisation'. This stigmatisation might have the effect of influencing both a person's self-identity and their interactions with others. This has been illustrated in a model by Field (in Field & Taylor, 1997:141) and represented here in figure 5.1 below.

This model of stigmatisation shows how experiences of impairment can be influenced by the social interactions people have. For the participants in the research under question in this thesis we have seen that there has been significant alteration in social interactions that participants perceived as attributable to their specific conditions. Participants often saw this changing social status to be a result of their changing physical status rather than on wider societal influences of negative labelling. Participants gave accounts of people avoiding them and generally surmised this was due to embarrassment or awkwardness about what to say, as supported by Bury (1982); however there were some accounts linking this avoidance to negative attitudes. These issues may have been difficult to identify though in this research with its focus on individual perceptions of people with life limiting conditions. Greater

insights about negative attitudes or labelling would arise in research with a focus on friends and families reactions to life limiting conditions.

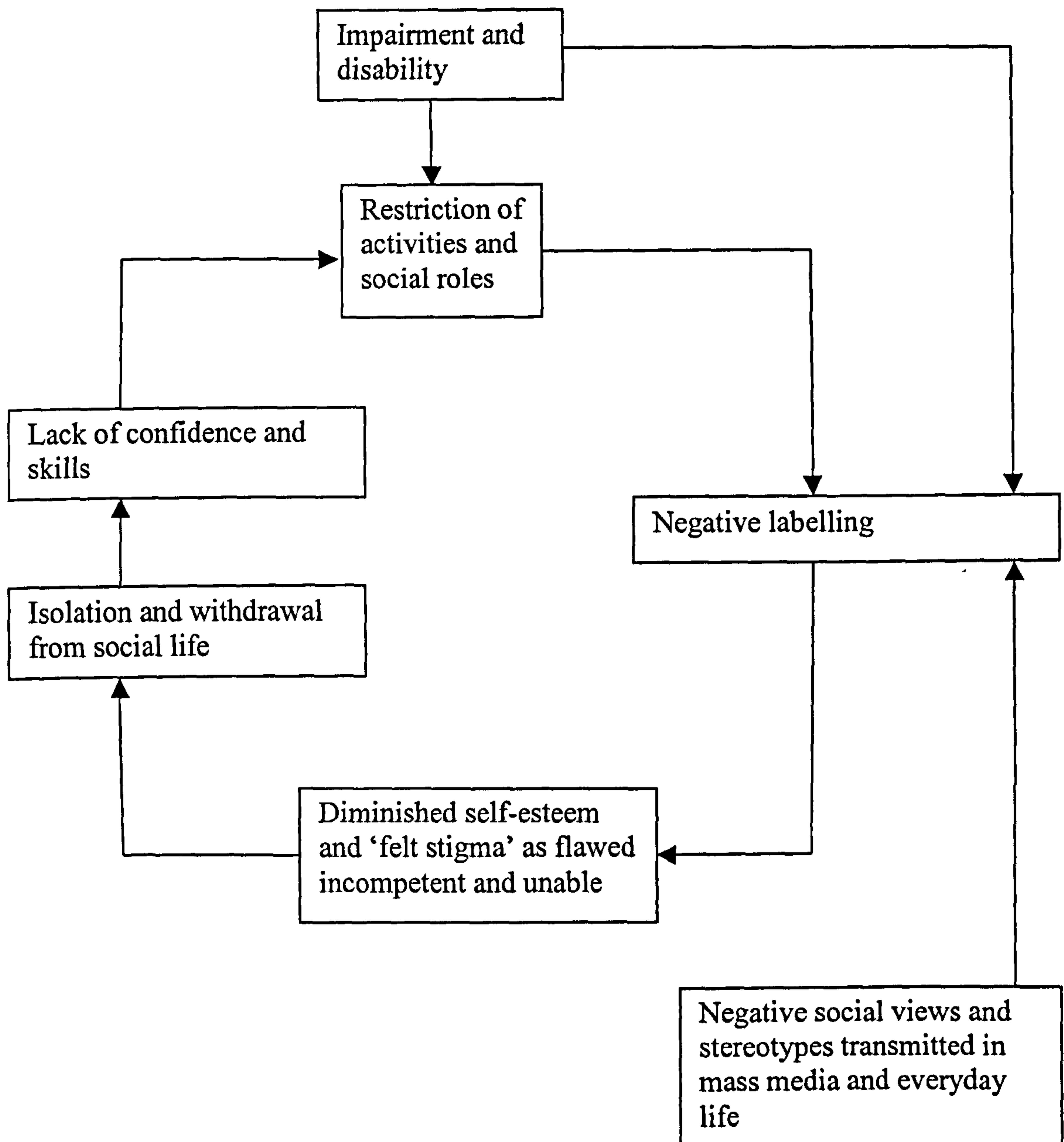


Figure 5.1: Feedback between stigmatisation, self-esteem and participation in social activities (Field in Field & Taylor, 1997:141)

There are other aspects that may also be at play in this relationship dynamic that could affect interactions with people who are considered to be dying. Elias (1985:10) states, “The sight of a dying person shakes the defensive fantasies that people are apt to build like a wall against the idea of their own death”. In some way then the reminder of

ones' own mortality may have an affect on a persons' withdrawal from a relationship with a person who is visibly deteriorating and/or dying. The same author adds:

Death is one of the great bio-social dangers in human life. ...death...is pushed more and more behind the scenes of social life...For the dying themselves this means that they too are pushed behind the scenes, are isolated.

(Elias, 1985:12)

This isolation has been evident in the current study with participants referring to a withdrawal of some friends, of being made to feel different, of keeping their fears and feelings to themselves, and of feeling invisible. As Mel said "It is a lonely walk". Hopkinson and Hallett (2001) reflect this loneliness and sense of distance from people that participants previously knew, in their research with people with a cancer diagnosis. Other research has reported similar issues. Exley's (1998) focus was on the management and negotiation of self-identity in people who were dying. Participants in this research, who all had advanced cancer diagnoses, reported how some relationships changed completely, participants "spoke of acquaintances avoiding contact with them in the street, and friends and family no longer visiting" (Exley, 1998:169). Other areas in Exley's (1998) research are supported by the current study. There were issues of participants perceiving that since diagnosis and relationships changing people saw them as 'different' (Exley, 1998:171), family members being overbearing (Exley, 1998:172), family and friends being uncomfortable in talking to participants because of their diagnosis (Exley, 1998:173), and of participants feeling like 'outsiders' due to how people responded to them (Exley, 1998:181).

It is interesting that although Exley's work has people with a cancer diagnosis as its focus, there are many similarities in the findings with the research presented in this thesis that includes accounts from participants with a broad range of conditions (these similarities with other non-cancer conditions was acknowledged by Exley, 1998:216). Exley's stated aim, though concerned with individual experience, was specifically to explore individuals' identity changes and challenges to identity when faced with a life limiting condition. The discussion in her thesis draws on participants' accounts that support the understandings of dying people being devalued and marginalized. In terms

of self identity the claim is that an awareness of dying is a negative challenge to self-identity and that 'emotional work' was undertaken in order to manage the feelings and emotions of both the participants themselves and others. Later it is explained that this was in order to reassert participants' more valued roles and to manage the disruption to their lives (Exley, 1999; Exley & Letherby, 2001).

In the research presented here currently there are indications of participants managing the presentation of themselves to others in order to facilitate a positive reaction and to ensure ongoing contact. Some participants did consider that it was possible to distance some friends and family from themselves and hence kept their emotions contained. Contrary to Exley's research though, the research under discussion here had a wider remit and whilst gaining personal insights it also gained accounts of participants' perceptions of external effects upon them. The impact of services upon them and the effect other people had upon them was considered in some detail by participants.

Other research within hospices and with people with a cancer diagnosis also highlighted the loss of relationships encountered by participants noting "such withdrawal stemmed partly from the stigmatising effects of illness, coupled with the knowledge of family and friends that the patient was going to die" (Lawton, 2000:148).

Participants in this research suggested that some friends had false assumptions about them and feared becoming carers or just did not know what to say or how to act in their presence. Despite, or because of this, participants identified the importance of maintaining relationships and often adapted what they said about their conditions in order to achieve this. An issue about negotiation of relationships with friends and family was highlighted. This negotiation needed to occur on a daily basis and was dependant on how participants were feeling on a particular day. On bad days contact or planned activities needed to be postponed. This though, caused some participants to consider whether they were being perceived as a fraud and they were aware of this changed one-sided non-reciprocal relationship in which very often they could not return favours. Bury's (1982) much earlier work identified this specific point.

A positioning of self was also referred to whereby participants presented themselves in particular ways. This required alteration depending upon who participants were with. This implies some sort of impression management, a form of control of image to the outside world (Goffman, 1959). Associated to this is a form of personal withdrawal whereby participants protected a secret self, a self that was not shared with others and this seems to suggest a way of holding onto a degree of power in relationships or of a decision to refrain from sharing distressing issues with the related risk of being further isolated socially. This may in part be due to participants' perception that some friends and family were embarrassed and found it difficult to talk with them about their condition.

Many participants in this research spoke about difficulties with friends and families who for various reasons became less close and supportive following their diagnosis. Interestingly though it was only participants with a cancer diagnosis who actually commented on relationships with friends changing because these friends were embarrassed. Ralph pointed out that friends did not know what to talk about, Val baldly stated that people are 'just embarrassed', and Greg recalled how people had hidden from him. It has been suggested that this embarrassment is not necessarily because death is a taboo subject but that 'death talk' does not seem appropriate in polite conversation (Kellehear, 1984; Walter, 1991).

Participants' relayed a sense of different lives being carried out in parallel to each other in the research presented here. As Chris's partner and carer Clare said, "They've got their lives to carry on in..." and implicit in this seems to be both a regretted acceptance of this situation and a perception of marginalisation. The importance and value of fostering contact with others in similar situations was also present in many accounts. This in part seemed motivated by awareness that people without the condition, or any experience of it, were embarrassed or fearful and were likely to withdraw.

A study about women's experiences of Multiple Sclerosis (Reynolds & Prior, 2003) also raised similar issues about challenges to relationships. The research describes some friends and family members as 'not being able to cope with the MS' and of the continual effort required to resist 'turning partners and children into caregivers'

(Reynolds & Prior, 2003). This complex negotiation of relationships was clearly described in the research presented in this thesis with participants having their own unique ways through this difficult domain. We have seen how Hazel actually enrolled the services of friends and family when needed but we also saw how Jess was very careful not to ask or expect help from family and friends. Hazel's attitude may be due to the extreme reaction amongst people around her at the time of her first being unwell and obtaining a diagnosis. There may be some indication here that personal attitudes are fluid and are shaped by both personal values and differing reactions of others in a person's social network.

5.7 Difference/Individuality

Within the theme of difference/individuality we saw how participants identified a sense of being seen and treated as different since diagnosis of their particular condition whilst they strived to maintain their own individuality. Invisible impairments and impairments that were variable in nature could cause difficulty in enabling others to acknowledge the condition and the issues this brought. A perception of possessing a discreditable condition was evident for some participants. Many participants needed to accept care and support from health and/or social care staff but participants still endeavoured to be self-governing and to retain their self-esteem. We heard how participants' felt different but realised they were basically the same person they had always been. Having their particular condition led them to develop new perspectives on life and their problems; life was often seen and lived very differently.

Participants described a balancing act involving the control of information that shaped how people perceived them. Some participants controlled who to tell about their condition or how much to tell. Others framed their responses to people based on decisions about how much they wanted to divulge or on how much they thought people could understand and empathise. The notion of balance was also noticeable in participants' sense of personal control. Occupying a flexible and pragmatic approach to life and life's problems ameliorated feelings of being out of control for some participants. Relearning and adapting to a new situation with their particular condition

was present for some participants and it was also clear that a positive sense of themselves and of the world around them existed.

Stigma has been described as a relationship between attributes and stereotypes, which is used to discredit an individual (Goffman, 1963:12). Whilst this work is very old and the language used inflammatory and disablist in contemporary terms it remains of use in relation to the work in this thesis. For example, several participants in this research gave accounts that indicate the presence of stigma-like issues. Becky for example described how people did not understand her and very quickly made judgements about her in light of her HIV+ diagnosis. It has been suggested that HIV+/AIDS is a particularly stigmatising condition (Alonzo & Reynolds, 1995). However it was not only the participants with HIV+ who had this experience. Jess for example found that since diagnosis with MS people tended to have already made their minds up about her based on their understanding of this diagnosis. She felt that people were likely to say things like 'oh you've got MS so I'll treat you like that'.

This difference making that may be caused by a stigmatising process has been considered to be dealt with by narrative work with people who had a cancer diagnosis (Mathieson & Stam, 1995). These authors suggest 'that patients begin to feel like different persons as a result of the early signals of threat to identity: body cues, relationships under stress, and encounters with medical institutions' (Mathieson & Stam, 1995). Here the discussion is about the 'renegotiation of identity' and of a post-diagnosis 'revised narrative'. The assumption here appears to be upon stressing the changes, or the differences, individuals face and the work required within individuals to adapt to this new and different position. This identity work has a focus on internal processes but is also influenced by social processes. What has been emphasised in the research in this thesis however is the impact stigmatisation has on the participants. Stigmatisation, utilising the theoretical approach of the social model of disability, is seen as an external disabling entity and as a problem of and for society rather than simply for the individual with a life limiting condition.

Despite some participants raising issues that can be seen to be the effect of stigmatising actions, participants also spoke clearly about promoting their individuality. Jess again spoke of an exhausting 'battle' with these negative

perceptions and of consciously holding on to who she is. Simon spoke of people having to take him as they find him and Sheila also spoke of being strong and not dwelling on what might have been. The tone here is of participants attempting to exert their individuality.

5.8 Independent/Dependent

The theme of independent/dependent conveys participants' efforts to maintain independence despite increasing levels of dependence on others and on services. This theme is a central one in this research and its significance extends across all themes. Participants relayed their attempts to counter paternalistic carers and to convey the specifics of their condition and needs. We saw a tension here with participants needing to accept care and support but also needing to have some control and to retain decision-making powers both on a personal level and on a wider level. Independence was often a challenge to achieve due to participants' impairments and the restrictions that followed, but independence could be judged in small everyday achievements that participants developed as they adjusted to their changing conditions.

There was a management of dependence in which participants showed resilience to hold onto whatever independence they could despite challenging physical demands and unhelpful systems and values which made it difficult to have a say and influence things. In research with people with a cancer diagnosis Hopkinson & Hallett (2001) identified that 'many (participants) spoke of how their illness prevented them continuing with activities they enjoyed or considered of value, which had damaged their sense of self-worth'. This prevention of undertaking activities 'considered of value' might be seen in terms of a threat to independence. Wollin et al (2006) highlighted the devastation loss of independence and the need to rely on others brought to people with multiple sclerosis.

It is important here to highlight that there are different understandings of independence though. A conventional understanding concerns individuals being independent in everyday activities i.e. being able to care for one self, to cook for one self, to be self-sufficient and to not require assistance from others. An alternative

understanding concerns the attainment of the right to be free of the influence and control of others. Whilst a person may require assistance or support in order to fulfil tasks of daily living as mentioned above, this critical understanding of independence prioritises the right for people to have the support available they require to maintain their independence, to control their lives and the support they need to accomplish this. This alternative understanding and defining of independence has grown from resistance to professional-client relationships that can be dependency-creating (Oliver, 1990:90).

For participants in this research we have seen how gaining the assistance and support required was not straightforward. Many participants described how their conditions affected them and gave accounts of their struggles to gain the assistance they required. This was most marked in participants who had non-cancer conditions but other issues around attaining independent living were present for all participants regardless of diagnosis. This is concerned with the reactions of and relationships with others. To set the context for this discussion it is necessary to draw on some work by disabled writers regarding independence and disabling effects of impairment.

The independent living movement in Britain has its roots in disabled people's attempts to leave residential care (Morris, 1993:17). The history and development of a 'social movement' of disabled people has been explored in the literature review, chapter 1, and work on principles of independence has stemmed from this movement. Independent Living is a philosophy and a movement of disabled people who work for self-determination, equal opportunities and self-respect. Four assumptions behind this philosophy have been identified:

- That all human life is of value
- That anyone, whatever their impairment, is capable of exerting choices
- That people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives
- That disabled people have the right to participate fully in society

(Morris, 1993:21)

Independent living does not mean that disabled people necessarily want to do everything for themselves nor that they do not need other people. To receive assistance or support in tasks of daily living does not equate with dependence rather, 'if a person who needs such help maintains control over how the help is provided then they retain their independence and their responsibility for themselves' (Keith & Morris, in Morris, 1996:94). Independent Living concerns accessing the support to live on as equal terms as possible with non-disabled people. Conceptually, it is important to be clear that the term independent living is concerned with having appropriate support and assistance rather than the ability to do everything for one self. The concept is particularly helpful when regarding people with life limiting conditions who may be able to lead as independent a life as possible which will be likely to include the support and assistance from others, whether paid or unpaid.

The difference between impairment and disability was outlined in section 1.5 but a common perception of impairment is one that equates with the inability to do things for one self, which then leads to the assumption of dependence. The alternative understanding of independence counters this assumption and places emphasis on control and choice maximising independence. Control over one's own life and the personal assistance or support that one may require is what is suggested to promote independence. Work conducted on codes of conduct and practice for social care staff highlights this very point but shows that service users have a common experience of having control taken away from them and therefore being put in dependent situations (Shaping Our Lives, 2001). As one way to take the philosophy of independent living forward and to bring practical applications into reality, Centres for Independent Living (alternatively known as integrated or inclusive centres) have been developed over the last 20 years or so. One such centre states that it 'exists to apply disabled people's own ideas and experience to develop peer support systems and to influence public services and policies' (Gibbs, 1999). Campaigning, support, and promoting independence on the terms discussed above are the general aims of these centres. It is important to note that in a recent consultation about what a wide range of service users wanted from social care, it was not only disabled people who spoke in terms of maximising independence but a range of different groups (Beresford et al, 2005:24).

These priorities for independent living put forward by service users themselves is receiving attention from government with the green paper 'Independence, Well-being, and Choice' which identified that people want to maximise the control they have over the way social care supports their needs and to support people to live as independently as possible (DH, 2005b). Responses have been welcomingly cautious amongst stakeholders however with fears of under resourcing and enforced reliance on informal carers. Issues of control and choice for users of health and social care services have now been given a high profile in the white paper that ensued from the consultation (DH, 2006b).

This perspective on independence is important in the discussion of the findings in this thesis. Whilst participants in this research gave accounts of their limitations due to physical changes from their particular condition they also very clearly relayed the limitations and hurdles placed in their way that denied them independence, or to be more explicit, independent living. These structural limitations might be seen in terms of poor or unresponsive service provision for example.

5.9 Services

Participants gave many accounts of their experiences and thoughts about the services they received (or felt they needed but did not receive) from different providers of health and social care. There were many examples of good practice from health and social care staff with participants valuing respectful and helpful staff. We also heard examples of effective and beneficial services. Unfortunately participants also relayed many more accounts from their experience of health and social care that left a lot to be desired.

Within the acute hospital setting we heard about staff that were dismissive, disinterested and unhelpful. We also heard about services within the hospital that were difficult to access, dirty, and which failed to communicate adequately with other services or departments about individuals. At times getting needs met felt like a battle for some participants in hospital. In primary care (care provided in the community) we heard accounts of professionals who were unhelpful, made participants feel as if

they were being a nuisance, did not listen, and who did not communicate effectively. Participants found social care home care services to be inflexible, impersonal and unreliable in terms of the timings of visits. Accessing new equipment and financial reviews were also identified as difficult areas.

Hospice care brought much fear with it in the early stages, although this was quickly allayed following referral and discussion or attendance at the hospice. Within the day hospice, participants found that talk of cancer was rare but this was not necessarily considered a negative thing. Contrary to this though, Greg reported feeling that he could talk openly about his situation. It might be that having permission to be open is sufficient and that getting on with living was given greater emphasis. The withdrawal of a lymphoedema service at the hospice was regretted. On the whole though, hospice care and support were highly praised and valued by the participants in receipt of it, particularly in terms of day care provision. There was a sense of commonality felt in which the sentiment “all in the same boat” was highlighted. We have seen that several participants who attended the hospice day centre made this comment in chapter 4, services.

Research specifically focused on a hospice day care service also highlighted this view, with a participant making the same specific point, “I think it’s the perfect place here because we’re all in the same boat” (Hopkinson & Hallett, 2001). This appears to be directly linked to feeling less alone and to being able to be understood by others when in everyday life some distance between one’s personal experience and the experience of others exists. There is also commonality in the research presented in this thesis and Hopkinson & Hallett’s (2001) research that highlights positive factors of hospice day care provision such as feeling welcomed, accepted, given time, and of a perception that staff were genuinely concerned about the people attending. Other research has similarly identified positive views of hospice day care (Seymour et al, 2003). Accounts from the research presented in this thesis indicate that the hospice facilitates opportunities for genuine informal social support.

It is important to recognise the difference in accounts between participants who had access to palliative care services at a local hospice and those participants unable to access these services. The hospice offered services to people with cancer and motor

neurone disease only, at the time of this research. On the whole, hospice provision was highly regarded with the day centre having very favourable accounts relayed about it. Generally, participants in this research with cancer and who accessed the hospice relayed confidence in the care and support available there, a trust in their ability to contact a named person with any problems, satisfaction with relationships with staff they came into contact with, and reassurance that their family would be supported following their death. They also had experienced appropriate treatment for physical symptoms, which led to these participants feeling that they would have a comfortable and peaceful death within the hospice.

Alternatively, participants with other non-cancer conditions who could not access the hospice and its services but who utilised other services relayed accounts depicting problems in many areas. Many of these participants did not feel adequately supported nor did they always feel appropriately treated. They did relay accounts of positive experiences with some staff but also highlighted many unhelpful encounters and a far greater sense of struggling to maintain effective relationships. For these participants there was a greater worry for the future in terms of the care and support they may need as their condition progresses and their impairments worsen. We also heard about the difficulties these participants faced in knowing who to contact and in getting satisfactory help or advice.

This point is endorsed by research with people who have a diagnosis of Motor Neurone Disease (MND) (Hughes et al, 2005). Participants here described the approach of some professionals as 'distant and divorced' and also relayed how some professionals had a 'lack of knowledge and understanding of MND and its impact on people's lives' (Hughes et al, 2005). Service users with a cancer diagnosis who accessed hospices have identified having someone to contact for advice, information, and support as important also and in contrast to some participants in this research considered this need to be met (Seymour et al, 2003; Ingleton, 1999). In research with non-cancer participants Seamark et al (2004) concur that having a person to contact for advice and support was acknowledged to be important but absent for these participants with COPD.

The difficulties that many participants with non-cancer conditions faced were compounded by the fact that it was not as simple as being able to access hospice care and support or not. Hospice palliative care services may not be the answer for everybody as either these services are not acceptable to them or their particular condition is not considered to be at an advanced stage and therefore they would not meet hospice referral criteria. However many aspects of this type of care and support could be transferred to other settings.

From the accounts in this theme we can clearly identify factors that participants considered as important to them when accessing health and social care services. Here are some of these things:

- Being listened to and believed
- Staff that are interested in service users
- Being treated with respect
- Departments that communicate well with each other about service users and their particular issues and concerns
- Departments that are accessible, effective and supportive
- Staff that can be trusted and who are knowledgeable of service users and their conditions
- Staff who act as advocates working with service users
- Contactable named health or social care staff is important.

These points and the accounts from participants in this research about the quality of care and support received are very similar to findings presented in research by Morris (1993:113) over a decade before. This research included the accounts of fifty disabled

people all of whom required varying degrees of personal assistance in their daily living tasks. This research will be discussed in more detail in section 5.12 below however it is salient to note here that similar issues regarding relationships with health and social care staff and services provided were reported. The research in this thesis corroborates many findings in this much earlier study. A partnership project involving representatives from a cancer support group and researchers undertook a local project in cancer care and also identified some similar service orientated recommendations such as the need for a patient-centred approach and for access to knowledgeable health professionals for advice (Goodare & Nadim, 2004).

Details about the experiences patients had of the services were not captured in research by Edmonds et al (2001) but, as in the research in this thesis, differences in service provision were noted and this was related to the kind of condition people had. The existence of this difference in service provision depending upon condition is agreed by Jones et al (2003) who conclude that 'congestive heart failure patients and their carers have unmet needs in terms of palliative care provision...'. Lewis and Stephens (2005) also accept differences in service provision in their literature review of palliative care for people with heart failure.

In research with participants with advanced cancer there are reports of hospice care that are supported by the research presented in this thesis. Exley (1998:107) highlights the concerns and fears of some participants when first referred to a hospice but as in the current study, found more positive experiences than negative. As in the current study, participants in Exley's (1998:107) research particularly valued the more human qualities such as clear and unhurried communication with staff, being treated with respect and dignity, and an informal but professional attitude. Having access to a person with knowledge about the condition and who had time to discuss issues was raised in research with people with MND (Hughes et al, 2005). Research conducted by and with disabled people that focused on Centres for Independent Living (Barnes et al, 2002) identified many of the same issues with services organised by non-disabled led organisations that have been highlighted in this research. Disabled people in this research stressed the lack of flexibility and continuity offered by much statutory service provision. Issues of a lack of control over services and of

unsatisfactory relationships with staff were highlighted and these are particularly similar to issues raised in this thesis.

From the preceding discussion of all of the themes that make up the findings of this research it is clear that social aspects do have an influence on participant's experience of life limiting conditions. This is evident in terms of relationships and services. The challenge for the participants in this research has not been purely about physical symptoms but also about social encounters, attitudes and environmental barriers to living life as fully as possible.

5.10 Reflection on agreements and differences in data interpretation and findings generation: Service User Research Advisory Group and researcher

In this section I will consider aspects of data interpretation and findings generation in an attempt to capture differences and similarities in interpretation between members of the Service User Research Advisory Group (SURAG) and myself. It needs to be remembered that data analysis was a collective enterprise and not based on one person's interpretation of the data. This section is not concerned with the process of data interpretation or the collective nature of it as this has been described in the methods chapter, chapter two. The eight final themes were presented in the findings chapters (chapters three and four), and were the themes agreed and accepted by members of the SURAG and myself following our lengthy data analysis stage of the research. This period of interpretation and the formation of service user orientated findings offer a unique contribution and will be critically examined in this section. The involvement of the SURAG in interpretation provided some themes that are shared with previous research but, importantly, some further themes unfound previously within the field of life limiting conditions and palliative care. In addition to this, the themes that were shared with previous research were provided with a new emphasis by the SURAG in the research presented here.

First, a little background to the SURAG that illustrates the level of 'engagement' members brought to the research from the outset will be given. This is presented in

order to assist understanding about the individual and collective experiential knowledge that was present from the outset but which further developed over time. Experiential knowledge will be discussed in section 5.11.8 below.

