UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

School of Nursing and Midwifery

Palliative Day Care

A community for People with

Progressive and Life-threatening Conditions

by

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ABSTRACT

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
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Doctor of Philosophy

A STUDY OF PALLIATIVE DAY-CARE

By Heather Anne Richardson

The main aim of the research was to learn about the nature of palliative day care (PDC) from the perspective of those using the service. It explored how patients experienced this service, including the value that they ascribed to it. In addition, the research considered whether patient experience varied between palliative day care services and to what the similarities and differences in this experience could be attributed. It also identified how patient views of PDC compared with the views of others involved in this service and the degree to which they were reflected in descriptions of PDC contained in the literature including that pertaining to models of palliative day care.

The research comprised two case studies of palliative day care which purported to provide different models of care. The case studies were based on a methodology of constructivist inquiry, and built on data collected via observation, interviews, examination of documents/visual information and a focus group. These were collected and analysed within a hermeneutic dialectic process to develop a joint construction of the service. Data collected in this process were then subjected to further analysis to develop a proposition regarding PDC that explained patient experience of palliative day care and its benefits from the perspective of its users.

The experience and views of patients using both services studied were broadly similar. Patients experienced the service as a place in which they could meet others who shared their condition or were sympathetic to their situation. This meeting took place in a pleasant and supportive environment and offered opportunities for new friendships, companionship, diversion and creativity. Those who joined the service identified it as a valuable source of social support, replacing that which had been lost as a consequence of their illness. A proposition is posed within the research based on the shared experiences of PDC across the services which suggests that palliative day care serves as a community, to which people with progressive and life threatening conditions can belong. It is particularly important for those whose social being is at risk.

This research serves to confirm many of the recent findings related to the nature of PDC according to its users, namely its offer of social support. It makes a unique contribution to knowledge in its proposition which serves to identify the structural elements of this service and its processes of care which give rise to this support. The proposition serves as an explanation for previously perplexing aspects of the service and proposes an overarching model of PDC that encompasses the variation in provision between individual services.

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CHAPTER 1
INTRODUCTION

1.1. Introduction to the research

This thesis describes research into palliative day care (PDC) for adults, a rapidly expanding component of palliative care (Higginson et al. 2000). As the name implies, PDC is a non-residential service that seeks to meet the needs of people with progressive and life threatening conditions. In this setting, as in others providing palliative care services, the emphasis of care is on improving the quality of life for people whose illness is likely to end in death. This is achieved through the identification, assessment and treatment of their physical, psychosocial and spiritual problems (World Health Organisation 2002).

Whilst there are over 250 PDC services in the United Kingdom (Hospice Information 2004) representing a sizeable proportion of this country's palliative care provision, it has been suggested in the past that PDC is the palliative care service least understood by professionals, patients and their carers (Leiper 1995). This is partly attributable to the paucity of research related to this service in the past; a gap that has recently begun to be addressed. However key questions remain unanswered, including those related to the experience of people who use this service. Little information is available regarding what difference PDC makes to its users, to what this difference can be attributed and whether it varies between services. The degree to which services vary according to their care style or approach is also unclear. One of the recurring themes in previous research relates to different models of PDC that are thought to exist. Mention is made, for example, of medical and social models (Eve & Smith 1994), creative models (Higginson et al. 2000) and a rehabilitative model (Hopkins & Tookman 2000). However little is understood at present about the nature of these models, their determinants or their outcomes, and how they compare with each other.

These gaps in knowledge about PDC could have important consequences for the service if those with responsibility for planning, purchasing, managing and providing PDC are unsure of its value to users. Ultimately it could place the service at risk, given the emphasis in the current healthcare arena to provide care for which the costs have been balanced against the benefits (Bosanquet 1999). In the short-term, lack of clarity by referrers regarding the value of PDC for its users could serve to deny individuals who might benefit from the service the opportunity to attend.

1.2. Origins of the research

A group of health professionals working in a palliative day care unit (hereafter described as DC1) were considering expansion of their service and found little in the literature to help them in their decisions regarding its future shape. As a result they decided to commission a piece of research that would help them decide how care should be delivered in this setting in the future. Specifically they wanted to identify elements of their provision that were particularly valued by patients and were keen to know of gaps in provision according to its users. Funding for the research was sought and granted by the local National Health Service (NHS) Trust of which the hospice was a part, and I was appointed as a full time student to undertake the research. Those commissioning the research remained involved through membership of a steering group that watched the development and progress of the research and provided me with an introduction to DC1 – a service of which I had no experience prior to becoming a student.

I was drawn to the research by my past experience of working in palliative care as a nurse and later as a manager. In both roles I had felt dissatisfied by my lack of understanding of PDC. I was unclear about who should be referred to the service, what they could expect to gain from attendance and how its provision compared to other palliative care services. As a manager I tried to address some of these questions through discussion with those involved in the service. This process revealed little, other than the fact that PDC was much more complex than I had

realised, arising from the variety of stakeholders involved, many of whom held conflicting views regarding the role and value of this service and the relative importance of its constituent parts. When I contacted other PDC units to discuss these issues I became aware of differences between the services provided despite using a shared name of "Day Care". This gave rise to new interest regarding the variable styles of provision and what effect they had on those using them.

My own curiosity about this service, combined with the requirements of those commissioning the research gave rise to a study concerned with gaining a greater understanding about the nature of PDC, principally from the perspective of users[1] of the service. I was interested to learn about how patients and their families/carers viewed the service and to learn about the value that they ascribed PDC and its particular elements. Thereafter I was keen to explore whether user views of PDC varied within and between services. I was also interested to learn how user views of PDC compared with those of others involved in this service and the literature concerned with PDC, including that related to models of care. Underpinning this curiosity was a commitment to engage with users in a participatory way, so that they could influence the shape of the research and any changes in service provision arising from the research.

1.3. Approach to the research

The research comprised two case studies of PDC services (DC1 and DC2), chosen on the grounds that they purported to provide different models of care. They were informed by a brief preliminary study of a third service to assess the practicability of the proposed methodology. The case studies were underpinned by a constructivist view of the world which sees reality as a social construction of the mind (Guba & Lincoln 1989). Their methodology was one of constructivist inquiry within which stakeholder views of the service are brought together through

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[1]Users in this context refers to people who are attending PDC and those who have attended in the past, their families/informal carers. Those attending PDC are sometimes referred to as "patients" in the thesis. This reflects the source material – either the vocabulary of the participants or the terminology used in the literature cited.

a hermeneutic dialectic process to develop a new joint construction of the service
(ibid.). This is, by nature, a highly participatory process. The focus of each case
study was the claims, concerns and issues held by users of the service and its other
stakeholders, adapted from a form of evaluation known as Fourth Generation
Evaluation (ibid.). These were explored through interviews with participants,
augmented by observation of the service and examination of documents, and
confirmed in a focus group towards the end of data collection in one setting. Data
collected were analysed by a process of constant comparison. When the two case
studies were complete, the data they had yielded were subjected to further analysis
to identify an explanatory proposition regarding PDC based on the experiences
and views of users of this service. Throughout the process of undertaking this
research, my own contribution to the process has been acknowledged and
monitored in a reflexive manner.

1.4. Introduction to the thesis

The thesis comprises nine remaining chapters, written in a style that reflects the
aims of the research and the chosen research approach.

Chapters 2 and 3 provide the theoretical context for the research. Chapter 2 draws
on literature concerned with the PDC and also the experience of living with a
progressive and life threatening condition. Chapter 3 considers the activity of
seeking a user perspective of healthcare as described in the literature, specifically
that which engages users in a participatory way as a basis for service development
or change.

Chapter 4 describes the approach to the research including the philosophical
underpinnings of the study, its methods of data collection and analysis. Within the
chapter, I explore methodological issues arising from the chosen approach and the
ethical considerations associated with undertaking research in a hospice setting.

Chapters 5 and 6 describe the new joint constructions of DC1 and DC2 respectively, based on the views of individual patients using these services. The descriptions utilise the vocabulary of these stakeholders wherever possible to reflect the aim of the research to describe PDC from their perspective. For example, users of the service are referred to as "patients" and "family members" to reflect the terms used by those involved in developing the joint construction to refer to service users. The joint construction is prefaced by an introduction to the service and its contexts to help the reader understand its detail. It is followed by a section of comment and discussion that encompass my views of the construction. This etic, or outsider, perspective is separated from the main description of the joint construction to enable the reader to identify my contribution to the findings.

Chapter 7 introduces the proposition regarding PDC based on users' perspectives of the service – that of PDC as a community. It describes the community and its benefits to its members. It also considers the negative consequences of belonging to it and variations within the proposition.

Chapter 8 puts the proposition into context. It identifies literature that supports the construction and that which offers explanation regarding its various facets.

Chapter 9 offers my reflections on the research. It considers the findings of the research, its strengths and weaknesses, my contribution to the research and its legacy for my future.

Chapter 10 concludes the thesis. It provides an overview of the research, summarises the findings and identifies the contribution of this research to existing knowledge, including that which is unique. It also highlights the implications of the findings for policy, practice and research and the recommendations that arise from them.

CHAPTER 2

THE LITERATURE REGARDING PALLIATIVE DAY CARE

2.1. Introduction to the chapter

This chapter introduces PDC, the focus of the present study, according to the literature. It provides contextual information about the service, describes PDC and its offerings, the different models of PDC purported to exist, and their outcomes. It also describes who uses PDC, how they are referred, their experience of the service and its benefits.

The chapter includes a section regarding the experience of people living with a progressive and life threatening condition. It has been included in the belief that this information will help the reader understand users' experience of PDC described later in the thesis. This section is not designed to offer a comprehensive review of the literature related to the experience of living with a progressive and life threatening condition; instead it describes the prominent related themes arising in the literature.

The chapter concludes by considering how the literature informs the present study and how it potentially adds to this body of knowledge.

2.2. The search strategy

An extensive search was undertaken initially to identify literature concerned with PDC. The databases and terms utilised within this process are described in Table 2.1. As I became familiar with the research in this area and their detail, other literature was sought through further searches and follow-up of cited references, to build the detail of existing knowledge regarding this service.

I then undertook a search of the literature regarding the experience of living with a progressive and life threatening condition. I accepted the suggestion in the literature that this was multifaceted in nature (Copp 1998) and for this reason

sought literature that would provide a variety of perspectives of the experience, including those that were sociological in nature. The databases searched and the terms used are described in Table 2.1.

Area of interest	Databases searched	Terms used
PDC	CINAHL, BNI, HMIC, Medline, AMED	Day Care, Hospice Day Care, Palliative Day Care, Day Hospice
Experience of living with progressive and life threatening conditions	Web of Science, AMED, Cancerlit, CINAHL, PsycInfo, Medline, BNI	Patient experience, user experience, carer experience, terminal illness, dying, cancer,

Table 2.1. Databases searched and terms used to identify literature included in Chapter 2

Literature identified through the searches was subjected to critique regarding its quality and potential contribution to the current study. The criteria used within this process are described in Appendix 1 along with a table that offers examples of this process. The degree to which various papers and articles met the criteria is reflected in the place that they occupy within the chapter. Their influence on the shape of the current study and its methodology is also an indication of their perceived value in these respects.

2.3. The origins of PDC

PDC is a long established service within the life of the hospice movement in the UK. This movement was established in the mid 20th century in response to advances in medicine which had resulted in an increasing emphasis on cure rather than care and on treatment in hospital rather than at home (Addington-Hall & Higginson 2001). Whilst the consequences of these advances were highly positive in the main, they were costly for some, namely those with chronic and terminal diseases (ibid.). In particular they led to a shift in focus away from the patient as

an individual to that of a "malfunctioning body", giving rise to impersonal care (p.2. ibid.).

It was this situation that the modern hospice movement sought to redress. St. Christopher's Hospice, which opened in 1967 and is generally considered to mark the beginning of this movement, provided research based terminal care and education to facilitate its spread (ibid). Care at St. Chrisopher's Hospice was concerned to relieve the physical suffering of people coming to the end of life; in addition there was a commitment to maintaining the quality of remaining life and addressing the distress associated with the spiritual, social and psychological demands of dying (Clark 1999; Saunders 1998). Initially this care was provided within an inpatient unit, but was extended over the period of the next decade to enable terminally ill people to remain at home for as long as possible (Addington-Hall & Higginson 2001). This extension included the establishment of informal day care facilities, which were established at St. Christopher's Hospice in 1974/75, marking the beginnings of PDC (Hospice Information Service 2000).

Hospice care now encompasses inpatient, community and hospital based services, as well as day care units providing hospice and palliative care to people who are dying and their families/carers (Hospice Information 2004). It has grown exponentially since its inception, hospice care currently being estimated to reach 250,000 people with advancing illness each year in the UK (Hospice Information 2005).

Its success is, in many respects, undeniable. Within the UK, hospice/palliative care is now considered by the Department of Health to have a crucial role in the care received by people with life threatening conditions such as cancer and their carers (Department of Health 2000b). In addition it has an established place in medical training and provision, having been recognised as a medical speciality by the Royal College of Physicians in 1987 (Addington-Hall & Higginson 2001). Its support by the general public is also clear, demonstrated by the annual receipt by the English hospices of over £270 million in 2002 in the form of voluntary income

(D.Praill, Help the Hospices, Personal Communication 2005). At a global level, hospice and palliative care units are established in over 100 countries, across six continents, adapted to suit local needs and culture (Hospice Information 2005).

Even so, criticism has been levelled at the Movement. Concern has been expressed in the past about the development of this form of care outside the NHS and its concern with a relative few of those facing the end of life (Douglas 1992). More recently, a review by the House of Commons Health Committee has highlighted the inequities in current provision of services relating to geography, patient and disease groups (House of Commons Health Committee 2004). The concerns of the committee reflect national statistics regarding utilisation of hospice care which indicate that well over 90% of patients receiving specialist palliative care have cancer, that younger people receive disproportionately more palliative care than older people and that nationally over 95% of palliative care uses are white (The National Council for Palliative Care 2005a) Significant questions remain regarding the effectiveness of palliative care and its particular interventions and models of care (Bosanquet & Salisbury 1999). This makes the already complex process of responding to new and increasing needs for palliative care in an arena of finite resources even more difficult to achieve (ibid.).

It is within this context that the first purpose built PDC service was established at St. Luke's Hospice in Sheffield in 1975 (The Hospice Information Service 2001). Professionals working in the hospice conceived the idea as a means of developing and improving the care that they already offered to people with progressive and life threatening conditions (Cockburn & Twine 1982; Wilkes et al 1978). They were concerned about the level of support and follow-up available to patients living at home and their families, particularly those who had recently been discharged from the inpatient unit or were awaiting admission to it. In response they built a day unit attached to the hospice, which provided a variety of services including emotional and social support, rehabilitation and basic nursing care. They believed the new service to be effective and recommended it as a simple and valuable development in the provision of hospice or palliative care (Wilkes et al

1978). Their recommendation that any PDC unit should be attached to an inpatient unit has been strongly adhered to, resulting in over two thirds of the total number of current PDC services in the UK being configured in this way (hospice information, verbal communication 2004). PDC has grown exponentially over the last 20 years, the number of PDC services in the UK now exceeding the number of inpatient hospice services (Hospice Information 2004). Day Care is viewed by the general public as an integral part of hospice care and receives much public support for its work (Help the Hospices 2001;Help the Hospices & Independent Hospice Representative Committee 2001).

Given this history, it could be argued that the goals and values of PDC are derived from, and reflect those of the Hospice Movement. It is certainly concerned to redress care that has been offered to terminally ill people in the past. In so doing, it gives emphasis to care rather than cure, to quality rather than quantity of life and to treating the dying person in a holistic way – key elements of palliative care (Doyle et al 1993; Saunders 1981; Saunders 1993). In keeping with the definition of palliative care recently offered by the WHO (2002) its care is concerned with the prevention and alleviation of suffering for both patients and their families who face the problems associated with life-threatening illness. This is achieved through the assessment and treatment of problems, whether they are physical, psychosocial or spiritual in nature (ibid). Even so, questions are posed by the literature as to the degree to which PDC is an integral and essential component of palliative care provision. For example, recent guidance for palliative and supportive care commissioned by the government does not identify PDC as a minimum requirement of specialist palliative care to be made available to anyone with cancer or another life threatening condition in England and Wales (National Institute for Clinical Excellence 2004a). In addition, there are calls for further work to review and clarify the position of PDC within the arena of palliative care on the grounds of cost effectiveness and appropriateness (Clark & Seymour 1999;Goodwin et al. 2003).

2.4. An overview of current provision

It is estimated that there are over 10,000 PDC patient places available over the period of a week in the UK (Copp et al 1998; Higginson et al 2000). The number of places offered by individual PDC units varies between two and 50 a day (Eve et al. 1997), available between one to five days a week in each centre (Eve & Smith 1994).