From very early in the research I noted in my research journal an emerging 'different take', or a different perspective, on participant data and the research approach from members of the research group. The very first SURAG meeting in November 2002 was mainly concerned with getting to know each other, discussing the role of the group, and agreeing ground rules for our meetings. However I was surprised by member's openness to discuss their own conditions and situations and the engagement with the task at hand. At this first meeting members were clear that they wanted outcomes to flow from this research in terms of changes for people with life limiting conditions with someone suggesting we lobby politicians with our findings when we have them. It was recognised that this research group was not a 'support or self-help group' but members acknowledged the need for such a group and identified that one may develop as a spin-off from this group. In bringing their own experiences and insights members readily engaged with many central issues and started from a place of some considerable understanding regarding the circumstances and difficulties of people with life limiting conditions. This may now seem obvious, but for me at the time this was a very interesting new understanding. I had anticipated that members would offer insights on the research in terms of ensuring it remained ethical and in making insightful suggestions on many aspects like the interview questions and in analysis of data, but I had not fully recognised the identification members would have with participants. I had not fully recognised the level of self-disclosure members would be willing to accept that came from their reading and working through of what participants were telling us.

I also never felt that members came with pre-held assumptions that would get in the way of the research but rather they were able to see the aim of the research, and later the situation of participants, because they also had first hand direct experience of the very thing we were exploring. During our analysis of data stage for example, that as we have seen in section 2.4.3 was a systematic and considered stage, SURAG members raised any difficulties they had in understanding participants' experiences or accounts. There were just two issues with assumption making and these are referred to

in section 5.11.6. In analysis session three we were discussing the account offered by participants' with cancer who were describing their awareness of having a limited time to live and of still being determined to do things. A SURAG member, who herself had debilitating and advanced COPD, spoke of how humbling it was to read this. She went on to reflect that she couldn't say how she would deal with this certain knowledge of the proximity of death. Despite sharing some similar issues with participants brought about by her condition, this SURAG member illustrates awareness that understandings cannot be presumed solely on the basis of having a life limiting condition in common. Another example can be found during analysis session nine when one SURAG member had considered some of Delia's attitudes to be negative. Group discussion followed which ensured that closer inspection of the transcript and her meaning was taken in order to clarify the point from the participants' perspective rather than making assumptions. Further to this SURAG members, because of their experience as service users, readily identified the issue and hazard of assumption making when reviewing transcripts. I suggest they had a critical understanding of assumptions and an awareness to be wary of them. In analysis sessions with participants Jess and Hazel for example, SURAG members discussed the issue of difference and how assumptions cannot be made based on having particular conditions.

The second meeting focused on three different areas. There was the area of considering what I had placed on the agenda for the meeting, then discussion within the group related to the research issues, this was characterised by talk on how death is seen by people and families in particular, by talk about how a person can lose control and voice when he/she has a life threatening condition. Thirdly, talk was of a supportive nature. Members spoke of their personal needs and dilemmas, and they received advice and supportive comments from other group members and amongst the group. Members with non-cancer conditions could not access the local hospice but even when group members who have access to the hospice services spoke of the hospice favourably and others stated their desire to have similar help there was no hint of animosity. At the time in my research journal I noted that there seemed to be a mutual interest between members about what help each person gets and an acceptance that this is how systems are set up currently. People with cancer seemed to be recognising the inadequacies in service provision for people with non-cancer disease.

In our fourth SURAG meeting in April 2003 the group looked at my initial analysis of 'Simon's' data in order to consider the range of questions in our interview schedule and whether they needed altering to capture accounts on issues the research was focusing on and to see if members recognised the issues raised. I wrote in my research journal at the time that issues from this interview seemed to resonate with most of the group. 'Simon' had cancer but SURAG members with other conditions felt there were very many similar issues with themselves and their situations (this is elaborated on below). One member felt it was very accurate to highlight that social services do not offer practical help. There was also discussion about relationships prompted by this transcript. SURAG members stated how some people remain very good friends, stand by them and offer great support and understanding but most members seemed to have experience of friends withdrawing from them as 'Simon' had. Several members also endorsed the concern for their partner in the future on many different levels.

From the preceding short background information about the SURAG in its first meetings it can be seen that there was a mutual understanding between research participants and members of the SURAG. As well as solidarity between SURAG members occurring very quickly, there seemed to be a very quick sense of solidarity and understanding between research participants and SURAG members with a readily engaged reflective stance taken. This sharing of common ground taken from individual experiences has been considered by Borkman (1976), in relation to her research with self-help groups. This research highlighted that the pooling of experiences of a number of people enables the common factors and common ways of coping with the experience to emerge whilst retaining 'the uniqueness of each individual's situation' (Borkman, 1976). Therefore the processing of similarities and differences between individual experiences of the same situation can lead to recognition of the knowledge required to help oneself (Borkman, 1976). I would extend this to claim that this processing of similarities and differences between individual experiences of the same situation can not only lead to recognition of the knowledge required to help oneself but to a recognition of what could be helpful to all people in this situation. This issue of knowledge that arises from shared experience will be considered in more detail in section 5.11.8 below.

We now turn to the analysis of data and firstly to the initial analysis that I undertook as data was gathered.

5.10.1 Initial researcher thematic analysis

The themes I identified myself following initial analysis of participants' data are presented in table 5.2 below. The themes were identified following a line-by-line reading and rereading of the transcripts. As themes were formed supporting participant data were added to existing themes and new themes formed as required. The SURAG were shown these themes as they were completed following each episode of data collection and comment and critique of them was encouraged. The aim of myself undertaking this first analysis was to ensure we all fully engaged with the data as it was collected, thought about it and the themes or categories raised, and became used to this interpretive aspect of the research. This was successful in that SURAG members contributed to discussion of these themes and issues raised during our meetings and it was also an effective way to reduce the transcripts into manageable portions.

It can be seen from table 5.2 below that of the seven themes initially identified by myself just three concurred with the themes finally identified and agreed by the SURAG and myself following our collective data analysis stage. These were the themes of diagnosis, relationships and services. Four themes that I identified were not taken on by the group as final themes although there were overlaps as well as differences. It is clear that all the themes identified in this initial analysis phase undertaken purely by my self were macro, all-encompassing themes. On reflection it is interesting that I selected such broad themes and this may have been due to inexperience, being influenced by such themes in published research I was aware of and/or a lack of engagement with the data at this early phase of the research.

Table 5.2: Initial themes identified by researcher.

THEMES
Diagnosis
Lifestyle
Coping strategies
Relationships
Services
Self-philosophy
Future orientation

The final research data were collected in March 2004 and the group then moved on to the collective analysis stage of the project. The group and I saw the collective stage of data analysis as crucial to this participatory project. We all saw the group's analysis as having the possibility of being different to mine and of focusing upon service user concerns that may have been missed by myself with my professional background and lack of direct experience of the conditions central to the research.

The process of analysing the data was discussed and agreed within the group two months before analysis began. I produced some guidelines to assist with the analysis that was discussed in the group with regard the guidelines usefulness and acceptability. Principles of service user involvement in analysis were debated in the group and this was a form of training. This included debate about our own assumptions, value judgements, and the key questions to have in mind when undertaking analysis. I also led some informal training about thematic analysis and the suggested analytic process I was suggesting we follow (see annexes J and K). Another aspect to assist the collective analysis stage was the utilisation of an adapted interpretive framework that I again offered informal training in its use (Adapted from Hart, in Winter & Munn-Giddings, 2001:249). These various guidelines are more fully discussed in the methods chapter, chapter two. Following this preparation collective analysis began in June 2004.

5.10.2 Agreements in data interpretation and findings generation (shared themes)

I will now consider particular differences and similarities between the group's interpretations during the collective analysis stage and my own initial analysis. I will begin with agreements, areas where my initial themes and the SURAG themes concurred.

Agreement between the group and myself came fairly readily in the areas of 'diagnosis', 'relationships', and 'services'. The data was very convincing in the content from these areas and these three themes will be considered first. As can be seen in table 5.2 and mentioned above, I had identified all three of these themes in my initial analysis. This analysis was developed iteratively over time following each episode of data collection.

5.10.2.1 The theme of diagnosis

Both the SURAG and I identified the macro-theme of 'diagnosis' as questions regarding the participants' condition were asked at the outset of interviews or group discussions. This theme was made up of further micro-themes. We had much data about the period just prior to diagnosis and the experience of gaining a diagnosis itself. Interestingly though, from the thirteen transcripts I only identified accounts for this theme from seven of them and the SURAG only identified accounts from six of them for this theme. The SURAG identified diagnosis theme comments from one participant that I had not and I identified diagnosis theme comments from two participants that the SURAG did not. The number of transcripts from which accounts were included in themes, noting the differences between myself and the SURAG, can be seen in table 5.3 below.

Table 5.3: Occurrence of participants/transcript accounts included in final themes.

Final themes	No. Transcripts from which accounts that illustrated this theme were identified by the SURAG	No. Transcripts from which accounts that illustrated this theme were identified by the researcher	No. Transcripts from which accounts that illustrated this theme were identified by both SURAG & researcher combined
Diagnosis	6	7	8
Fear	6	0	6
Anger/ Frustration	10	0	10
Grief	10	0	10
Relationships	10	12	13
Services	10	13	13
Difference/ Individuality	12	0	12
Independent/ Dependent	13	0	13

It is important to note that all the transcripts from which illustrative diagnosis accounts were not found were from interviews that took place at the beginning of the data collection period. In reviewing these interviews and comparing them to later interviews it is apparent that the opening question in the early interviews was slightly different to later ones. The opening question was slightly restrictive whereas this same question asked in later data collection requested information not only about the period of diagnosis but also about events that had taken place between diagnosis and the present time. Differences in responses were noted that stem from this slight change in opening question.

In terms of differences between the SURAG interpretations and my own for the theme of 'diagnosis' there are some interesting points to note. When the group identified comments from transcripts that they felt 'fitted' within the theme diagnosis they also

offered a separate commentary about their selection. This additional commentary occurred for all themes that the group identified and developed transcript by transcript. The commentary is in fact a level of interpretation by group members. For example, with Becky in mind for the theme diagnosis, their additional interpretations note that they felt that Becky had made a decision to keep living and that her perception about dying had changed over time. This additional interpretation by SURAG members was translated into the body of the findings chapter as it shaped how Becky's contribution on diagnosis was written. As for all of these 'extra' interpretations made by SURAG members about the experiences of all participants' in all themes, these interpretations have been woven into the findings chapter where it was clear that they did actually connect with the theme.

5.10.2.2 The theme of relationships

The theme of 'relationships' was another theme that was identified by both the group and myself. We can see in table 5.3 above that the SURAG identified participants' illustrative accounts for this theme from ten transcripts whilst I identified supporting accounts from twelve of the thirteen transcripts. There was just one transcript that I failed to infer any illustrative accounts of the theme relationships from. However the SURAG did identify accounts from this transcript, which were included within the theme. I had included these same accounts from this transcript under my theme of lifestyle because it was about friends withdrawing and not socialising with the participant any longer. During collective analysis and re-immersion in the data I did agree however that it was in fact a salient comment on changing relationships. How relationships changed for participants since having their particular condition was widely reported and taken forward as a theme by both myself and the SURAG. Most accounts from participants that I had categorised in my initial analysis within this theme remained in the finally agreed theme of relationships and contributed to the writing in the findings chapter for this theme. However when I re-examined my initial analysis for relationships in light of all the finally agreed themes I did reclassify some participant accounts to other themes that were more appropriate. I was able to re-categorise from relationships to the final themes of grief and anger/frustration (Group discussion 03/04); difference/individuality (Becky); independent/dependent (Edith). This occurred because on reflection and in light of the final generated themes, these accounts were clearly more suited to the new themes.

An example of this is an account given by Becky that I had originally allocated to the theme of relationships. She was describing her rationale for telling some people about her HIV+ status and not others when she spoke of the difficult balancing act that it was. Whilst this would 'fit' within the theme of relationships it appeared to be more congruent in the final theme of difference/individuality as it described the negotiation Becky undertook between being herself and in protecting her 'difference'. For Becky this difference was her HIV+ status and her uncertainty of how others would treat her if they knew this diagnosis. Another example of this reclassification is seen with Sylvia (Group discussion 03/04). I had originally allocated her accounts of changing family dynamics to the theme of relationships. In light of the new theme of grief though I felt it was more illustrative of this theme as her comments were about a loss of spontaneity and how this felt. This type of data consisting of quite complex experiences and accounts can be categorised in more than one-way. Themes are often interconnected. With the benefit of the final themes though, that originated from our collective analysis, I could clearly see the benefit of categorising data according to the new themes. It was not a case of forcing data into categories but rather of being conscious of the appropriateness of this re-categorisation. It was an awareness of a more acceptable emphasis offered by the new themes.

5.10.2.3 The theme of services

'Services' was the last of the three macro-themes that I had initially identified and which concurred with those finally agreed upon by SURAG members and myself. Table three illustrates that I identified supporting accounts for this theme from all thirteen transcripts and that the SURAG identified supporting accounts for this theme from ten transcripts. Both the SURAG and myself identified many accounts of participants referring to services in many different ways. It is interesting to consider why it was that the SURAG failed to find any illustrative accounts from three transcripts for this theme. These transcripts were for Jess, Mel, and Becky. I had identified several clear supporting accounts from these three transcripts for this theme and so it is surprising that the group did not. During our analysis sessions the SURAG members had identified accounts that referred to services from these three participants' but they were not selected in the theme generation phase.

There appear to be two possible reasons for this situation. Firstly there may be a pragmatic reason for the SURAG failing to identify any accounts of services from these participants to support this theme. After analysis sessions we held the theme generation sessions where the group agreed the final themes from what we had analysed. There were four theme generation meetings and the three transcripts in question may have been rather lost amongst the other transcripts. These afternoon meetings were normally very busy and a great deal of material was reviewed, discussed and decisions taken. Alternatively, it is clear from reviewing the typed analysis sheets for these three participants that there was a great deal of emotional material present and discussed by the SURAG. SURAG members commented on Mel's analysis sheet for example that they had found her transcript somewhat confusing and some of her accounts ambivalent. The SURAG readily identified Mel's fear, depression, and attitudes to dying. Other similar strong emotional aspects were identified for Becky and Jess. Perhaps for these three participants SURAG members identified with, or found it easier to acknowledge the impact of living with their particular condition rather than to tease out other accounts, i.e. services, that may have been more hidden to them.

5.10.3 Disagreements in data interpretation and findings generation (Different themes)

The clearest differences in interpretation between the SURAG and myself come in the next five themes that were made during our collective data analysis and theme generation sessions (fear; anger/frustration; grief; independent/dependent; difference/individuality). I had not identified any of these themes myself during my earlier initial analysis of transcripts.

5.10.3.1 The theme of fear

Early during the collective analysis stage of the research SURAG members began identifying participant accounts that they thought said something about fear. In fact from the first analysis session onwards accounts that eventually came to form this theme of fear were identified. There is an audit trail of documentation which illustrates this as well as all the other analysis and processes of theme generation for all themes. These accounts of fear built up over time during data analysis and led to it becoming an obviously discrete theme in its own right.

Following the agreement of fear as a theme there were some initial analysis sheets that I had completed that I now went back to and was able to identify some accounts that I could now see were congruent for this theme. An example of this is the transcript for Sheila. She had spoken of her concerns for the future when the time came that she was more dependent on others. Sheila spoke about trying not to think about it but did accept that it did play on her mind. I had placed these accounts into my initial theme of 'future orientation' but on reflection saw the appropriateness of the theme fear for these accounts. Delia was similar in this way. I had identified some of her accounts under my initial theme of 'self/philosophy' however the SURAG disagreed and considered her comments about wanting a warning of death to be concerned with fears of approaching death and of a fear of stopping breathing in her sleep. Some SURAG members felt very strongly about this. For me, this re-categorisation was concerned with enabling data to be allocated within a much clearer theme than I had originally done. As has been stated earlier in this section my initial themes were very broad and the final themes generated collectively were much more usefully specific.

For other transcripts there were accounts of fear identified by the SURAG that I had completely failed to capture in my initial analysis. An example of this is the transcript of the group discussion with participants who attended a hospice day centre (01/03). I had captured a notion of fear in my analysis but this was mainly concerned with participant's initial fear of the hospice being relieved after contact with hospice staff, and of the hospice comforting participants in terms of their fear of the dying process. On reflection I can see I placed a positive interpretation on the issue of fear. SURAG members, whilst also recognising that the hospice can reduce the fear about dying badly, captured accounts from these participants that showed the extent of their initial fear of referral to the hospice, their vivid fear of how they might die, and the fear of getting a diagnosis of cancer.

The theme of fear developed by the SURAG promoted this theme directly without losing it within a more benign theme. I suggest that in keeping my initial themes, as I may of if this was not a participatory project, fear would have been obscured amongst other macro themes and therefore the impact would have been far less. Members of the SURAG were able to identify illustrative accounts of fear in participants'

transcripts and convincingly promote fear as a discrete theme in itself. Those close to the experience of living with a life limiting condition achieved this then whereas I may have been restricted in my analysis by a professional distance that promoted diffuse themes. I suggest that this has been the case in other non-participatory research (i.e. McPherson et al, 2001; Horne & Payne, 2004; Barnett, 2005). My initial themes actually avoided identification of emotion in any overt or specific way.

5.10.3.2 The theme of anger/frustration

Anger/frustration is another theme identified by the SURAG with members gleaning direct accounts from participants' transcripts that brought this theme alive. Many accounts were identified that illustrated participants' anger and frustration both about the impact of their conditions on themselves and their lives, and anger and frustration about other connected issues. Here it is important to note additional interpretation comments made during analysis by SURAG members in relation to this theme. Having identified Jess's accounts about the tiredness of MS and her fight against it for this theme, the group raised the frustration of her not being able to do anything about it. When Sheila described living with her condition in terms of it being very restrictive, again the group highlighted the frustration of having to cut things out (daily activities) as one gets worse. Edith highlighted the lung damage she had received following her treatment for breast cancer and the group identified her anger about this and about being let down by a system that failed to apologise or to give her adequate explanations. The SURAG also identified the anger and frustration emphasised in the group discussion (03/04) by Sylvia who gave accounts of her level of dependency. SURAG members highlighted her frustration regarding everyday things like not being able to pick things up from the floor and not being able to do her bra up. SURAG member's perspectives certainly identified these issues in terms of anger and frustration that I would not have identified. It is likely that this is due to their closeness to the experiences participants raised. They may not have had identical experiences to those of participants' but they had experienced similar problems and faced similar issues and concerns. I contend that this is a further demonstration of the particular contribution of this participatory approach.

As I did for the theme of fear, when the theme of anger/frustration was identified and accepted as one of our final themes I reviewed the initial analyses that I had

completed earlier and was able to identify some accounts that were clearly related to this theme. I had categorised some of Mel's accounts in my theme of 'self-philosophy' for example. When I reviewed the transcript in light of our newly formed theme of anger/frustration I was able to see how this theme clearly emerged from the data here. For example, Mel had been speaking about the condition making her bitter and twisted and described it as 'like having a weight round your neck'. I could now appreciate that this illustrated Mel's anger and frustration with her COPD. This again illustrates the ease with which researcher interpretation can be benign.

5.10.3.3 The theme of grief

SURAG members identified grief as a discrete theme, identifying many examples from transcripts of accounts that illustrated this theme. The additional interpretation comments for this theme unsurprisingly focused on issues of loss. Loss of life for Jess who was no longer able to do many everyday things; loss of physical ability for Sheila who 'could do less, and less, and less'; loss of employment and home for John; and a loss of liberty and choices identified from the group discussion (11/03) and Maisie, Bessie and Val in particular. I was able to readily see participant accounts emerge that were congruent with this new final theme when I returned to my initial themes. Hazel for example, seemed to clearly describe her grief when she spoke of her depression and feelings of guilt when she was mysteriously struck by her physical deterioration by an unknown cause. I had categorised this in my initial theme of 'self/philosophy'. For Chris and his carer Clare also, on reflection there seemed to be obvious references that were congruent with this theme of grief. When I had identified accounts of Chris now being unable to do anything, of their whole life changing, I had categorised this in my initial theme of 'lifestyle'. This again suggests an unnoticed process on my part to keep emotion at a distance and to prefer wider themes as also evident in earlier studies (i.e. Lawton, 1998; Carter et al, 2004).

On reading through the transcripts these three themes were readily identified by the group. Members were not always identifying different accounts from transcripts than me but they obviously were categorising them differently. This fact seems likely to stem from both their own particular experiences of the conditions included in the research and also from their ability to understand the issues faced by participants', an

empathy borne of mutual experience and understanding. The next two themes were also identified by the SURAG rather than by myself initially.

5.10.3.4 The theme of independent/dependent

The theme 'independent/dependent' identified by the group most closely aligns to the theme 'coping strategies' initially identified by myself, but there are differences here. During the fourth SURAG meeting members considered my initial themes in relation to 'Simon' (as highlighted above). Their comments about the accounts I had placed in the theme of 'coping strategies' indicated an agreement with them. The specific things that 'Simon' had said that I felt could be encompassed under the theme coping strategies were his comments about pushing the condition to the back of your mind, about striving for independence, being pragmatic and living with your condition, and his fatalistic attitude. Group members agreed that getting on with it was one way of summing up living with a life limiting condition. They also felt that fatalism should not be confused with accepting the situation or purely focusing on the depressing nature of living with ill health. Members were expressing caution towards passivity and a 'giving up' attitude. At this early stage of the group's life there was an awareness of how personal issues or attitudes can be construed by people out side of the direct experience.

Further to this I suggest there were early signs of a new and as yet un-named theme emerging from the group. The theme that later was described as independent/dependent. Additional interpretive comments during analysis from SURAG members are particularly salient here. Jess had been raising the issue of people having preconceived ideas about her because she had MS when a member of the group added an insight about a possible fear of dependency. It was felt that Jess was putting on a brave face and there was discussion about the masks that people wear in order to appear independent.

As for the previous themes, I reviewed my initial themes when 'independent/dependent' was agreed upon as one of our final themes. I could not only now look back and see accounts in my initial theme of 'coping strategies' that were consistent with the new theme of 'independent/dependent' but could also see how accounts emerged from some of my other initial themes illustrative of the theme

'independent/dependent'. Hazel is one example. Her accounts about the type of person she was and how she did not have a say in her new accommodation both of which I had categorised as 'self/philosophy', clearly related to this new theme of 'independent/dependent' and the implicit tensions between the two concepts. Re-categorisation made the analysis of the data a deeper stage compared to my rather macro and relatively emotionless initial analysis.

5.10.3.5 The theme of difference/individuality

The theme difference/individuality identified by the group also most closely aligns to the theme initially identified by myself of 'self-philosophy', but there are differences here also. The group made clear additional interpretive comments for this theme. For example when Sheila's account about her friends not appreciating how seriously ill she was because she still looked quite well members of the group commented on this difficulty of people understanding someone and how they feel when 'your looks are not pitying you' as one SURAG member said. Also when Becky was offering her account of adjusting to a lack of control, group members added that when faced with this type of experience it was important to have a strong mind set, a strong sense of purpose. Again in looking back at my initial themes I could clearly see how this new theme emerged from the data. John is an example here. He had clearly spoken of the two sides of himself that he switches between depending on whether he is hospital or not. I had categorised this in the theme of 'coping strategies' but on reflection could see the congruence with the theme of 'difference/individuality' as he struggled to control his 'difference'.

It is important to recognise that SURAG members oversaw the re-categorisation of my initial themes. Members checked a sample of my initial themes with me for this incorporation of my initial themes into the new final themes we had generated. Having decided that this process of incorporation could occur the group asked me to continue this process and feed back to them. I found this difference in interpretation and theme generation very interesting and I was more than agreeable to utilise the themes generated by the group. I was satisfied that the process of analysis and theme generation was systematic and thorough as well as being convinced of the service user emphasis. The SURAG generated themes made sense to me and I appreciated the different approach to data analysis and theme generation offered by them. Some

issues about service user involvement in the analysis stage of the research are described in section 5.11 below.

5.11 Service user involvement in the research process

The impact of service user involvement in the research process was an important part of this research and this has been illustrated above in section 5.10. In this next section a more critical reflection will take place. There are two main areas in which service user involvement has had an impact. The first is in the area of the research product itself, in the contribution towards the completed research project, the research findings and recommendations. This contribution in the research project has been explained in chapter two, methods, and the previous section, section 5.10. In this section focus will be upon service user involvement in the process of actually 'doing' the research and reflection will also occur on the participatory nature of this research. As we have seen, members of SURAG have been involved with this research from its inception. The SURAG met as a group over thirty times with the most intensive period of regular meetings of the group occurring during the phase of data analysis. There has been a high level of motivation, commitment, and a desire to see the research project completed. SURAG members have attended and importantly contributed at all stages of the project. There is a typed documentary audit trail of all the groups meetings, which includes the meetings agendas and accompanying notes on the content of these meetings and decisions made within them.

5.11.1 Beginnings of involvement in the research

On reflection with SURAG group members it is clear that there was a great deal of trust and goodwill amongst members in coming to the first meetings. Some members later explained their depth of isolation, under confidence, and recent lack of interaction with 'strangers'. Some members had quite a low opinion of themselves brought about by their own experiences of their particular conditions. Simply attending the first SURAG meeting was an achievement that was not fully recognised by me at the outset. My mind was occupied by thoughts of explaining the project in more detail, maximising people's involvement, facilitating effective group working, getting people to the venue, as well as concerns for the people themselves. Reflections

by some members illustrate how anxious they actually were at the first meeting and how they had doubts as to their ability to socialise, to contribute without letting themselves and others down, and how they had concerns about their physical abilities.

5.11.2 Motivations for involvement

Members of the SURAG relayed some very moving reasons for getting and staying involved in the research. For some it was about being involved in something very different, of 'escaping' from their everyday reality, but also it was about 'making a difference' for others in the future. Research was seen as a way of highlighting issues of concern that people in a similar situation might have and of trying to do something about these issues. There was also an awareness of some members feeling of some value again having previously been in receipt of a great deal of care and support themselves. Now there was a chance to make useful contributions once again.

5.11.3 Collective working

Despite individual differences between members of the SURAG, coming together as a group and focusing on a specific project brought much joint learning and solidarity to the fore. As interviews were completed and transcripts reviewed there was an engagement with participants as well as with each other. Members cared about each other and indirectly for research participants as they compared and discussed participants' experience in light of their own. Group members acknowledged the effect of bearing witness to research participants' accounts of their own experiences with their particular condition. It wasn't solely in the space of meetings that members thought about participants' accounts but reflection continued outside of the meetings. Mutual learning was a progressive process and in many ways, reaching the stage when findings and recommendations were agreed as a group became the culmination. It was here that the threads came together and what had been strived for was achieved.

5.11.4 Personal development/empowerment

The process of working together was not all straight forward. SURAG members themselves invariably had occasions when they were less well and shared particular problems with group members. Added to this members were often affected by accounts they read from research participants. There was a sense of empathy for some participants, sadness for others and anger felt for those participants who seemed to be

getting a raw deal from services or life in general. Members of the SURAG, though, were both determined and dedicated to be as involved as possible in the research. There was a real sense of ownership and desire to complete the research. Indeed the passion about the project was quite tangible at times and was a great motivating factor for myself. Members of the SURAG also found their involvement and participation in the research to be motivating and rewarding. Working together was a powerful experience in fact that had many more positive factors than negative, which must go some way to explain the length of time members maintained their involvement for.

Many members of the group felt empowered in different ways. Honorary contracts with an NHS Trust were obtained for three people who particularly wanted to have greater involvement in the research. Some members were very clear about the positive effect their research involvement had on them. For some the involvement was like a new lease of life enabling them to rediscover latent or new skills. This empowerment was not 'given' to members as such because I would suggest it is something a person has to achieve for one's self. However the correct environment is a prerequisite for attaining feelings of empowerment and this, I would argue, was facilitated by the mutual working and power sharing that all of us were a part of in the SURAG. Boote et al (2002) raise the question as to what the intention of service user involvement in the research process is. Is it to increase the 'user satisfaction of the end product' or to empower and democratise the research process (Boote et al, 2002)? I would argue in favour of both these outcomes, as well as to lead to new knowledge and suggestions for change as identified by service users. This has been put forward by Munn-Giddings (in Ferreira et al, 1998:89) who emphasised that coming together collectively with others who share common problems, issues or aims (to one self), can lead to the personal and collective development of members of such groups which may include an increase in knowledge base, skills, experience, self-confidence and self-esteem.

In terms of empowerment I would say that it was personal empowerment rather than political empowerment that members gained from their involvement in the research. Personal empowerment has been defined as being concerned with issues like enhancing individuals' confidence, assertiveness, and skills whilst political empowerment is concerned with engendering change that increases power at the

social, political, cultural and economic levels for people involved (Beresford in Hanley 2005:15). It may be argued that social power was increased for some members of the SURAG as they rediscovered neglected roles and forged new links with others, partly due to their research involvement. However it is at the personal level where members saw clear changes. A joint reflection on this project, and with a specific focus on the service user involvement in it, has highlighted some of the challenges to involvement for service users with life-limiting conditions but has also emphasised the substantial positive influence of involvement on those involved and on the research itself (Cotterell et al, 2006).

Evans and Fisher (in Shaw & Lishman, 1999:112) drawing on their own experience of working with service users in research note that 'we see a growing need for professionals to recognise the potential research expertise of service users, and to work with service users in developing and conducting research'. They go on to clarify that involving service users in research is not only achievable but constructive to research and it can reveal otherwise hidden skills and experience of service users (Evans & Fisher in Shaw & Lishman, 1999:113). As discussed above this has certainly been the case in this research. Service users have not only rekindled forgotten skills and expertise but have contributed in a significant way to the research project. What makes this particularly unusual is that it is palliative care service users involved here, an under recognised group to be involved in research.

In many ways it can be seen that this participatory research has been meaningful to service users. Their involvement has not been tokenistic. The object of their involvement has not been purely the pursuit of their views but has been the effective involvement at most stages of the research. What service users want from research has moved far from a passive notion of involvement and it has been said that service users now expect '...to offer their own analyses, interpretations and plans for action' (Beresford, 2001). This point and the general tenet of the preceding discussion in this section would seem to be at odds with points made by Cornwall and Jewkes, (1995). Here the issue of service users' involvement increasing unhappiness is raised (Cornwall & Jewkes, 1995). This may be seen as a paternalistic view but I feel it warrants attention particularly in light of some thoughts prevalent in palliative care and outlined below. It is possible that service users involved in research such as this

may see their lives in different ways following access to accounts of others' experiences. It has been highlighted above how SURAG members shared similar experiences to participants, and reading and discussing participants' accounts in transcripts brought a high level of engagement with participants' lives and problems. It is possible that some service users respond negatively to such access. Perhaps their difficult and unwelcome situation can become self evident for the first time.

This may be a particular concern within palliative care research where issues of research with 'vulnerable' people have been thoroughly discussed (Aranda, 1995; Beaver et al, 1999b; Seymour & Ingleton, 1999; Casarett & Karlawish, 2000). Johnson and Plant (in De Raeve, 1996:93) in considering the effect of involvement in research for participants, were particularly concerned that people with cancer may have four main 'costs' to face. Participants might learn something from the researcher they would prefer not to know; they may be reminded of the events or reality of their own situation; the reliving of events may be disturbing; involvement may raise doubts about their clinical status (Johnson & Plant in De Raeve, 1996:93). Nevertheless this cannot be used as a reason not to involve palliative care service users in research. This must surely be an issue of support, personal choice and information needs. Information about the likely material at the centre of investigation and support during the research process are both important issues. Paternalistic attitudes and protective platitudes should surely not replace opportunity for joint participative working conducted in supportive and enabling ways. The term 'vulnerable', sometimes used to describe people with life limiting conditions, whilst intending to be a good faith term promoting caution and maximising protection of very ill people, can also be seen as a way that disguises the strengths and qualities of these same people.

5.11.5 Support and training

Support consists of many factors. As well as support for emotional needs that may arise, support may be required in terms of resources that may be crucial to the success of involvement. Support has also been identified as essential in terms of adequate funding to enable suitable training for service users to take part (Vernon in Hanley 2005:17). Without such training empowerment is difficult as people are not invested with the knowledge with which to share power with the researcher and to be involved in equal ways. Funding and the absence of structured training was certainly an issue

in this research. There was no real funding available for the involvement of service users and hence nor for training. Training was in fact achieved via informal sessions within meetings provided by myself. This was a draw back in this research and an issue that I would seek to resolve in any future participatory research planning. The issue of appropriate funding and training for involvement in research has been highlighted as a key principle for successful service user involvement in research since the inception of this project (Telford et al, 2004b).

The informal training I provided occurred as required and on issues identified in group meetings. Early on in the research for example I led a session about the SMD. It is salient to note that members of the SURAG seriously thought this through, discussed it at length and acknowledged it as helpful to the research. Moreover, members considered it as useful in terms of their own lives and experiences. Other training focused on specific aspects of research.

Training externally to the SURAG meetings were via conferences attended when one or two members and I were presenting our research, and a free research day offered by the Research and Development Department in the Trust employing me and attended by members as delegates. The aspect of funding that was provided was my salary and support for myself to conduct this research alongside the service user members. In effect I was the only person involved with the group being paid which is a very unequal situation and may cause problems in terms of power and value judgements. I invariably felt grateful for being funded to undertake this research but guilty for being the only paid person. I was certainly perceived by SURAG members in a particular way being the sole 'researcher' (as I was employed as a research fellow) and doing this as part of my (paid) job. The indirect investment in the service user involvement in this research by way of my financial support to develop and work with the SURAG does need acknowledgement, although did then generate some issues within the project. These issues were not significant for members of the SURAG though.

Utilising this participatory methodology as part of doctoral study may be seen as quite a luxury and an option less sustainable within the demands of conventional professional research practice with its pressurised struggle to obtain funding and the

usual integral time pressures. Lewis (2002) highlights the short-termist research agenda and the pressure of the Research Assessment Exercise that equates with university staff needing a quick turnaround of projects. This does not lead to great incentives for joint working to occur. Over thirty meetings of at least two hours in length may be viewed as a financial burden in itself without considering preparation and unaccounted support functions that are integral to successful service user involvement initiatives in research. There are also the supplementary meetings that occur such as sub-group meetings to take forward specific writing projects, preparation meetings for presentations, and of course the attendance at conferences themselves with service user members of SURAG.

Viewing service user involvement in research comparably to conventional research practice may however be a mistake. Service user involvement in research offers certain advantages that conventional research does not deliver and experience of this project enables detailed reflection on such advantages. Rather than engaging in internecine discussion that focuses on the relative merits and demerits of these approaches it is probably wiser to focus on the value of differing approaches whilst acknowledging the privileged position of an established conventional research approach.

5.11.6 Interpersonal aspects/engagement with the research

Unlike some other research involving service users (Faulkner, 2004) this project did not generate strong tensions between members of the SURAG. However there were some issues that caused irritation amongst some group members or concern to myself. There were two instances, during the data interpretation phase, when certain value judgements and assumptions were brought to the fore by SURAG members that were disconcerting. The first specific example is of two SURAG members who focused on the transcript from Chris, who had experienced a stroke, and his partner Clare during one of the first analysis sessions. This session was one of two focusing on Chris and Clare's transcript and was held, as the two members could not make the designated SURAG meeting. During this session points were made about Clare, the carer, being over-controlling of her husband and there were suggestions made that she needed to be needed. These points were based on accounts she gave and the particular SURAG members read in the interview transcript about not being able to trust social service

carers to be alone with her husband and other similar comments. Clare had said this as she had experience of carers not doing things properly for her husband who really could not communicate much at all. Clare felt she had to supervise the carers at least initially when they first started coming to their house. Clare had also spoken of having to rush when she left the house so that she was not a very long time away from her husband. She also worried about leaving carers she did not know very well in their house unaccompanied, both for Chris's sake and in case something was stolen.

Clare's concerns and comments brought forward judgements from these two group members that I felt were disrespectful, unhelpful and which missed other salient points. Interestingly a different three members of SURAG also spent time on this transcript and treated it in a very different way concluding that loneliness was a central theme for this couple and that Clare was frightened by their situation but was 'putting a brave face on it'. Both myself and other members of the group dealt with these assumptions at the time, within SURAG meetings. Discussion ensued about these statements and the assumptions were challenged. Interestingly when these particular analysis sheets were reviewed by the whole group at the time of generating themes the assumptions were not accepted. Reviewing the tape-recorded theme generation session in question it is clear how group members gently challenged the assumptions by refocusing on other issues such as fear for Chris and Clare's resistance to dependency.

I suggest that such assumptions or judgements could be made by lone researchers without the consideration, reflection and challenging of them that occurred in this participatory project.

At times exception was taken to personal comments made by a group member. This particularly occurred between one particular member and one or two other members. When reading certain transcripts the person concerned, on occasion, challenged participants' way of living with their condition that made these other group members feel like this was also a challenge on themselves, almost by default because of their own, perhaps quite similar experiences. I think it is fair to say that some SURAG members more readily identified or empathised with participants than others. When a comment was made in the group about the perceived need for a participant to think

more positively, for example, some group members became upset and angry feeling misunderstood.

On occasion a group member would highlight the fact that how they were being made to feel in the group was exactly how they were made to feel at home or when in contact with friends or professionals. On these infrequent occasions it felt as though the research was being replayed within the SURAG meetings. Such strong identification with participants' may be considered to be both a positive and negative aspect with this approach. However this type of comment was always challenged in the group and led to in-depth discussion about the nature of the conditions, how people are treated, and how people are often made to feel. Whilst being uncomfortable and at times upsetting for individuals concerned these discussions were often very illustrative of the wider experience of living with life limiting conditions. What was extremely helpful was that group members could engage in this discussion and there would invariably be some acknowledgement about seeing the other's point of view in the end.

In many ways these in-depth discussions that originated from participant transcripts, but which extended into a group discussion at the personal level for members, were highly productive in research terms. They brought to the fore some key issues and emotions that participants and group members experienced and enabled detailed exploration of them. This in some way may have in fact contributed to the groups forming of such emotionally orientated final key themes. It also contributed to a high level of engagement with the research and the group. One of the astounding aspects of this research for myself was witnessing the level of commitment members of the SURAG exhibited and their high level of engagement with the research. There was a strong desire to see the research through to its conclusion. Members made it quite clear that, even with the death of group members that was very upsetting and felt as a big loss individually and as a group, it was important to them to see the research successfully concluded. In some ways this determination to succeed stemmed from the desire to complete it in memory of those group members who had left or who had died.

Reviewing the tape-recorded analysis and theme generation sessions, the depth of SURAG members' engagement and participation is very clear. These sessions were often over two hours in length and the detail of members' reading and understanding of the transcripts was impressive. The theme generation sessions were richly detailed sessions that were orientated to making sense of and achieving greater understanding of the analysis sessions we had previously conducted. This process was similar to what Van Manen (1997:97) called interpretation through conversation, whereby data or questions are interrogated and interpreted collaboratively.

5.11.7 Critical evaluation

This research, at its outset, strived to fulfil a participatory approach in which service users were central to the research at all stages. It set out to offer a new and critical position on the subject matter, the experiences and needs of people with life limiting conditions. When the research began, although a participatory research approach was clearly taken, no one involved could have predicted where the research and our working together would go. I had aims to make the research as inclusive of members of the SURAG as possible but I was inexperienced in this research approach despite having read and discussed the possible benefits and challenges.

Members of the SURAG have been involved in a wide range of activities associated with this research. An idea of the range of contributions of SURAG members is given here:

- Helped with the phrasing of interview questions
- Gave insights based on their own experiences, about participants responses
- Reflected on whether we were gaining the depth of information we had hoped for
- Raised important points about research information as we reviewed it

- Commented and advised on the researcher's style and level of sensitivity to participants
- Very involved in making sense of all the data (data analysis)
- Involved with teaching about the research and how we have done the research

On reflection there are certainly things I would have liked to have done differently. I would have liked to have been able to have worked with service users on a project that was more fully an idea and concern of theirs and in which they were involved in designing i.e. service user controlled research. It would have been better to have facilitated research training that service users identified as requiring or to have been able to bring in the research expertise that service users identified as being important. Service user involvement in data collection with training could have been an option for those interested.

On the other hand, working on service user prioritised research questions would be more likely to occur with an established user group, which then decided to work with researchers to conduct the project. This would have been more in line with a service user controlled research approach. In the main, the service users involved in the research here were people not involved collectively before this research began. They were not members of any type of user group. Four original SURAG members knew each other from attending a hospice day centre together but the remaining members did not know each other at all. Were it not for this project, in all likelihood, they would not have been involved in any research project. They would not have had the experience nor formed the contacts and friends they have. In the field of disability research it may be possible to work with an established group of disabled people who meet in a politically active way. This may be as part of an Independent Living Centre with aims to lobby and pressurise changes to both policy and practice. Within cancer care it may be possible to work with an existing group and this may be a site-specific group such as "Breast Cancer: An environmental disease" (<http://www.nomorebreastcancer.org.uk/index.html>), a breast cancer education and pressure group. In palliative care there are fewer opportunities though to engage with

people who are organised as a group. Developing a new group removed the likelihood of strained dynamics that established groups might have though. Further to this, a group newly formed with the intention of working on a research project, could work in a way sympathetic to the aims of a service user controlled group.

Another aspect that could have been developed differently concerns the interview schedule. Questions could have focused more on external social influences and then may have been in greater keeping with the social model of disability. Some of the questions could have focused more critically on the influence of social attitudes and assumptions. Framing questions differently may have elicited different responses and may have delved more deeply into 'disabling' situations. Asking for examples of situations in which either services or people treated them as disabled first and a person second may have brought forth very clear indications of these influences.

Whilst identifying accounts about external influences, particularly services, I do feel that the questions could have had a greater orientation to social forces that can impinge on participant's lives. There was a tendency for the questions to bring about responses about individual experiences rather than enable participants to question external and social factors that perpetuated their experiences or issues. It may be surprising that this occurred given the input of the SURAG with all their own direct experience to draw on. However, as discussed above, service user members of the SURAG were not experienced 'activists' nor were they 'political' in terms of being collectively organised to challenge or shape policy. I take responsibility for failing to consider the wider questions we should have considered asking participants. This reinforces some opinion, which challenges the ability of non-disabled people being able to recognise the influence of social and structural forces on disabled peoples lives (Bailey in Barnes and Mercer, 2004:147). Despite this my feeling at the outset though was to develop a fairly neutral interview schedule, this was also the thought of SURAG members, rather than risk leading participants' into responses.

We have seen above how engaged and personally empowered members of the SURAG were as a direct result of being involved with this research. This in turn enabled members to become involved in other initiatives and even to be at the centre of a feature in a social care journal (Sale, 2005). In section 2.4.3 of the methods

chapter and above within section 5.10 we have seen how the SURAG was implicitly involved in the analysis stage of the research and the formation of themes. This concurs with Barnes (2001) who proposed this collective generation of knowledge as an essential component of effective research within the field of disability studies. It also concurs with work by Oliver (in Corker & French, 1999:191) regarding the importance of generating experiential knowledge and Mercer (in Barnes et al, 2002:245) who stressed that research conducted within the social model of disability approach requires those involved to reach a sense of empowerment. It is clear from the preceding section that service user orientated knowledge in the form of the research themes has been achieved, as has the sense of empowerment by some members of the SURAG.

Another factor that contributes as a form of quality control strategy is the clear and documented account of the process and decision making that has been achieved during the collective analysis phase of the research. This has been described in section 2.4.3 of the methods chapter and we saw here that a clear paper audit trail can be shown to link SURAG members and my collective analysis to the final research themes presented in the findings chapters. Identification of key text from transcripts through to the formation of initial and then final themes can be proven. I make a confident claim for the robustness of this stage of the research and the resulting genuineness of the findings.

We have seen in this section how some unhelpful judgements about participants were made by some members of the SURAG occasionally and in section 5.10 how an additional interpretation based on members' own experiences was also made. It could be suggested that this indicates that bias was at play or that service users involved in this research projected their own perceptions or beliefs onto participants' data. I am confident that this was not the case. As has been previously described (section 5.10), the rare occurrence of assumptions being reached was always challenged and as a group SURAG members were able to retain focus on the data. Arguably this bias was less likely to occur and to impact on research findings than in conventional sole researcher projects. Whilst presented to be discussed here, judgement making of participants was a rarity. The analysis stage of the research was taken very seriously by SURAG members who agreed to and followed the guidance provided in training

by myself (Principles of service user involvement in analysis in annex K). When we began the analysis we had been working together as a group for about eighteen months and members of the SURAG were very familiar with the data and the research process. Beginning the analysis session was greeted with anticipation and excitement. A typical point was made by one member of the group at the first analysis session who felt the analysis questions I had provided and described were interesting and helpful. This person added 'I'm excited by this process, it's like the bubbles you did (initial analysis) were above the surface of water say and our interpretation is about what lies below'.

There were comments about the data that illustrated great empathy and sensitivity towards participants and their accounts. I contend that the collective analysis, whilst enabling service users to engage with participant accounts utilising their own experiences, remained focused on the data and participants' meanings. As a group it was ensured that this was the case and often if an interpretation was offered about a particular participants' meaning the person presenting this would track back in the transcript to illustrate their point. The group then went to the same extract in the transcript and discussed the accuracy and meaning of the interpretation. As the researcher and as a relative outsider to the experiences being discussed I found this process to be very effective and reassuringly robust. All interpretations required 'evidence' from the data. Lone researchers are not immune from following their own assumptions, which is why checks such as asking an independent researcher to analyse a sample of transcripts are performed. I suggest that the SURAG offered a balanced approach to data analysis and I argue that this collaborative approach to data analysis is an effective method to counter what Hollway and Jefferson (2001) have called the "defended subject" from whom interviews fail to provide holistic data.

I also suggest that the presented findings will resonate and engage the interested reader and convey a rich insight into the lives and emotions of participants and hence concur with Sparkes (2001) proposition of authenticity in research. Some of the detailed accounts that make up the findings are very moving and also very thought provoking with the themes of, and relationship between, difference/individuality and independence/dependence particularly offering a different perspective within the field of palliative care research.

5.11.8 Experiential knowledge

To conclude this section on the service user involvement in this research it is important to consider the aspect of knowledge brought to the research and its findings by members of the SURAG. Experiential knowledge has been referred to within the literature review, section 1.4.9, in relation to service user involvement in research broadly. Here, a brief consideration of experiential knowledge in relation to this research will take place.

For Munn-Giddings (in Ferreira et al, 1998:92) it is clear that experiential knowledge developed over time by service users can challenge 'existing orthodoxies of "knowledge" - both professional and political'. Knowledge gained from direct experience rather than from professional and/or academic education will surely be different and depending on the attitude of professionals may well be challenging. This challenge will be particularly evident in areas of disagreement. We have seen in section 5.10 above how this research, with the findings generated via service user interpretations of the data, has led to some different conclusions compared to my professional and research orientated findings. My initial analysis led to broad themes rather than the more specific and emotionally orientated themes that emerged during the collective analysis phase by the SURAG. Glasby and Beresford (2006:281), in arguing for a 'new understanding of what constitutes valid knowledge', call for greater emphasis to be placed upon the experience based knowledge of practitioners and service users. This stance acknowledges the marginalized and often devalued opinion of service user 'evidence' or knowledge held by conventional academic and medical researchers.

It has been highlighted that service user knowledge differs in fundamental ways to professional knowledge, one of which is the emotional dimension which service users are able to vividly portray (Borkman, 1976). In terms of this research and its findings, along with the service user involvement within it, we can see that interpretation has been holistic and emotional. Service users involved in the research have interpreted data with a focus on services that people experience or need, participants' insights about these services, and the effect of these services on participants and the staff that work in them. Aspects of this may be viewed as service evaluation albeit with service users centrally located within the evaluative process. However, the level of emotion

included in the findings section of the theme services may well reflect the involvement of service users as data analysts (See section 5.10 for a fuller discussion of this point).

The other findings identified also indicate the level of emotional engagement brought by the involvement of service users in the interpretation process as well as the degree of prioritisation of the emotional content concerning living with a life limiting condition. Three themes were clearly focusing on emotional aspects of living with a life limiting condition (Fear; Anger/Frustration; Grief) but all themes can be seen to abound with emotion. I suggest that this emotional resonance is directly attributable to the central involvement of service users in data interpretation, the involvement of people living the experience themselves.

In a discussion of self-help/mutual aid groups other aspects regarding experiential knowledge have been raised. Within these groups it is highlighted how a reconceptualisation of situations can occur with members promoting different understandings of their situations, important understandings that arise from the 'experience of having and living with a problem' (Munn-Giddings in Ferreira et al, 1998:88). The findings in the research presented in this thesis may be seen in this way, as reconceptualisations, as different understandings, and certainly as understandings influenced by this collective working of people who share the experience of living with a life limiting condition.

It is further argued here that this collective knowledge production gained via participation with people having similar experiences to one self can be seen as an informal political activity, that can be challenging and/or complementary to more formal political activities (Munn-Giddings, in Ferreira et al, 1998:91). There can be influences that filter wider than the group itself then as well as internal group related influences such as personal development, creativity, ownership, and empowerment (Munn-Giddings, 2001).

People who use mental health services have been described as 'experts by experience', in that these are people who know what it is like to experience distress, and 'to be on the receiving end of treatments and services' (Rose, 2005). This was

also true for members of the SURAG. Members have not only grounded themselves in the worlds and lives of research participants and attempted to make sense of this but have also utilised their own experiences within this process. This is a distinctive aspect in this research. Knowledge has been developed which 'synthesises people's different understandings and perspectives on their common (and varied) experience' thus moving from 'individual experience to collective knowledge' (Beresford, 2003:39).

Those involved in research adhering to a participatory approach, whether service users, professionals or others, will each have their own unique experiences and knowledge. Experience is not the sole domain of service users just as knowledge is not the sole domain of professionals. There may well be particular service user knowledge, as there may well be particular professional knowledge, but there are also likely to be interconnections here. Service user researchers for example are likely to possess both experiential knowledge and a form of professional knowledge that may be to do with knowledge of research. Whilst professionals may be able to draw upon direct experience themselves so too can service users make use of both professional and other forms of knowledge. SURAG members for example possessed a wide and rich variety of experience and knowledge. Members drew upon their experiential knowledge but also upon their knowledge gathered from their own different professions, careers, and other life experiences. These were in the form of knowledge gathered in teaching, engineering, nursing, voluntary organising, local politics, involvement in community groups, campaigning and lobbying.

5.12 The placement of this research within the field

In this section I will compare the research presented in this thesis with other research and relevant documents conducted in the same or congruent fields. That is research and policy that has as its focus people with life limiting conditions whether defined conventionally, usually by professionals, or defined as such by participants. I will consider differences in findings and methodologies with the intention of illustrating the specific contribution of this research and to establish the place of this research in this field of inquiry. In considering other research here it is important to note that

SURAG members had a limited awareness of the existing literature. In initially developing the research idea and in completing the research protocol I had engaged with some of the literature and this was mainly in the area of policy in cancer and palliative care, and in service user involvement in research. I was familiar with some of the literature around social isolation and loss of control some people with life limiting conditions can experience and over the course of my studies I have engaged with a range of literature including literature in palliative care.

It was once the findings were agreed though that I fully engaged with the literature that specifically connects with the themes presented in this thesis. This was not a decision of method as such but rather a pragmatic one. I was aware that a collective analysis might engender findings that I could not foresee and I was also aware of wanting to avoid placing an overtly professional understanding on emerging themes. Although, as has been illustrated in section 5.10 of this chapter, my initial analysis was in fact professionalised. Grbich (1999:30), in considering the nature of theory/concept-generating research, advises resistance to submission to the influence and direction of previous research. Some grounded theorists also prefer to have only a light awareness of the existing literature concerning the field of inquiry (Seale, 1999:92; Cutcliffe, 2000; Bluff in Holloway, 2005:150). For me, the involvement of service users in the research required an unencumbered interpretation of data and brought an unknowness to the end product. It was for these reasons that I was not fully aware of the literature that connected to the findings presented in this thesis at the outset.

For SURAG members there has been very limited awareness of the literature. Over the course of working on this research I have periodically given members items to read but these have been primarily concerned with research and research methods i.e. articles about service users working with researchers on projects and information about the analysis of data. Rather, SURAG members came to this research and the analysis and generation of findings without fore knowledge of the body of writing about palliative care and service users needs. Their knowledge originated in their own personal experience as service users. This point is important as it highlights that the research findings presented in this thesis have been arrived at independently due to the central role SURAG members played in analysis and theme formation. In section

5.13 I will consider the relevance of this point. Leading on from the findings SURAG members defined their own recommendations to be taken forward from the research. These recommendations were couched in terms of 'key lessons for health and social care staff' and are shown here:

- Service users should be treated with greater respect
- Service users should be listened to seriously, heard and their concerns acted upon
- Staff should be prepared to learn from the knowledge that service users have gained from their direct experience
- Staff should treat service users with sensitivity and understand their experiences and needs
- Service users should be involved as active participants in all aspects of palliative care provision. This involvement should be at the level of decision-making within services as well as in consultation about services
- Service users should be involved in staff training in order to maximise understandings of long term conditions/palliative care issues and needs
- Service users should have access to a named clinical nurse specialist and/or other appropriate specialist staff
- Service users with palliative care needs should be invited to participate in research as partners with researchers
- Service users should receive a seamless service from health and social care in which departments and specialities communicate effectively with each other

SURAG members developed these recommendations over time with the aim of disseminating the research and recommendations. They are presented here in order that these service user recommendations can be kept in view when other research is discussed in this section. It is important to note that these recommendations are generic having evolved from all the findings in this research and are not specifically orientated to the field of palliative care. They were not intended as instructions on how to provide a good palliative care service and further work would be required to develop them into a set of guidelines for palliative care service providers. Rather the recommendations are applicable to any service and act as a set of principles that any health or social care service could be based upon.

This section is divided into three areas where different approaches to research are discussed in relation to the research presented in this thesis. The three areas are not rigid categories of research but I have attempted to broadly distinguish the type of research approach taken in the studies discussed. This has not always been easy, as methodology is not always clearly described. The main description of these studies occurs in section 1.4 of the literature review.

5.12.1 Conventional methodologies

I take conventional methodologies to mean methodologies that can be seen to occupy a position within positivism and this can be said to be research that engages in survey research utilising questionnaires and the quantitative method of statistical analysis (Crotty, 1998: 6). Some qualitative research may also be identified in these terms.

Despite having a restricted remit, illness self-management, work by Corben and Rosen (2005) for The King's Fund raised some issues that the findings in the current research echoed. For example the suggestion of key workers or care co-ordinators that are a point of contact to direct people to appropriate services or support is a similar idea to one of the recommendations in this research. Unsurprisingly though, the recommendations were focused on Primary Care and Acute Trusts improving skills of professionals in terms of illness self-management and on Strategic Health Authorities to develop information resources. Being a policy-orientated document with minimal direct service user involvement as either participant or as part of the research team the

final product distances itself from many of the concerns and experiences reported in the research presented in this thesis.