In its current form PDC rarely exists in isolation from other hospice services. Copp et al (1998) who undertook a telephone survey of 131 PDC services describe how nearly 90% of the services that they studied were attached to both an inpatient hospice unit and/or a home care team. As such, PDC often serves to complement the work of other hospice services, and is noted to provide a sensitive introduction to inpatient services (Corr & Corr 1992), additional support for hospice patients living at home (Fisher & McDaid 1996; Wilkes et al 1987), and assessment and treatment of symptoms for outpatients (Wilkes 1980). Proponents of the service believe that it has the potential to adopt a central role in shaping the care package that people at home receive and providing the link between home care and inpatient support (Fisher & McDaid 1996b), subject to confirmation by further research (Myers & Hearn 2001).

PDC has broad objectives which encompass those that are social, psychological, physical and existential in nature (Higginson et al 2000). Based on a questionnaire study of 40 PDC centres in North and South Thames, Higginson et al (ibid.) suggest that common to all PDC services is the provision of physical, social and spiritual support with added layers of care provided in slightly different ways by individual services. This holistic provision is confirmed by Douglas et al (2000) who studied five PDC services in more detail through observation over a five week period in each setting. According to Slater (2001) this comprehensive provision is at the heart of the value of PDC for its users, but is also the reason for the complexity of PDC that she and others note (Myers & Hearn 2001).

2.5. Details of the care on offer in PDC

According to the literature PDC units provide a core set of similar services which offer a spectrum of support (Douglas et al. 2000), including that which is social, psychological and physical in nature (Copp et al 1998; Douglas et al 2000; Higginson et al 2000). This care commonly takes the form of symptom control, basic nursing care, complementary therapies, creative activities, counselling and advice (Copp et al 1998; Higginson et al 2000).

The offer of social support in this setting dates back to the early PDC services which were set up to provide opportunities for social interaction (McDaid 1995). However research regarding the nature of this support is limited. One exception to this is the ethnographic research conducted by Langley-Evans and Payne (1997) which reveals it as an environment conducive to social talk and one in which patients can explore their experience of illness in a light-hearted and unthreatening way. In doing so patients are able to maintain an optimistic outlook and a fighting spirit.

Symptom control has assumed an increasingly central role in this setting, most services offering opportunity for ongoing review of patients' symptoms as part of their care (Higginson et al 2000). However the findings of Goodwin et al (2003) are equivocal about how effective symptom control is in PDC. In recent years, technological advances in palliative care and changes in patterns of provision have changed the face of symptom control, verified by the availability of blood transfusions, intravenous treatments and subcutaneous infusions of drugs in some PDC services (Copp et al 1998). According to Hargreaves and Watts (1998) , this shift is acceptable to patients who see it as part of a holistic and flexible approach to their care needs, although others have cautioned against this trend on the grounds that it could place the hospice philosophy at risk (Holmes 2001).

Over the course of the years, opportunities for rehabilitation have been assigned to the service (Hockley 1993; Hockley & Mowatt 1996). This is possible, according

to Hockley and Mowatt (1996) when rehabilitation is redefined to acknowledge the particular needs and limitations of people with advanced disease. As such the aim of such care is to enable the person and their family to adjust and readjust to a rapidly changing (and often deteriorating) situation as a means of effecting positively their quality of life and making the time lived worthwhile (ibid.). This process, according to Doyle (1998) is concerned with making the patient into a person again,

Elfred (2004), in an overview of rehabilitation and advanced disease provides details of the nature of this rehabilitation in palliative care, and specifically physiotherapy. She suggests that physiotherapy is valuable in reducing functional deficits, which give rise to weakness and deconditioning in people with advanced disease. She also advocates therapeutic exercise as a means of alleviating fatigue, improving functional capacity and quality of life. Her recommendations are based on research regarding rehabilitation in oncology (for example Graydon et al. 1995;Marciniak et al. 1996 cited in Elfred 2004) and also that which is specific to palliative care and end of life (for example Shee 1995;Yoshioka 1994 cited in Elfred 2004).

Such aspirations are the basis of the redesigned PDC service described by Hopkins and Tookman (2000) who have shifted towards a rehabilitative model of care in response to changing needs and expectations of their users. Those working in this setting are confident that this new focus in PDC has had a significant impact on patients' quality of life (K.Hopkins, personal communication, 2000). However, there is no evaluative data available to support this assertion currently.

The paucity of evaluative data in general regarding rehabilitation in PDC is notable and represents a significant gap in the literature. It is a question which is likely to attract increasing attention, not least as providers and purchasers of palliative care seek to implement the recent guidance for improving supportive and palliative care which cites rehabilitation as a major way of improving quality of

life (National Institute for Clinical Excellence 2004a). Elfred (2004) amongst others highlights the opportunities provided within PDC to provide multi disciplinary rehabilitation, suggesting that it should serve as an aspiration in the event that provision is currently underdeveloped. The specific nature of this provision however is unclear, and there is limited research to draw on currently to guide such development.

Creative therapies are available in a proportion of PDC units (Higginson et al 2000). They are purported to restore self esteem (Frampton 1986), to re-establish a sense of control in patients (Stevens 1996), and to foster hope in those using PDC (Kennett 2000). Shaw (2000) describes how sculpture making was of value to patients both in terms of the physical experience of the making and the capacity of the sculpture to carry their identity into the future. Mayo (1996) and McLoughlin (2000) both ascribe therapeutic value to the activities of group art therapy and poetry respectively on the grounds that they provide purpose, inspiration, realisation of one's creativity and opportunities for expression and growth.

The milieu of PDC would seem to be an important backdrop for the care provided. Hopkinson and Hallet (2001) describe how participants of PDC felt relaxed and comfortable in this setting, as a consequence of feeling welcome, accepted and understood. This arose from the time that they were given and the consideration shown by staff and volunteers working in this setting. This finding is supported by other anecdotal descriptions of PDC services in the literature (for example Carruthers 1995).

In some PDC settings care is extended to patients' families and carers (Higginson et al 2000), a valuable but often hidden part of the service (Copp et al 1998). Services available to carers in this setting range from advice and support to practical help including home sitting services and equipment loans (ibid.). The provision of respite care has been identified as an important component of the service of PDC (Corr & Corr 1992; Fisher & McDaid 1996b; Olson 1989),

although Myers (2001) cautions against assuming that this is always perceived as helpful by the carer, given the lack of research in this area.

2.6. Models of PDC

The literature proposes various models or styles of PDC according to their emphasis of care (Eve & Smith 1994; Higginson 1996), differences between which may account for the various labels ascribed to PDC services, including day-hospice, day-therapy and the day-centre (Myers & Hearn 2001).

The classification of PDC services according to their model of care was introduced in 1994 by Eve et al who identified two key models of PDC in the UK. On the basis of data collected from 172 units, the authors suggested that PDC services could be divided into two groups according to whether they placed emphasis on medical input, or concentrated more on social activities. Until recently, definition of these particular models and description of their detail were lacking in the literature despite repeated citation of this work in subsequent research and tentative attempts to interpret findings on these assumptions (for example research by Copp et al 1998). Given the unsatisfactory nature of existing knowledge as to whether these models existed and what the nature of their practices and culture were, Copp et al (ibid.) proposed further research in order to gain insight and understanding into the complexities and functions of the different models of PDC.

The research reported by Higginson et al (2000) began to address this gap in knowledge. Their research included a section on how those running the services saw their service in terms of these two models. The findings from this study did not support a clear distinction between the models, suggesting instead that most PDC services fall somewhere between the two. They also propose that the term "creative" might be a closer description of the care provided by those services previously identified as offering a social model of care. A qualitative study of PDC (Goodwin et al. 2002) builds on this work. It suggests that patient experience of PDC was similar across services purporting to provide different models of care (as

defined by those providing the services), with most value being placed on the social contact offered therein.

Another perspective on the models of PDC is offered in the unpublished work of Langley-Evans (1999) who describes four distinct models of PDC based on the various ways that PDC is construed. Drawing on data collected in three PDC units using an ethnographic research design and analysed according to the work of discourse theorists, she identifies various discursive environments with markedly different inherent social relations. PDC as an 'outpatient clinic' is construed as a specialised unit for the monitoring and palliation of patients' symptoms. In this environment nurses are viewed as specialists doing the work of the clinic and patients are considered passive recipients or objects of care. PDC as a 'social club' is considered a place to meet people, make friends and have fun. Here, the formal roles of staff member, patient and volunteers are secondary to the role of friend and patients are considered active as friend, entertainer and/or audience. PDC as a 'care home' is understood to be about providing a warm, comfortable environment in which staff can give patients special care. In this environment patients are afforded special care by the staff and as such are passive, dependent and child like. PDC as the 'rehabilitation unit' is seen to provide therapy, where patients are helped to enhance their creativity, independence and life satisfaction. In this setting patients are in a position to give as well as receive and relationships are based on co-operation and reciprocity. The author suggests that these models of care may overlap in practice and proposes further research to explore their relevance, prevalence and dominance in other PDC settings.

A new model of PDC appears to be emerging. As mentioned earlier in the chapter Hopkins and Tookman (2000) describe the evolution of their PDC Unit from a service based on a social model of care to one that focuses on rehabilitation. This model has developed in response to a changing picture of cancer and its care whereby patients are referred earlier in their treatment to palliative care services, have more complex problems as a result of extended treatment and are living

longer with increased levels of disability. Patients attend the new service for therapy, social support and outpatient medical and nursing assessment. They use a "spine of services" which include the outpatient clinic, nurse led clinic, the day suite and support groups. In addition they are offered other elements of care on the basis of individual needs and goals. This model of care is attractive to leaders of other palliative care services who are keen to shift the nature of their care to that which is short term and problem focused (Day Care Leaders, verbal communication, Day Care Leaders Conference 2002).

2.7. Providers of PDC

PDC is commonly provided by a team comprising paid staff and volunteers (Spencer & Daniels 1998). Staff members belonging to this team vary between services in terms of their numbers, qualifications, professional background and skills (Bray 2001; Copp et al 1998; Faulkner et al. 1993). In the UK the majority of PDC services are led by a nurse, a smaller proportion being led by occupational therapists or psychologists (Bray 2001).

Medical input to PDC is identified as valuable in this setting according to the literature (Edwards et al 1997; Sharma et al 1993; Tookman & Scharpen-von Heussen 2001). This is related to the high incidence of uncontrolled symptoms in patients attending the service which respond to medical assessment, treatment and review in PDC (Edwards et al 1997). Research has indicated that patients found medical presence in this setting reassuring and some attended specifically for this reason (Sharma et al 1993). Even so, medical input varies in nature between services, some units having no input at all (Copp et al 1998; Faulkner et al 1993). It has been suggested that this variation is a consequence of organisational issues rather than philosophical ones, and has been identified in the past as the reason for the different perceptions of the purpose of PDC held by its various stakeholders (Faulkner et al. 1993).

Volunteers are important contributors to PDC and are used in most PDC services (Copp et al 1998; Higginson et al 2000). They provide a number of different services, ranging from nursing and complementary therapies to creative activities and providing companionship, often supporting the professional team (Bray 2001; Carruthers 1995). They are seen to have particular therapeutic value arising from a shared experience of terminal illness, many of them being bereaved themselves (Jones 1996). In addition they offer the softer aspects of caring, including compassion, which arguably have often been lost in mainstream healthcare (Mount 1992). In return they enjoy a high degree of satisfaction, arising from making a difference to the lives of others and opportunities for personal growth and development (ibid.). Jones (1996) highlights the potential stress experienced by volunteers working in PDC, such that additional structures are required to support them if they are to function effectively and limit the emotional cost of their work. In addition they need strong leadership and adequate training to enable them to participate productively in the care of patients using palliative care services (Mount 1992) and to understand and work according to agreed practices (Addington-Hall & Karlsen 2001). This provision has been variable in the past, some volunteers having little or no access to supervision. Bray (2001) suggests that this is disturbing given the close involvement of volunteers with a vulnerable group of patients.

2.8. Outcomes of PDC

The literature describes a variety of purported benefits to patients attending PDC services, including an improved quality of life of patients (Kennett 2000; Stevens 1996; Thompson 1990), longer stays at home (Stevens 1996), a less traumatic introduction to hospice inpatient care (Corr & Corr 1992; Doyle 1993a; Thompson 1990) and increased self-esteem (Hopkinson 1997). In addition positive outcomes have been identified for carers (Higginson et al 2000; Stevens 1996). However it is difficult to draw firm conclusions from these assertions, in particular the degree that they reflect the experience of those using the service. Often they are based on professionals' views and assumptions, at best derived from informal feedback

from users to those caring for them (Slater 2001). Furthermore, where research identifies professional views of PDC alongside those of users there is evidence of disparity between the views (for example Macdonald & Macdonald 1992). Some research exists where outcomes according to users are identified, for example those described by Hopkinson (1997). However, they are not linked to the models of PDC purported to exist.

In 1998, Spencer and Daniels called for evaluation of PDC and suggested that specific, targeted measures be identified as a basis for this. A major programme of evaluation of the service was undertaken subsequently (Douglas et al 2000; Goodwin 2000; Goodwin et al 2002; Goodwin et al 2003; Higginson et al 2000). Those involved in the evaluation reported difficulties associated with evaluating PDC given the complexity of PDC and methodological difficulties associated with conducting research in palliative care (Douglas & Normand 2001; Goodwin, Higginson, Myers, Douglas, & Normand 2003). Even so, there are interesting conclusions. Goodwin et al (2003) suggest that PDC addresses more than health related quality of life including that related to social support or social contact. The qualitative component of the study, reported by Goodwin et al (2002) indicates that the most important thing about PDC for those using the service was meeting other people, who they could talk to and who would understand their situation. They call for further studies to examine the effectiveness and cost-effectiveness of PDC, with a focus on elements of PDC that are important to patients, including its important social function. These are likely to be different to those considered in other health care evaluations and may be difficult to measure in the light of this (Myers 2001).

2.9. Users of PDC

This section describes the characteristics of those using PDC according to the literature, their reasons for referral, their attendance patterns and their needs.

2.9.1. Characteristics of those using PDC

PDC is essentially a service for people with cancer. This is consistent with other palliative care services despite calls to extend this provision to people with other diagnoses (Doyle 1993b; Harris 1990). The survey by Higginson et al. (2000) found that 90% of all patients using the PDC services that they studied had a diagnosis of cancer, the remaining 10% including patients with HIV and AIDS, motor neurone disease and stroke. This finding is comparable to the survey conducted by Eve et al (1997) whose findings indicated that as many as 96% of patients using PDC have cancer. Higginson et al (2000) express concern about this finding. They suggest that the reasons for referral to PDC extend beyond cancer, the implication being that people with conditions such as terminal heart disease, stroke, respiratory disease and dementia could benefit as much as cancer patients from attending the service. Interestingly the first PDC service described by Wilkes et al. (1978) sought to care for patients with a variety of conditions including those that were considered chronic, rather than terminal in nature.

Traditionally PDC has been a service for people who are older. Research by Copp et al (1998) found that the majority of patients in over 130 units were aged between 61 and 80 years. Goodwin et al (2002) note that most of the 120 patients that they studied who attended PDC in the London Region were over 65 years old. However, efforts are being made by those running services to buck this trend. The last few years have witnessed attempts by many services to address the needs of younger patients who might benefit from this service through the provision of dedicated days for their use (Higginson et al 2000), the uptake and outcomes of which are currently unreported.

Other sociodemographic characteristics of those using PDC services noted in the literature include being white and retired from work (Goodwin et al 2002). The same study reports that one third of the group studied lived alone. These are findings similar to those reported by Edwards et al (1997) from a much smaller study. Otherwise there is a disappointing lack of data regarding social support at

home for those using PDC. This gap in knowledge needs to be addressed given the suggestion in the literature that people using PDC are often those who are socially isolated (Hockley & Mowatt 1996), and the inclusion of social isolation in the referral criteria of many PDC services (Goodwin et al 2002; Higginson et al 2000).

2.9.2. Reasons for referral to the service

In addition to social isolation, patients are also referred to PDC for respite for carers, psychological support, monitoring, symptom control and assessment (Higginson et al 2000). In general, eligibility criteria for the service are inclusive. They are concerned only with ensuring that patients referred have advanced and progressive disease and that they are likely to benefit from attending the service (ibid.). They reflect a gap in knowledge concerned with the characteristics of people who are particularly likely to benefit from attending the service. Fisher and McDaid (1996b) have attempted to address this by suggesting that the group of patients for whom referral to PDC is indicated are those who are not actually dying but whose ability to fulfil their usual roles is compromised. However this suggestion draws on experience of PDC rather than research.

2.9.3. Attendance patterns of users

The length of period that patients attend PDC is highly variable within services ranging from a few weeks to many years (Higginson et al 2000). The reasons for the longevity of attendance for some patients are uncertain, and further research is proposed regarding the variability in length of attendance and the benefits and disadvantages of discharge for these patients (ibid.). There is suggestion in the literature that some PDC units experience difficulty discharging patients even when they have no further requirements for specialist support (Myers & Hearn 2001), an observation supported by stories of service provision (for example Johnson 2001). It has been suggested that these difficulties may be a consequence of the lack of suitable alternative day care when specialist input is no longer required (Myers & Hearn 2001).