Participants in the current research for example gave very clear and unequivocal accounts of living with and managing their conditions, but in their own terms. The recommendations that SURAG members formed (as above) based on the findings were mainly focused in the area of the relationships between service users and professional health and social care workers. The conditions that participants lived with are not clear in the King's Fund research but it may be that their conditions were not as advanced as participants in the current research. The lack of involvement of service users within the King's Fund research is another aspect that may explain the general lack of service user orientated recommendations in its report.

A survey captured a great deal of information and is interesting in terms of the comparisons between the needs of participants who had cancer and those who had heart failure (Anderson et al, 2001). As the questionnaires were devised by professionals around specific problem areas it is not surprising that results are also very problem orientated highlighting how many times problems occurred for the participants that took part. Frustratingly, and a common limitation of this kind of research, there was hardly any detail about these problems that might give some insight to the participants' perceptions and priorities about them. For example, although 30% of participants with a cancer diagnosis in the sample reported a loss in their independence there was no indication of the nature of this (in conclusion this is in fact acknowledged by the authors). This study is indicative of research conducted within the positivistic sphere and comparing this research to the research presented in this thesis is very problematical because of the epistemological and methodological differences. The research in this thesis offers much rich and in-depth data. These are data that have been influenced at collection and analysis stages by people with the conditions at the centre of the study and consequently the findings are therefore not particularly problem-orientated but rather defined by service users themselves.

5.12.2 Qualitative methodologies

Qualitative methodologies considered here are those that encompass such approaches as ethnography, grounded theory, or phenomenology for example. They normally

would not include service users in the research team other than perhaps requesting the views of service users on written research information to fulfil ethics and governance requirements.

Horne and Payne (2004) were able to offer in-depth accounts from participants with heart failure and there were some similarities in findings with the research presented here. Running through the three themes were issues that have been prioritised and presented differently in the research presented in this thesis. Many issues that have been classified as 'Grief' in this research were raised. Participants' gave accounts of many losses they encountered due to their heart failure such as the loss of physical ability, loss of friends, and loss of a future. Participants' raised issues of dependence that again concurs with the current study. Other than mention these issues, and unlike the current study, dependence was not explored in any depth. As we saw in chapter 3, the current study highlighted independent/dependent as a theme in its own right and presented many vivid accounts from participants about this negotiation between independence and dependence. Fear and frustration was also clearly an issue raised by participants in Horne and Payne's (2004) research but again somewhat hidden in a range of different sub-themes such as 'Talking about Death' and 'Feelings and Attitudes'.

These issues, that corresponded with accounts from participants' in the research in this thesis, were found within other themes identified by the researchers indicating that the service user involvement in the research in this thesis brought issues to the fore in alternative ways. For example, whilst loss or grief issues were prevalent in Horne and Payne's (2004) research they were subsumed within researcher-prioritised themes. A similar point is highlighted in research by Carter et al (2004) who identified some issues for participants with regard to negative reactions from friends but desisted in highlighting these as significant aspects of their research. Indeed their question that gained responses regarding relationships asked for examples of any worthwhile experiences arising from their current situation rather than enabling a wider set of responses to occur (Carter et al, 2004). It is not therefore surprising that responses about positive hospice services and reactions of others were given. It may be more surprising, given the question asked, that participants did highlight friends

who were too embarrassed to see them and others who stopped seeing them through feelings of awkwardness.

There are some similarities between this previous research and the research presented in this thesis. Namely this is to do with what is called independence in the research in this thesis. Here it has been highlighted how participants gave accounts of striving for independence, of resisting dependence, and of challenging assumptions and perceptions that fostered a view of participants' as passive and accepting individuals. In the research presented here, living with a life limiting condition was shown to be affected by external structures and assumptions with participants' resisting passivity and individualised notions of coping. The application of the social model of disability in the research presented here may help to explain this alternative prioritisation of key issues. Hughes et al (2005) also endorse this point in their research with people who had a diagnosis of MND, when they highlight that 'living with MND is not characterised by reaction and passivity, but rather, people were proactive in their approaches...'.

Themes in research by McPherson et al (2001) resonate with the themes initially identified by myself in the current study and appear to indicate a professional prioritisation of themes such as 'personal/intrinsic factors', 'external/extrinsic factors', 'perceptions of normality', and 'response to discrepancy'. Despite the language in which the themes are presented there are however some very similar issues identified to that presented in this thesis. The overarching theme 'taking charge' has a similar emphasis to the theme of 'independent/dependent' presented in this research. Whilst McPherson et al (2001) interpreted participants' as conveying accounts about accepting and adapting to their impairments they also point to participants' taking responsibility for their life, being involved in self-management, and striving to be autonomous and self-directed. These researchers appear to be mainly concerned with individual's response to their condition but do acknowledge wider influences that impact on individuals that are related to their impairments. They acknowledge this however without making connections to principles in the social model of disability for example.

Barnett (2005) also raised some similar themes to those in this thesis such as the fear and frustration the condition brings and the social losses experienced. However the other two themes were focused on very physical aspects of living with COPD. Physical aspects were certainly very evident in the current research but themes were structured very differently prioritising emotional aspects of the conditions participants' had and also the balance between independence and dependence for example. Further to this, in her discussion Barnett (2005) has a focus on coping with COPD and coping strategies. A key difference with the current research is in this research's linkage to external social forces that impact on individuals rather than focusing on individual adaptations to life limiting conditions.

Lawton's (1998) ethnographic study set in a hospice is difficult to compare to the research presented here due to such differences in perspective. It could be that the participants in Lawton's research were far closer to death than those in this research and hence different issues arose. A considerable period of time was spent within the hospice during fieldwork and so in a way quite different aspects were being considered. However no sense of what difference this research may mean for people requiring hospice care is conveyed. The person at the centre of the study, people mainly with a cancer diagnosis, remain invisible in her writing much in the way she suggests they do in their daily lives. This may be a central concern for research conducted in this way, although I do not claim this is so for all such research. This particular research though appears to have distanced itself from the people who were 'studied' and from the experiences of those same people. I do claim that the involvement of the SURAG enabled this possible outcome to be resisted in the current research.

5.12.3 Collaborative methodologies

The term collaborative methodology is taken here to mean research conducted with service users. That is research that in some way attempts to include service users at some or all stages of the research process in democratic ways and that attempts to equalise research relationships. Research will be highlighted as participatory or user-led for example when they are discussed.

There are two main areas of convergence between Croft et al's (2005) participatory study and the research presented in this thesis. This convergence is the areas of findings and method. Firstly the findings will be considered. Whilst Croft et al's (2005) research had a specific focus on one aspect of palliative care service provision findings between the two projects share many similarities. Croft et al's (2005) research had a focus on one professional group within palliative care and therefore raised issues in relation to this group but broad themes were raised about the quality of both the social workers themselves and how they delivered their practice. In chapter 4 of this thesis and summarised in section 5.9 above we have seen how participants in this research valued certain 'person skills' from professionals and how a respectful relationship and professional but supportive practice was given great emphasis. Croft et al (2005) also raised such issues as themes from their research. The research designs had many similarities too. The central role of service users in both steering groups and the advisory group is apparent from Croft et al's (2005) research. Service users with life limiting conditions came together and offered their perspectives on a range of issues to do with the research. Having different steering groups over the course of the project with different service user members was a pragmatic way of involving service users who are likely to be very ill. The similarities in findings, concerning the importance of relationships, between the research reported in this thesis and Croft et al's (2005) research may be in some part attributable to this involvement of service users within the research. Unfortunately though it is not clear as to how involved service users were in the analysis of data and so it remains uncertain as to the influence of findings in line with service user insights and interpretations.

This process of service user influence in analysis and findings generation is clearer though in other work that focused on issues about the welfare state (Beresford & Turner, 1997). Although this research had a very different aim to that discussed in this thesis, to enable welfare state service users to have a say in the discussion about the future of the welfare state, there were some comparable findings. The Citizen's Commission research identified issues in the areas of the funding of welfare, benefits, and the education and training for people to be self-sufficient for example, but it also raised issues about independence and services. 'Independence not dependence' was

one of the key themes in Beresford & Turner's (1997:141) research with the Citizen's Commission.

It was identified how service users in the research wanted the support to be able to live independently and to be able to contribute to society. In the context of this research this was associated to a perception of being trapped in the welfare system and of wanting ways out of it. Three main components were that people did not want to be pushed into institutions or other separate services, people didn't want to have to rely on partners, family or friends to 'look after' them but instead to have suitable, flexible services when needed, and finally people did not want to have to rely on benefits but rather wanted to be self-supporting. In the current research we have seen in section 3.8 and in section 5.8 that participants' struggled against increasing dependence. Specifically we have seen that despite needing to rely on help and support from others, participants' also tried to resist relying on family and friends. Others clearly wanted to be able to live their lives to the fullest despite living with a serious condition. They wanted the right help and support to enable this to happen, for some the direct payment scheme offered more independence.

As in the current research, the Citizen Commission also identified negative experiences of services in health and social care (Beresford & Turner, 1997:146). Participants' in both projects raised issues about services that were of a poor quality, that were inadequate and unresponsive, and that service users were powerless to influence. Due to differences in aim and focus of these studies there are obvious differences in the findings generated. However there are also clear similarities as just described. Can this be in some way due to the central role of service users in the conduct of the projects and particularly in the data analysis stage of the projects? We will return to this in section 5.13. It is also clear that, as for this research, the Citizen Commission research was influenced by the social model of disability and emancipatory research (Beresford & Turner, 1997:26).

Morris's (1993) research also shares some striking similarities with the research presented here. This is most evident in the area of health and social care services. It was highlighted how there were many accounts of services being unresponsive to participants needs:

The general experience...was of services which were not able to respond to either particular or changing requirements and the restrictions on the level and type of service delivered in consequence created major restrictions on their lives.

(Morris, 1993:105)

There was evidence that service users were required to 'fit to the service' rather than the other way around. We have seen in chapter 4 (services) of this research that many participants' relayed accounts of inflexible services and of struggles to convince managers of their differing and changing needs. As in the research presented in this thesis, Morris (1993:113) not only found issues with services and the delivery of these services but with relationships with health and social care staff as well. Difficulties with these relationships were common with patronising, insulting and at times abusive behaviour being experienced.

There are some specific examples in Morris's research, which have also been identified, in the current research. For example, a gay participant found her carers homophobic, they did not make any attempt to understand her life and it was very clear to her that they were only in her home to assist her get up in the mornings, she would not have ordinarily had them in her home other than for this reason (Morris, 1993:113). The experience of Jess in the current research concurs with this as we have seen in chapter 4 (services) and in chapter 3 (section 3.7, difference/individuality) where Jess describes how carers can have a pre-planned attitude to her based on the fact of her MS diagnosis. Jess speaks clearly of the tension between the necessity of accepting assistance and the distress caused by carer's negative attitudes. It is evident in the current research that there is a need for services to treat people as individuals and to offer appropriate support, choice and control.

There were three main areas identified in Morris's (1993) work that were not explicitly highlighted in the current research. Firstly, in the research presented here and unlike Morris's research there were no participants' interviewed who were receiving residential care and hence no accounts about this were given. Secondly, Morris (1993:89) highlighted in her research the role disabled people played as

caregivers themselves. This may have been in the form of emotional support to those who gave them personal assistance but was also concerned with more formal assistance to children, partners or parents. It is highlighted that disabled people do not want to be denied the possibility of fulfilling this role but that for some providing assistance to a family member was required in the absence of statutory services or support. It is argued that being denied the support that would enable a disabled person to offer support to others is to thwart their independence and their participation in caring reciprocal relationships (Morris, 1993:100). Thirdly, participants in Morris's (1993:72) research raised issues about receiving help within personal relationships i.e. having assistance provided by a loved one. Different challenges and benefits of this situation were identified with the main issues being around the danger of dependency, both threats to and increased autonomy, protecting loving relationships, and the risk of emotional or physical damage.

The areas of people as caregivers themselves and of receiving personal assistance from loved ones are the two striking differences with the research presented in this thesis. It is worth considering why these two areas did not arise. Over 50% of participants in the current research lived with a partner and most had close family members locally. When reviewing section 3.6 in the findings chapter (relationships) we find only very limited reference to issues that could be seen as participants being caregivers or of receiving assistance from loved ones. The main focus in this theme is on the challenges to relationships and the distance encountered with people to whom participants' were previously close. Greater emphasis is placed on the support and assistance received from others. Hazel mentioned that she had been used to caring for others rather than others caring for her and Delia mentioned her 'supportive family' but other participants spoke more of the rejection of others and the difficulties with friendships. These points concur with Bury's (1982) point that chronic illnesses disrupt normal rules of reciprocity and mutual support. We have also seen in section 3.8 of the findings chapter (independent/dependent) that some participants had wanted to ensure arrangements were in place for when they had died in order to save their partners and families some difficulties and this could be construed as a form of indirect care giving.

It may be that the participants in the current research are less well than those in Morris's research although this is impossible to say because no information was given by Morris as to participants' conditions or severity of those conditions. Also the participants in the current research saw themselves as having a condition that was life limiting and perhaps their families did also. This may have affected their opportunities to offer care to others around them. Although over half the participants' had partners at home most were also in receipt of care or assistance at home from statutory services, namely social services. It may be that loved ones felt unable to offer care or that they did but this was not relayed by participants in this research. The research was overtly directed at the experiences of participants rather than informal 'carers' although participants were asked to discuss their relationships. These areas of difference are interesting and are not easy to explain. Whilst there is work on relationships there appears to be no overt reference to these two specific issues within the literature on life limiting conditions reviewed for this thesis.

In a series of user led research initiatives some common themes that resonate with aspects of the current research can be seen (Shaping Our Lives, 1998; 2001; 2003a; 2003b). Issues concerned with professional and service user relationships, as well as how service users are perceived and treated are central to this work and it does not seem to be coincidence that this work has significantly similar themes to the research presented in this thesis. The Shaping Our Lives work especially but also, to a lesser degree, the current research has service users centrally involved in it and this would seem to enable issues that are concerns of service users themselves to be stressed.

To reinforce this point it is useful to consider work conducted over the last few years that has been evaluating services provided by Centres for Independent Living and other user-led services for people with a wide range of impairments (Barnes et al, 2002). This work has shown that user-led providers of support were far more focused on individual's needs and the quality of the relationship between provider and client than conventional providers. Research with service users centrally involved would seem to keep the issues of importance to service users themselves clearly in sight.

From the field of mental health two particular collaborative projects have been discussed in which the process of the projects and the outcomes were clearly

influenced by the service users involved (Rose, 2004). Whilst being clear about the challenges facing service user involvement in research Rose (2004) is also clear about the possibilities. Possibilities to maximize upon the experience of service users, possibilities to promote the standpoint of service users, and possibilities to promote the knowledge that service users have gained (Rose, 2004).

I would suggest there are more links between the research presented in this thesis and those highlighted above from the fields of mental health research, disability research, and user-led research rather than with research from within palliative care and the aforementioned conventional and even the qualitative research methodologies. I would also further suggest that this research has been critical. Critical in the sense of positioning the research in a different orientation to the kind of research normally occurring in palliative care currently. Whilst palliative care research has been very productive in highlighting the day-to-day and personal experiences of living with life limiting conditions, primarily cancer, it has failed to position itself socially by highlighting social forces that may also impact upon individual's lives.

In considering this section it is important to emphasize that SURAG members were not aware of any of the literature or research drawn upon and, importantly, nor were they aware of any of the findings from this body of work. I suggest that it was the central involvement of service users in this research, by way of the SURAG, that goes some way to explain the differences in findings between this research and other research discussed within this and other sections of the discussion chapter.

5.13 Thesis conclusion

The findings presented in this thesis have been arrived at independently as previously described and corroboration with certain studies, or aspects of these studies, has been illustrated. I have been able to show linkage to work in a wide range of disciplines regarding the experiences and needs of people with life limiting conditions. This, I argue, provides confirmation of common experiences. It is particularly interesting to note that corroboration has been much more likely with studies that have service user involvement or the social model of disability as a central tenet within them.

In this last section of the thesis I consider to what degree the aims of the research have been achieved and what key points can be claimed from it. There are discrete outcomes from this research, only one of which is this thesis. There are also contributions that stem from both the research itself and from a production of knowledge.

Firstly it is important to revisit the original intentions of the research. The aim was to gain access to the views of service users about their experiences of living with life limiting conditions and about what they wanted and experienced from palliative care locally. Capturing accounts from participants about experience of life with their conditions was essential to complete the related aim to establish what service user needs were in terms of support and care services. These two aspects are different and yet closely related. Gaining accounts of the links and impact of external social influences was also an aim, along with how these social factors may affect people's lives. Lastly, the involvement of palliative care service users in the research process was intended to be a focus for learning and reflection.

It is important to note here that this research was a small project in terms of its sample size, 25 participants took part, and in that it was conducted in one locality in the South of England. Whilst in conventional terms this would suggest a difficulty in the ability to transfer or generalise these findings to another setting, I suggest that these collective findings, which concur and add to previous findings in a similar field or conducted in a similar way, offer their own unique contribution to the field. I am also confident that the process and product of this research has been explicitly illustrated, giving the reader opportunity to judge the effectiveness of the collaborative nature of this project and the service user orientated findings.

5.13.1 Issues and concerns identified by this research

We have seen how a great deal of information has been gained about living with life limiting conditions. Within this, participants spoke of their needs and often about how these needs were either not met or were inadequately met. It was clear that for participants with non-cancer conditions, experiences of services were very different locally to those with a cancer diagnosis. Palliative care, mainly provided by a hospice and available to people with cancer, was reported on favourably but in contrast

experience of other providers of care and support was patchy in quality. From these areas favourable comments were normally reserved for some individual professionals, day centres, or support groups. Palliative care was not commented on explicitly by participants with non-cancer conditions as they were either not aware of palliative care or not in receipt of it. This was also the case for these participants in terms of the identification of palliative care needs. Awareness about what palliative care may offer in terms of meeting some individual needs was absent. Many issues were highlighted though in which participants' felt they were treated poorly or inconsiderately.

This research has clearly identified the strong need for a pursuance of a diagnosis when faced with symptoms and the impact that diagnosis with a life limiting condition has on individuals and their families. The research has also prioritised the emotions that can be experienced by people who have a life limiting condition. A quite unique facet of this research has been this emphasis placed on the emotional aspect of living with a life limiting condition. This emphasis has been on the fear, anger and frustration, and the sense of grief that participants experienced. These emotions were not only concerned with what individuals experienced personally but also reflected responses and effects of others around participants. Indeed relationships with others were given great emphasis in this research, particularly in terms of the need for continuation of genuine and sincere relationships over time and in terms of the struggle with assumptions and stigma about participants' conditions, or changed physical ability and some friends' withdrawal from contact. Despite some disabling stigmatising experiences this research also highlighted participants' efforts to resist feelings of difference and illustrated efforts to promote individuality and to retain a sustained sense of self.

Other aspects that have been clearly identified in this research concerns issues of independence, individuality and the use of services. Independence will be discussed further in section 5.13.5 below. It has been clear that in the midst of negative circumstances participants' accounts indicated a desire and an ability to perceive themselves in positive ways. Participants wanted to be seen by others in this way also, to be seen as the individual they were albeit a different or changing individual but one who was of value and of continued significance. A wide range of concerns participants had with the health and social care services they either came into contact

with or required but did not receive have been raised. Key themes about services that participants raised as important were helpfully identified by SURAG members and consisted of issues that corroborate other research in which service users have had a central role.

5.13.2 Contrasting issues and concerns between participants with cancer and participants with non-cancer conditions

In terms of the research, we have seen how marginal participants with non-cancer conditions felt in many ways. This marginal feeling was associated to both individual aspects for participants living with their conditions but also had a clear social dimension. Participants with non-cancer conditions widely indicated that they felt unsupported and relayed their difficulties in getting their needs identified and acted upon. Participants with a cancer diagnosis who could access a hospice relayed far fewer concerns on this point. Participants with non-cancer conditions were also more likely to identify a struggle to obtain the services and support they felt they required compared to participants who had a cancer diagnosis.

A related point here is the value that participants with cancer placed on accessing a hospice and its day centre facility. Participants with non-cancer conditions were unable to access this resource at the time of data collection. The participants with non-cancer conditions also identified a desire to support and be supported by others in a similar situation, however this was mainly achieved only by participants with cancer who accessed the hospice day centre. This research has identified unmet need for participants with non-cancer conditions and clear service provision differences between participants with cancer and those with non-cancer conditions. These points have been corroborated by the SURAG.

The other differences between participants with non-cancer conditions and those with cancer was that it was the latter who reported friends being embarrassed and not knowing what to say to them; it was mainly participants with cancer who spoke about planning and arranging for their deaths and protecting or helping their families after they had died; participants with cancer had fears of dying allayed by their contact with and experience of care and support in the hospice; it was mainly, but not solely, participants with cancer who initially saw their diagnosis as a death sentence.

Across conditions there were many common issues as well. This was very clear in themes highlighting emotional aspects of these participants' lives as well as in accounts given about relationships that were affected negatively since diagnosis with conditions included in this research. All participants struggled with maximising their independence and exerting their individuality. An aspect of this research, which is unusual to see within palliative care, is this issue of independence as discussed in section 5.8. There were similarities also in the impact diagnosis had on participants and on the range of losses, frustrations and restrictions participants felt were present in their lives. All participants gave many accounts of services and shared many experiences of poor services or relationships with a variety of professionals. It is interesting to note here that relationships with professionals were of high importance to service users and not purely technical expertise. To some extent all participants encountered the stigmatising effects of living with a life limiting condition.

It is also interesting to note that there were some accounts that were likely to have been quite specific to particular conditions. For example two participants who were HIV+ feared their partners contracting the condition and the participant with ME had particular problems in gaining her diagnosis at a time when scepticism about this condition was rife.

5.13.3 The research in the context of palliative care

Another point in need of consideration is the placement of this research within palliative care. In some ways the research here is a challenge to existing practice as hospices tend to have a particularly fixed understanding of palliative care, who should be in receipt of palliative care and of the notion of care. This research has deliberately included a wide range of conditions and shown how understandings of chronic or long-term conditions is changing with evidence emerging suggesting that non-cancer conditions require similar palliative consideration to those people normally associated with and in receipt of hospice provision, people with cancer. This research has clearly identified many similarities in concerns between people who have cancer and people who have other conditions. Having such a mixed sample of participants' has enabled these commonalities to be shown. Members of the SURAG also identified these commonalities when considering participant data.

We have seen in sections 1.2.3 and 5.12 that research has previously compared experiences of people with different conditions, often one particular non-cancer condition with cancer, but I argue often without the detail presented here. Taking this route has meant however that individual conditions have not been explored in great depth. In effect though, what has been achieved is a more inclusive project in which participants were self-identifying as living with a life limiting condition and perhaps defining this in a broader way than professional groups have hitherto done. We have seen in chapter 1, literature review, how opinion is slowly changing within palliative care that is now enabling debate and evidence accumulation about the needs of people with non-cancer conditions and for these needs to be acknowledged and acted upon. This research has not focused upon physical symptoms as much other palliative care research has done but rather has produced wider understandings of living with a life limiting condition. Whilst participants were not asked directly to describe their particular symptoms, due to the questions asked there were opportunities to focus on these aspects. However participants chose to examine wider issues that have not been so readily identified in palliative care research.

5.13.4 Research process and outcome issues

An important aspect of this research has been the participative approach taken which has brought with it some challenges but also many benefits. In chapter 2, methods, and section 5.11 of this chapter we have seen the extent of service user involvement in this research. There have been achievements of this research in terms of both process and outcome benefits for service users, the research itself and myself. In terms of process, service users have benefited by way of their own personal development, empowerment, and support found within the SURAG. I have benefited by meeting all the SURAG members, learning from them and with them, developing friendships, and from their unique input to the research. In terms of outcomes, the research benefited throughout but particularly at the analysis and theme generation phase when the direction of the research and its findings really did shift. Data analysis supported or confirmed many previous research findings even though members of the SURAG were unaware of these previous findings. This adds a new confirmation to the key issues facing people with life limiting conditions as well as adding unique insights of its own.

It is worth noting that a study of the impact of service user involvement within eleven research projects in London highlighted that the projects which generated the most positive experiences for service users were those that treated service users as partners (Barnard et al, 2005:69). The research presented in this thesis was conducted in such a way as to engender ownership of the project amongst members of the SURAG with a high contact between myself and the group that assisted group members to feel they had a big say in the research (Cotterell et al, 2006). Despite some members identifying the project as 'Phil's research', in that it formed part of PhD study, all members wanted the project to succeed and believed in the project as a way of gaining service user insights and of raising service user concerns and priorities. In light of this it is worthwhile to consider if I was the 'owner', or at least the 'manager' of this research. Over the course of the project I was concerned by this 'ownership' issue and tried to ensure the project was democratic and that members of the SURAG had an equal voice and an equal say in decision-making. I always wrote an account of our meetings (minutes) and distributed this to members prior to the next meeting along with an agenda for the next meeting that was linked to, but developed on, from the previous meeting. The agenda was always open to alteration by SURAG members and this was made clear to members. However, it was always myself who wrote the minutes. The project did take on a certain life of its own though, that I could not have predicted at the outset and this was due to the influence of SURAG members. At times I was more like a supporter or friend of members who requested information from me or who queried different aspects of the research and I then considered and responded in discussion at the following meeting. Rather than being the 'owner' or 'manager' of the research I consider my role was more of a facilitator.

In terms of the research process I would argue the participatory approach worked and is a contribution, methodologically, within palliative care research. A useful approach to the involvement and engagement of service users in palliative care research has been achieved. The SURAG was effective and especially in the data analysis phase of the research.

The success of the service user involvement in this research is particularly significant considering the potential difficulty involving people who have life limiting conditions. We have seen in section 1.3.9 that it is considered a challenge to involve

service users in palliative care research and this project has offered some balance to the hesitancy about involving service users in palliative care. The length of a project and the short life expectancy of people with palliative care needs has still remained an issue, but has been managed by combining a range of service users with a range of conditions and differing prognoses. Membership of the SURAG was diverse and novel in terms of the mixture of conditions of which members had direct experience.

Another distinct contribution has been in the area of drawing the research to an end with the SURAG members. The ending has been managed thoughtfully and effectively with advanced planning, discussion and the penultimate SURAG meeting set aside for ending work by way of a reflective group exercise (See annex M). One SURAG member in particular had been anticipating the ending of the project and the group with sadness. For all involved, myself included, there were competing emotions around our ending: sadness, regret, excitement, fulfilment and a sense of achievement.

The reflective exercise enabled us all to consider four specific questions and reflect on different aspects of the project and the group. Members' thoughts were written on post-it notes and pinned on a flip chart size drawing of a tree, for all to see the range of comments from each other. All members were given an A4 size, typed and laminated colour version of these four trees with our comments on at the last meeting, as a closing memory of the group. This exercise enabled us all to discuss our work over time, the people we knew and who helped us, as well as our achievements and outcomes. Our last meeting was focused on the future and our dissemination plan. At the close of the SURAG we agreed to keep in contact informally for two reasons. Firstly in order to disseminate the research together as we are presenting the collective analysis phase of the research at the INVOLVE conference in autumn 2006 for example as well as organising local events. Secondly because we are jointly taking forward members development of a self-help/campaign group.