According to the study by Higginson et al (2000) the most common pattern of attendance at PDC is weekly, although the authors state uncertainty about whether this pattern reflects the needs of the patient or those of the organisation. For those patients that attend more often, there is no information about their needs compared with the other patients, neither is there detail of the decision making process that affords them a more frequent pattern of attendance than others. Given some of the reasons for referral such as symptom control and respite care (ibid.), a question is raised as to whether weekly attendance is sufficient to meet these needs.

2.9.4. The needs of people with progressive and life threatening conditions

There are just over 600,000 deaths each year in the UK each year (Office for National Statistics 2004b). In 2001, 70% of deaths were caused by cancer, ischaemic heart disease, respiratory diseases and cerebrovascular diseases (Office for National Statistics 2005). It is predicted that the same conditions will form the top five causes of death in 2020 (Murray & Lopez 1997). These are conditions which could have a palliative period, identified as a period when the disease is progressive, no longer curable and where the emphasis is on the quality of life of the patient (National Council for Hospice and Specialist Palliative Care Services 1999). For individuals with these conditions, regardless of its trajectory, it has been estimated that the majority will experience problems that would benefit from palliative care (ibid.), including that on offer from PDC (Higginson et al 2000). In an exercise to estimate need for palliative care, Higginson identifies that in a typical population of 500,000 people, there will be 1,400 cancer deaths each year and 3,450 deaths from potentially progressive non-malignant disease (National Council for Hospice and Specialist Palliative Care Services 1999). Of these she estimates that 1,200 of those with cancer will suffer pain, plus a number of other symptoms (ibid.). Similarly 2,300 people with other progressive conditions will have pain, probably in conjunction with other symptoms, including trouble with breathing, feeling sick and mental confusion (ibid).

According to the literature, a progressive and life threatening condition has a number of key characteristics that give rise to particular needs in those it affects. The first is its threat of death, the second relates to its potential chronicity and the third is concerned with its advancing nature.

Despite highly variable and improving survival rates for people with cancer (Dickinson 2000;Quinn et al. 2001), the literature suggests that the experience of those facing such a diagnosis is one dominated by a fear and belief that they are infact dying (Kellehear 1992; Krause 1993; McNamara 2001). According to Pattison (1977) they enter the living-dying interval, a time of considerable tension as the terminally ill person strives to continue living whilst also preparing to die (ibid.). The experience of dying is multi-dimensional, involving individuals in a range of physical, psychological, social and philosophical/spiritual responses (Copp 1997). These, according to formative theories about the process of dying, include the reactions of anger, depression, fear, anxiety, shock, guilt and despair (Buckman 1993; Kubler-Ross 1969). It is a period that is difficult and frightening for most people given the death of self that they must face, even when their physical symptoms are well managed (Copp 1997). As such it is a time of potential crisis (Abiven 1996), which can result in chaos if those who believe that they are dying do not receive adequate help and support in the period between diagnosis and death (Pattison 1977).

Aspects of these theories would appear to be supported by empirical evidence. Young and Cullen (1996), who undertook a study of 14 dying people describe how these individuals experienced mental distress as a consequence of their illness. It arose because "they had to give up their future" (p.37 ibid.), as a consequence of the seriousness of their condition, and because "procrastination about death could no longer be preserved quite intact; it had to be replaced by the much more disturbing possibility of the truth" (p.38 ibid.). The individuals they studied described how the intimations of mortality came, not only from those caring for them, but also from changes in their own bodies. This gave rise to repeated losses

and a struggle for independence. Work by Exley (1998) regarding the experience of dying in 19 patients describes how people diagnosed with cancer felt that their diagnosis had changed their lives irrevocably, even early on in the illness. They felt invaded by the cancer, out of control and faced major changes in their relationships (ibid). Epidemiological research by Cartwright (1991) suggests that over one-third of people in their last year of life suffered from depression, based on reports from their carers. Whilst there is no exploration as to the reason for this depression, the author does conclude by noting that "dying was often an unpleasant and painful process and there remain many inadequacies in our services to alleviate the distress and create a comforting and supportive environment for the final event in our lives" (p.87 ibid.). However, empirical evidence also exists of positive experiences arising from living with the knowledge of impending death, serving to challenge elements of the aforementioned theories. For example, Exley (1998) describes how a terminal diagnosis improved aspects of life for some of her research participants. It served to provide individuals with permission to do things that they would not have ordinarily done or encouraged a positive change in behaviour (ibid.). Similarly Fife (1994) describes how individuals living with cancer sometimes described improved relationships and a new and positive perspective on the opportunities that remained for them. As such they could maintain a positive perspective of themselves and their future, and thereby continue to find life worthwhile (ibid.). The different responses, according to Olson et al (2001) relates to whether individuals have a reason to continue living, some making adjustments to their lives and moving on, whilst others became "mired in the emotional distress experienced" (p.296 ibid.).

The chronicity of some progressive and life threatening conditions becomes increasingly pertinent as advances in medicine mean that people with potentially fatal conditions survive much longer even when they cannot be cured. In addition the prevalence of chronic illness has been linked to longer life expectancy – a characteristic of the UK population within which 26% are aged 65 years or older (Office for National Statistics 2004a). The result is that more people are likely to

die as a result of serious chronic disease (WHO (World Health Organisation) 2004). According to McNamara this results in a paradoxical situation of "extended life and extended dying" (2001 p.3). This enduring characteristic of terminal illness has been considered by Glaser and Strauss (1968) and by Copp (1998) who describe a trajectory of dying in which death is certain but at a time unknown. Chronic illness is characterised by its longevity and dominant position in people's lives, whereby sufferers are required to manage its various and significant consequences along with the symptoms and treatment that the condition gives rise to (Locker 1983; Locker 1999). The consequences of chronic illness include social isolation, estrangement and problems with self-esteem and identity (Locker 1999) and a sense of being a burden (Charmaz 1983). Cartwright (1991) also highlights the prolonged experience of mental confusion, depression and incontinence in people who were 75 years or older, arising from her study of changes in life and care in the last year of life.

The advancing nature of progressive and life threatening conditions is linked to an uncertain disease trajectory which may contribute to the experience of crisis which can accompany receipt of a diagnosis such as cancer (Wood & Tombrink 1983). It potentially produces various new symptoms in the sufferer (Bruera 1993), which can be distressing in nature and may be linked to concerns regarding the likelihood of suffering in the future and the level of relief likely to be available (Hinton 1967). Research which considered symptoms in people during their last year of life highlights a high incidence and multiplicity of symptoms in people with cancer and other conditions, with over 80% of people with cancer and 67% of people with progressive non-malignant disease experiencing pain (Cartwright 1991). A comparison of the prevalence of symptoms in people in the last year of their life in 1967 and 1987 revealed similar levels in many symptoms despite advancements in hospice care and symptom control during the same period (ibid.) For some people anxieties about unrelieved symptoms lead to an increased wish to hasten death (Kelly et al. 2003). Advancing disease commonly leads to changes in bodily function reinforcing the growing realisation that death is imminent and

unavoidable (Young & Cullen 1996). It may result in physical impairment which can make the sufferer housebound and physically dependent (Lawton 2000). It can also result in problems that affect self-image, sexual identity and sexual functioning (Wood & Tombrink 1983). As such it may have a negative impact on the sufferer's mental health status, resulting in depression (Vachon 1993; Wood & Tombrink 1983). Loss of physical strength and ability to care for oneself, and the related loss of emotional and intellectual abilities is also likely to reduce the quality of life experienced by the patient (Tigges 1993).

These characteristics of progressive and life-threatening conditions can result in a lonely, fearful, confusing and debasing experience for the sufferer. They also have ramifications for those caring for someone with this condition.

The loneliness associated with having a progressive and life-threatening condition may arise as a consequence of a number of factors:

➢ The preparation made by those around the patient as they anticipate the loss of the patient. This has been termed "social death" by Sudnow (1967) who describes a process of withdrawal on the part of professionals and relatives in anticipation of the patient's demise. It is a frequent and normal response to impending loss (Germino et al 1995; Hinton 1984), but one which leaves the patient increasingly alone as he/she approaches death.

➢ The stigmatising effect of having a diagnosis of a potentially incurable condition such as cancer, which serves as a socially discrediting attribute that is permanent in nature (Exley 1998; Goffman 1963). Stigma attached to cancer and similar conditions is well documented in the literature (McNamara 2001), cancer being assigned a status in contemporary society that means that "a surprisingly large number of people with cancer find themselves being shunned by relatives and friends" (Sontag 1987 p.10). Goffman (1963)

suggests that those who feel stigmatised withdraw from situations or find themselves ignored, demanding that they spend increasing time alone.

> The place of death in modern society. In this context death is unacceptable given society's orientation towards youth, vitality and the future (Mellor & Shilling 1993). As a consequence distance is established between the living and the dying (Bauman 1992; Lawton 2000). Elias (1985) in his book "The loneliness of dying" describes this process of separation as "Pushing dying and death further than ever out of sight of the living, and behind the scenes of normal life in more developed societies" (p. 85). The consequence of this is that whilst the living can deny or forget the existence of death, those that are dying are increasingly alone.

> Changes in relationships that people with such a condition face. There may be loss of equality in these relationships on the grounds that the sufferer no longer has the same capacity to plan for the future as the other (Exley 1998; Lawton 2000). The sufferer and their significant other(s) may cease to communicate with each other because of the pain and distress that discussion is likely to invoke or because the nature of their anxieties are different (Germino et al 1995). As a consequence patients and their carers feel increasing isolation, even within relationships that have been highly supportive in the past.

> The increasing likelihood of living alone towards the end of life. Research by Cartwright (1991) which considered the living arrangements of people in the last year of life and compared similar data collected in 1969 and 1987 highlighted the significant increase of people who lived alone (15% in 1969 compared with 32% in 1987).

Fear related to having a progressive and life threatening condition is induced, according to Field (1996), by the experience of dying in contemporary society. Within this context, fear is mainly concerned with the process of dying and the

impact of death upon close others. He describes the modern dying role as one which has no value and is amorphous and unstructured in nature. It is previously unrehearsed and transition to it is not only involuntary on the part of the terminally ill person but also unmarked as a rite of passage. As a consequence, those facing death in modern society are often also confused and anxious, and feel uncertain, vulnerable and socially unsupported within the process (Giddens 1991; Mellor & Shilling 1993).

The debasing nature of this condition, which serves to threaten one's sense of identity can give rise to profound suffering (Shaver 2002b). It is the consequence of its debilitating and invasive nature (Exley 1998), its impact on the person's ability to undertake social roles and responsibilities accepted in the past (ibid.), and the chronic nature of the condition from which sufferers experience discrediting definitions of self (Charmaz 1983). "Biographical disruption" (Bury 1982 p.169) can result, giving rise to a disturbance of the structures and knowledge concerned with everyday life, which demands a fundamental review of the person's biography and self concept. This redress is possible when the sufferer reorganises their story to accommodate and account for illness (Williams 1984). However this is difficult to accomplish for people with conditions such as cancer given its largely unknown aetiology and the negative connotations attributed to the condition (McNamara 2001; Sontag 1987). Seale (1995) suggests that this redress is possible for the dying person and those caring for them when they engage in "reflexive formation of self" (p.598) by attributing heroism to the experiences of approaching death and caring for the terminally ill person. He proposes that this is most possible in a context of open awareness as described by Glaser and Strauss (1965) within which both the patient and those caring for him/her acknowledge that he/she is dying.

Carers of people with progressive and life threatening conditions also have needs, which are significant in terms of their frequency, level and nature. It is estimated that there are over 5.7 million carers in the UK, many of whom are likely to have

been caring for someone who is terminally ill.(Hospice Information 2005). Research findings during the 1990s identified informal carers in palliative care as having extremely high levels of unmet need and distress (ibid.), these needs including those that are financial, practical, psychological and information based (Harding & Higginson 2002). It is acknowledged that this role is a highly stressful one. The stress of carers may arise from their lack of knowledge regarding the caring role, concerns about meeting the needs of the patient, role changes, lack of social support, difficulties interacting with others and fear of being alone (Blank et al. 1989). When the condition is an enduring one, further strain is imposed as a consequence of the ongoing demands for care, the burden endured by the sufferer and their withdrawal from those around them (Conrad 1987). The literature suggests that carers need practical help at home, social support, financial help, spiritual care, and information to cope with this situation (Pottinger 1991; Sykes et al 1992). These requirements need to be addressed in the light of the assertion that the family's care experience during the palliative phase has a bearing on members' health and their ability to function during the early bereavement period (Kristjanson et al. 1996).

The experience of having a progressive and life threatening condition is not entirely negative. As described earlier, positive aspects of living with the knowledge of a terminal illness have been identified in the literature, with claims that the last stages of life can be an opportunity for positive achievement and fulfilment (Saunders 1983), emotional healing (Shaver 2002a) and enhanced relationships (Fife 1994). This is possible when the likelihood of death is embraced rather than ignored, and when the focus of the dying person is on the opportunities offered within life remaining rather than their impending death (Gullickson 1993). When people are dying, it has been suggested that is the desire of professionals working in palliative care to ensure a 'good death' for their patients in which there is closure and peace for all concerned (Payne et al 1996). However, it is proposed that this need may serve to stifle individual patterns of dying in their patients (ibid.). As a consequence a newer notion of the 'good

enough death' has been identified which seeks to ensure that the preferences and the values of the dying person are attended to (McNamara 1997).

2.9.5. User experience of PDC

Literature describing user experience of PDC is limited. A review of the literature about PDC reveals a widespread belief amongst professionals in PDC that it is one that is highly valued by those using it (Slater 2001). Limited research concerned with user views of PDC supports this viewpoint, particularly findings derived from a phenomenological study of PDC comprising interviews with 12 patients (Hopkinson & Hallet 2001) and research by Goodwin et al (2002), who interviewed 120 users regarding their experience of PDC, its most important aspect and any downsides.

The value that patients place on PDC is based, to a great degree, on the relationships that are established in this setting. The service offers opportunities for people who are chronically and terminally ill to meet other people, including those who understand their predicament (Goodwin et al 2002;Hopkinson and Hallet 2001). These relationships offer opportunities for patients to share stories and to feel understood (Hopkinson 1997; Hopkinson & Hallet 2001). As a consequence they feel less socially isolated and more supported in their illness (Goodwin et al 2002; Hopkinson and Hallet 2001). They also felt "normal" again (Goodwin et al 2002; Hopkinson and Hallet 2001; Lawton 2000). Hopkinson and Hallet (2001) draw on the work of Goffman (1963) as they define this normality as freedom from the negative consequences of their disease.

The milieu of PDC is also important according to users. It was experienced as relaxed, friendly and welcoming (Goodwin et al 2002; Hopkinson and Hallet 2001), and as such contributed to an experience of feeling comfortable, accepted and understood (Hopkinson & Hallet 2001). This was a consequence of the efforts made to develop a homelike environment – a feature of PDC identified in an ethnographic study of a PDC service (Lawton 2000). It was also linked to the time

given and the consideration shown by those working in this setting, including the time offered in this setting to chat to others involved in the service (Hopkinson & Hallet 2001).

Users also place importance on the activities of PDC. They serve as new interests and encourage and motivate participants in this setting (Hopkinson and Hallet 2001). Kennett (2000) who explored the experiences of terminally ill patients engaged in a PDC based creative arts project from a phenomenological perspective identifies positive expressions of self-esteem, autonomy, social integration and hope arising from this activity. Suggestion is made in the literature that PDC activities may also serve a subtle but important role in enabling patients to address their imminent death in an unthreatening and manageable way (Hockey 1990).

The process of attending PDC has value in itself according to its users. They enjoyed the opportunity to get out of the house (Goodwin et al 2002; Gunaratnum 2001) and also the opportunity afforded them in this setting to make decisions and thereby gain some control in their lives (Hopkinson & Hallet 2001). This served to enhance their self-worth (ibid.). Lawton (2000) describes how patients attending the service she studied actively engaged in creating and sustaining an "alternative reality" in this setting. This was experienced as a safe retreat, within which death was distanced, their physical deterioration and dependency was masked, they could engage in family like relationships and become part of a communal group. Engagement with this reality offered patients reinstatement of their lost self through its provision of "the one space available to them in which they felt that they could 'be themselves' and 'live with their cancer' (ibid.p.40). Attending PDC also enabled patients to be diverted from the consequences of having a chronic or terminal disease, including their occupation of a sick role, their physical limitations, feeling stigmatised and socially isolated (Hopkinson & Hallet 2001).