It is reasonable to consider if an alternative methodology may have brought greater satisfaction or benefits to both the members of the group or to the research findings. Action research is one methodology that appears to offer possibilities for a different kind of involvement and an involvement that may have been appealing for SURAG members. With the reflection and action cycles there may have been a possibility of

SURAG members being part of the research team and engaging directly with other people who have life limiting conditions in a developmental way over time. This may have satisfied members who had identified in this research the desire to become more closely involved with participants. Alternatively, in a service user led research project SURAG members could have had greater choice with regard exactly what aspect of the research process they wanted to become more involved in. This may have been in the initial design and bidding stage and/or in data collection. Alternatively they may have invited researchers to assist at one or more stages of the project.

There are similarities in the focus of research that is conducted collaboratively but I argue a distinct and quite unique contribution from this palliative care orientated research, in terms of methodology, is that of the collective analysis and theme generation stage as described in chapter 2. This was not only an impressive undertaking as described previously, but of particular interest is the nature of the quite 'critical' research findings that an otherwise non-political and non-activist group of service users were involved in generating. The SURAG were people who came together solely for the purpose of being involved in this research but this involvement led to the challenging findings that have been presented in this thesis.

A further point concerns the nature of the interviews and group discussions themselves. In what way were they respectful of participants? In an extract from an interview (annex G) the dialogic and gently probing interview style can be seen. I did not want to present myself as the 'expert' in any way but rather of an interested, perhaps partisan, supporter who wanted to facilitate a presentation of the participants' experiences from their perspective. The SURAG were very helpful here in reflecting on data collection and in stressing the need to keep the people involved, and their feelings, clearly in sight. Supplementary probes and summaries of participants' responses to questions were not aggressive or in any way intended to make participants contradict themselves but were intended to enable a thorough exploration of the issue concerned.

In considering this participatory research methodology in the field of palliative care, some key lessons for successful involvement of service users have been illuminated

by this research. These are presented here as an indication of the key aspects that helped this project and may help with future projects, rather than as an exhaustive list:

- An epistemology and methodology that is compatible to the aims of joint working and exploring beyond personal experience, needs to be in place as a starting point.
- A partisan researcher stance committed to furthering service user concerns.
- Research relationships whereby researcher and service users have respectful and democratic relations.
- Promoting individual experience whilst highlighting collective accounts and experiences.
- The utilisation of methods of data collection that avoids disempowering participants.
- Combining a range of conditions in any steering group/advisory group, which include people at different stages of their condition.
- Offering suitable support and training as part of the program of research, both informal and formal. Regular contact, up dating and inclusion whether face-to-face, by telephone or in writing is essential.
- Ensuring service users remain at the centre of the project having an equal say in the direction, process and outcomes of the research.

5.13.5 Contributing knowledge

In considering underpinning assumptions in this research, the social model of disability has been a key factor influencing the perspective of the research to broaden its focus on societal and environmental issues as well on individual issues. This has been primarily noted in the effect on participants of health and social care services

that treat people in terms of their impairments rather than their needs for support, choice and control in their everyday lives. There is also a direct link here to the notion of independence and its prioritisation in this research.

The influence of the social model has also been noted in the process of the research with service users involved in a more equal relationship with the researcher than in most conventional research methodologies. This connection to different fields of inquiry such as disability studies is a further unique contribution to knowledge generation in palliative care research. It is clear that this connection was of particular assistance in enabling an alternative understanding of the notion of independence to occur. The connection also helped in many other areas of the research. It meant that, as well as revealing many accounts of the experience of life with a life limiting condition and of services, we went further and considered societal impacts on participants that came through in many of the themes in the findings of this research. Despite a suggestion that the social model deflects attention from individual concerns and impairments it is clear that both individual concerns and societal influences on peoples lives have been raised in this research.

As has been indicated in section 1.2.2, understandings about the nature of palliative care and who has access to palliative care services are evolving along with understandings about long-term conditions. The connection to the social model of disability is therefore timely with the Disability Discrimination Act (2005) extending its remit to include cancer, HIV+ and MS and the Disability Rights Commission (DRC) (2006) acknowledging the disadvantages that people with long-term conditions face. The DRC also endorse a link between the social model and palliative care, as well as identifying rights at the end of life to support, choice and participation (Zarb, 2006).

The notion of independence has been extended here, in light of ideas from the field of disability studies as discussed above, to suggest that the absence of control and choice in all aspects of peoples daily lives will be dependency creating. This lack of control and choice for people with life limiting conditions can be most evident and have a great impact in the area of the services and support required for people to fulfil their daily lives to the maximum. It has been noted that 'service users are sometimes

stereotyped as passive and dependent' (Turner & Beresford, 2005b: vi), and this can be especially so in palliative care. The insights from participants with life limiting conditions about the notion of independence are particularly interesting, add additional knowledge to this debate and encourage a reconsideration of paternal and individual assumptions. Instead of a one dimensional negative understanding, evidence from this research suggests that people with life limiting conditions require opportunities to fulfil independence on their own terms and as may be appropriate to their own unique circumstances. These insights are an example of the 'compelling insights' referred to by Kincheloe and McLaren (in Denzin & Lincoln, 2005:306) in section 2.2.6 of the methods chapter.

As well as being a distinct theme in its own right, independent/dependent was in fact a central and overarching theme with this negotiation between independence and dependence being evident across all themes. Participants gave accounts of struggling against their diagnosis in order to exert their independence. This was achieved in some measure but dependence was invoked by physical reactions to conditions and by the negative reactions of some friends and family members. The fear of dependency at some future date was evident for some participants whilst poverty was dependency creating for others. There were many accounts relaying a struggle with carers, both paid and unpaid, who far from maximising a sense of independence and control fostered a sense of dependency and submission to others will. This struggle was evident for many and some participants illustrated their need to resist higher levels of care.

Within the theme of 'grief' it was clear that, for some, there was an implicit sadness associated with a perception of a loss of independence. Changes in functioning and enforced requirements to re-learn many aspects of life were clearly illustrated. The difficulty of leaving work in terms of a loss of social relationships that impacted on independence was also described. Within the theme of 'services' this negotiation between independence and dependence was also evident with one participant particularly highlighting their battle in hospital to receive what was required. Within this theme there were also constraints put on participants by a social services homecare package of care, whereas for another participant independence was enhanced by their carers who were employed under the direct payments scheme.

It is clear then that whilst highlighting a wide range of experiences regarding living with life limiting conditions, this research has raised the importance of independence, control and choice for people who live with these conditions. The impact of being diagnosed and living with such conditions has been illustrated through the first hand accounts of service users. This research builds on previous research that has also identified similar and different aspects of living with life limiting conditions. This research goes further however in proposing that independence and independent living occupies a central position for people with these conditions. Striving for, and maximising independence, control and choice whilst living with life limiting conditions is seen to be a key requirement. Commonly, participants indicated negotiation with physical, social and emotional aspects of their conditions whilst attempting to live as fully and independently as possible. In particular there was a quest for choice and involvement in decision making on issues concerning them, a sense of maximising empowerment in daily lives and having control of the environment around them was seen to be important. This included control both within relationships and a range of services and support that participants required. There is a clear dynamic and progressive link between passivity on one side of a continuum and personal empowerment on the other. Participants strove to move along the continuum towards empowerment in a range of areas and in particular towards independent living.

The findings of this research have clearly illustrated the profound distress and quite shocking and frightening experiences that participants have encountered. Allied to this though, it has been clear that participants strive to focus on living life as fully as they are able. This focus on life and living rather than on a life and a person that is dying has been emphasised throughout the findings chapters. A reprioritisation of life and relationships has been clearly illustrated. We have heard of fear being reduced for participants with cancer, which has enabled engagement in life. For many participants life has taken on a battle like aspect as well as a sense of being peripheral to the main stream. An extreme example of this battling notion was one participant who had, whilst taking some control of her situation, totally eradicated the record of her life. A balance was often sought between a reality of extreme changes in many spheres and participants endeavour for a vision of greater choice, control and independence as mentioned above. This research has highlighted how participants' friends and family,

in addition to health and social care services and members of staff, can contribute to or impede participants' attempts to achieve autonomy.

One final contribution to knowledge is the emotionality of the findings that was given primacy by the service users in the SURAG. It was made clear in section 5.10 that there was a distinct difference between this emotional emphasis within the findings, my initial interpretations and other previous research in this area. The prioritisation of emotions as central findings in a study with people who have life limiting conditions is of interest and novel. We have previously seen how emotional impact can easily be over shadowed within research findings formed solely by researchers. Service users involved in the research as members of the SURAG enabled this emphasis to occur by way of the knowledge they possessed that originated in their direct experience. I acknowledge the value offered to this research by SURAG members and argue that this research and its findings are more firmly embedded in service users concerns because of their involvement.

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ANNEX A

A summary of the conditions participants' in the research experienced

Cancer

It is thought that '...over 75% of cancers in developed countries are attributable to environmental factors and are in principle avoidable', however, 'apart from smoking and sunlight there is little indisputable evidence concerning the causation of the bulk of malignant disease' (Rees et al, 1993:16). Malignant disease is a classification of cancer that indicates it cannot be controlled and is likely to prove fatal, and benign disease refers to cancer that is unlikely to spread to other organs or parts of the body and which is unlikely to recur following treatment. Other terms used include advanced cancer, which is the term generally associated with malignant cancer in which the cancer has spread from a primary site to other areas of the body (secondaries).

According to the National Institute for Clinical Excellence (2004a:3), 'over 230,000 people in England and Wales develop cancer each year, and cancer accounts for one quarter of all deaths'. On a global perspective cancer is thought to be the cause of 12% of all deaths worldwide and is the second most common cause of death in developed countries (World Health Organisation, 2002:xii). Despite this level of incidence and the number of people who die from cancer each year the first National Cancer Patient Survey showed wide variations in the quality of care delivered across the country (DH, 2002).

It is suggested that cancer is a stigmatising condition, which contributes to the fear experienced by many people with this diagnosis (McNamara, 2001:32). In earlier research with people who have a cancer diagnosis, cancer has been highlighted as a metaphor for death, and this research also identified significant changes in these people's identities, and in their relationships with others (Exley, 1998:218). The 'impact' of having a cancer diagnosis, especially advanced cancer, has been clearly described and this 'impact', compared to other non-malignant conditions, can be argued to be readily understood by the general public.

Cerebral Vascular Accident (CVA or Stroke)

Cerebral Vascular Accident is the term widely used to explain the event of a blood vessel in the brain bursting, and is also referred to as stroke. Stroke is the third most common cause of death and the most common cause of adult disability in the UK (Wolfe et al, 1996:3). It is estimated that 130,000 people in England and Wales have a stroke and that about a third of this number of people are likely to die within the first 10 days, about a third are likely to make a recovery within one month and about a third are likely to be left disabled and needing rehabilitation (The Stroke Association, 2005). There are many different classifications of stroke which include subarachnoid hemorrhage and there are a wide variety of possible causes of stroke including genetic predisposition, hypertension, and high cholesterol levels.

The incidence of stroke is closely linked to age with 0.8 per 1,000 of the male population and 0.7 per 1,000 of the female population having a stroke amongst 45 to 54 year olds, rising to 9.4 per 1,000 of the male population and 7.4 per 1,000 of the female population having a stroke amongst 75 to 84 year olds in the UK (Wolf et al, in Barnett et al, 1992:4).

Beech (in Wolfe et al, 1996:102) gave an indication of the geographic inequality in the services provided for people who experience a stroke. It has also been highlighted how the most impaired survivors of stroke are only able to be in private accommodation (i.e. at home), if they have an identified carer, and that informal carers (i.e. family members) play an important role in 'filling the gaps in formal service provision' (Wilkinson, in Wolfe et al, 1996:245).

Deaths from stroke for most people are not sudden, some will occur over a few days whilst others who initially survive will live with high levels of impairment for some months (Rogers, 2003). As highlighted above, approximately one third of people who have a stroke will go on to live with disabilities in need of rehabilitation and variable levels of functioning. Some will live with weakness or inability to use their arm and leg

on one side of their body, difficulty or inability to speak, difficulty or inability to swallow, and some cognitive impairment.

Chronic Obstructive Pulmonary Disease (COPD)

COPD is an umbrella term for a number of conditions, including chronic bronchitis and emphysema, all of which make it harder to breathe. COPD leads to damaged airways in the lungs, causing them to become narrower and making it harder for air to get in and out of the lungs. The word 'chronic' has nothing to do with severity, it simply means the problem is long-term (British Lung Foundation, 2005). The National Institute for Clinical Excellence expand that 'COPD is characterised by airflow obstruction. The airflow obstruction is usually progressive, not fully reversible and does not change markedly over several months. The disease is predominantly caused by smoking' (National Institute for Clinical Excellence, 2004b:2).

COPD accounts for over 25,000 deaths in England and Wales each year (Office for National Statistics, 2000). A recent study suggested that severe COPD is in effect a terminal illness with people experiencing multiple symptoms, inexorable decline in activities of daily life, and social isolation (Seamark et al, 2004). In recent years there has been a spiralling interest in COPD and the palliative care needs of people with COPD in particular (Shee, 1995; Skilbeck et al, 1998; Chavannes, 2001; Shee, 2003; National Institute for Clinical Excellence, 2004b). Skilbeck et al (1998) highlighted the physical need for people with this diagnosis identifying that 95% of their sample experienced extreme breathlessness, 68% fatigue, 68% pain, with 87% being unable to take a short walk around the house and 82% finding their social life greatly affected.

Along with the acknowledgement about the palliative care needs of people with COPD there has been a debate about the appropriateness of people with COPD being accepted for palliative care within hospices in the UK. It has been said that the challenge to redress the unmet palliative care needs for people with this diagnosis has now been delivered (Shee, 2003).

Heart failure

Heart failure can be caused by a variety of heart conditions. 'Heart failure is a complex syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the heart to function as a pump to support a physiological circulation. The syndrome of heart failure is characterised by symptoms such as breathlessness and fatigue, and signs such as fluid retention' (National Institute for Clinical Excellence, 2003:b). The incidence of heart failure is thought to be one new case per 1,000 population per year increasing to more than ten cases per 1,000 population in those 85 years and over (DH, 2000).

Heart failure often has a poor prognosis, with survival rates worse than for breast and prostate cancer (Sanderson, 1994). It has also been reported that 'there is evidence that people with heart failure have a worse quality of life than people with most other common medical conditions', and that 'palliative care can contribute to the care of those with heart failure...' (DH, 2000). In considering end of life issues for people with heart failure it is acknowledged that there is 'considerable unmet palliative needs...' (National Institute for Clinical Excellence, 2003b). Research by Murray et al (2002) clarified the uncertain prognosis for people with heart failure and that they rarely discuss end of life issues with their professional carers.

As for COPD there has been debate and acknowledgement about the palliative care needs of people with heart failure and the appropriateness of people with heart failure receiving palliative care (Addington-Hall & Gibbs, 2000; Deronzier & Giletti, 2001; Horne & Payne, 2004).

Human Immunodeficiency Virus positive (HIV+)

HIV+ is a virus, which attacks the body's immune system. In order for someone to become infected, a sufficient amount of HIV must enter the blood stream. HIV is found in body fluids such as the blood and sperm of infected people. Following infection the body's defence mechanism of white blood cells will keep the HIV infection under control. This may be for several years. After a period of time though, HIV will begin to

weaken the body's immune system, which usually fights off any infections (Terrence Higgins Trust, 2003). HIV infects white blood cells called CD4's and uses them to replicate more HIV in other CD4 cells. Over time the body's ability to fight infections can be greatly reduced leaving the person vulnerable to contracting a number of other infections which normally they could have resisted.

Since the infection was first detected in the early 1980's there have been over 32 million people infected worldwide (Bannister et al, 2000:310). When HIV is at the stage of producing symptoms the infected person can expect to have enlarged lymph glands, and to have certain infections such as herpes, pneumonia and other skin and mucosal infections. In more advanced HIV people can develop forms of malignant cancer (Bannister et al, 2000:313).

AIDS (acquired immunodeficiency syndrome) has been the term used to describe late stage infection when the body has been open to uncontrolled opportunistic infections. This was a particularly common term in the early years of the epidemic but late-stage or advanced HIV are now the preferred terms (Terrence Higgins Trust, 2003). Current drug therapy can successfully reduce the level of HIV in the blood and has had a dramatic effect in improving the health and life expectancy of people with HIV. However, it is not yet known what the long term effects of these drugs may be or whether the improvement people are experiencing can be sustained indefinitely (Terrence Higgins Trust, 2003).

Multiple Sclerosis (MS)

Multiple Sclerosis is a condition of the central nervous system. The central nervous system is made up of your brain and spinal cord. The brain controls bodily activities, such as movement and thought, and the spinal cord is the central message pathway. Messages are sent from the brain to all parts of the body, controlling both conscious and unconscious actions. Surrounding and protecting the nerve fibres of the central nervous system is an important substance called myelin, which helps messages travel quickly and smoothly between the brain and the rest of the body. In multiple sclerosis this protective coating around the nerve fibres is damaged (Robinson & Rose, 2004:1).

It is thought to be an 'autoimmune disease' which means that ones own immune system attacks itself and over time the nerve fibres protective myelin coating is eroded. The nerve fibres subsequently become less and less effective at transmitting messages which in turn leads to greater difficulty in controlling muscles or certain sensory activities in various parts of the affected person's body (Robinson & Rose, 2004:1). As well as myelin loss, there can also sometimes be damage to the actual nerve fibres. It is this nerve damage that causes the accumulation of impairments that can occur over time. As the central nervous system links all bodily activities, many different types of symptoms can appear in MS. The specific symptoms that appear depend upon which part of your central nervous system is affected and the job of the damaged nerve (MS Society website, 2005).

MS is the most common cause of severe impairment in people between the ages of 20 and 50 years (Cantrell et al, 1985; Harrison, 1986). Problems associated with MS are difficult for doctors in a District General Hospital to manage; local rehabilitation and support services rarely have specific expertise in MS; and MS leads to the experience of significant social and psychological problems (Wade & Green, 2001).

There are many different forms of MS but the standard classification describes three distinct patterns of MS:

- Relapsing/remitting MS - is characterised by symptoms coming and going. Periods of good health or remission are followed by sudden symptoms or relapses.
- Secondary progressive MS – follows on from relapsing/remitting MS. There are gradually more or worsening symptoms with fewer remissions.
- Primary progressive MS – from the beginning, symptoms gradually develop and worsen over time.

(National Institute for Clinical Excellence, 2003a)

The two most common problems associated with a diagnosis of MS are fatigue and loss of bladder control. Fatigue can be unpredictable and variable in intensity, whilst bladder problems range from an increased urge to pass urine to incontinence. People living with MS can also encounter many other symptoms such as pain, loss of mobility, problems with speech, eating and swallowing difficulties, depression and cognitive problems, eyesight and hearing problems, and problems with sexual relations (Robinson & Rose, 2004:4). Associated with these areas are related issues with loss of independence, work place problems, financial and housing problems.

Myalgic Encephalomyelitis (ME or CFS)

ME, also referred to as Chronic Fatigue Syndrome (CFS), is a complex condition characterised by the symptom of chronic and severe fatigue of unexplained cause that consists of periods of remission and relapses (Pinching, 2000). ME is not only a complex condition but it also has a complex history. In the UK, the term Myalgic Encephalomyelitis was first used in the 1950's to describe symptoms experienced by doctors and nurses in the Royal Free Hospital London (Wessely et al, 1998:128). The symptoms included unusual motor and sensory problems, myalgia (muscle pain) and emotional distress. It was initially thought to be a form of polio but this was soon found to be false and in the absence of a verifiable diagnosis the affected people were thought to be involved in mass hysteria and were shunned by their colleagues, thought to be contagious and labelled as experiencing a 'hysterical reaction' (Wessely et al, 1998:129).

Whilst ME has become a popular term to describe this condition, professionals prefer what they feel is a more accurate term, Chronic Fatigue Syndrome, and it is suggested that there has been a popular movement amongst people with these symptoms that has a 'strong and passionate antipsychiatry rhetoric' (Wessely et al, 1998:324). These same authors (Wessely et al, 1998), all psychologists interestingly, go on to link the 'ME movement' to both politics and to popular protest. The Report of the CFS/ME Working Group to the Chief Medical Officer (CMO Report, 2002:5) acknowledged these

differences in terminology and causation and therefore chose to utilise the joint and inclusive term of CFS/ME. Jackson (2002) explained that those who have the condition prefer the term ME “...as they feel that chronic fatigue is an umbrella term for symptoms that occur in other illnesses, such as fibromyalgia, thyroid disease and depression”. Addressing concerns that a diagnosis of ME is still regarded with scepticism and that it is not seen as a legitimate condition, the CMO Report made clear that CFS/ME “...is a genuine illness and imposes a substantial burden on the health of the UK population” (CMO Report, 2002:1).

For people with ME symptoms can vary greatly in severity and duration. Richardson (2002) highlights a range of symptoms that may be experienced including, fatigue, malaise, and muscle pain provoked by increased activity, with sleep disturbances, cognitive impairments (i.e. short term memory loss), nervous system symptoms (i.e. dizziness, light sensitivity, and balance difficulties), and digestive disturbances also being possible symptoms. Alongside these symptoms, for people with severe forms of the disease, “...additional problems of invisibility, barriers to accessing all forms of care, variable responses to treatments, and under-representation in research” are also experienced (CMO Report, 2002:44).

ANNEX B

Ethnography and an overview of the period of participant observation

Ethnography

At an early stage of the research I was very interested in ethnography or specifically a critical ethnography and I sought to establish the compatibility of this approach with the epistemological and theoretical influences that I was comfortable with. Teaching from a lecturer I respected during my research training, at the commencement of my doctorate, influenced me to explore this possibility. On close examination there appeared to be many aspects that I felt were compatible with my research influences but I was aware that my methodology needed to accommodate and illuminate processes of social control, disempowering structures, oppressive relationships and lead to a reflexive and collective account of the research.

In describing the feminist post-structuralism that shaped Hey's research Mauthner and Hey (1999:73) describe how this ethnographic research '...revealed symbolic forms and social rituals usually naturalised in previous investigations...'. The suggestion appeared to me to illustrate the possibility for an ethnographic research that adds further dimensions to the analysis of social settings. Support for a critical, rather than traditional, ethnography suggested that the focus of this critical arm of ethnography '...accounts for the historical, social, and economic situations', and further, that critical ethnographers '...realize the strictures caused by these situations and their value-laden agendas' (Fontana & Frey in Denzin & Lincoln, 1994:369). Van Maanen (1988:13) added that an ethnography '...irrevocably influences the interests and lives of the people represented in them-individually and collectively, for better or worse' and that it '...requires at a minimum some understanding of the language, concepts, categories, practices, rules, beliefs, and so forth, used by members of the written about group. These are the stuff of culture, and they are what the fieldworker pursues' (Van Maanen, 1988:13).

Patton (1990:67) also suggested that the critical assumption guiding ethnographic inquiry is that '...every human group that is together for a period of time will evolve a culture' and that the purpose of ethnographic data '...is to *describe* the setting that was observed,

the activities that took place in that setting, the people who participated in those activities, and the meanings of what was observed from the perspective of those observed' (Patton, 1990:202). The characteristics of people and the different groupings in this social environment is the arena in which the research takes place.

The methods of observation and informal interviewing are the mainstay of this methodology and alert the researcher to patterns that exist in this particular culture. This approach enables the researcher to focus upon interactions, actions, behaviours, daily routines, conversations and language that occur in the social world (Mason, 1996:61). Within these discussions though there seem to be implicit and at times explicit endorsements of a naive realism. There is a suggestion of the researcher observing an almost passive external reality and of being able to capture this reality as if in a test tube to measure and quantify in positivist terms. For example Patton (1990:55) talks of the neutrality of the researcher and calls for the complete opposite of the approach called for in the emancipatory research paradigm for example, where a partisan attitude is emphasised. Neutrality to the extent of detachment from the people who are the focus of the research is something I did not endorse and whilst being aware of my beliefs and assumptions I was not prepared to pretend that I did not hold them. I wanted the findings of this research to be able to improve things for the people at the centre of the study. Even in traditional ethnography the desire has arisen to improve the lives of those 'under study' as Foote Whyte concedes:

"I suppose no one goes to live in a slum district for three and a half years unless he is concerned about the problems facing the people there. In that case it is difficult to remain solely a passive observer"

(Foote Whyte, 1955)

Other ethnographers recognise that as a methodology it has a reputation and it '...has its own brand of *machismo* with its image of the male sociologist bringing back news from the fringes of society, the lower depths, the mean streets, areas traditionally 'off limits' to

women investigators' (Morgan in Roberts, 1981:86). Despite this Morgan suggests that, for his research, this methodology contributed positively to a way of '...seeing gender as something shaped and patterned in interactional contexts rather than as something unchanging that is brought to every encounter' (Morgan in Roberts, 1981:91).

At the time I felt there did seem to be a consistency between a critical ethnography, critical inquiry, the influence of the social model of disability and some aspects of feminist research. I thought a critically positioned methodology sought to cast light on power relationships and to be alive to the commonly held values and assumptions that exist in the social world. I saw a critical ethnography as enabling the researcher to see things from the perspective or standpoint of the participants.

I understood that the research relationship is directly affected by the methodology followed and I saw this as important due to the influences I was persuaded by, namely the social model of disability and an epistemology informed by feminist thought and Freire's work. At the time I also saw that an ethnographic methodology is such that the forming and maintaining of relationships during the research is an essential part. I was sure that a critical ethnography was reflexive regarding the position of the researcher and the researcher's relationship with research participants. This critical stance is a distant relation to the more traditional ethnography that advises us that;

“...the researcher has to learn to sustain relationships with people with whom one normally might not easily mix, and to exploit his emotional involvement with them for data...”

(Punch, 1986:16)

This deceptive relationship is in no way appropriate for the participatory approach of research I was trying to achieve. Punch (1986:83) does go on later however to urge caution about the possible negative affects of field research and a possible 'betrayal' of the researched. I saw a critical ethnography as critical at all levels; within the area of

research relationships broadly which includes working with participants and participants influencing the direction of the research; questioning at all stages of the research process including analysis and the findings; and, as Davis (2000:203) highlights, places the ethnographer in a position to counter 'hegemonic discourses'. Thomas (1993:28) added to the 'evidence' for me when he discussed a 'participatory ethnography' in which knowledge production becomes a collective enterprise, researcher and researched, as does its use (Thomas, 1993:28). Skeggs (in Atkinson et al, 2001:430) also contributed to my serious consideration of this approach with her view of ethnography as liberatory and inclusive of the voice of participants.