Within these broad findings, individual patient experience of PDC varies. The literature suggests that this depends on how patients respond to their condition

(Hopkinson & Hallet 2001). Differentiation is made between those that simply tolerate their condition and want to be cheered up and diverted from their illness and those that want help to adapt to their illness and seek opportunities to talk about it and to learn new skills to help them achieve personal goals (ibid.). According to Hopkinson and Hallet (ibid.) both approaches can be accommodated in PDC given its holistic and individualised approach to care. In commenting on ethnicity and the challenge for PDC Gunaratnam (2001) describes differing values accorded to PDC by those from minority ethnic groups as a consequence of their wider social contexts and previous experiences. These, she suggests, affect the degree to which they can take advantage of the service or make demands on it. For example she describes how a Jamaican woman she interviewed placed value on the service. This patient found company and support in this setting and was able to get out of her home environment in which she was alone most of the day. This opportunity was made possible through the provision of transport to and from the Day Centre. In contrast, Gunaratnam (ibid.) describes a Jamaican man who rarely talked in PDC, concerned that if he were to strike up conversation he might incur racial wrath. This was based on previous experience of racism which had affected his ability to use the service to meet his needs.

2.10. The policy context of PDC

PDC, like other palliative care services is operating in a policy[2] context that is rapidly changing. The last 10 years have witnessed substantial changes in government policy concerned with the organisation and funding of health services, due, in part, to a change in government during this period (Clark et al 2000). The current government pledged to modernise the NHS through the implementation of a 10-year strategy of investment and reform (Department of Health 1997). This plan has major implications for hospice and palliative care services, including those based within the voluntary sector, given their growing place in mainstream provision (Seymour et al 2002; Trueman 2001).

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[2] "Policy" as used here is based on an approach to policy proposed by Stacey (1991) and quoted in Clark and Seymour (p.132). She offers a definition that is wide-ranging in character and encompasses all decisions which affect the way in which health care is delivered.

During this period there has been considerable debate regarding the nature and definition of care provided by hospices and other providers of palliative care, and differentiation thereof. In 1995, efforts were made to describe the spectrum of palliative care available, in acknowledgement that services were variable according to who provided them, how and in what context. That proposed ranged from a palliative care approach, which could be provided by any health professional informed by knowledge and practice of palliative care principles, to specialist palliative care, provided by professionals for whom palliative care was their core speciality (National Council for Hospice and Specialist Palliative Care Services 1995). In 2000, the spectrum was amended to include a new element – intermediate palliative care, described as palliative care provided by professional carers working full time in palliative care but not accredited as specialists in palliative care (National Council for Hospice and Specialist Palliative Care Services 2001). This proposal served to differentiate between hospices/ palliative care units according to the degree of complexity that they sought to address in their care, reflective of how specialist their staff were (ibid). However, soon after it was considered necessary to revisit these definitions again in the light of changes in government plans for the development, payment and monitoring of cancer and palliative care services. At this point a significant shift in approach was proposed. In the past, any definitions had been based on what was already being provided. Now, the definitions proposed that were based on an ideal of what should be provided, and particularly that required to ensure equitable access to a range of specialist palliative care services (ibid.). Consultation followed regarding the proposal that any differentiation between services be based on who provided it, rather than the definition of palliative care itself and that any care deemed as specialist should be multi disciplinary in nature (ibid.). A briefing produced by National Council the following year continued in this vein, differentiating general palliative care from specialist palliative care according to whether it was provided by professional carers who would ordinarily be involved in a user's care, or by professional carers who specialised in palliative care (National Council for Hospice and Specialist Palliative Care Services 2002). In addition the briefing

identified differences between palliative care and supportive care available to people with cancer, arising from the work of NICE which has developed evidence based guidance on supportive and palliative care (National Institute for Clinical Excellence 2004a)

There is no evidence that this debate has served to improve care for users, and despite being the cause of much discussion by hospice and palliative care providers, there is suggestion that the process has only resulted in confusion (Doyle 1993b). However, whether a provider is deemed specialist or not has important ramifications. These currently include minimum standards for care provision and the availability of additional funding from government to support specialist services, and the new proposed funding scheme by the government – Payment by results for specialist palliative care services (;Department of Health 2002;National Institute for Clinical Excellence 2004a).

Within this context Myers (2001) identifies four forces for change that face PDC in the future. She identifies first the challenge to demonstrate effectiveness, including that related to cost. The second is concerned with the challenge to prove quality of care, the third is concerned with the challenge of providing generic palliative care and finally she notes the challenge of funding. These form the basis of the remainder of the section.

The basis of the first challenge is the current emphasis on evidence based practice. Health care services are required to provide evidence of their effectiveness and cost effectiveness (Department of Health 1998a; Department of Health 2000a). By the same token providers of health care are required to base decisions regarding service delivery on research regarding effective care (ibid.). This has led to the development of the National Institute for Clinical Excellence which is responsible for providing national guidance on treatments and care for people using the NHS in England and Wales (National Institute for Clinical Excellence 2004b). This organisation has recently produced guidelines regarding the provision of

supportive and palliative care (2004a) which serve to inform purchasing decisions in the future.

The second challenge is related to the government commitment to improving the quality of care that patients receive. As a consequence there are more clearly defined national standards of care, a new framework for quality improvement and a commitment to learning user views as a basis for planning, developing and evaluating services (Department of Health 1997; Department of Health 1998a; Department of Health 1998b; Department of Health 2002). New monies have been made available to enhance care for specific groups of users including older people and those with cancer and coronary heart disease, their expenditure guided by National Service Frameworks (Department of Health 2000a). Cancer services have been radically reorganised and developed as a means of improving them and ensuring equitable provision across the country (Department of Health 1995; Department of Health 2000b). Their reorganisation has lent palliative care an integral role in cancer care, and emphasis is placed on providing access to specialist palliative care for all cancer patients who need it, and improved coordination between NHS and voluntary palliative care services for the benefit of their patients (Seymour et al 2002). The government seeks to achieve this by encouraging working partnerships between providers of care in the public, private and voluntary sectors, one consequence of which may be better integrated packages of care for individual patients (Department of Health 1997; Department of Health 1998c).

The challenge of funding relates, in part, to changes in the way that palliative care services are funded from statutory sources. Within the new NHS, commissioning responsibilities for local health services fall into the remit of Primary Care Trusts which comprise general practitioners and other members of the primary care team (Department of Health 1997; NHS Executive 1999). It has been suggested that this may have positive implications for palliative care services as greater emphasis on community services may direct more resources into palliative care (Myers 2001).

However the same author suggests that the priorities of local Primary Care Trusts may undermine the existing balance and integrated nature of some palliative care services if, for example, they choose to fund more home care provision at the expense of PDC.

The challenge of generic palliative care relates to the call for palliative care to be made available to people with progressive and life threatening conditions other than cancer (Department of Health 1995; National Council for Hospice and Specialist Palliative Care Services 1997a; National Council for Hospice and Specialist Palliative Care Services 1998; Standing Medical Advisory Committee (SMAC)/Standing Nursing and Midwifery Advisory Committee (SNMAC) 1992). In the past, these people have been identified as the "disadvantaged dying" on the basis that they receive no specialist palliative care, and redress of this situation is required (Harris 1990). Their level of need for palliative care is notable (Addington-Hall & Karlsen 1999; Higginson 1997) including that on offer from PDC (Myers 2001).

This policy context has major implications for the future of PDC, which is arguably made precarious given the lack of evaluative data regarding PDC (Spencer & Daniels 1998). Furthermore, concern about costs of this service, within an arena of finite resources, raises questions regarding the future position of PDC. Goodwin et al (2002), ask whether PDC should continue to operate as a specialist service or whether it would be better positioned as a less specialist satellite service providing a mix of medical/social day care. Similarly, Clark and Seymour (1999) propose that PDC which provides long term social support as its core activity, may be more cost effective if delivered by non-specialist services.

Myers (2001) makes suggestions as to how PDC might rise to the challenges that it faces in the future. They include engagement with large-scale research studies to learn whether or not PDC is effective, for whom and under what circumstances. She also proposes diversification and further integration with other services to

enable PDC to respond to new groups of patients in the future. Day-care leaders present a divided picture about the future shape of PDC in this context. Some are keen that their service makes a transition in their provision to a model of day therapy similar to the service described by Hopkins and Tookman (2000) to ensure value for money and effectiveness of provision (PDC Leaders, verbal communication, Day Care Leaders Conference 2002). Others are concerned that this move will result in the loss of its elements of greatest value, namely its social support which is available for as long as required (ibid.). Any decisions such as these need to be based on local needs assessment in order that services of the future reflect patient needs rather than the philosophies and perceptions of service providers (Spencer & Daniels 1998). Knowledge about patient needs is currently lacking (ibid.), which limits the opportunities available to those involved in PDC to tailor the service to reflect them, even if they are committed to do so.

2.11. How the literature and the current study relate to each other

The literature described in this chapter has played a major role in shaping the current study by focusing its aims and guiding its methodology. In specific terms, there are four main areas within the literature regarding PDC and the experience of its users that the current study seeks to develop. They are related to the nature of PDC, its models of care, who is likely to benefit from the service and its outcomes according to users. The methodology chosen to address these aspects is described below, along with assertions regarding the contribution of the current study and its findings to existing literature.

With regard to the nature of PDC, detail is lacking in the literature, particularly from a user perspective. For this reason the research has been designed to add detail regarding the nature of PDC from this perspective. The chosen research strategy – that of case study, enables examination of two PDC services in a multi-faceted way, with attention to the structure and process of care in this setting and the values underpinning the service. Details of the wider context of the service can also be captured in the description of each service. In providing this detail, it

builds on existing knowledge regarding PDC (such as that generated by Douglas et al.2000 and Higginson et al 2000) and addresses gaps identified by other researchers (for example Goodwin et al.2002 and Goodwin et al 2003). New information about the nature of the service also enables some consideration about the place of PDC within the arena of supportive and palliative care – a question posed in the policy and academic literature.

In relation to models of PDC, the literature calls for research that examines the complexities and functions of different models of PDC, their impact on the care offered and the extent to which the different styles of provision identified by professionals reflect user experience of the service (Copp et al 1998; Goodwin et al 2002). The current study seeks to address this gap in knowledge by studying two services that purport to provide different models of care and which are presented in a way that allows comparison between them and the pertinent literature. The development of the proposition builds on this work by identifying shared experiences by users of each of the services, and considering these in relation to models of PDC as described in the literature.

The literature also reveals a lack of knowledge about the characteristics of people attending PDC and their contexts that give rise to a need for PDC. The research methodology – that of constructivist inquiry, serves to link users' experience of PDC with the various contexts of their lives through its exploration of their constructions of the service. As such it offers information about the circumstances that people with progressive and life threatening conditions face, within which attendance in PDC is felt to be particularly helpful. This knowledge could be helpful in ensuring that services are targeted more efficiently in the future (Myers 2001). User constructions of the service are compared with those of other stakeholders of the service including providers of care. As such the current study begins to answer the question posed by Myers (2001) as to whether users of PDC receive what they really need from the service or what the providers believe that they require.

Finally, there is an outstanding call for evaluative studies of PDC within the literature (Spencer & Daniels 1998). Where evaluation has been attempted in this setting this has been limited by the outcome measures used which have reflected professional views of PDC rather than user views (Goodwin et al 2003). The current study seeks to provide new information about the value of PDC and its constituent parts according to its users as a precursor to further evaluation of the service. The focus of the case studies – users' claims, concerns and issues about PDC - will facilitate this. Such findings are timely given the increasing emphasis on user views as a basis for the development and evaluation of services (Small & Rhodes 2000). They could also help to differentiate PDC from other services from the perspective of users of PDC, another gap identified in the literature.

2.12. Summary of the chapter

This chapter has considered literature regarding PDC and its users. It describes a body of knowledge which, until recently, was relatively small and which requires further work to substantiate early findings. This research responds to that need and also the growing interest in user views within the current policy context of healthcare, described in more detail in the next chapter. Its chosen methodology, which is described in Chapter 4, has been designed specifically to meet some of the gaps in knowledge. The degree to which this research is successful in this regard is considered in the final chapter of the thesis.

CHAPTER 3

THE LITERATURE - GAINING A USER PERSPECTIVE

3.1. Introduction to the chapter

This chapter examines literature concerned with the activity of learning how users view healthcare services. How users' perspectives are sought and utilised in the arena of health care is a complex issue, encompassing practical, philosophical and semantic problems. The chapter does not seek to provide a comprehensive review of the process or these complexities; instead it provides some theoretical context for the research described in this thesis which sought to learn user views of PDC. The terms used for the initial searches of the literature were "patient views", "patient opinion", "user views", "user opinion", "research" and "involvement". Further searches were then undertaken with the added terms: "terminal care", "palliative care" and "hospice care".

3.2. Introduction to the process of gaining a user perspective

The processes of learning user views vary according to purpose and underpinning values. User involvement, an increasingly important element of the rhetoric of modern health care provision, is placed at one end of the spectrum. This approach affords users choice and control in their care and enables them to become involved in shaping it, either at an individual or a csollective level (Oliviere 2001). At the other end of the spectrum is more traditional research, within which the user has a temporary role, concerned mainly with providing raw data (Tower 1999). The research described in this thesis leans towards user involvement in its commitment to engage with patients in a participatory way, enabling them to influence the shape of the research and changes in service provision based on the findings of the research. For this reason, literature concerned with user involvement is heavily represented in the chapter.

3.3. The activity of user involvement

User involvement is a needs based process in which those "most centrally touched by a problem [are elevated] to a position of enhanced rights to shape provision and treatment" (Gott et al. 2000 p.3). Some believe that this is achieved through locally organised groups of service users (for example Harrison & Mort 1998); others are less specific as to the means by which users participate in the process of planning, monitoring and developing health services (for example Crawford et al. 2002). User involvement differs from public participation, a utilitarian process that provides opportunity for local communities to influence plans for service delivery, within which priority is given to services considered to benefit the greatest number (Small & Rhodes 2000). Part of the difference between these two approaches relates to the distinction between the needs of users and their wants. Mediation between the two serves as a point of potential tension for Government, purchasers and providers of care, and raises ethical concerns for researchers of user views (Seymour & Skilbeck 2002; Small & Rhodes 2000). Seymour and Skilbeck (2002) call for "understanding to what extent users are invited to participate in research to give voice to their own wants, to pass judgement on what constitutes 'essential' needs for others, or to have their views trawled for evidence of the latter" (p.216). They caution that without this perspective researchers run a risk of misleading participants about the outcomes of the research, which may leave participants feeling disappointed and disillusioned with the process.

In its ideal state user involvement serves as a philosophy rather than a procedure, inherent in the structures, practices, expectations and responsibilities of care providers. As such "it is like democracy or justice, although it sits, conceptually between these two. It is about privileging the voice most affected by ill health and saying that it is just so to do" (Small and Rhodes 2000 p.221). Within this definition, "users" of health care are not only those that currently access and utilise services. They also include those who are not in receipt of services although they need them, because they are unaware of the services available or have been refused services. Alternatively appropriate services may not exist to meet their

particular requirements. Small and Rhodes (2000) are concerned that these particular users are typically those excluded from discussion regarding their views of healthcare. They cite the work of Barnes and Walker (1996) who urge particular attention to their almost indiscernible voices.

Beresford (2003) differentiates between a top down managerialist/consumerist approach to user involvement and that which is bottom up and democratic in nature in his consideration of its various origins and ideologies. He ascribes the former to initiatives by the state, policy makers and service providers who seek data regarding consumer preferences in order that they can fashion their services accordingly. In contrast the latter is an emancipatory process, giving service users the opportunity to determine the shape their care provision and in so doing, offering them additional control in their lives. These two approaches result in different degrees of integration and empowerment of users in the process and give rise to various classifications of user involvement (see Gott et al 2000, Iskander 1997 and Poulton 1999 for examples of user involvement classifications). The variation in integration and empowerment is a consequence of when and how users are involved in the process (Sullivan 1994), what information they receive (Jordan et al. 1998), how inclusive existing structures are (Hunter & Harrison 1997) and the means by which user views are sought (Jordan et al. 1998).

There are mixed views in the literature as to the benefits of user involvement. Proponents identify benefits both for the individual and for the organisation engaging in this activity (Bradburn et al. 1992; Cahill 1998; Connelly 1987; Gray et al. 1995; Zola 1987). Others are more ambivalent about the impact that user views make to the process of planning and developing services and the success of user involvement to date (Crawford et al. 2002; Small & Rhodes 2000). Skeptics point to risks arising from the process including tokenism, service users becoming co-opted onto managers' agendas and suppression of critical questioning by users arising from collaborative models of involvement (Beresford & Campbell 1994; Forbes & Sashidharan 1997; Lindow 1994). Other dangers identified include the

confusion of consumerism with empowerment, possible coercion of users to be involved and distorting priorities when some groups have a louder voice than others (Small & Rhodes 2000).

According to the literature user involvement is a process that needs further development to ensure that it is beneficial, and to enable the rhetoric of user involvement to become reality (Poulton 1999). It has been suggested that the limited success of user involvement to date be related to a lack of commitment to utilising these views in planning, purchasing or providing services. Harrison and Mort (1998) describe a complex situation in which professionals state commitment to involving users, but only take on their views if they reflect those of the professionals. When this is not the case the process of user involvement is called into question on technical issues, a consequence of which is that the views of the users are discounted.

3.4. The context for user involvement

Interest in the perspective of the user of health care services has increased substantially over the last decade or so, during which time there has been increasing interest in user views within mainstream health care to determine, shape and evaluate services in this arena (Poulton 1999). This is mostly due to a new political interest in the views of those receiving services, reflected in health care policy during this time (for example Department of Health 1991; Department of Health 1997; NHS Management Executive 1992). These government directives place importance on learning how users view the services available to them as a basis for planning, delivery and evaluation of services. This emphasis on user involvement has remained a key element of health care policy since the early 1990s despite a change in Government during this time and major amendments to the structure of the NHS as a consequence.

Government interest in user views is explained in various ways. Some suggest that it has arisen from a recognition that care provided historically has not adequately

reflected the experiences and concerns of those using them (Seymour & Skilbeck 2002). Others believe that it is just another way for those in power to justify and legitimise their position (Harrison & Mort 1998). Still others propose that it can be traced to a need to convey legitimacy to a system suffering increasingly from democratic deficit (Small & Rhodes 2000).

Whilst government policy has undoubtedly given impetus to the interest expressed in learning the views of users, this pursuit is a consequence of other factors too. User involvement has been fought for over the years, often by particularly disadvantaged people, who have been keen to change the culture of care (Sang 1999). It has its early roots in the in the disabled people's movement (Beresford 2003) and mental health field (Tower 1999), user participation forming part of their ideology concerned with inclusion, autonomy, independence, human and civil rights (Beresford 2003). At society level, the interest in user involvement reflects a change in the willingness of the general public to challenge the authority of those previously deemed experts, which Small and Rhodes (2000) suggest belongs to late or post modernity.

This pattern of involvement is apparent in end of life care, particularly cancer care. There is evidence of bottom-up development of user involvement initiatives in oncology as long as 20 years ago (Gott et al. 2002). Since then government legislation, such as the Calman-Hine Report (Department of Health 1995) has required that this activity be expanded and developed. This requirement has been reiterated, along with an emphasis on providing patient centred care in more recent policy documents, for example the NHS Cancer Plan (Department of Health 2000b). Even so, more involvement of users in end of life care is required in the light of a number of current policy and societal changes. These include the increased demand for community services by terminally ill people, the availability of continuing care and the issue of euthanasia (Small & Rhodes 2000). In addition, the views of terminally ill people with non-cancer conditions are particularly underrepresented and as such need to be given voice (Wilkinson et al. 1999).

3.5. The value of user views and their involvement

The views of users of health care services can influence healthcare services at a number of levels. At a strategic level they are valuable in relation to the identification of health care needs (Poulton 1999; Tranter & Sullivan 1996) and planning and policy development (Gott et al 2002; Hunt et al 2002). Traditionally, users have been poorly represented in activities such as needs assessment (Ingleton et al 2001), but there is increasing evidence that their input is essential to ensure a balanced perspective (Tranter & Sullivan 1996).

User views are also seen to have value for healthcare services at an operational level. They are identified as helpful in the development of patient-centred practice (Hunt et al 2002), the evaluation of local health care services (Edwards & Staniszewska 2000) and implementation of clinical governance programmes which assess and ensure the quality of care provided (Department of Health 1998a). The subjective stance of users is seen as increasingly important in this context as it is acknowledged that professionals have limited insight into the experience of illness and its treatment. McKinley (2001) for example argues that "only people who are living with all that it means to be dying....can state what is of value to them" (p.27). For this reason, service outcomes need to be based on what patients and carers say is important to them (Devery et al 1999) and local services planned accordingly (Edwards & Staniszewska 2000).

At the level of individual care, user views can help to influence decisions regarding the patient's care options and treatment plans (Tritter & Calnan 2002). This shift towards inclusion of users in clinical decisions and care is one endorsed by recent government policy (Department of Health 2000a; 2000b; 2001b). It has been shown to be beneficial to users (Fallowfield et al 1994) although Tritter and Calnan (2002) caution against the belief that all users are able and willing to be involved to this degree. Finally the voice of the user is called for to guide healthcare research including the processes of commissioning, planning and

undertaking research and disseminating the findings (Beresford 2003; Department of Health 2001a).

3.6. Means of learning users' views

Despite increasing importance being assigned to gaining users' views of health care, there is little consensus regarding the most effective means of obtaining this viewpoint (Crawford et al 2002). A scan of the literature reveals a wide spectrum of approaches, but relatively little guidance for purchasers, providers and planners regarding which approach to utilise, or their relative strengths and weaknesses. Some mention is made of the conditions required to achieve participation of users in service planning and evaluation. These include information for users, a positive culture supporting public involvement, an organisational strategy underpinning this work, training and support for staff that are responsible for implementing it, adequate resources and evaluation of the process (Donaldson 1995; Small & Rhodes 2000). Innovative approaches are also called for to ensure a rewarding experience for users (Gott 2004).

One approach that has been utilised in the past to learn user views of health care is the patient satisfaction questionnaire (Chambers et al 2003). This is seen as a relatively quick and simple way of incorporating user views (Department of Health 1997). Whilst this has a long history of use and remains an important means of learning how users perceive health care provision (Rogers et al 2000), doubts have been expressed regarding the validity of findings arising from this approach (Chambers et al 2003; Edwards and Staniszewska 2000). There is disparity between the high level of satisfaction identified by questionnaire and views collected from the same participants by other methods (ibid.). These differences are explained by the use of quantitative methods commonly adopted by questionnaire methods which limit the opportunity afforded to users to describe their experience of care or its context (ibid.). They are also a consequence of the often-general nature of the questions posed in such questionnaires (Chambers et al 2003).

Questions have been posed regarding the use of user satisfaction in healthcare. Some see it as a central concept of healthcare evaluation (Robbins 1998) but others are uncertain about its relevance in this arena (Edwards & Staniszewska 2000). Fakhoury (1998) highlights problems of measuring patient satisfaction in patients receiving palliative care. The author identifies methodological, theoretical and technical problems related to using satisfaction as an outcome measure of the quality of this care and suggests that the approach, instruments and interpretation of satisfaction research in palliative care needs to be tailored to the speciality and the unique needs and experiences of those using these services.

Other approaches are based on research methods that have been adapted to explore how patients experience illness, treatments and care provided to them. Focus groups are identified as a means of learning about patients' experience of illness and their care (for example Raynes et al. 2000). Reference is also made to the use of interviews with patients and carers as a means of eliciting their views (Tritter & Calnan 2002). Central to the strength of these approaches in learning users' views is their qualitative nature. Qualitative methods help to capture the complexity of patients' experiences of healthcare by enabling a process-based enquiry; they also serve to place the experience within the context of their wider lives (Edwards & Staniszewska 2000). A qualitative approach allows users to determine the agenda for their comments (ibid.) and limits the opportunity for preconceived concerns by professionals to "colonise" user experiences (Devery et al 1999 p.6). It allows users to challenge the concerns of professionals (ibid.) and enables exploration of subjective well-being, a central component of quality of life (Robbins 1998). Even so, a recent systematic review of papers regarding the involvement of patients in the planning and development of health care only identified four qualitative studies out of a total of 42 (Crawford et al 2002). Where qualitative and quantitative methods are used to complement each other, it has been suggested that both approaches are enhanced (Tritter & Calnan 2002). This is the basis of the research undertaken by Rogers et al (2000), concerned with understanding dissatisfaction with hospital based care in the last year of life. They used a mixture

of open and closed questions which enabled them to both explore users' dissatisfaction in relation to the care received and also to assess the level of the dissatisfaction.

A collective approach to learning users' views is that of consultation with user groups, which currently serves as the most common form of user involvement (Gott et al 2002). Literature produced in the early days of user participation identifies groups as the main means by which people could become involved (for example Beresford & Croft 1993b). However it has some limitations. Gott et al (2002) propose that this approach may serve to disenfranchise the majority of users who do not have the opportunity to influence service policy because they are not in a group. Furthermore, they suggest that there are certain categories of people who do not tend to join user groups such as people from ethnic minorities, those with advanced disease, people with rare cancers and those living in remote areas where access to user groups is difficult. They describe variable degrees of interaction between user groups and providers, either because the users had another agenda (such as a need for support) or because they felt isolated or excluded.

Other means of learning user views that are identified in the literature include stakeholder days, public meetings, meeting with targeted groups, representation on committees, review of complaints and deployment of users as visiting inspectors or evaluators of services (Morris 1996; Small & Rhodes 2000). They are part of a growing, and much needed menu of innovative approaches that overcome practical difficulties of involving vulnerable users in decisions regarding service delivery and planning, including those who are seriously ill (Small & Rhodes 2000). Two such schemes that sought the views of elderly people are described and applauded in the literature (ibid.). They utilised user panels and volunteers who worked jointly with users to consider the assistance they required that would enable them to enjoy a good quality of life.

Whatever the approach to learning user views, the ethics of this activity must be considered in its design and implementation (Pollock & Pfeffer 1993). Efforts are required to avoid moral coercion where the opportunity for involvement becomes one of obligation and involvement is seen as a condition of receiving services (Small & Rhodes 2000). The literature also cautions against using methods that appear to represent user opinion, but then distort it on the grounds that they are not sensitive to the complexity of patient response to health care (Edwards & Staniszewska 2000). How user views are utilised is also an ethical issue. A plea is made for outcomes which facilitate changes in care delivery, rather than being restricted to providing data for provider-led plans (ibid.). This role is essential if user involvement is to be meaningful (Beresford & Croft 1993a; Croft & Beresford 1997). According to Seymour and Skilbeck (2002) the balance between the demands of the research process on users and its outcomes is an issue of morality.

3.7. Learning user views about palliative care

User involvement and attention to user views has been identified in the literature as an integral component of the philosophy of palliative care. The link arises from its concern to meet the unique and individual requirements of those who are dying and their families, and its commitment to learn about their specific needs and wishes (Hopkinson & Hallet 2001; Oliviere 2001). This could explain the observation that the hospice movement is one area of planning and service delivery which has a history of actively seeking to involve service users and their carers (Small & Rhodes 2000).

Even so, the process of learning how users perceive palliative care services is a complex one. This complexity is a consequence of a number of factors.

First, patients' experience of illness and the context of their wider lives determines their understanding of the process of user involvement, the accessibility of their views and how willing they are to engage within it (Small & Rhodes 2000). Small

and Rhodes (ibid.) suggest that the nature of a progressive and life threatening condition challenges the development of a user involvement agenda, as it denies a future perspective and any secure sense of knowing what to expect within it. Those with such a condition may have a present orientation and a central concern related to the new challenges that they face on a regular basis; in this context interest and commitment to shape care in the future for themselves and others is not predominant (ibid.). Furthermore they may need to deny aspects of their situation for their psychological survival (ALS Society of Canada 1994) which makes honest review of their situation difficult to achieve.

Second, the complexity arises from the ethics of involving people who are nearing the end of their lives in research. In the past it has been proposed that it is unethical to involve people who are dying in any research (for example De Raeve 1994). Others have argued that it is essential as a means of identifying unmet palliative care needs (Mount et al. 1995) and developing appropriate services for the future (Seymour & Skilbeck 2002), subject to the practicalities of undertaking the research (Field et al. 1995). In considering the ethics of researching user views of palliative care Seymour and Skilbeck (2002) call for models of research that reflect the values and philosophies of supportive and palliative care. They suggest that this "requires striking a fine balance between the ethical duties of providing care and support, nurturing independence and autonomy, and achieving research outcomes that are rigorous while also being accessible and meaningful to users" (p.219). Specifically they stress the importance of planning and executing research in a way that ensures that the participant is well informed about the nature of the research, its likely outcomes and the role of the researcher. It must also be undertaken in a way that places the needs of the participants over that of the research (ibid.). In addition they propose that respondent validation is sought in relation to the findings and that the findings are made accessible and comprehensible by users.

Third, methodological challenges exist in conducting research into peoples' experiences of having a progressive and life threatening condition such as cancer (Entwhistle et al.2002). Entwhistle et al (ibid.) identify a number of methodological concerns related to the collection of data, their interpretation, synthesis and presentation in palliative care research. They call for further research that addresses issues such as participant rates and profiles, the appropriateness of methods, biases in peoples' accounts and the place of participants in the interpretation and presentation of findings (ibid.). A systematic literature review of patient and carer preference for, and satisfaction with, specialist models of palliative care suggests that methodological flaws in research in a palliative care context are the major reason for the dearth of firm conclusions that are available (Wilkinson et al 1999). These flaws include the likelihood of attrition, scarcity of subjects, heterogeneity of case-mix, uncertainties of attributing change to the intervention and difficulties in quantifying the impact of the assessors (ibid.). According to Addington-Hall (2002), there is a key methodological difficulty of defining a "palliative care patient" and inherent sensitivities associated with undertaking research regarding their healthcare experiences.

Fourth, practical problems face the researcher seeking to learn user views of care offered towards the end of their lives. There is suggestion, for example that staff seek to protect palliative care patients from involvement in research projects and consultative exercises (Parkes 1995). In addition Addington-Hall (2002) highlight difficulties knowing when the final stage of life has been arrived at and how long it will last. Small and Rhodes (2000) describe how people who are dying have other priorities at this time and how the nature of final illness can make communication of wishes and needs difficult to achieve. They suggest, as a solution to these problems, that user views are sought in advance or by proxy. Carers as proxies for patients is a feature of palliative care research in the past, given the practical and ethical concerns of researching terminally ill patients (Addington-Hall et al 1991; Sykes et al 1992). It has been suggested that this is a valid source of information (Field et al 1995) although there is evidence that

patient and carer accounts of the same situation can be different (ibid.). These differences are not simply a consequence of an alternative perspective; they may also arise as a consequence of a change in perspective on the part of the carer when the situation of caring is considered in retrospect (Small & Rhodes 2000). Robbins (1998) suggests that whilst proxies such as home carers can serve as important sources of information about some aspects of being terminally ill, this will only be of partial value and suggests that where possible listening to the story of both will help to create a fuller picture.

Fifth, philosophical issues remain unanswered as to who represents a user of palliative care services, how they perceive themselves in relation to the services that they need and receive, and whether they wish to be involved in planning services that they are unlikely to benefit from themselves (Gott 2004).

Even so, there are persuasive arguments for pursuing this agenda at the current time. Given the difficulties of engaging with users of end of life care, people who are terminally ill or dying become users who are vulnerable to exclusion and neglect in negotiations regarding the services that they require (Small & Rhodes 2000). Their vulnerability lies not only in their inability to be heard, but also because assumptions are made, in the absence of their voice, about the nature and level of their need. They are a relatively small group whose needs are not represented by others. As such they are losers in a consumerist model in which priorities will be set in favour of the majority and the most vocal (ibid.). This potential exclusion is concerning given the high level of need of those facing imminent death (ibid.). Perhaps most importantly there is suggestion in the literature that despite this vulnerability palliative care patients want to be involved in planning and evaluating the services that they use (Beresford 2000).

3.8. Links between the literature and the current study

The literature described in this chapter guides the current study in the following ways:

First, it suggests that there is value in involving users in the process of exploring PDC. The literature suggests that this activity has value for the user (Crawford et al. 2002), on the grounds that it can be an empowering and fulfilling process (Small & Rhodes 2000). It also provides much needed information that enables services to be configured in a way that reflects user needs, preferences and priorities (ibid.). The Hospice Movement is potentially at a point of major change in terms of its service provision and user profiles and will benefit from increased knowledge about how users perceive palliative care (Small & Rhodes 2000). Moreover the voices of users of end of life care are often particularly quiet, making an active search for them vital to ensure their views are represented (ibid.). Oliviere (2001) suggests that further research into what service users want from palliative care is essential to furthering user involvement, and making clinical practice in this setting more evidence based. The current study seeks to achieve this and in so doing, builds on the literature regarding user involvement in palliative care. Specifically it assesses the degree to which user involvement in PDC is possible and acceptable.

Second, the literature provides some important pointers as to how a user perspective is gained in an ethical, beneficial and effective way. It calls for an approach that enables users to be involved throughout the process of the research including the implementation of change in response to its findings (Edwards & Staniszewska 2000). In this context, it is suggested that a broad definition of users be adopted whereby the research of users extends beyond those currently using the service, to include those who have refused or left the service (Small & Rhodes 2000). The ambitions, methods and outcomes of the research need to be transparent and unambiguous (Seymour & Skilbeck 2002). They need to consider the wider context of users lives, experiences and psychological processes (Edwards & Staniszewska 2000). They must also bring together the health care delivery system and the world view of those whose views are being sought (Small & Rhodes 2000). To learn this detail, qualitative methods of gathering the views are likely to be more effective than quantitative ones (McIver 1993). The

application of these principles to the research of user views in palliative care are assessed in the current study.