I was further persuaded that critical ethnography was a possibility by some feminist researchers who suggested that this methodology was compatible to their research aspirations. Nader (in Hymes, 1972:1), for example, highlighted that '...ethnographic writings can and do inform human conduct and judgement in innumerable ways by pointing to the choices and restrictions that reside at the very heart of social life'. This critical ethnographic stance influenced by feminist concerns is not, however, without its own problematic issues. One such issue is the ambiguous problem of the closeness/distance dichotomy. Reinharz (1992:68) points out the feminist values of an '...openness to intimacy and striving for empathy...' which should not be confused with '...superficial friendliness...'. It is suggested that this intimacy can lead to a transformation for both researcher and participant and an outcome is '...friendship, shared struggle, and identity change...' (Reinharz, 1992:68). This closeness to research participants has been open to criticism though. Hammersley for example suggests that a critical ethnography is '...simply research directed towards serving the interests of some particular group, whose interests may conflict with those of others, including those of other oppressed groups' (Hammersley, 1992:119). This criticism is likely to be directed to all research that attempts to change research relationships though.

Other problematic issues have been raised that point to the ethnographic researcher, who utilises participant observation as a method of data collection, engendering a degree of mistaken identity and simultaneously being experienced as observer, helper, and ally

(Goodley,1999:38). This identity issue is a serious concern if the researcher does not wish to be deceitful. The boundaries of who you are, researcher, friend, supporter or advocate is an important issue when utilising the epistemological and theoretical positions outlined at the beginning of this chapter.

Early in the research I thought a critical ethnography was able to accommodate participatory approaches to research and therefore to be participatory. On reflection I feel I was as influenced by the critical inquiry position as by the ethnographic methodological position. Perhaps I was also interested by the tradition of ethnography to tell the story of people, to illustrate issues and bring interesting social situations to a wide audience. I also feel I may have been influenced by an unconscious biomedical assumption that had been instilled via many years of working as a health professional. My consideration into the applicability of a critical ethnography for this research was, I think, a distraction. It was very interesting and may have been of some value, but my starting point was a participatory research with service user involvement in the process and product of the research and later I returned to this same position. Critical ethnography's pedigree and foundation, epistemologically and theoretically, is of some relevance to this research, but it is participatory research's principles that I decided should be the over riding influence in this research.

I describe the participant observation phase of this research below. It was this phase that confirmed for me that an ethnographic approach was not compatible with my research influences. My core values for this research surrounded issues of collectivising the research process, paying attention to power issues within relationships with SURAG members and participants, sharing decision-making and of maximising opportunities for involvement. The completion of a period of participant observation felt as though it was taking me further from these values.

An overview of the period of participant observation

The aim of this section is to offer a picture of the period of participant observation.

Firstly though, a short introduction to participant observation as method of data collection will be given.

Traditional social science observational techniques relied upon not influencing the 'field' and in gathering unadulterated and unbiased snatches of 'reality'. This reality could be documented, measured, counted and verified systematically with the observer researcher positive in the fact that he/she had not contaminated the subject of their study. It becomes a technical data collection method. It was a different participant observation that I considered might work with the methodology I was following. This participant observation placed emphasis on the researcher becoming involved within the research field. Thomas (1993:28) explains a 'participatory ethnography' in which knowledge production becomes a collective enterprise, researcher and researched, as does its use with the process being empowering for research participants who have greater authority given to their voice.

Added to this, feminist research approaches suggested that feminist participant observation valued openness to intimacy and strived for empathy (Reinharz, 1992:68). There does seem to be an uncomfortably close relationship here between closeness with research participants and a shared quest in the research process and with the concern for influencing research participants unduly, which may lead to what has been termed reactivity. This reactivity leads to participants offering what they think the researcher requires or acting in ways that is not in keeping with their usual behaviour. This may happen if the participant wants to deliberately alter what the researcher is observing and interested in or may occur in response to an awareness of being on display.

With ethics in mind it could be argued that, as an observer, participants require to be informed and periodically reminded of the observer's research intentions. This honesty can reduce any risk of manipulating participants but it may be contended that reminding participants of the researcher's motives may cause reactivity. Within an emancipatory

approach to research though, this honesty and openness is important. I thought I could accommodate this fine line between reactivity and an empowering, participatory/emancipatory research approach. Whilst it may seem that the two terms participant and observation are in some ways contradictory, as mentioned above, others argue that in fact there may be more of a reciprocal relationship between them with participation bringing about change in the researcher leading to new observation, while in turn this new observation changes how he or she participates (Rabinow, 1977).

More traditional ethnographers suggest that unobtrusiveness and 'selecting a setting that does not call direct attention to your activities' will increase the chances for successful observational research (Spradley, 1980:48). A post-modern approach however, emphasises 'a personally involved, politically committed ethnographer, not the morally neutral observer of positivism' (De Laine, 2000:28). Consequently this post-modern participant observer, with influence from the field of feminist ethnographic research methodology, is discussed in terms of building collaborative, reciprocal, trusting and friendly relations with those studied and enabling the connectedness that forms between them and others to be valued. I was influenced by this interpretation of ethnography and saw some compatibility with principles in the participatory and emancipatory research approach. I envisaged an open and involved relationship with participants, even a partisan stance where I collaborated with participants in exploring the context and culture in which they lived.

I envisaged that the researchers role, when taking this open stance to field work, could become a more ambiguous one with such close relationships established that there exists concern with both bracketing and immersion. A continual negotiation of how involved and how personal is helpful to the research and to the participants was also envisaged. I was therefore aiming for a style of participant observation that was far removed from the distanced objective researcher noting the reality of this world before me. What I was hoping for was to gain access to the meanings, which participants assign to social situations (Burgess, 1984:79). I saw the value of being a participant observer as lying in

the opportunity that is available to collect rich detailed data based on observations in a 'natural setting'.

Introducing the period of participant observation

I wanted to gain access to a social situation where a group of people with life limiting conditions came together in a setting that is not uncommon. An important point is that this setting was available to people with only two types of life limiting conditions, Cancer and Motor Neurone Disease. Whilst the fieldwork here was not long, in terms of traditional ethnography, I will describe an aspect of everyday life for this group of people. This group of people, primarily people with advanced cancer, came together regularly for a period of several weeks and I thought the milieu created would be of interest because of its uniqueness to these people.

I spent about two hours once a week with this group of people for four months. I attended on the same day each week in order to focus on one group of service users. Their day in the day hospice would begin at about 10am and finish at about 3pm. They would have about an hour for lunch and a rest in the middle of the day. I did not want to be present for the bulk of their day as I thought they may need time for themselves without my presence. In total I was present in the setting on fourteen occasions that totalled twenty eight hours in the day hospice. This included the introductory time and involvement in the day hospice was brought to a conclusion with a group discussion in which six people participated. Participant biographies are included in annex E.

In order to record what occurred and my thoughts and insights over time I kept daily notes in a journal that I wrote up immediately following each episode of field work as well as writing key comments in a small note book I kept with me at all times.

Setting

The setting for the participant observation was the day centre of a well-established hospice in the South of England. This hospice provided a service for adults in a mixed

urban and rural area with a population of approximately 200,000. The site for participant observation was the hospice's day centre that was attached to the in-patient unit.

The day hospice could cater for fifteen patients each day and was open from Monday through to Friday. The majority of patients attended once weekly but some attended twice weekly and very occasionally three times a week.

Aims of the participant observation

I wanted to see what could be learnt from spending regular time with a group of people who had advanced cancer, in a setting that brought them together to socialise. I intended to gain an insight into a part of a small group of people's lives by joining in with them for a part of their day on the same day every week for a four month period.

Access to the site

Permission was obtained from a member of the management at the hospice and I discussed my proposal with staff in the day centre and then with the service users who attended on the designated day of my participant observation. The staff included the person in charge of the day centre, a nursing sister, a staff nurse, activity leader and a complementary therapist. The service users attending the day centre all had a diagnosis of cancer and normally numbered ten people. After discussing the research and my aims I left the staff and the service users with written information about the research and the participant observation. From the start the staff were keen on this part of the research. At this initial introduction stage one service user spoke to me about her discharge from hospital following chemotherapy with no follow up support. She said 'I could have been dead for all they knew'. In contrast, another service user commented on staff in the hospice who had all been 'delightful'. In the group of service users I confirmed that I was interested in all aspects of their experiences with services and relationships with others. At this stage I was pleased with the initial acceptance of the idea of my presence amongst them all but I was concerned that service user may not have been easily able to decline participation. I made this clear in talking to both the service users and staff. I particularly

stressed to staff that in their talking with service users to convey the message that non involvement was perfectly reasonable.

I returned the following week to answer any queries and to establish if they were agreeable for me to conduct the observation in the day centre. I talked individually with service users to discuss any queries or concerns they had about the research and my presence with them as part of the research. At this stage one service user declined to be included and I gave a guarantee that I would not include any of their comments in the research. This was accepted by the individual concerned. There was by no way a blind acceptance by the others. I was asked about the extent of involvement in the research by one person who worried that more would be expected of him later, I was probed as to why carer's experiences were not included in the research, I was asked to guarantee that I would not talk to one person's GP, and I was also led to discuss research that purely raises issues and recommendations the sponsor expects. My experience at gaining access shows that people with life limiting conditions are able to discuss any reservations and to negotiate participation. Nine participants in all were involved in the observational aspect of the research. Of those nine participants, six were involved in the observational aspect of the research and a group discussion. Of those same nine participants, three were involved only in the observational aspect of the research.

Reflection on period of participant observation

I felt as if I stood out as an impostor in the day centre when I first entered. I felt awkward and anxious as it did not feel natural to me to sit and spend time with these people in this setting. However, the service users seemed to readily accept me albeit with a quizzical and novelty perception of me and my presence with them at the beginning. I was immediately struck by the peripheral activity in the day centre. Normally the service users would be engaged in an activity, although this was not compulsory and occasionally service users would not join in but read or sleep. Other than the main activity there would be a great deal of activity with various day centre and hospice staff or volunteers going about their work. This sometimes involved talking to service users or removing them to another venue for discussion or another activity such as massage. All service users,

including new attendees, appeared to readily accept without question this peripheral activity and interruption.

My journal relays early doubts I had on the ability to gain 'useful data' in terms of the research and the appropriateness of the method of data collection itself. During the first two visits there appeared to be little opportunity for service users to talk with each other about their situations and experiences and consequently little time for myself to have informal conversations with service users about the issues of interest in the research. Planned activities took up most of the time I was present and therefore I altered the timing of my visit the following week. I found that service users soon appeared comfortable with my presence and were welcoming of me. I joined in activities and staff led the days in an informal and friendly way.

For the great majority of time the day centre was a good humoured place and there was a core of service users who joined in with staff in light hearted conversation. It was accepted that service users could come and go as they pleased and they could go to a shop or café area, smoking room, or outside. It was not often that service users would leave the day centre though of their own volition. On occasion someone might visit a friend in the in-patient unit. Val for example spoke of visiting a friend who she had been worried about. Visiting this person was obviously a relief to her, to see how she was more relaxed and comfortable. Two weeks later she told me how this friend had died in the hospice and about how peaceful she was in the end. She specifically said 'that's the great thing about this place. You know when it's your turn you'll be well looked after'.

Conversely though she went on to say that you couldn't really escape what was going to happen to you. She said it is a double-edged sword in that it is brought home to you that you are going to die.

I considered negotiating more time in the day centre in order to have more time, perhaps over lunch, to speak with service users. I decided against this though as I thought it would impinge too much on their time together. For many this was the only time they had out of their homes each week and I decided having a researcher present for the majority of the

time would be too intrusive. I also questioned if service users shared my feelings of awkwardness. They did not show that this was the case although I know that some did give voice to an uncertainty as to my presence with them despite my earlier explanations. On an early visit for example, Greg asked me, 'you here for your rest then'? This fed into my doubts as to the usefulness of this exercise for any of us.

Despite my concerns I did engage in some informal conversations with service users about their experiences of their conditions and services. Harry for example spoke with some distress of inconsiderate health care staff he had encountered in the local hospital. He did not want to be specific at this stage as he found it very uncomfortable to elaborate. On another occasion, some weeks later, Harry spoke of a conscious decision to maintain a link with the hospice so that when he became less well he would have access to the hospices services. He felt he was treated with respect at the hospice and was surrounded by people who knew what they were doing. He made it very clear that he would not go back to the hospital. He described being left in pain for long periods at the hospital. He said this only changed when a doctor from the hospice visited and altered his pain killers. That night was the first that he slept through pain free which gave him great confidence. He said 'I knew that would be the place I would need in the future – not hospital'.

Harry also poignantly relayed how he had requested that his consultant not tell him any details about his cancer or his prognosis only for the same consultant in out patients to say 'get on and enjoy the rest of your life' which Harry took to mean he little time left to live. He was disappointed and depressed about the consultant's statement. Lily spoke in a very matter of fact way about having 'terminal cancer' and her need to move into residential care. Malcolm spoke of inconsistency of home care personnel. Val spoke with me about feeling very lucky she was able to attend the day centre. She explained that she thought more people ought to be able to attend and said 'we are a lucky, select few really'. On another occasion Val also observed that people in the day centre do not talk about their problems. She added that she thought that this was best.

I feel I got a glimpse of the changeable nature of attending the day centre for attendees in terms of their co-attendees. On attending the day centre there were often absences and usually no explanation as to why particular people were not present. I did note on one occasion however that all the service users seemed to know of Greg's hospice admission and I wondered how as I never heard anyone talking about it. The decline of individuals was also highly visible. Over the course of the time I spent in field work I could clearly see some service users becoming much thinner and heard directly from them of their falls, encounters with emergency services and struggles with various symptoms.

I have previously explained that early in this period of field work I had doubts as to the appropriateness of this method. This uncertainty persisted throughout this period and I was very aware of not wanting to put my research questions overtly on the agenda of discussion with service users. Consequently I didn't. They were after all, in part, trying to get away from their conditions and, as I have also stated, conversation did not naturally occur about their conditions and thoughts about it.

My ending of field work was planned in advance and I spoke to each participant before my last visit individually about their involvement and to thank them. On reflection I feel that the day centre environment was a stable one and participants included in this phase of the research received a great deal from attending. I do not feel that my presence in my role as researcher overtly disturbed participants. It is interesting that participants here did not really speak with each other about their conditions, treatment or other experiences. Attending the day centre appeared to be a light and uncomplicated experience. There were some insights gained into motives for attending and into the lives of these participants but this was forthcoming only after probing from myself. Participants will have been aware of others who suddenly were not there or who were obviously less well but attention did not dwell on this issue. At least not openly.

It was helpful to end this period of fieldwork with a group discussion as it seemed to round off this episode and to enable participants to give fuller accounts of their experiences. Were it not for this it would have felt as though participants did not have an

opportunity to get across their thoughts on the many different aspects of living with a life limiting condition. I would have felt as though I had denied them an opportunity to have their say. I feel that I did maintain a respectful relationship with participants however the issues that made me uncomfortable were to do with seeing myself as an outsider with motives that were not always clear to participants. Interviews and group discussions were one off encounters in which it was relatively easy to explain what was expected and to enable participants to feel safe and clear as to their part in the research. Despite little overt comment that displayed confusion or uncertainty in participants I felt as though this was the case for participants in this method of data collection.

ANNEX C

Service User Research Advisory Group – Membership

Name	Experience	Time span in group
Paula Clarke	Service user	November 2002 to April 2005
Di Cowdrey	Service user & chair West Sussex Disability Network	September 2002 to completion of project
John Kapp	Carer & member of Sussex Cancer Network Patient Forum Group	November 2002 to completion of project
Mandy Paine	Service user	November 2002 to completion of project
Rick Wynn	Service user	November 2002 to December 2005
Catherine	Service user	December 2003 to July 2004
Mo	Service user	November 2002 to December 2003
Sally	Service user	November 2002 to August 2003
Steve	Service user	November 2002 to May 2004

ANNEX D

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NHS Trust

version 4 endorsed April 2004

‘Influencing Palliative Care Project’ Service User Research Advisory Group

Terms of Reference

Composition of the group

People living in the Worthing locality who have direct or indirect experience of life limiting conditions, being patients, carers, former carers or health and social care professionals with relevant experience/expertise.

Purpose of the advisory group

The group was established in November 2002 to share with the researcher the knowledge and experiences of people living with life limiting conditions. To ensure that it remains in tune with their concerns and needs it aims to enable group members to influence the research at all stages of the research process.

The group is not a support group, pressure group or a representative body for people with life limiting conditions but rather an advisory group to give advice and direction to this research project. Group members will have influence on the outcomes of the research i.e. in terms of action or change supported by the findings of this research.

Terms of Reference

1. Group members will consider the research questions, how the research is conducted and its progress.
2. Group members will consider the responses from participants and offer views about the relevance of their accounts received and/or gaps in accounts obtained.
3. Group members will prioritise and raise service user concerns for the research to focus upon.
4. Group members will discuss their understandings and interpretations about the information gained by this research project.
5. Group members may become involved in formal or informal teaching opportunities about the research if they feel comfortable doing so.

Guidelines for working together

In all meetings the following principles will be observed:

- ❑ Confidentiality will be agreed and respected.
- ❑ There will be respect for each person's opinion and point of view.
- ❑ We will be non-judgemental and sensitive to each other's experiences.
- ❑ All experience will be valued.
- ❑ One person will speak at a time and be offered the respect of being listened to.
- ❑ Everyone will be given the opportunity to participate.
- ❑ We will support and be honest with each other.
- ❑ If clarification is required it should be requested and provided.
- ❑ It is acceptable to disagree but should be done so within the above parameters.

ANNEX E

The research participants

‘Simon’ – At the time of his involvement in the research Simon was 75 years of age and had been diagnosed with cancer of the lung for two years. He also had pre-existing health conditions of emphysema, diabetes and minor heart problems. Because of the emphysema he hadn’t realised that there were even more serious problems until he had a routine x-ray and was found to have inoperable lung cancer. He was treated with radiotherapy.

Simon described himself as a fatalist in that he had been a cigarette smoker and had worked in coalmines for two years. He attributed getting cancer to his lifestyle but also explained he was quite pragmatic about this situation saying ‘I’ve got it and I’ve got to live with it’.

He had been attending the day centre in the hospice for approximately six months. At the time of interview he was attending the day centre twice a week. Simon lived with his partner. He took part in one face-to-face interview.

‘Chris’ – Chris was 66 years old when interviewed. He had experienced a stroke about two and half years previously and was dysphasic (Impaired speech). Chris was able to reply yes or no to direct questions but otherwise was unable to communicate by speech. His initial stroke had been caused by a burst blood vessel in his brain and since then he had had several smaller strokes.

Chris was referred to me via a contact at the Stroke Association. On first hearing of the research his partner was very keen and wanted to let people know what it is like for people like themselves. On first contact I spoke with his partner and main unpaid carer who informed me that Chris could answer questions in a direct way but not elaborate.

Chris needed assistance to do all daily personal tasks and was hoisted in out of bed. The face-to-face interview was carried out at his bedside with his partner mainly answering

questions but via Chris who agreed, or disagreed. He followed the entire interview by engaging eye contact between his partner and myself.

‘Mel’ – Mel was a 53-year-old woman at the time of her interview. She had been asthmatic since the age of six and as an adult had developed bronchitis. Four years earlier she developed emphysema and bronchiectasis, which together formed her diagnosis of Chronic Obstructive Pulmonary Disease.

Mel lived on her own. She frequently had chest infections and was normally taking antibiotics and steroids. She had to do postural drainage of her lung fluids twice daily. Soon after diagnosis with Chronic Obstructive Pulmonary Disease she was advised to stop paid work. She took part in one face-to-face interview.

‘Sheila’ – Sheila was 62 years of age and had Chronic Obstructive Pulmonary Disease and heart failure, which was diagnosed within the previous ten years. Sheila needed to have oxygen from a cylinder fifteen hours each day. She had stopped paid work two or three years after diagnosis. She had a friend living with her who also acted as her unpaid carer. Sheila took part in one face-to-face interview.

‘Jess’ – Jess was 50 years of age and had multiple sclerosis, which was diagnosed in the late 1980’s. Jess lived on her own but had paid carers assisting her four times each day. She organised and paid for her own carers via the direct payment scheme. A few months prior to the interview Jess had a colostomy and an ileostomy formed so that she didn’t have to wait for carers to visit in order to go to the toilet. She took part in one face-to-face interview.

‘John’ – John was 38 years of age and had HIV+, which was diagnosed fourteen years previously. He had had some AIDS defining illness such as PCP (Pneumocystis Pneumonia) and pancreatitis. He was on combination drug therapy. John lived with his partner and had some family both locally and further a field. He had been unable to work for a number of years and took part in one face-to-face interview.

‘Becky’ – Becky was 44 years of age when she participated in a face-to-face interview. She had been diagnosed with HIV+ twelve years previously and had been on combination drug therapy for eight years. She lived with her partner and some of her friends and family knew of her condition and others didn’t. Becky was able to work in paid employment occasionally and had a good network of friends locally. She took part in one face-to-face interview.

‘Hazel’ – At the time of her interview Hazel was 58 years of age. She had been diagnosed with ME (Myalgic Encephalopathy) seven years previously. Hazel lived on her own with the help of daily paid social service carers who visited twice daily and she had a daughter who lived locally.

Hazel contacted me about the research following reading about it in a local user newsletter and I visited her and spent an afternoon with her prior to her participating in the research. She wanted to know more about the research and palliative care and I wanted to find out more about ME. Hazel was able to describe how she lives with an uncertain future and, she felt, many palliative care needs. She described herself as living with a ‘life stealing’ condition. She took part in one face-to-face interview.

‘Val’ – Val was 69 years of age and had a diagnosis of stage three multiple myeloma when she first participated in a group discussion with other people who attended the hospice day centre. Val lived with her partner. She had been attending the hospice day centre for four months and had received her diagnosis just over two years previously. She also had rheumatoid arthritis diagnosed for five years. Val had received three cycles of chemotherapy and considered herself to be in remission. When she participated in her second group discussion and the observation phase of the research Val was 70 years of age. Her involvement was in two group discussions at her request as she was still a patient in the day hospice on my return ten months after the first group discussion there.

‘Fiona’ – Fiona was 61 years of age when she was a participant in a group discussion. She lived alone and was diagnosed with bladder cancer three years previously. Just under

one year previously she had been told she had secondaries in her pelvis area. Fiona's two children had died and she had one member of her family still alive. She had been attending the hospice day centre for four months when she took part in the group discussion.

Fiona died three months after her involvement in the research ended. Prior to her death she was an inpatient in the hospice but was discharged to a nursing home where she died three weeks later.

'May' – May was 69 years of age when she participated in a group discussion. May had a diagnosis of cancer of the oesophagus made nine months prior to her involvement in the group discussion. Her cancer was discovered when being investigated for another complaint. She had received both chemotherapy and radiotherapy. She had been attending the hospice day centre once a week for four months and had also spent one week in the hospice for respite. May lived alone but saw her daughters regularly.

May died in the hospice eight months after her involvement in the research ended. She remained in the hospice for the last three weeks of her life.

'Ralph' – Ralph was 74 years of age when he participated in a group discussion. He had a diagnosis of cancer of the oesophagus and a few months before his involvement in the group discussion he'd had a stent put into his oesophagus so that he could swallow. Prior to this he had lost 3 ½ stone in weight over a three-month period. Ralph's doctors had said that chemotherapy was not suitable for him and told him he had a few months to live. He had been attending the hospice day centre once a week for three months. Ralph lived with his partner and their sons were close by.

Ralph died in the hospice two months after his involvement in the research ended. He was an inpatient in the hospice for two days prior to his death.

'Edith' – Edith participated in an interview when she was 79 years of age. Edith was diagnosed with breast cancer with secondaries in her appendix as well as with lung damage, which was due to radiotherapy treatment for breast cancer that burnt her lungs. Two years prior to interview Edith had needed to be resuscitated twice following a pulmonary embolism. She also had significant lymphoedema in one arm. She lived with her partner and contacted me following reading about the research in the local press.

Edith needed to have oxygen via a cylinder fifteen hours daily, was wheelchair dependant due to her level of breathlessness. Her partner undertook all domestic chores and personal care requirements for Edith. She had supportive children and grandchildren.

'Maisie' – When she participated in a group discussion and observation phase of the research Maisie was 77 years of age. She had non-Hodgkin's lymphoma, which was diagnosed thirteen years previously. She completed a course of chemotherapy at the time and the lymphoma returned about a year prior to her research involvement. She received radiotherapy to the spine for this (when she'd had spinal cord compression. This is the cancer pinching the nerves in the spine that control the functioning of the legs) and then one year prior to her research involvement Maisie had a pleural effusion (fluid in the lung), which needed to be drained and further chemotherapy was given to her.

Maisie lived alone following the death of her partner four years previously. She had been attending the hospice day centre weekly for four months when her involvement in the research began. Maisie died in hospital two months after her involvement in the research ended.

'Bert' – Bert was 85 years of age when he participated in the observation phase of the research. He had a suspected primary bowel cancer and had secondaries in his liver. When I first talked to Bert to gain his consent to participate in the research he spoke of difficulties accessing stroke rehabilitation services. He had experienced a stroke sometime before we met.

Bert died during the second month of the observation phase.

‘Pete’ – Pete was 48 years of age and he participated in the observation phase of the research. He had a frontal glioma (cancer in the brain). Pete died at home seven months after his involvement in the research finished.

‘Greg’ – Greg participated in a group discussion and the observation phase of the research when he was 67 years of age. Greg had cancer of the colon and secondaries in his liver. He had been diagnosed about six months prior to his involvement in the research. He had been feeling unwell for sometime before he went to the doctors, but following this first visit to his GP he had been into hospital and operated on within three weeks.

Greg had been an inpatient at the hospice for one two week period and had been attending the day centre for three months at the start of his involvement in the research. He lived with his partner and died at home two months after his involvement in the research ended.

‘Malcolm’ – Malcolm participated in a group discussion and the observation phase of the research when he was 79 years of age. He had the diagnosis of non-Hodgkin’s lymphoma. He was diagnosed ten months prior to starting his involvement in the research but he had been having ongoing health problems for nearly a year before he was diagnosed. Following diagnosis Malcolm had chemotherapy and four months before getting involved in the research he had septicaemia (blood poisoning) during one course of chemotherapy. He had been attending the day centre for two months at the start of his involvement in the research. He lived alone.

‘Harry’ – Harry participated in the observation phase of the research when he was 68 years of age. He had the diagnosis of unknown primary with secondaries in his bones. He lived with his partner.

Harry started attending the day centre one week into the observation phase and was involved in the research for over two months. He stopped attending because of his physical deterioration. Harry died in the hospice four weeks after his involvement in the research had finished.

‘Lily’ – When she participated in a group discussion and the observation phase of the research Lily was 84 years of age. Lily had a diagnosis of cancer of the ovary (stage 3) that was diagnosed 18 months before her involvement in the research began. She was told the ovarian cancer had spread to other areas and she immediately had an operation to remove the ovary. Following this she needed another operation as she had an obstruction in her bowel. At this time a colostomy was formed. Nine months before she got involved with the research she had the secondaries diagnosed in her bowel and during the preceding few months had noticed a sharp decline in her energy levels.

She had been a widow for thirty years, had a son, and lived in residential care. Lily started attending the hospice day centre when the observation phase of the research was under way. She was involved in the observation phase and the day centre for nearly three months. Lily died in a nursing home three weeks after her last involvement in the research.

‘Bessie’ – Bessie participated in a group discussion when she was 78 years of age. She was diagnosed with Basal Cell Carcinoma (skin cancer) on her head six years previously but had actually had a lump in this place for about twenty-five years. In the time since diagnosis she’d had eleven operations on the cancerous area on her head including skin grafts and had now been told that it won’t heal. Bessie had previously been an inpatient in the hospice for one week in order to get her medication sorted out. She started attending the hospice day centre on the day of the group discussion and consented to participate on that day having had time to read through the research information and ask questions about it.