Third, the literature provides some indication of the outcomes that the research can hope to achieve. Seeking user views about PDC is likely to generate information about the service that will be of value to providers and purchasers of PDC if the research is guided by the priorities of the participants (Sykes et al 1992). It indicates the such research could influence service provision in the future if those managing the service are willing to make changes to shape the service to the requirements of those using it (Small & Rhodes 2000). The degree to which this is possible in PDC and reasons for this are assessed in this study.

3.9. Summary of the chapter

This chapter describes literature concerned with the activity of gaining a user perspective of healthcare. The literature portrays a process which is timely, potentially beneficial to users of services in the future and also to those involved in providing the service. It also describes a complex activity, aspects of which require further research. Its guidance regarding research into user views has influenced the chosen research approach which is described in the next chapter. The strengths and weaknesses of this approach and learning points are identified in Chapter 9. Finally the contribution of the research to knowledge regarding the process of gaining user views of palliative care services is identified in Chapter 10.

CHAPTER 4

THE RESEARCH APPROACH

4.1. Introduction to the chapter

This chapter describes the approach adopted within this research to collect, analyse, interpret and present its data. It identifies the theoretical basis for the decisions made regarding the research approach and provides details as to how it was implemented at a practical level. It begins by identifying the research strategy chosen to answer the research questions, then identifies the underpinning philosophy and principles of the research before describing the detail of the approach.

4.2. The research aims and questions

As described in Chapter 1, the main aim of the research was to learn about PDC from the perspective of those using the service. In seeking this perspective I wanted to learn how patients experienced PDC, what value they placed on the service and its various elements, how it related to the context of their lives and their experience of living with a progressive and life threatening condition. I was also interested to learn how this compared with descriptions of PDC provided by other stakeholders[3] of the service and that contained in the literature.

A secondary aim was to consider whether patient experiences of PDC varied between services. If it did, I was interested to know whether this related to the models of PDC purported to exist in the literature, or whether it was a consequence of other factors. If there was commonality in patient experience of

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[3] The term "stakeholder" in this context refers to anyone with a stake in the performance, outcome or impact of the service being studied (Guba and Lincoln 1989). In this study they are individuals or groups of people involved in, or affected by, PDC and include patients and carers, staff and volunteers, referrers, managers and planners of the service.

PDC across services, I was keen to identify and describe this experience, and then consider it in the light of the literature regarding PDC.

The questions guiding the research were:

i.   How did patients construct[4] the services provided in DC1 and DC2

ii.   What elements of the service were particularly important within the patients' constructions of PDC?

iii.   Did patient constructions of PDC vary between services?

iv.   What factors contributed to variations between PDC services?

v.   How did the patients' construction of PDC services compare with that held by other stakeholders of the service?

vi.   How did the patients' construction of PDC compare with descriptions of PDC in the literature, including that concerned with models of PDC?

4.3. The research strategy

Case study research was chosen as the research strategy to answer the research questions and its aims. Case study has been identified as a research approach that facilitates examination of a phenomenon as a whole, including it complexity and its context (Punch 1998). In addition the phenomenon is viewed within a perspective of its "ordinary pursuits and milieus" (Stake 1995 p.1). The approach to case study used for this research is based, in the main, on that described by Robert Stake, a major proponent of case study research (Stake 1978; Stake 1983; Stake 1994; Stake 1995). This choice was made in the light of his philosophical standpoint in relation to research – that of constructivism (Appleton 2002) which reflected the philosophical underpinnings of this research.

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[4] The term "construction" as used here is based on the definition offered by Guba and Lincoln (1989) of a "created reality" (p.143), formed by a person or persons to make sense of the situation in which they find themselves. A construction consists of certain available information configured into some integrated, systematic formulation, arrived at through a complex series of interactions.

This research comprises two case studies of PDC services, termed DC1 and DC2. A third, much smaller case study was undertaken prior to the studies of DC1 and 2 to inform the detail of the methodology and ascertain its feasibility. An overview of the case studies is provided in Figure 4.1.

Preliminary study: A study of a nurse led PDC unit to assess the feasibility of the proposed methodology over a period of three weeks	**Study of DC1:** An intrinsic case study of a service purporting to provide a social model of care over a period of six months	**Study of DC2:** An instrumental case study purporting to provide a medical model of care over a period of five months

Figure 4.1: An overview of the case studies included in this research

The site for the preliminary study was chosen to reflect its purpose of testing the practicability of the chosen research approach. The service used for this purpose had been the focus of research on other occasions and the staff members were aware of the demands and benefits of this process. They were happy to accommodate me for a short period and to provide feedback regarding the experience of participating in this research so that I could amend my plans accordingly.

The unit serving as DC1 was predetermined at the outset of the research. According to the typology of case study proposed by Stake (1995), it was an intrinsic study - that is one in which "The case is given. We are interested in it, not because by studying it we learn about other cases or about some general problem, but because we need to learn about that particular case" (Stake 1995 p.3). This reflected the requirements of those commissioning the research who wanted to know more about DC1 in particular.

DC2, by contrast, was an instrumental case study useful when "we....have a research question, a puzzlement, a need for general understanding and feel that we may get insight into the question by studying a particular case" (Stake 1995 p.3). It was chosen to address the research questions concerned with variations in patient constructions of PDC across services and the reasons why. Given this, I sought a service that purported to provide a different model of care to that assigned to DC1. This was felt to be social[5] in nature, although managers of DC1 had indicated an interest that the service should shift towards a more medical model of care. For this reason I sought a service that described its model of care as medical to serve as DC2.

In the process of recruiting DC2 I approached a number of services that were within travelling distance of the university and which purported to offer a medical model of care. If they were interested to engage in the research I provided details of the research and my expectations of any service that I was studying as a basis for their decision as to whether to take part. Once the service had agreed to be involved I provided written information for patients, staff and volunteers about the study and went to the Unit on at least one occasion to introduce myself to the participants before I formally started to study the service. This was the same pattern of preparation that I engaged in before commencing the preliminary study and study of DC1, as a basis for gaining their co-operation with the research.

In DC1 some additional meetings were offered to ensure that I understood the requirements and expectations of those involved in commissioning the research. I set up a forum called the Clinical Liaison Group, which met on two occasions prior to the start of the research, to which all staff, volunteers and patients involved in DC1 and the wider hospice service were invited. The meetings were informal and their purpose was to introduce the research, identify any concerns and engage

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[5] Staff working in DC1 and 2 used the terms "social" and "medical" as descriptions of their model of care without formal definition. However, exploration as to their meaning revealed that they were based broadly on the emphasis of their work, the social model being focused on social support and the medical model being concerned with the provision of clinical care, alongside social support.

people in the process of the study. They were attended by between ten and twenty people on each occasion, and served to establish the beginnings of collaborative relationships between the research participants and me, as the researcher.

4.4. The philosophical underpinnings of the research

This research was based on a constructivist view of the world that sees knowledge and truth as created rather than discovered (Guba & Lincoln 1989). In describing this ontological stance Guba and Lincoln (ibid.) propose that there exist multiple, socially constructed realities ungoverned by natural laws, causal or otherwise. They suggest that these constructed realities are created by individuals or groups of individuals to make sense of the situations in which they find themselves. As such a construction consists of certain available information configured into some integrated, systematic, comprehending formulation, and is created through the interaction of the constructor(s) with information, contexts, settings, situations and other constructors (ibid.).

This philosophical perspective was chosen as the basis of this research for a number of reasons. First I had become aware of a variety of views regarding PDC, both in the literature and in my own experience which I was keen to explore. Using a research approach based on a constructivist perspective enabled me to do this in a way that offered parity to a variety of viewpoints without having to negate one in the light of another. Second I believed that exploration of patients' constructions would enable me to consider their views of PDC within the wider context of their lives. Importantly, their construction of PDC would incorporate their experience of illness and other aspects of life outside PDC, as well as their perceptions of the service. Third, it resonated with my own experience of the world, thereby relieving me of any paradigmatic conflict in undertaking the research.

These philosophical underpinnings influenced many aspects of how the research was planned and implemented. For example it determined the setting for the

research, the role of the researcher, how data was collected and analysed and how the issues for exploration within the case were identified. These are described in Section 4.6. of this chapter as the conditions of entry for constructivist inquiry.

4.5. Principles guiding the research

In planning the research I formulated principles upon which my actions as a researcher would be based, with particular attention to three issues: the ethics of the research, its quality and the acceptability and effectiveness of the research methods.

4.5.1. Ethical considerations

The key ethical considerations in this study related to the vulnerability of the patients who would be participating in the research, given that many of them were terminally ill. In the light of this, I was keen to plan and conduct the research in a way that was considerate to their particular needs, and in keeping with the guidance offered in the literature (for example that provided by Beaver et al 1999 and De Raeve 1994). Concerns regarding the ethics of the research were reinforced in the process of making applications for approval from the relevant Local Research Ethics Committees (LRECs) (three in total) who reviewed the plans for the research and the information I had prepared for the participants. One committee requested details of the interview questions subject to giving approval. Otherwise all the committees granted approval without changes to the original application. The key implications of researching vulnerable people, particularly those nearing the end of their lives, are described below.

> ➤ It required that I gave priority to their wishes, over and above those of the research agenda. At a practical level it meant, for example, that in the event that an interviewee became distressed the interview was immediately terminated and the wishes of the interviewee with regard to the data collected was respected at all costs. Similarly if a participant cancelled plans for an interview, no efforts were made to encourage them to rethink this decision.

➤ It called for voluntary, informed and process consent from patients and their family members. This resulted in a complex process of providing information and seeking consent for its various components in an ongoing way throughout the process of collecting data. See Appendix 2 for copies of the information sheets and consent forms issued. Figure 4.2 depicts the full process for gaining consent for observation of individuals in Day Care and examination of documents pertaining to them. A similar process was followed for the interviews and focus group. I considered it essential that all patients received information regarding the research and for this reason asked staff members to tick off on a form when the information sheet had been given to the patient. Staff members became responsible in this way for ensuring that all existing and new members received the information sheet before I met them.

➤ It demanded that confidentiality be afforded to the participants so that they could speak freely without fear of reprisal from those involved in PDC in the event of negative comments. In DC1, this required particular attention given that one of my supervisors and members of the Steering Group were important stakeholders in this service. As a consequence I was careful not to discuss the comments of individual participants with them in a way that enabled identification of their identity. In addition my supervisor withdrew from the supervisory relationship for the period that I was collecting data in order to protect patients, staff members and volunteers who might otherwise have been recognised by her. I encouraged patients to seek advocates in those around them if they preferred not to engage in the research but lacked confidence to tell me this themselves. I introduced the research through the staff members and wrote to patients' GPs, once they had provided consent, to inform them of the research and to offer my contact details in the event that they or the patient had concerns about the patient's involvement.

Prepare and distribute information sheets to all involved in Day Care prior to entering the setting to undertake the research.

On entry to the site, check with staff whether any patient has expressed a wish not to take part.

If yes

If no

Do not approach for consent for participation in the study

Meet participant and check they have received information sheet.

If yes

If no

Do not observe or examine documents related to their care. Do not approach for interviews or any other element of the study

Reiterate their freedom to make a choice as to whether to take part and confirm process for gaining consent

Check willingness to be observed and allow documents pertinent to them to be examined

If no

If yes

Provide additional information regarding interviews.

Gain consent for observation and examination of documents pertaining to their care.

Seek consent from patients and anyone else being interviewed.

Provide information to potential participants of focus group

Seek consent from those who agree to take part in focus group prior to it starting

Figure 4.2. Consent procedure used in the research

One particular ethical issue emerged during the course of the research, which related to its design. I became aware of the issue as I disseminated my findings to staff and volunteers working in DC1. Whilst the findings that I described were positive in the main, staff members and volunteers working in DC1 felt distressed by them and reported new difficulty relating to their patients. It transpired that the joint construction I had described was at odds with their beliefs regarding patients' experiences of PDC. Whereas they believed that patients placed particular importance on the activities and care provided in DC1 for example, my research revealed that patients placed greater value on the relationships that they established during their attendance in DC1. They were also shocked that patients would undertake treatments as a means of pleasing their carers, rather than placing value on the therapeutic value of the treatment to themselves. This discrepancy jeopardised their conviction that they understood why patients valued PDC and how it made a difference to their lives. In turn this shook their belief that they were making a significant difference to patients' lives by addressing them. This belief was key to their motivation to work in this environment and was often their source of strength when faced with the stress of relating to people who were terminally ill. In learning from my research that their perception of how patients experienced DC1 was not always shared by the patient the premise for their work was shaken. Furthermore they described how it made them uncertain in their relationships with patients that they knew had taken part in the research, many of whom were still attending the service at the time of the presentation. In the light of this response I was much more careful about the timing and content of my presentations in DC2, providing more detail regarding the principles underpinning a constructivist view of the world and the value of learning these different constructions. I was not aware of any of the same distress in DC2 on leaving it. This difference could have been attributable to the changes I made to the presentations but could also have been due to the level of support and awareness of a different group of staff. Alternatively it may have reflected the fact that DC1 was the object of interest for those commissioning the research and the findings were deemed to be important in shaping the future of the service in this setting. This may have served to generate

anxiety in those involved in the service when findings that they perceived as negative were presented.

4.5.2. Ensuring the quality of the research

Hammersley (1998) identifies two broad criteria for assessing the quality of research – validity and relevance- that have been used to guide the planning, implementation and presentation of this research and its findings. This choice is based on his view of the function of research – "to produce knowledge that is of public relevance" (Hammersley 1998 p.62) and his belief that the function of the research should determine which criteria to use (ibid.). It is also the result of reading the literature concerned with this issue, in which these criteria are identified as particularly valuable in this respect (Mays & Pope 1995;Murphy et al. 1998).

The criterion of validity is defined as "the extent to which an account accurately represents the phenomena to which it refers" (Hammersley 1998 p.62). To ensure research that was valid, I engaged in a variety of activities.

First I developed a research audit trail that would enable the reader to know the process that gave rise to the research findings. This is a detailed record of the collection of data and their analysis, as prescribed by Rodgers and Cowles (1993). It took the form of research diaries in which I recorded methodological decisions, descriptions of how data had been collected (including number of hours and types of data collection) and details of the analytical process.

Second, I engaged in a reflexive approach to the process of collecting and analysing data that would enable me to identify the contribution that I had made to the research and its findings. This was important in the light of the role that I adopted within the research where I actively engaged with the people who I was studying as a means of discovering and exploring their constructions of PDC. This approach lent a subjectivity and a degree of involvement on my part that will have

influenced the findings (Murphy et al 1998), of which I needed to be aware (Mason 1996). According to the literature researchers engaging in this approach need to reflect on the impact of their prior assumptions, the relationships that they develop whilst undertaking the research and how their presence will have affected the services and the people who they have studied (Creswell 1998; Mays & Pope 2000). To do this I noted on a regular basis my presumptions, values and motivations in relation to the research, as recommended by Glesne (1999), starting to do this before I began data collection. I also kept a diary which charted my feelings associated with doing the research and comments about the ways that these were likely to have influenced the research. When analysing the data, I would re-read my diary and records of my reflections on the process in conjunction with the data collected, considering any connection with each other. About once a month I met with another research student to discuss the experience of doing the research, my findings and interpretations – a process of peer debriefing as recommended by Lincoln and Guba (1985). During the period of data collection I also met with a clinical psychologist working in palliative care to discuss what impact the research had made on me.

Third, I sought to identify negative incidents within the case studies as a means of avoiding holistic bias, a term used by Sandelowski (1986) to describe the actions of making the data look more patterned than they are. In so doing I was looking for data that were inconsistent with the emerging analysis and incorporating them into the studies.

Fourth, I gave attention to the issue of fair dealing (as described by Murphy et al 1998), that is giving attention to the various perspectives that I encountered in the research, rather than describing a single viewpoint as a basis for my findings.

Fifth, I proposed terms of reference for the Steering Group described in Chapter 1. This activity was undertaken early in the life of the research, and served to clarify the role of the Steering Group. It enabled open discussion regarding the possible

tensions that could arise for me as researcher, as I sought to meet their interests in the research whilst providing research that was unbiased in this respect. It was agreed that the Steering Group would simply watch the progress of the research and act as a point of reference and help in the event that I experienced any practical difficulties in carrying out the research. This role was adhered to during the course of the research.

The criterion of relevance is defined as the production of research findings that are "relevant to issues of actual or potential public concern" (Hammersley 1998 p.70). To meet this I considered the degree to which the research provided participants with new perspectives on their issues, its contribution to existing knowledge regarding PDC and how transferable its findings were to settings beyond those studied. The relevance of the research was attended to in its initial plans which took into account the requirements of the commissioners of the research, its participants and the wider audience that it would reach through publication. Its relevance was also monitored during each study in terms of how valuable its findings were in informing local decisions. The relevance of the findings will also need to be considered in relation to this thesis, in terms of how well they are presented and their accessibility to those who plan or provide PDC.