She lived with her partner and had children and grandchildren locally. Bessie died in the hospice two months after her involvement in the research had finished.

'Delia' – Delia was 76 years of age when she participated in an interview. She lived alone and was diagnosed with Cryptogenic Fibrosing Alveolitis (hardening of the lung tubes, from an unknown cause) two years prior to her interview. She was in hospital for unrelated surgery when it was noted that she had problems with her breathing. She was unable to have the operation because of this problem. Delia also had angina, arthritis and was in need of two hip replacement operations and one knee replacement operation but because of her breathing difficulties she was unable to have these. Delia needed oxygen via a cylinder on occasions but mainly during the night. Delia had been referred to two different hospices by her GP but both had refused to accept her as a patient because she had a condition that they did not cater for.

Delia was referred to me by her GP after reading about the research in a project newsletter I had sent to her. She had two daughters fairly local to her, a son further a field and two grandchildren.

'Sylvia' – Sylvia was 55 years of age when she participated in a group discussion. She had been given a diagnosis of multiple sclerosis nearly eight years prior to the group discussion. Her condition began with her falling repeatedly. The diagnosis took about ten months to be made after she had brain scans, a lumbar puncture and other scans. Sylvia's condition had deteriorated to the point that her legs would no longer work and she was dependent on a wheelchair.

Sylvia lived alone since her partner left her three years previously and she had two sons and grandchildren locally. She attended a social services day centre and was on the direct payment scheme whereby she employed her own care staff.

'Wendy' – Wendy was 57 years of age when she participated in a group discussion. She had a diagnosis of subarachnoid haemorrhage (bleeding into the space between the skull

and the brain), which had occurred nearly fourteen years prior to her involvement in the research. Following emergency surgery at the time, Wendy had been left with severe weakness in her left arm and leg, as well as speech difficulties and memory problems. She had received speech therapy to help her regain communication and had to relearn many everyday tasks. Wendy had to continually work on many aspects of daily life, like telling the time, in order to remember.

Wendy lived alone but had one daughter who was local to her, she had social services home carers to help her at home and attended a social services day centre.

ANNEX F

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Participant Information Leaflet

Study title:

An exploration of what service users want and experience from palliative care: A participatory study

You are invited to take part in a research study that I am undertaking. I am a researcher working for Worthing and Southlands Hospitals NHS Trust and started the research in autumn/winter 2002. Before you decide whether to take part it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information please contact me, my contact details are at the end of this leaflet. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Purpose

Specialist palliative care is provided for people with life limiting conditions and offers a range of services to help with physical, psychological, spiritual and social concerns. Locally, St. Barnabas Hospice is the main provider of specialist palliative care, but has traditionally provided a service for people who have advanced progressive Cancer or Motor Neurone Disease only. There is a

growing impetus nationally to extend the provision of palliative care to all persons with a life limiting condition. A life limiting condition is one where a cure for the problem is not available and normal life expectancy is not considered likely. Of course not everyone in need of palliative care will have their lives shortened but unfortunately some will.

The primary purpose of this research is to gain the views of service users and potential service users about what they want and experience from palliative care locally. This will include the individual's experience of how people relate to them and how, if at all, this has changed now they are living with a life limiting condition.

Why have I been chosen?

You have been asked to participate in this study because you are a service user or potential service user of palliative care generally and St. Barnabas Hospice specifically. In all 20-30 people will be involved in this study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information leaflet to keep and I will ask you to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. The decision to withdraw at any time, or a decision not to take part will not affect the standard of care you receive.

What will happen to me if I decide to take part?

In order to find out how effective or not a particular service or range of services is and how relationships may influence this, I need to ask the people who use the service or services themselves. In this study people will be interviewed by me and asked various questions or asked to participate in a discussion group. The discussion group will be a gathering of a small number of people brought together to discuss various issues about their experience of services and will be facilitated by myself.

I will also ask a small number of people (6-8 of the total involved) to work more closely with me over a period of time so that an ongoing picture can be gained of their experiences. If you are involved in this part of the research I will ask you to allow me to spend periods of time with you over a two to four month time span. During this time we will spend time together wherever you receive your care. By joining in with you I can observe and be involved first hand in your experiences. We will discuss how much time you are prepared to spend with me and agree this weekly. It will vary but could be one or two half days a week if you attend a day center for example, or an hour or two weekly when you are in contact with people about your condition or, perhaps attending an outpatient clinic.

What do I have to do?

I will contact you and, if agreeable to participate, a date and time will be made to meet. Any further questions you may have will be addressed then. Having agreed to participate does not stop you from pulling out of the study at any point without giving a reason.

What are the possible disadvantages and risks of taking part?

In talking to someone about your condition you may find yourself getting upset. It is sometimes surprising, that sitting down and focusing on your situation with someone who is receptive and a good listener, can be very thought provoking.

You can't always predict where the interview will lead. Therefore it is very important that you and I know that participation can stop at any time if you become uncomfortable. Feeling tired is also a potential problem as talking for short periods of time can be exhausting for some people living with a life limiting condition.

If an aspect of the research should upset anyone then there will be someone available to support you. Some people will already have people they can talk to, whether it is family or friends, their General Practitioner, District Nurse or other healthcare staff like specialist nurses and this may well be sufficient. For people known to St. Barnabas Hospice access is available to a range of personnel who may be able to help. For those people not known to the hospice and who have no other appropriate support available, access can be made to a qualified professional (e.g. counsellor) free of charge for a maximum of six sessions. I will be in touch with you after any research related contact to see how you are, and I can help with putting you in contact with the appropriate person for support if needed.

What are the possible benefits of taking part?

This study is not intended to offer medical benefits. Some people, however, do like being involved in research that, whilst not directly helping them, may be of benefit to others. Others like to have a say and describe what they feel about their condition and how they have been treated. Service user's unique knowledge of their condition and services available is beneficial for the development of services at the hospice and locally.

What happens when the research study stops?

Everyone who participates in the research will be kept informed of its progress and specifically, given a copy of their interview, unless they don't want it.

What if something goes wrong?

If there are any areas of concern to you or a complaint about any aspect of the research that the researcher cannot address for you, then you are entitled to use the existing complaints procedure at Worthing Hospital.

Will my taking part in this study be kept confidential?

All information, which is collected, about you during the course of the research will be kept strictly confidential. Any information about you that we agree can be used, from your General Practitioner, hospital, hospice or community nursing notes will have your name and address removed so that you cannot be recognized from it.

What will happen to the results of the research study?

The results of the research will be utilized by the sponsor organization in considering the services they offer. Articles for publication in professional journals may occur. The whole research project will be written up as a thesis for submission for a doctoral award. You will not be identifiable in anything written or published.

Who is organizing and funding the research?

Worthing and Southlands Hospitals NHS Trust, Worthing is the funding organization and therefore responsible for the project's day-to-day management. It is sponsored by Brunel University in West London, which means they have responsibility for the research's academic and methodological quality.

Who has reviewed the study?

The research is being supervised by staff at Brunel University in London and has been approved by Worthing Local Research Ethics Committee.

Contact or further information

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I would like to thank you very much for agreeing to participate in this study.

Date: -

ANNEX G

Extract from an interview transcript - Jess

Phil	Thinking about the sort of people who you come into contact with, whether they're carers or professional health carers or friends or neighbours or whatever (pause) how do they treat you?
Jess	Er (pause) I think some people see er... are wary of er the wheelchair. I've noticed it more in this road.
Phil	Right.
Jess	And er I'm wary of "oh don't get involved she'll er you'll get caught and you'll have to do things."
Phil	Is that the impression that comes across from some quarters?
Jess	In in this road yeah because they're older.
Phi	Right.
Jess	They don't want to... I presume they don't.... they're too tired and they're too old and um people aren't keen or whatever, they don't want to be involved cos um to them it looks as though er somehow they could be made use of.
Phil	Right... right.
Jess	They're very stand offish.
Phil	Right.
Jess	Some I think it's just how they are anyway.
Phil	Right. Yeah.
Jess	They might just be people that keep themselves to themselves.
Phil	Yeah... yeah...
Jess It could be that sort of er environment around here that they are very sort of keep themselves and...but er you do find with people you think oh I could be called down and get just sort of um work
Phil	Umm.

Jess	I know one of my friends a long time ago, she had a child about six and he said to me, you know, "why does Mummy always come around here, when we go round other friends she sits and chats and talks when she comes round your house she works". I mean she used to come in and help and do some washing up sometimes...
Phil Umm...
Jess	... Cos she thought that was the best thing to do.
Phil	Umm, yeah
Jess	That's it...out of the mouths of children.
Phil	Umm.
Jess	That's fact. And er I used to try.... when my Mum and my sister came round...sit down and um socialise rather than them come over and just be doing housework....
Phil	...Um yeah yeah...
Jess	...Go out for a meal...
Phil	... cos that social side is very important for anybody isn't it?
Jess	Yeah and you want to make sure that er you know your Mother and your sister aren't thinking oh my god you know I've got to go over there and do some work, I mean they never did....
PhilYeah, they didn't have that attitude. So were you worried that they could get that attitude?
Jess	Well they could.
Phil	Yeah yeah.
Jess	I mean the child commented on it....
Phil	...Umm.
Jess	And er it's like everything else you can push it too far...
PhilUmm.
Jess	You've just got to... in those days I didn't need much...keep away from the sort of carers... but eventually you have to er go down that road.

Phil	Umm.
Jess	You have to do that.
Phil	Umm.
Jess	I suppose it's more impersonal.
Phil	Umm.
Jess	So ... the concept that I find er hard to comprehend is paid care but er...
PhilUmm ...
Jess	Um lots.... I mean I had er um Sikhs that lived across the road and they couldn't understand that ...
PhilUmm ...
Jess	... Because their concept with their families is care....
Phil Umm...
Jess And it's very unusual but that's the English way of doing things.
Phil	...Umm.
Jess	... That er we pay for our loved ones to be looked after.
Phil	And this is something you struggle with as well, you say the paid carers?
Jess	I find um.....
Phil	Having to pay people?.....
Jess I find it, find it er, it's not an idea that's very easy to understand, paid care..
Phil	... Umm. Umm.
Jess	It doesn't always work and it depends whether or not the carer is doing it for the money.
Phil	Umm.
Jess	Solely and utterly because they've got children and they can't do anything else....

PhilUmm....
Jess And they're doing that job and they don't particularly want to do it....
Phil Umm hum...
Jess They're forced into it because of time factors and ..
Phil Umm....
Jess But it's the job they can do today and not tomorrow....
Phil	...Umm...
Jess	... Whereas if they go into, they take on a full time job and er their children are ill they can't get sick pay....
Phil	...Umm...
Jess Whereas if they do this job and it's paid...lots of agencies are now doing it...more money per hour, no sick pay, no nothing....
Phil Oh I see yes....
Jess And then they just turn up, do the job and if they don't want to turn up and they've got trouble with their children, they just say oh I'm not doing it.
Phil	Umm and then the agency has to then try to find someone else?
Jess	The agency will find somebody else but it's the fact that they don't, er it gives them, the carers, er more freedom so they're not tied to...
Phil How does that feel to you?
Jess	Well that's what I'm saying it, it still depends on whether or not the carer is doing it... still doing it, particularly wants to do that work or not, if they're only doing it because it suits them.....
PhilYeah....
JessThe money...
PhilYeah...

JessThen you've got carers coming in solely and utterly to do work....
Phi	...Yeah...
Jess	... I mean you have to.... I think like working in a hospital you have to really want to work with people and do the job.
Phil	Umm. What's in your experience, um recently with carers have you got some in each. You know, some that care more and others that it is more a job really?
Jess	Oh yeah.
Phil	You've got a mixture of both have you?
Jess	Umm. You get different people that... some people are.... ignore the money.
Phil	Umm.
Jess	Um somebody said to me once when I worked in the hospital that was I, had I ever been ill, and I said yes and they said well you, you know more what people are going through and er you find carers that have experiences of disability or disability within their family er are often very good carers.
Phil	Umm.
Jess	They can accept it within their... as long as they can accept it within their family....
Phil Umm...
Jess And they make very good carers on the whole.
Phil	Umm hum. Umm.
Jess	If they can't accept it then they're worthless.
Phil	Umm.
Jess	But er you do need to have the er the (pause) desire to do the job.
Phil	Umm. Umm..
Jess	If they don't want to do the job but they're doing it only cos it suits their lifestyle...
Phil	Umm... yeah.

Jess	...a way of getting money in between taking the children to school, or if they're ill then it's a job they don't particularly want to do...
Phil	...Umm....
Jess	"Can you hurry up and get out of bed cause I've got six more different people to do..."
Phil	Umm. Yeah.
Jess	Somebody said that to me once.
Phil	Oh right
Jess	And er (inaudible) what I can do.
Phil	Yeah ... yeah.
Jess	You know you just have to sort of er, I think you have to sort of always maintain...um and not not be governed by others.
Phil	Umm.
Jess	That's the way I've been treated.
Phil	Umm.
Jess	If they want to say that, fine.
Phil	Umm.
Jess	...But you know that they're wrong.
Phil	Yeah... yeah....
Jess	...That you're er...
PhilSo you...
Jess	That you er, that you're sort of, you know your own sort of value.
PhilYeah. Yes...
Jess	...And that they're in, they're working for you and they're getting the money cause...if you weren't around they'd be out of work.

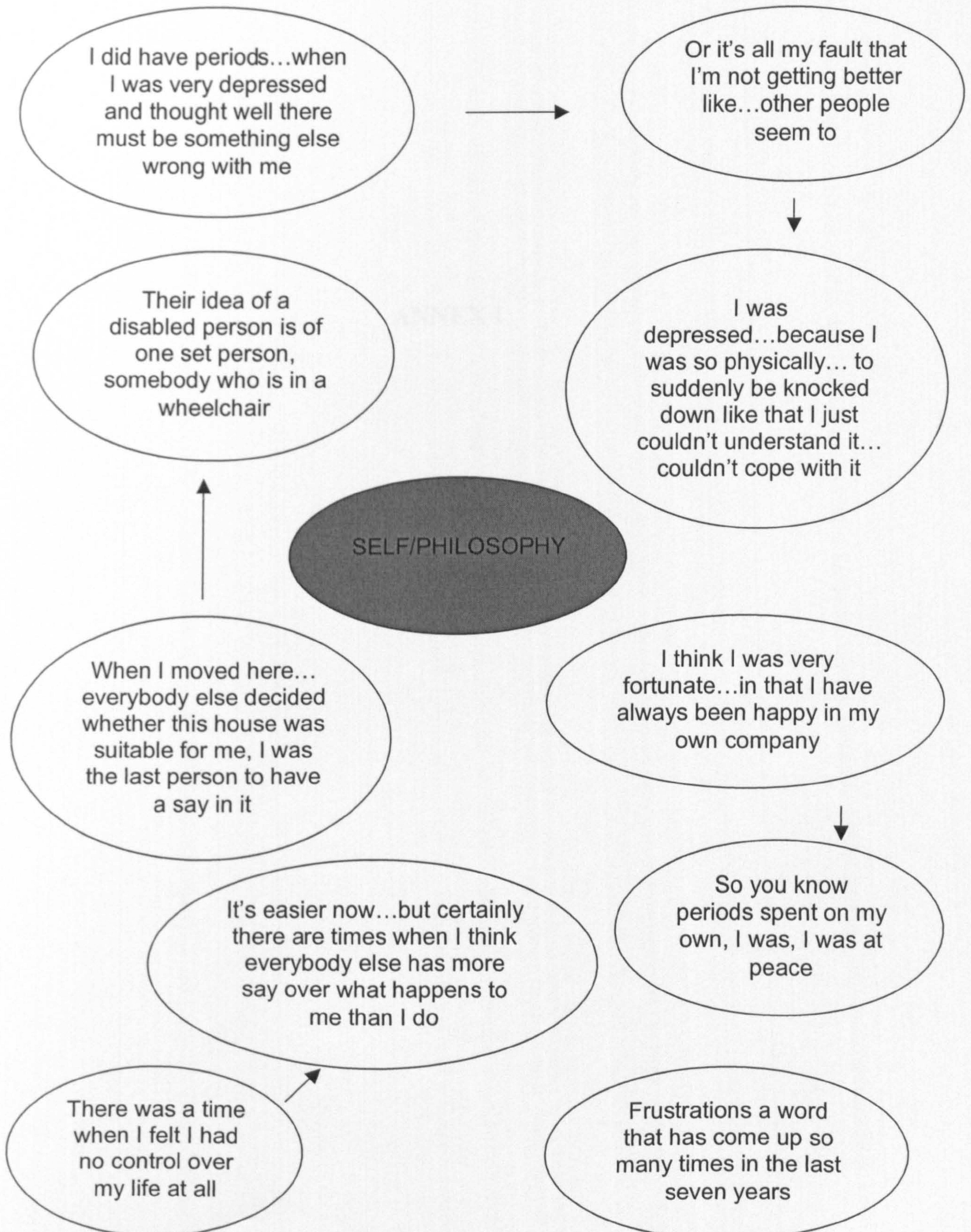
Phil	Yeah.
Jess	Look at it from the other way.
Phil	Yeah. Does that mean though you've got to be quite strong and sure of yourself inside really?
Jess	Umm. Which is um which I wasn't in eighty seven eighty eight and that's why I think it crashes you out and er you really are fighting the tiredness.
Phil	Umm.
Jess	Like anybody.
Phil	Umm... um.
Jess	Like anybody that's tired they gets unsure of themselves.
Phil	Yeah.
Jess	And er, "don't let them put you down...."
PhilYeah....
Jess	...But don't get um on the other side don't get too belligerent you know sort of...
PhilYeah...
Jess Have an axe to grind, you know as though you got, you know, sort of you know, an attitude you know, that they're all going to be always putting you down because....
Phil Because if you did...
Jess	... you'd be worse off then ever...
Phil	You'd be worse off than ever so it strikes me it's a bit like treading a fine line a bit?
Jess	Yes you've just got to make sure that, you know, you try and sit and think, you know, was it real or was it tiredness you know.
Phil	Yeah.
Jess	That's what you have to keep.... That's what I find you have to keep....
Phil	...Umm...

Jess Examining your reactions to something....
Phil Yeah...
Jess	...Is it me or is it the tiredness?
Phil	Yeah.... Yeah. I mean you sound very reflective...
Jess Umm...
Phil	... On on your situation and yourself and how you feel....
Jess	...Umm
Phil And and your responses to people and their responses back, is that natural or will, or have you always been like that?
Jess	Umm.
Phil	Yeah.
Jess	It's good and it's bad but... it's me.

ANNEX H

Initial diagrammatical analysis sheet – Hazel

Initial summary of P18 interview -23/07/03-No4.1



ANNEX I

Example of one interpretation sheet from collective analysis stage

**‘Influencing Palliative
Care Project’**

**19th meeting of the Service User
Research Advisory Group
2nd December 2004**

Ninth Analysis Session

Present:- Paula, Rick, Mandy, Di, John and Phil

Interview with P34 ‘Delia’ 15/10/03 (A woman with Cryptogenic Fibrosing Alveolitis, a lung condition, carried out in her home)

Theme/ Interpretation/ question no.	Interpretations
	<p>Opens with general discussion about the research and what we are all getting from it and hope to come out of it. (John) (P2-3) Similarities to COPD evident. This lady also has angina. Needs to use oxygen a lot. In a catch 22 situation-being told she should walk but is too breathless to walk any distance. Not able to keep up with people. Has to take many tablets. (P5) Limitations on her, very dependent on others. Out of breath. (Mandy) The way she talks about her oxygen is like she’s talking about the “Oxygen as a comfort blanket”. (P8) She has found social services to be quite useless. Services have let her down.</p>
1.7	<p>(Paula) (P9) Various pointers here about what it is like to live with a life limiting condition. Loss of sleep. Waking up at night due to breathlessness. Mouth is dry and stops you breathing properly. It’s difficult you have to rethink physically how you operate. It makes you more aware about things you would normally take for granted. You wouldn’t normally think about breathing. Everything becomes...not natural. It ceases to be spontaneous and natural. (P9 bottom) Talks about</p>

relying on others. Daughter very good. Everything is an effort. I think she is finding it very hard to accept she has to give up things that she would normally do without thinking about it. (A147) (P10) The fear generated through not being able to breath properly on this page. She says, "I don't want to wake up dead", and I know what she means. (Phil) What does she mean? (Paula) You're frightened to go to sleep sometimes in case you stop breathing, you don't wake up. (Di) I interpreted that a different way. She doesn't want to wake up and find she can't do anything. (Paula) But then she goes on to say, "I'd rather wake up than be dead", because she wants a warning of when it alls going to happen, that's what she starts to say on page 11. (Di) Yes she does, yes. (Paula) So going back to that...the body wakes you up somehow when you have a breathing problem. She goes on, "I want a warning to sort out papers". She is frightened of not being prepared, she is facing the end, she's facing...she's facing the future or lack of it. (Di) She wants everything tied up before... (Mandy) She wants to get her house in order. (Phil) Clarifies Di's interpretation. Di speaks of own lifelessness in the morning. (Rick) Agrees that she said she wanted a warning of her death. (Di) Yes as you read on that comes out. (Rick) (A214) She would like some preparation. (Paula) But you don't get it with this (COPD). (Di) You don't get it with this. (Mandy) No you don't. (Paula) You do with cancer, its possible you get it with cancer I don't know but with COPD you don't have this warning. (Mandy) Your oxygen saturation can just go off like that, boom. (Di) One minute you're OK. With some people unfortunately that is the end. Some people will die in their sleep of it. (Mandy) Sometimes your body is aware it is happening. Where she says I don't want to wake up dead, I've been to the point where if I go to sleep I won't wake up. In ITU they kept me awake so that I could concentrate on my breathing. That even happens at home. (Paula) (A232) So her condition severely restricts her life. She lives in a chair, hasn't the energy to move and we know what that's like.

1. 2. 7. 4

(Paula) (P12) Still about living with a life limiting condition but there is a slightly different way of looking at things on this page because she knows she has to learn to manage her condition. Talks about how she spends her time, reading, tapestry. You have to learn to manage it when you have a life limiting condition. (P13 top) She has a dilemma, a regret at not being able to do the things she used to-getting into a car. (P13 bottom) Question 4 and 7. I have crossed and crossed this out and rewritten it and crossed it out so there is something down there that I'm not sure about. She knows that the condition is incurable, nothing they

can do and that causes fear. She says, I know its terminal. **(Rick)** Talks about having a warning. Reads form transcript-she knows its terminal. She sees what is happening to her gradually. **(Paula)** (P14) (A295) She is very pleased with her lady consultant. She seems quite happy with the services she gets. (P15) Fear of not living long enough to see or do the things you want to do. There are constant milestones when you have a life limiting condition. Will I be here next Christmas? Will I be here for my next birthday? Will I see my children grow up? It doesn't go away that sort of thing really whatever condition you have got so that colours your thoughts all the time. That's a dilemma for me (In the text).

Question 1-She needs to have something to look forward to, to give her hope. Anything that gives you hope you latch onto it. (P15 bottom) She has information about her condition. (P16) She thinks well of the services she is offered. Resents it all terribly, certain amount of bitterness that it has come to this. **(Mandy)** (A331) The bit where she talks about transplants, heart lung transplants. People do ask about that when you have this condition. Someone said to Delia "why don't you have a heart lung transplant"? Delia thought it was daft. **(Paula)** (P17) Relationships with her family have been good but one good friend has caused her problems. Delia feels disappointed and let down. **(John & DI)** Spoke about their own experiences of friends dropping away. Some friends seem fearful when you are suffering a serious condition. Delia can't go dancing with her friends although she could go to watch and be part of it. Even if you can't do things because of the physical side you are still in there and you still want to do it. **(Mandy)** If you are living with a life limiting illness you loose your normality, you're not a normal person anymore, you are inside but nobody else can see that. **(Rick)** (A422) It's been obvious to me that we all take a positive attitude about what's wrong with us but she obviously takes the negative one. **(Di)** No it's the friend. **(Mandy)** No Delia doesn't. **(Rick)** Spoke of personal experience, turning a negative into a positive. **(Paula)** I certainly haven't come across that. I don't find her negative. **(Mandy)** She's still trying to do the ironing, she's been doing her laundry. **(Paula)** In view of her limitations she pushes herself to do what little she can do. She doesn't concentrate on what she can't do. **(Di)** But she's disappointed her friends will no longer go on holidays with her or go shopping with her. She wants to do it but she hasn't anybody to go with her. **(Mandy)** So her friends are ruling her life, her friends are making her decisions for her. **(John)** My perception is in the early part (of the transcript) she was concentrating very much on what she could do but later she changed. **(Di)** I think

	<p>you're right, as we're saying there were times when she didn't but then she came to terms with it and decided that she has got to get on with life. (Mandy) It's quite interesting reading it all the way through, seeing the changes as she goes through. (Di) Friends will tell what you can do and what you can't do, that's infuriating.</p>
1	<p>(Paula) (A470) It takes strength of character to be constantly saying to people, who are trying to help you, "I actually don't want your help on that one". Talk about individual opinions. (P18) Disappointed in a friend and that destroyed her faith in human nature but her family have been great. Depression spoken about on this page and is very much a part of chronic illness. She talks of 'black dog days'. Her GP has been good. (P19) Has received no help from social services. Too busy to help her. She says in several places that she had no help. (P20) All down this page she speaks of social services and her disappointment in them. (Rick) (A427) It seems to me what we are finding out here is that some people, like myself, we couldn't have had any more help than we have. (Mandy) It's the area you live. (Di) Unfortunately Rick, if you have cancer as a terminal illness there is so much out there for you, there isn't so much out there if you have other life limiting conditions. Like Delia says, she can get into bed herself, wash herself but what they didn't do and what she needed most was for somebody to come and do her house work for her and her shopping. Spoke of own limitations and experience. (Rick) It must come down to finance too.</p>
1, 4	<p>(John) (P22) (A572) Delia relays issues with dental treatment and dirty hospital. She's had a real basin full of different treatments. (Mandy) They also didn't take into consideration that she needed oxygen and she had to wait from 10pm to 4am for them to find oxygen for her. That's disgraceful. (Paula) That's reinforced on page 23 because she talks about injections that were also late, never on time. (John) (B002) (P26) She spoke about the doctors being arrogant. (Mandy) She compares herself and her condition with a friend who has a form of cancer and his care. (P31) She says because you have breathing problems everyone assumes it was caused by smoking and so it was self-induced. Further down page 31 she talks of having very few choices when living with a life limiting condition. She also has to gauge her choices with her capabilities. (P32) Illness has stopped her doing what she wants to do. (P33) She talks of her oxygen being her psychological crutch. Like a comfort blanket. (Paula) (B120) She talks about having her sleep interrupted by absence of oxygen. (Mandy) She goes on to say she wants</p>

a warning when she goes to die so she can put her house in order. She has lots of wishes she would like to see achieved but they are not really reachable. She has a real sense of humour. She wants to know what is ahead of you, bottom page 34. (P35) She seems angry with the illness, that it's in control of her sometimes and she resents it, but she thinks resenting it keeps her going. So she contradicts herself. She has drawn a positive out of a negative. She feels robbed of her independence and activity levels. Her illness is making her take a back seat. I think she feels really angry at the illness, that comes across, that's how I read it. It jumps out at me. (P36, bottom) She finds it hard to rest up. "I know that feeling when you are the back bone of the family, I can empathise with her". You find it hard to hand over the reigns when you can't do it. You loose your identity. (P38) She's got great respect for the doctors and nurses. (P41) Her friend can't accept her condition and keeps asking if she's better. (John) There is something here about Delia trying, and failing, to control the world around her. She has to say to her friend that she is not going to get better. (Paula) That was her way of coping with it.

Long discussion about positive thinking and attempting to make yourself better and how, for some, this isn't possible.

(B386) Discussion about the importance of information for people with life limiting conditions which needs to include the experiences of people who live with these conditions. (Paula) Everybody is searching for ways of improving what could be seen as a life limiting condition. Everybody wants it to go away, you would love it to be different, but if it can't be how can we improve what's left. (Di) Spoke about the set-up of the new group and the aim to share experiences. (Paula) Feels we need more education for people, the nation, to be more broad-minded.

(Di) (P43) She feels she is lucky to have a supportive family. She says there is a need for more support such as that for people with cancer. Discussed Delia's delay in diagnosis. (P45) They are saying she ought to walk more but like she says, she can't because she can't breathe. (Mandy) People don't believe you.

ANNEX J

Guide for the analysis of data

‘Influencing Palliative Care Project’

Service User Research Advisory Group

Thematic Analysis

What is the analysis about? What is important?

The challenge of this analysis lies in making sense of a massive amount of data.

This involves reducing the volume of raw information, sifting trivia from significance, identifying significant patterns (themes), and constructing a framework for communicating the essence of what the data reveals. We have begun doing this in our previous interpretation sessions.

It’s about fairly representing the data and putting it together in such a way that communicates what the data reveals in relation to the projects aims. We need to keep in mind the original questions that we were seeking to answer in the research.

We are trying to figure out patterns and themes that come out of all the data (transcripts) we have gathered and examined.

Once this is done we need to consider if we have any data that doesn't fit with our themes. These so-called 'negative cases' may be important to consider.

Process for Thematic Analysis

1. We will review each participant's interpretation sheet that we have previously completed.
2. As themes are identified they will be written one per sheet of flip chart.
3. As supporting comments from other participants are identified they will be added to the relevant flip chart.
4. Participant and page numbers will be recorded on the flip chart.
5. Key comments from participants will be written on the flip chart as they may constitute a sub-theme heading or illustrate the notion of the theme.
6. At a later session we will compare these themes with the 'bubbles' analysis that Phil did after each interview. We can note any differences or similarities.

ANNEX K

The principles of service user involvement in data analysis

‘Influencing Palliative Care Project’

Service User Research Advisory Group

Principles of Service User Involvement in Data Analysis

These principles are for discussion and aim to help the way we interpret the data and reach the findings:

- Setting aside or acknowledging our own personal assumptions (the data is the data)
- Setting aside or acknowledging our own personal value judgements
- Key questions to consider during interpretation and generation of findings are:

To what extent has injustice, prejudice, and oppression shaped participants experiences of living with their conditions?

AND

What things about living with life limiting conditions are illustrated that we didn't know before and that may need some action on?

- The complication of utilising our own experience whilst accepting participants experience on its own merit
- Interpretations and findings come from the data
- Research findings are a fair presentation of what participants have told us

ANNEX L

Key questions to aid interpretation

‘Influencing Palliative Care Project’

Service User Research Advisory Group

Key questions to aid interpretation – Stage one

1. What does this text tell you about living with a life limiting condition?
2. What does this text tell you about the services received or needed?
3. What does this text tell you about relationships with others?
4. What does this text tell you about wanting a choice or getting involved?
5. Are there any hidden meanings to this text? What are they?
6. Are there any contradictions in the text? What are they?
7. Are there any dilemmas or tensions in the text? What are they?
8. Is there anything that you are surprised by in this text? Why?

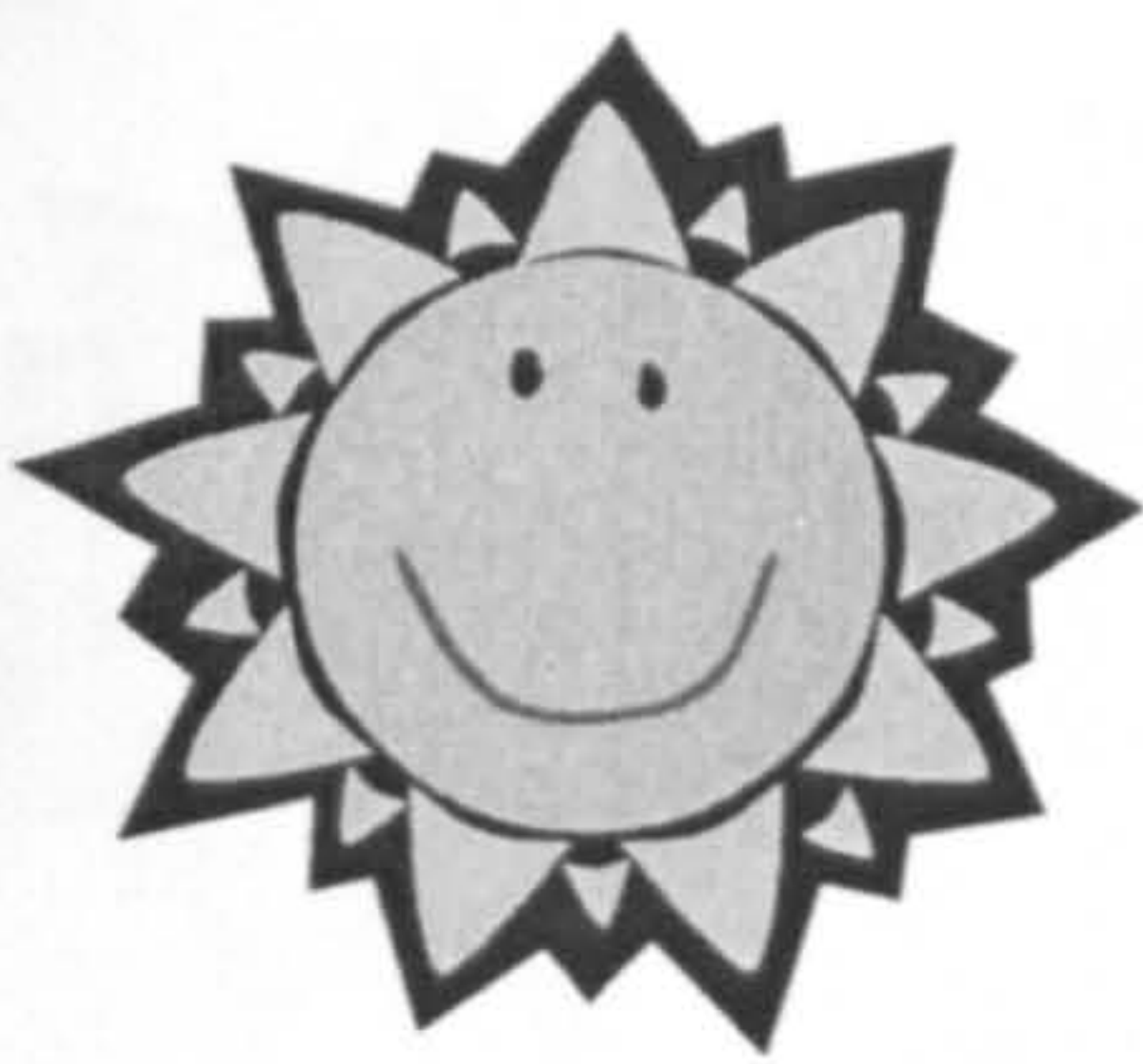
Key questions to aid interpretation – Stage two

1. Did reading this text raise particular emotions or reactions in you? What and why?
2. What personal values, feelings or experiences may have influenced your interpretation of the text? In what way?
3. Did the text have a familiar or a distant feel with regard your own experience? Can you describe?
4. What key lessons can you draw from this text?

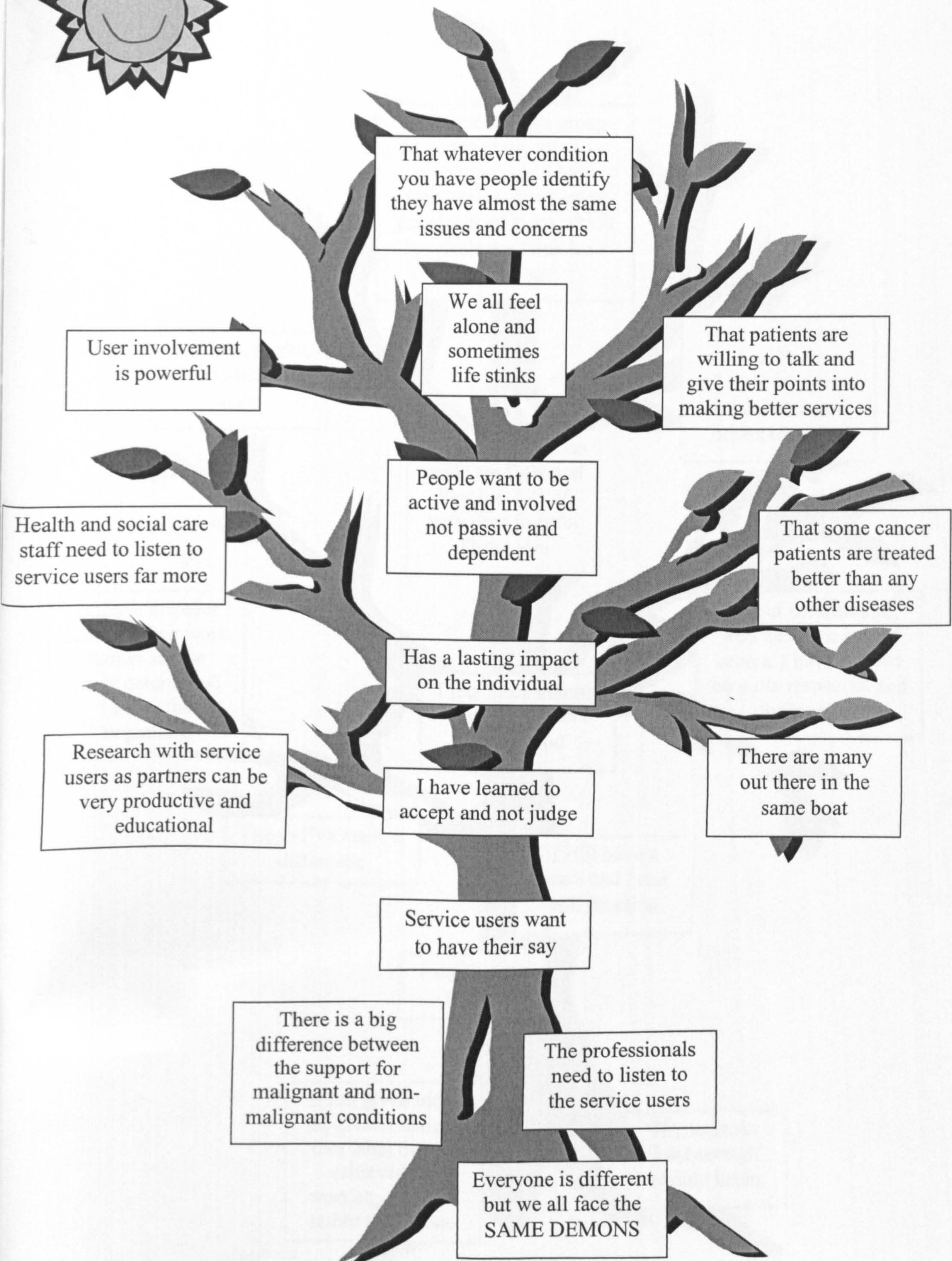
(Adapted from Hart, 2000 in Winter & Munn-Giddings, 2001:249)

ANNEX M

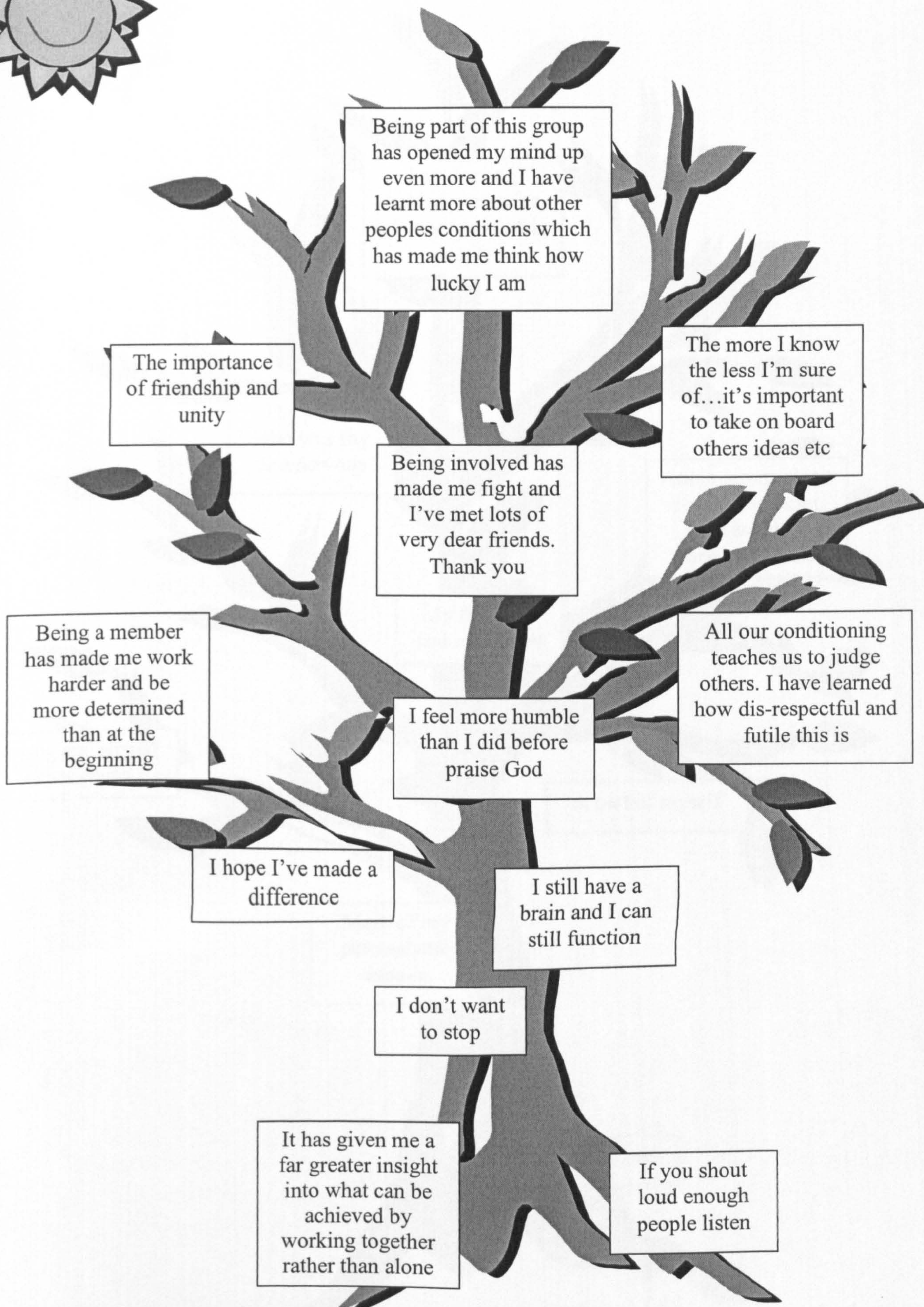
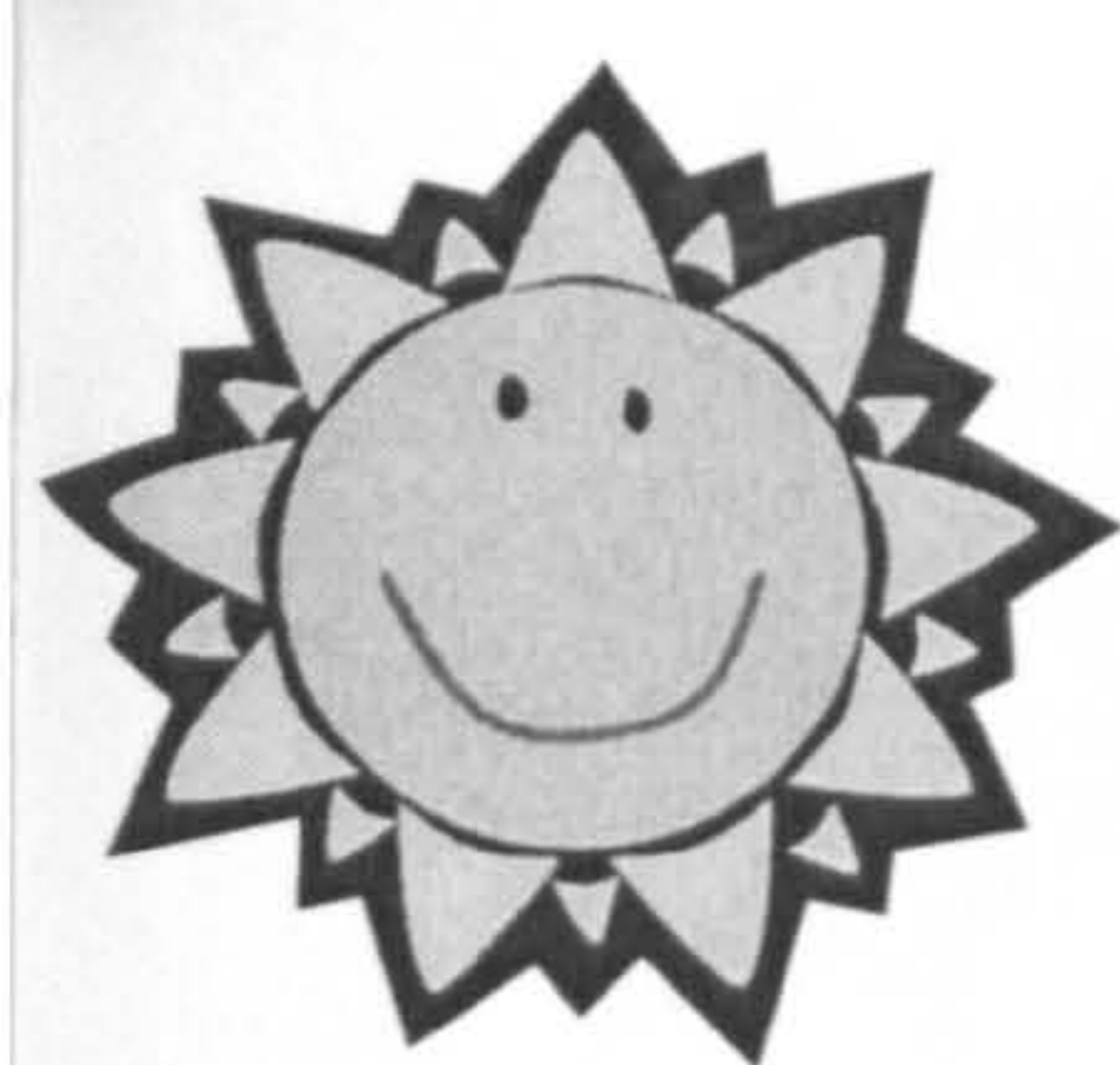
**Service User Research Advisory Group –
Closing reflections exercise - November 2005**

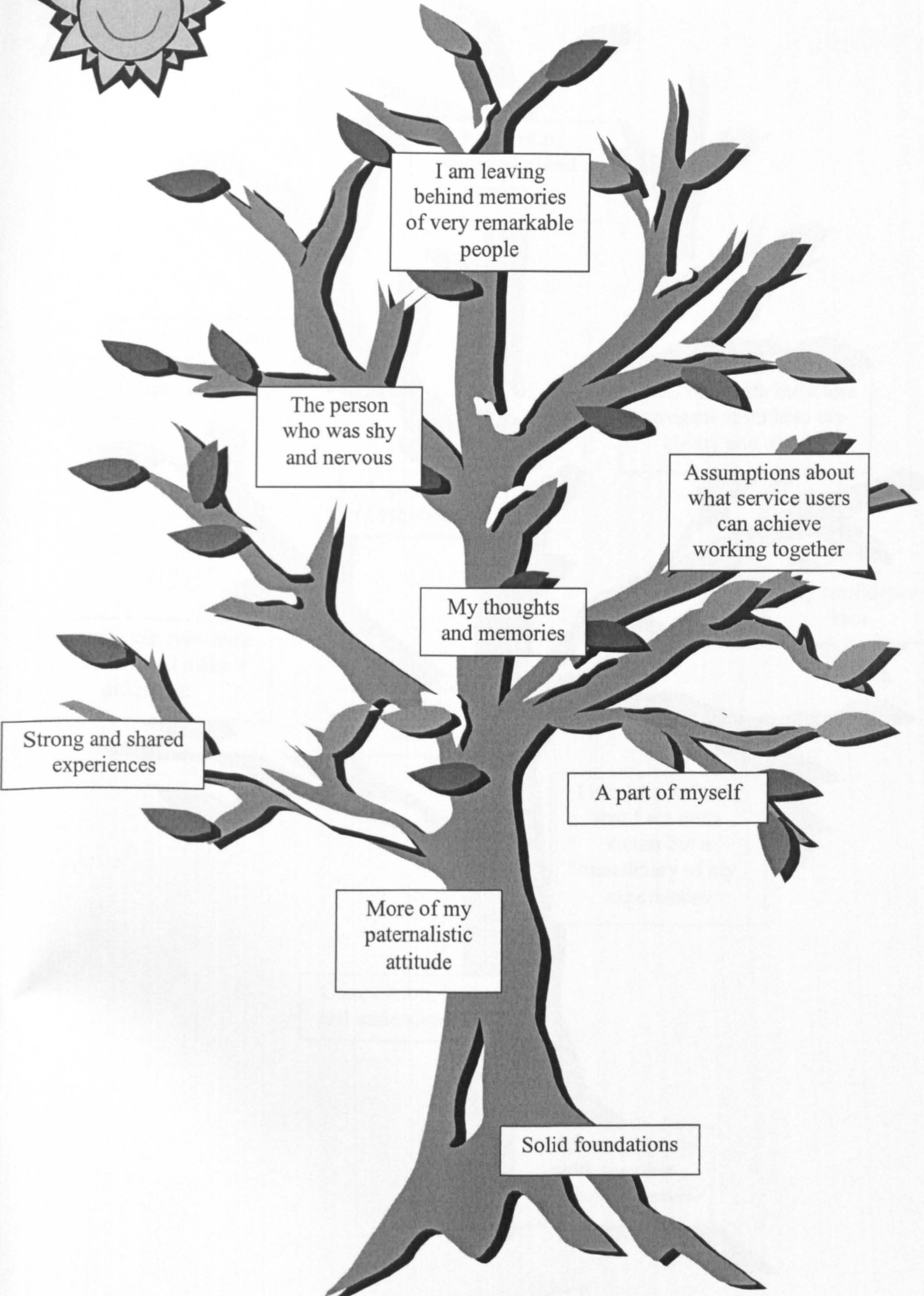
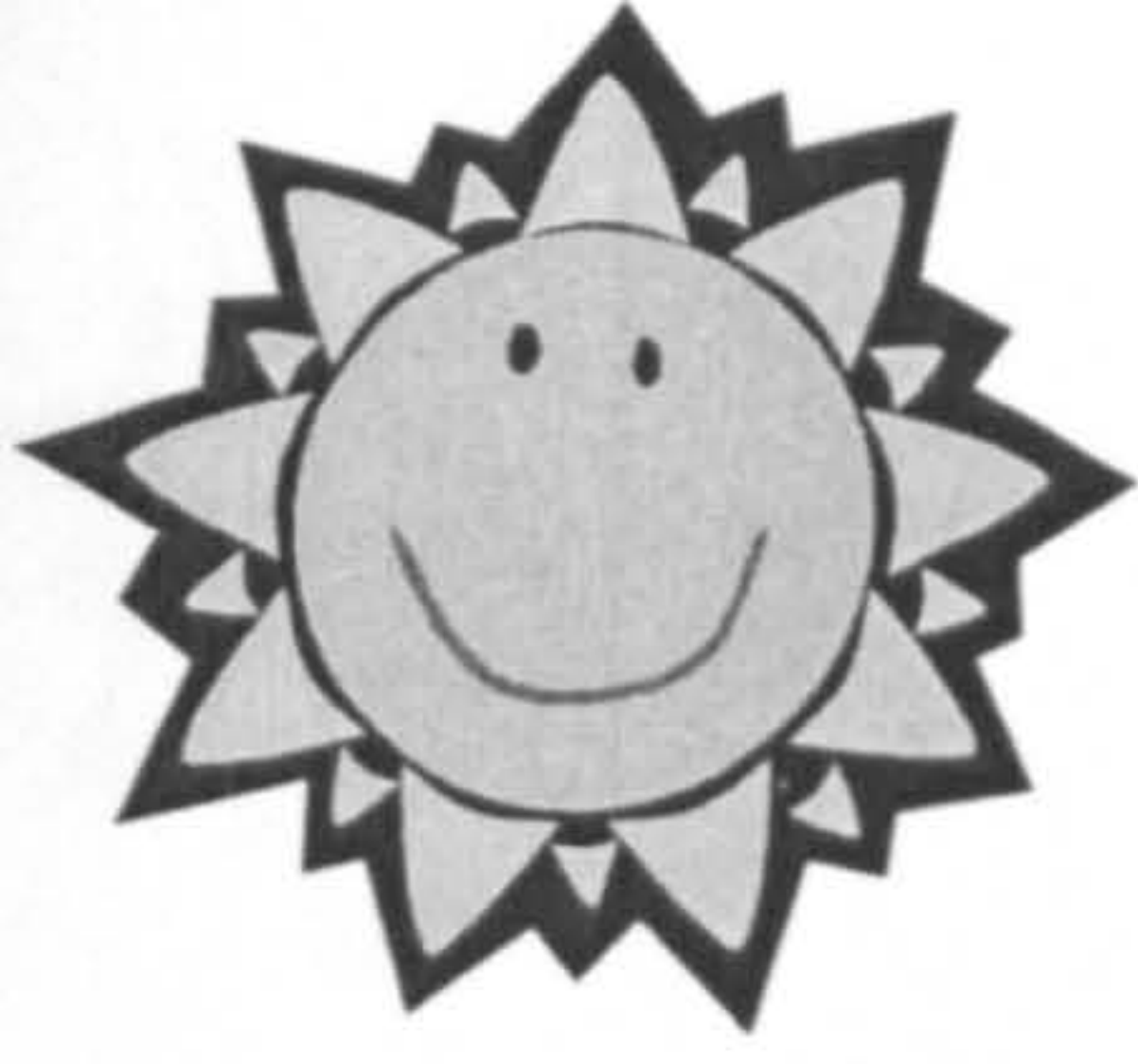


What have you learnt from the research about living with a life limiting condition?



What are the important things that you have learnt about yourself from being involved in the group?





What can you take with you from the experience of the research and the group into the future?