4.5.3. Ensuring the acceptability and effectiveness of the research methods

The research approach was regularly reviewed to ensure its acceptability to its participants, its effectiveness in achieving its aims, and in response to any ethical and practical issues that arose during the periods of data collection.

As portrayed in Figure 4.3. this activity took place formally at the end of the preliminary study and the study of DC1 to guide the remaining data collection. It was also appraised in an ongoing way during each study to identify and respond immediately to any aspects of the research that were unacceptable to participants or unworkable in a particular setting. This process led to the research approach

being adjusted during the course of the study in response to any such problems identified.

Figure 4.3. Review of the research approach
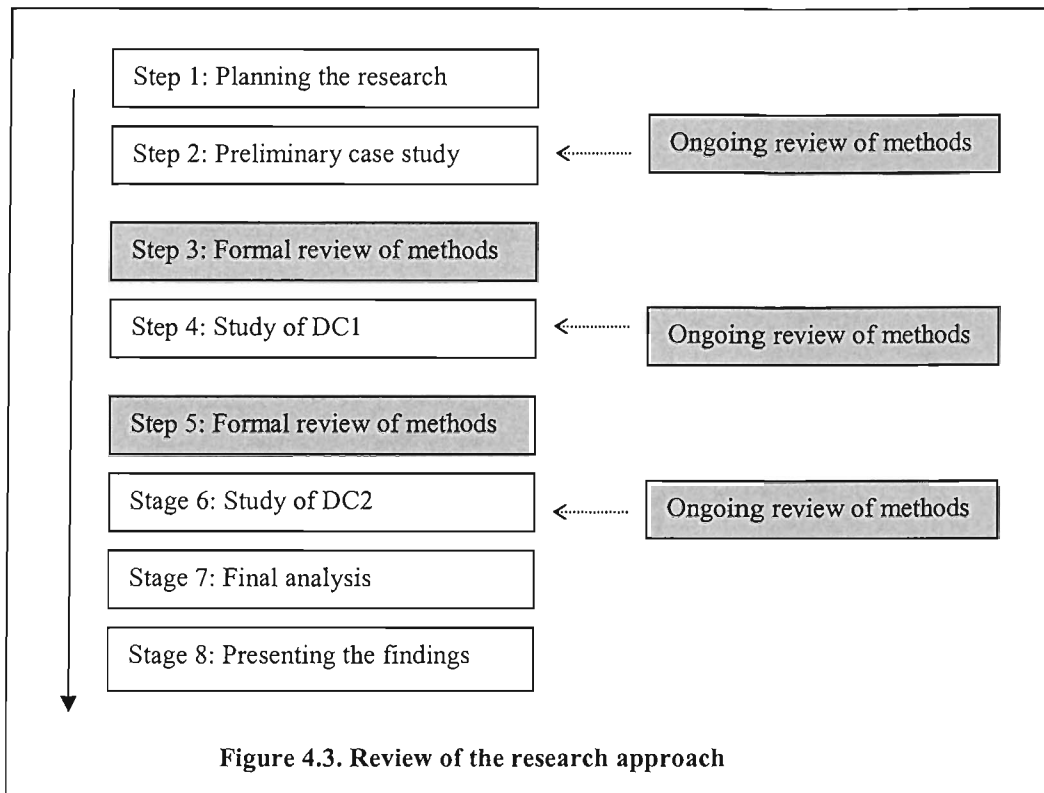
4.6. The methodology of inquiry

The cases were studied using the methodology of constructivist inquiry (Guba & Lincoln 1989; Lincoln & Guba 1985). An overview of the method is depicted in Figure 4.4.. Figure 4.5. provides more detail of its central element - the hermeneutic dialectic circle.

The aim of the methodology is to produce a joint construction of the entity being examined (in the case of this research DC1 or DC2) through a hermeneutic dialectic process. This process enables the constructivist investigator to "tease out the constructions that various actors in a setting hold, and, so far is as possible, to bring them into conjunction – a joining with one another and with whatever other

information can be brought to bear on the issues involved" (Guba & Lincoln 1989 p.142).
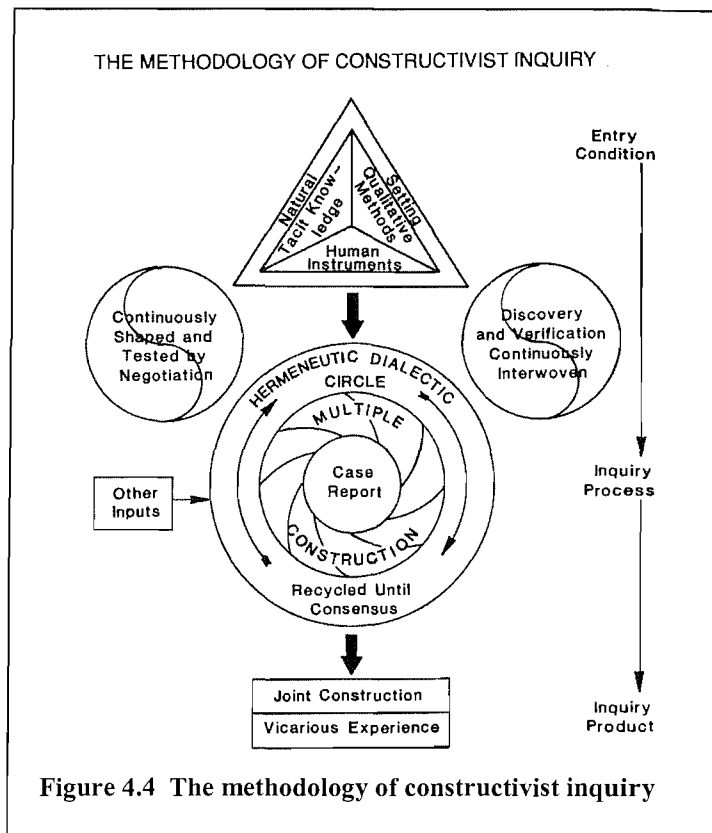
THE METHODOLOGY OF CONSTRUCTIVIST INQUIRY

Figure 4.4 The methodology of constructivist inquiry

(Reproduced from Fourth Generation Evaluation (Guba & Lincoln 1989) with permission of Sage Publications)

It is interpretive in character (hence the description "hermeneutic") and concerned with comparing and contrasting divergent views of the entity (hence the description "dialectic") with the aim of achieving a higher level synthesis of them all. As such the joint construction is grounded in the constructions of individuals but is more sophisticated and better informed than those held individually. This synthesis is achieved through an iterative process, depicted as the hermeneutic dialectic circle in Figure 4.5. in which the various constructions held by individuals are described and analysed, then subjected to critique by other constructors and revised to accommodate new information or more sophisticated comprehension. This process is repeated until consensus is reached on a joint construction of the entity; that is the point when the emerging construction has internal consistency and as such can be identified with by the participants in the

research. The hermeneutic dialectic process calls on a variety of sources of data to achieve this new joint construction. Interviews with the constructors are at its centre. They enable the researcher to learn how individuals construct the service and to gain their comments on the constructions held by others, including how other's constructions relate to their own and how elements of them can be explained. Data collected via observation and the examination of documents and other literature add detail to the construction and its contexts. They inform the interviews and build on data collected from this source. The construction is further enriched by input from the researcher related to his or her construction of the entity and the constructions of other stakeholders.
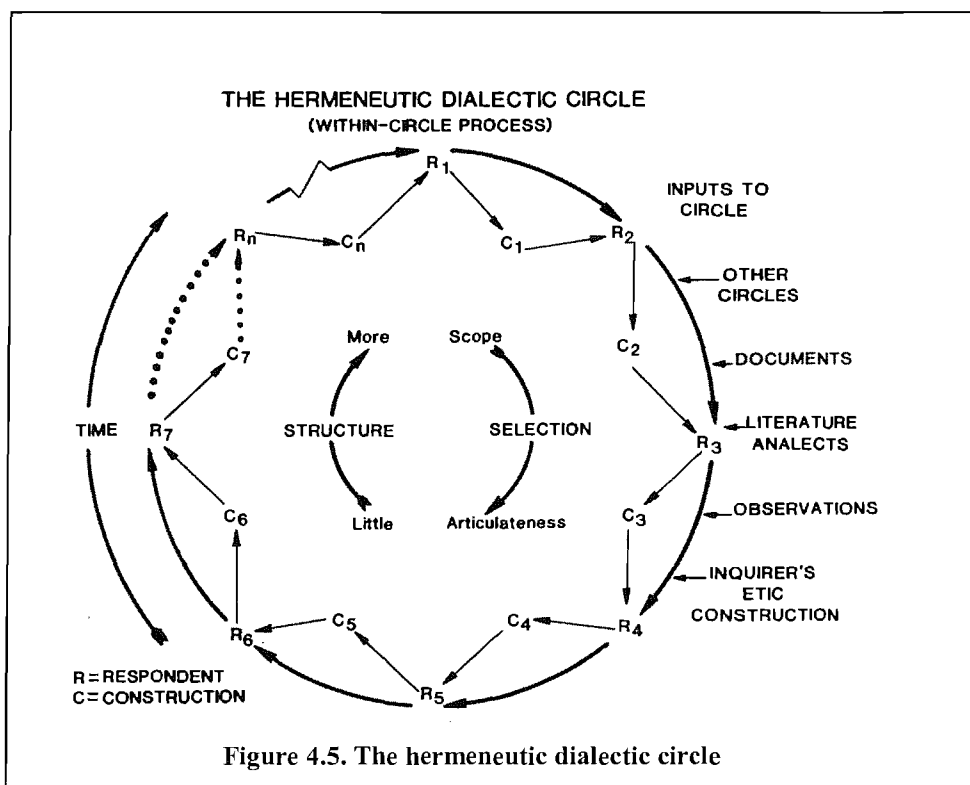
Figure 4.5. The hermeneutic dialectic circle

(Reproduced from Fourth Generation Evaluation (Guba & Lincoln 1989) with permission of Sage Publications)

According to Guba and Lincoln (1989) a joint construction will only be achieved when certain conditions of entry are met, which are identified in Figure 4.4.. These require that the study is undertaken in its natural setting, that it uses a human instrument to collect data, that it utilises qualitative methods of data collection and calls on tacit knowledge on the part of the researcher to guide the study

particularly in its early days. They also identify two key tenets of constructivist inquiry. The first is the importance of negotiation between the researcher and the research participants in shaping the processes and testing the outcomes of the research. The second is the interrelated processes of discovery and verification within this approach.

In practical terms, the joint constructions of DC1 and 2 were developed as follows. Study of the service would begin with observation and examination of documents as a means of defining the boundaries of the case, understanding its contexts and identifying issues for further discussion with participants. Interviews were then undertaken with patients to gain an understanding of how they constructed the service, based on the hermeneutic dialectic circle. Each interview was followed by its analysis in order that the construction and its interpretation could be presented to the next interviewee for comment. The interviews were interspersed with further periods of observation and examination of documents to illuminate issues raised in the interviews that could not be fully explained or were not completely understood. In addition interviews with other stakeholders were undertaken for the same reason. Once a joint construction had been tentatively arrived at, a final period of observation was undertaken in addition to a focus group in DC2, as a means of confirming the construction and ensuring it was complete. The contribution of the different sources of data to the studies of DC1 and 2 are described in Table 4.1. The various sources were key to developing as complete a construction as possible. Specifically, data collected via observation and examination of documents served as a vital means of focusing the interviews and understanding their detail and contexts. My own construction of PDC derived from my experiences and the literature was, at times, also introduced to the hermeneutic dialectic circle in an explicit way. I would, for example, describe my perceptions and interpretations regarding PDC during an interview, for critique and comment by the participant. It would then be incorporated into the construction or rejected based on the their response.

Method of data collection	Type of data gathered	Contribution made by the data to the research
Observation of the services studied	Observation notes, including personal reflections of what was observed	➤ Identification of the boundaries of the case ➤ Identification of new questions to be included in interviews ➤ Clarification of comments made during interview ➤ Confirmation of the detail of the joint construction and its completeness
Examination of documents pertaining to each service	Copies of whole or part of document, or my notes regarding documents if they could not be copied	➤ Contextual information regarding the services studied; ➤ Identification of questions to be included in interviews ➤ Identification of aspects of the service requiring further observation ➤ Clarification regarding issues identified during interview
Examination of patient records in each setting	➤ Descriptions of care received according to professionals ➤ Data regarding utilisation of the service	➤ Identification of shared characteristics of those using each service ➤ Identification of questions to be included in interviews
Interviews with patients using PDC and other stakeholders	➤ Notes of interview ➤ Tape recording of interview ➤ Personal reflections on interview	➤ New information regarding the interviewee's construction of the service ➤ Comments regarding the construction of others ➤ Clarification regarding issues of confusion identified during observation or examination of documents ➤ Development of codes and substantial codes related to the experience of patients using the service for integration into emerging joint construction
Focus group	➤ Comments regarding the proposed joint construction ➤ Information from participants regarding the value they placed on the different elements of the joint construction ➤ Tape recording of the group discussion ➤ Personal reflections on group	➤ Confirmation of key elements of the new joint construction for DC2 ➤ Identification of relative importance of the different elements of the joint construction related to DC2

Table 4.1. Contribution of the different sources of data to the studies of DC1 and DC2

The purpose of this was threefold and based, in part, on the suggestion of Guba and Lincoln (1989). Firstly it limited my subjective influence on the construction

by making it available for critique. Secondly it enriched the construction through the introduction of another perspective – in the case of my own it represented one belonging to an outsider. Thirdly, it charted my evolving thoughts about PDC, and helped to ensure they remained consistent with the views of the participants. This reflected the main aim of the research of learning about PDC from their perspective.

I chose this particular methodology for the research for a number of reasons:

➤ It provided opportunity to explore individual constructions of PDC, whilst also enabling the development of a joint construction of the PDC service being examined.

➤ Its approach enabled exploration of PDC without reference to theory to guide the process. This was important given the relative dearth of research available regarding PDC and patients' experience of it as described in Chapter 2, making an inductive approach to the research essential.

➤ I felt that its use of qualitative methods would embrace the complex, highly individual and changeable nature of patients' experiences of the service given their exploratory, fluid and context-sensitive characteristics (Mason 2002).

➤ I felt confident that its attention to data from a variety of sources would contribute to a description of PDC that would be as near to complete as possible and incorporate its contexts, as suggested by Creswell (1998).

➤ Elements of constructivist inquiry as described by Guba and Lincoln (1989) resonated with my own ambitions for the research. For example it demanded a high degree of participation by "the researched" in the collection, analysis and interpretation of data within a partnership relationship with the researcher. It also required that the researcher serve as the main research instrument. The degree to which this partnership relationship was achieved is discussed further in Section 9.3 – strengths and weaknesses of the research.

4.7. The focus of the case studies

The case studies focused on the claims, concerns and issues that patients and some other stakeholders identified in relation to PDC. Claims, concerns and issues are organising foci that Guba and Lincoln propose in their description of Fourth Generation Evaluation (1989) to capture the views of stakeholders in relation to the entity being evaluated, which they refer to as the evaluand. They define claims and concerns as assertions that stakeholders make that are either favourable or unfavourable to the evaluand. Issues are defined as "any state of affairs linked to the evaluand about which reasonable persons may disagree" (Guba & Lincoln 1989 p. 40).

These organising foci were adopted by this research given its interest in learning about the value of PDC from the perspective of its users. By using claims, concerns and issues as a basis for each study, patients were able to place a value on PDC according to their own needs and expectations of the service, and to make a judgement on the service on the grounds of its effects on them, whether intended or not. Guba and Lincoln (1989) stress that claims, concerns and issues arise out of the particular construction that has been formulated and reflect their circumstances, experiences and values. Thus in focusing on them the research does not limit valuation on the part of the patient to criteria that have been identified in advance by the researcher as in many other forms of evaluation (Robbins 1998), but considers instead what is important to the patient.

4.8. Methods of data collection

As indicated in earlier sections of this chapter a number of methods of data collection were utilised to establish as complete a picture of DC1 and 2 as possible. They were integrated through the hermeneutic dialectic circle described in Section 4.6., each making a unique contribution to the development of the joint construction, as identified in Table 4.1.

4.8.1. Observation of the service

Observation, as a method of data collection has been described as that in which the researcher immerses themselves in a research setting and systematically observes the various dimensions of that setting, together with its interaction, relationships, actions and the events within it (Mason 1996). It was used in this research to achieve a number of aims:

> ➢ To identify the boundaries of the case, that is who and what I should include in each case, as suggested by Stake (1995)

> ➢ As a means of becoming familiar with the service that I was studying and those involved in it

> ➢ To highlight aspects of the service that would benefit from exploration during interviews with those using the service (as suggested by Guba and Lincoln 1989)

> ➢ To build on insights offered by participants during interview by providing data that could not be collected in this way (as proposed by McCall & Simmons 1969)

> ➢ To provide new ways of thinking and viewing the service (as suggested by Erikson 1973)

> ➢ To confirm that the emerging joint construction encompassed the many elements of the service that were observable.

To achieve these aims the focus of observation was variable during the course of the study, moving from a broad perspective to one that was more focused and selective, before widening out again at the end of the study. This shift in focus has been described by Spradley (1980) and was adapted for the purposes of this research. In the early part of each study I attended the service on each of the days that it was open, spending most of my time sitting and watching the events and action within it. I sought at this point to identify who was involved in the service and how it operated. For this reason I was keen to observe anyone and everyone involved in PDC, and did not restrict my observation to any particular group of

people or activity. Once I had started conducting interviews, the focus of the observation changed, becoming much more concerned with the detail of the service that would inform the interviews and building on the data that the interviews generated. Towards the end of the study, I observed the service as a whole again, with the perspective of the new joint construction. At this point I was looking for incidents, interactions and other aspects of the service that did not fit with it. When this occurred, it indicated that the new joint construction was not complete on the grounds that there were some aspects of the service which were not reflected within it. In this event new information was sought through further interviews to develop the construction further in order that it could accommodate that which I had observed.

The role that I adopted as observer within DC1 and 2 was a participative one. It reflected the philosophical underpinnings of the research, which required that I interact with the participants to generate the data for the research (Guba and Lincoln 1989). It was also in keeping with the expectations of those involved in DC1 and 2 who were keen that I took part in the life of the service, and would draw me in if they believed me to be on the periphery. This experience was not unique to these settings or to me. Other researchers in PDC settings have reported similar difficulty maintaining less participatory roles as observers, because of repeated efforts by participants to bring the researcher into the action of PDC (Langley-Evans 1999). As a consequence I would spend the periods of observation sitting with patients and others involved in the service, engaging in the same activities, sharing their conversation and eating my meals with them. At all times my observation of the service was explicit and only undertaken with written consent from patients and verbal consent from staff and volunteers.

I observed DC1 and 2 for variable periods depending on the purpose of the observation, these periods ranging from a few hours to a full day. At the end of any period of observation I would make notes of what I had observed, also highlighting any issues that had been particularly surprising, disturbing or

interesting to me. During the day I carried a small notebook within which I made notes away from the patient area in order to remember small details such as comments made by individuals. The observation notes were used to plan and analyse data collected in interviews, and were referred to later as I developed my proposition regarding PDC. A set of observation notes have been included as Appendix 3 as an example of their style.

4.8.2. Interviews with participants

Interviews served as the principle means of learning the constructions of PDC held by people involved in the service. The majority of the interviews undertaken were with patients using the service, reflective of the main aim of the research to learn about PDC from their perspective. Other interviews were undertaken with patients who had left the service, staff and volunteers working in PDC, families of patients (specifically those that patients felt valued PDC) and other stakeholders of the service such as managers, referrers and planners to inform the joint construction belonging to those using the service. The organisation of the interviews and their analysis were consistent with the hermeneutic dialectic circle described by Guba and Lincoln (1989), depicted in Figure 4.5.

The interviewees were chosen on the grounds that they could provide specific information at a particular point in the process of the research to help develop the joint construction of the service. As such the sampling strategy was a purposive one, as described by Patton (1990). Those that were approached initially were identified on the grounds that they would offer a variation on the constructions learned so far, in this way contributing to a broad scope of information regarding the service. Those that were approached later were chosen for interview in the belief that they would be able to illuminate certain issues relating to the construction that had emerged from the data. As the researcher I would identify the sort of information I sought at any particular point in the study and then ask participants within the service to identify someone who could provide it. Often this process was undertaken within the interviews where the interviewee would be

asked to suggest the next interviewee on the basis of what we had explored together in our discussion. Thus, interviewees were selected contingently, meaning that the selection of the next interviewee was based on what had been learnt so far. They were also selected serially, that is no interviewee was chosen until the preceding interview had been completed. The decision about how many interviews to conduct and with whom was based on my sense of how "complete" the emerging construction seemed. As described earlier, if I then witnessed an event which could not be understood in the context of the construction, I would seek additional interviews to make sense of what I had seen.

In addition to sampling contingently and serially, I decided that in the event that someone involved in the service expressed a wish to be interviewed, I would plan to do so even if someone else hadn't proposed them for interview. In the event this situation didn't arose. It should also be noted that I identified a small group of patients as inappropriate for interview on entry to the service. These were those with profound cognitive problems that could have made informed consent difficult; also anyone with major communication problems that would make it difficult for me to understand them. In both studies these numbered only two or three and in neither setting were they proposed for interview by another participant.

There were two parts to most of the interviews undertaken in each study. The first was concerned with learning how that individual constructed the service, that is "to describe it and comment on it in personal terms" (Guba & Lincoln 1989 p.151). These constructions were built on the claims, concerns and issues that individuals held in relation to the service and were explored using a number of predetermined questions, including those arising from my observation of the service. An interview guide is included as Appendix 4, which identifies the sorts of questions that I used to learn how patients experienced the service. However in keeping with the open ended nature of the interviews that demanded an open and flexible approach to the content of the interview (Patton 1990), these questions

were disregarded in the event that the participant wanted to describe the service and their construction of it in their own terms. At times this approach meant that I did not collect all the information I had sought at the outset. However it also made way for insights that I had not anticipated - those "serendipitous learnings" that Glesne (1999) describes that emerge during the process of discourse.

The second part of the interview was to seek the views of the interviewee regarding the constructions of the service held by others. To enable this, it was essential to undertake the interviews and their analysis concurrently. Thus, when an interview had been completed with a participant (represented by R_1 in Figure 4.5), its content was analysed to identify "themes" which could be discussed with others (represented as C_1 in Figure 4.5.). When the next interview was undertaken, as well as learning the construction of the service held by this participant (R_2), the "themes" encompassed in C_1 were presented for their comment. Commonly this took the form of general statements regarding the views of others, such as "Others have highlighted the importance that they place on the relationships that they make here", followed by a question as to whether this resonates with their own experience, for example "Can you identify with that?". Analysis of this interview would then produce "themes" (C_2), not only related to their construction of the service, but also encompassing their critique of C_1. Thus, as each successive construction was formulated (C_3,C_4,C_5 etc), it was enriched through new information or better understanding of its component parts arising from discussion with subsequent respondents. On some occasions, interviews were undertaken with the single aim of exploring particularly salient elements of the emerging construction, for example the experience of joining or being discharged from the service or the nature of the relationships therein. In this event, the interview was highly structured in nature using questions identified prior to the interview that sought specific information.

In practical terms, I would approach a potential interviewee and ask whether he/she would mind being interviewed. Only those who had not indicated to staff

members any reservation about being interviewed (as requested in the information sheet) were approached. If they were agreeable we would agree a date and time for the interview and discuss the interviewee's choice of venue. I would then remind the interviewee of my intention to tape the interview and ask whether they had any reservation in this regard. If they did, the interview was not taped. On the day of the interview I travelled to the venue – usually the hospice, and occasionally individual's homes, set up any equipment required, prepared the questions and emerging construction for comment, and organised the consent form prior to the interview. Wherever possible I sought to ensure privacy for the duration of the interview. When the interviewee arrived, I offered thanks for their help, described the process of the interview and the right of the interviewee to terminate the interview at any point or to refuse to answer any questions posed. I also reiterated my promise to keep their views confidential. The interview then commenced, normally lasting between 30 and 60 minutes in length depending on how much the participant had to say and the state of their condition. I sought to interview most participants on one occasion only. This decision reflected the limited time available in each setting and the health status of many of the patients attending PDC who were often fragile and easily tired. When the interview was drawing to an end I would check out whether the interviewee had suffered any distress or required any support on leaving the interview. This support had been negotiated with staff working in PDC prior to the start of data collection and was offered to every interviewee. In the event it was never taken up as far as I was aware.

The single interview poses some questions about the quality of the data derived from the interviews in the light of the limitations of a single interview to establish sufficient rapport between interviewer and interviewee (Gordon 1997) and to learn the context of the information generated (Mishler 1986). I sought to overcome these potential shortcomings by engaging with participants during the initial period of observation, as suggested by Glesne (1999), and by becoming familiar with the various contexts of the participants through informal discussion with them prior to interview. On the few occasions when I felt that an interview had suffered from

insufficient rapport, or inadequate contextual knowledge I identified this in my notes regarding the interview and analysed it with these concerns in mind. The PDC leaders in DC1 and 2 were interviewed on two occasions, once near the end of the study to consider issues arising from the data collected.

Copies of the transcribed interview were offered to every interviewee at the end of the interview as part of the member-checking process that Guba and Lincoln (1989) and others recommend. Many did not wish to see them. The eight individuals that did were sent a copy within a week or so of the interview with an invitation to discuss the content further if they wished. This offer was never taken up formally. However it is interesting to note that participants would seek me out some days or weeks after the interview to explain some aspect of the interview, having given it some thought in the light of the constructions of others raised in the interview. This was commonly a very enriching process.

A copy of a transcribed interview is included as Appendix 5 as an example of the interview style.

4.8.3. Examination of documents and other visual information

Documents and other visual information such as notices, pictures, posters and memos pertaining to the service were collected and examined as a means of establishing the various contexts of each service, and alternative constructions of it. Often documents were important in establishing the history of the service. They were also invaluable in helping me to understand its culture. Information derived from documents commonly informed interviews; in turn they also helped to explain aspects of the emerging construction identified by interviewees.

The documents collected in this research include internal documents such as operational policies, job descriptions, minutes of meetings and correspondence relating to the service. In addition I was interested to look at leaflets, newsletters, posters, newspaper cuttings and other public information regarding the service.

Appendix 6 provides a list of the documents collected in DC1 and DC2. Prior to the studies I made a list of the sorts of documents I hoped to peruse based on a wish to learn about the operational, historical and policy contexts, as suggested by Mason (2002). This list was added to once the studies commenced to reflect the local availability of particular documents and the rich data found in unexpected documents such as letters and cards that I was invited to peruse during the research. These documents were read, annotated and indexed on collection as suggested by Lincoln and Guba (1985). Their annotation was concerned with their source, context and purpose to meet the stipulation that they were read and interpreted with their history and original purpose in mind (Yin 1994). Wherever possible they were photocopied and retained in the event that they might need to be referred to later in the study.

In addition data related to the individual patients being cared for in each of the settings were gathered and collated from the patient notes held in PDC. They included personal characteristics such as age and ethnicity and details of how patients utilised PDC, including length and pattern of attendance, reasons for referral and their source. Clinical information such as their diagnosis was also collected where available from nursing and medical notes. This information was summarised in the form of graphs and provided important contextual information related to the users of the services studied. See Appendix 7 and 8 for examples of the graphs generated for DC1 and 2 respectively. These data were quantitative in nature, seemingly at odds with the philosophical underpinnings of the research and the conditions for constructivist inquiry. However Guba and Lincoln (1989) suggest that this is acceptable in constructivist inquiry, providing that it builds upon the views of those being studied, rather than serving as an alternative means of understanding the service.

4.8.4. The focus group

Morgan (1997) defines focus groups as a group interview where interaction within the group is key to its outcomes. The focus of the interaction is a topic identified by the researcher who may also serve as facilitator (ibid.). Within the current study

the topic was the emerging construction of the service, the main purpose of the group being to confirm its resonance with those that had contributed to it. A secondary aim was to clarify the relative importance of its component parts.

The decision to undertake a focus group at the end of the case study was not made until study of DC1 was under way. It arose given the limited time that I had in each setting to complete the iterative process recommended by Guba and Lincoln (1989) in their description of Fourth Generation Evaluation. They suggest that "it may be useful to make the [hermeneutic dialectic] circle a second time" (p.153) in order to gain the views of early respondents about the constructions of others, but this was not a practical option in this research. For this reason I invited those that had contributed to the emerging construction to attend a group to comment on the new joint construction proposed. In doing so I felt that it could have some of the benefits of repeating the circle as Guba and Lincoln (ibid.) recommend. I thought that the group interaction, characteristic of focus groups might also be valuable in exploring areas in which there was not consensus in relation to the joint construction. Having developed this plan, I then applied for approval from the LREC to run a focus group in DC1. However approval was delayed by the LREC to a point that many of the patients who had taken part in the research were no longer attending the service thereby making the plan unfeasible in this setting. This represents a weakness in the methodology in my view.

The focus group undertaken in DC2 comprised patients that had been interviewed earlier in the case study. Whilst acknowledging that this denied input to the group by those that had been observed but not interviewed, I took a pragmatic approach as to who to invite, given the stipulation that such a group should not exceed 10 participants (Morgan 1997). Letters of invitation and information sheets were sent to all patients interviewed and if they expressed an interest to take part, they were provided with details of when and where the focus group would be taking place. At the point of inviting the patients to attend the Focus Group there were potentially 12 patients who could have accepted. In this event, I agreed with the

co-facilitator of the group – in this event one of my supervisors - that we would exceed the recommended number, rather than turning down patients who were interested to take part. In the event, only eight patients came, the remainder choosing not to attend for a variety of personal reasons.

The venue for the focus group was a room adjoining DC 2. The date chosen for the group was one when many of the patients who had indicated an interest to attend the group would be attending the service anyway. For other patients, special transport was laid on to enable them to come to Day Care. The day before the group, I contacted all potential members to ensure that they were aware of the plans for the group. At that point I reiterated their right not to take part if they felt any ambivalence in this respect. On the day itself, I arrived early to set up the room. Chairs were set around a table and the recording equipment and consent forms prepared. As participants arrived, they were offered a drink and encouraged to sit in a place of their preference. They were introduced to anyone that they did not know, and members were invited to wear a badge with their name. When everyone was present the aims of the group were reiterated and the consent of individuals sought. Ground rules concerned with confidentiality were established to which all agreed. Then the tape recorder was turned on and the focus group began, its agenda comprising two parts.

The first part was a presentation of my initial findings, after which group members were invited to comment on the findings, specifically the degree to which they thought these reflected their experiences of DC2. The key claims and concerns regarding DC2 were presented in the form of large cards, which provided a definition of each claim or concern, its contributing factors and consequences. When they had been presented patients were invited to comment on them in turn and then as a set. Opportunity was provided for the patient to expand on any comments made and for others to respond. At the end of this section, I summarised the responses that I had noted in relation to each claim and concern and these were noted by the co-facilitator. The second part was an exercise in which they were

asked to rank the various claims they had agreed on with regard to the service according to how important they perceived each one to be. The co-facilitator introduced this and patients worked individually using pen and paper. When they had completed this, they were invited to talk about the aspects of the service they felt were most important to them and differences in their individual preferences.

When this work was complete, after a period of about 50 minutes, patients were invited to make any other general comments about DC2 or the focus group and then discussion was brought to a close. Patients were invited to wait at the end if they felt the need for any further support, in the event of which I had arranged for staff members to be available. Then the tape recorder was turned off and the focus group transcribed verbatim.

A problem emerged in my plan to use the focus group as a means of checking the validity of the emerging construction. It became evident, as I listened to discussion between participants attending the group that in some instances they viewed the data that they had offered in their one to one interviews quite differently when they were operating as part of a group. In general they were keen to downplay any negative comments and reinforce the positive elements, particularly those proposed by others in the group. On reflection I wonder whether this was due to a sense of vulnerability in relation to the service and their subsequent need to affirm the value of what the staff and volunteers were providing rather than appearing critical. Emerson and Pollner (1988) refer to this phenomenon as the organisational context of member checks, related to the practical and organisational consequences of the research on the setting. Gott et al (2000) highlight such vulnerability in users of palliative care services, and suggest that this can make them fearful of disagreeing with professionals in case it jeopardises their current or future care.

4.9. Description of the data collected in each case study

The data collected in each case study are summarised in Figure 4.6..

The amount collected varied between services according to the purpose of the study, the way that each service operated and my confidence as a researcher. Data collected in each setting is described in more detail below.

Preliminary study:	Study of DC1:	Study of DC2:
- 15 hours observation - 4 interviews - Examination of leaflets regarding the service	- 120 hours observation - 35 interviews including 13 with patients - Examination of a variety of documents related to the service	- 220 hours observation - 36 interviews including 14 with patients - Examination of a variety of documents - Focus group

Figure 4.6. Summary of data collected in each case study

I gathered data for the preliminary case study over a period of three weeks, during which time I spent 15 hours in observation, undertook four interviews and examined their leaflets describing their service. Details of the interviewees are included in Table 4.2.. Prior to leaving I transcribed and analysed parts of all four interviews, providing a copy of the summary of the interview to one person for comments. At the beginning of the study I made a presentation about the research to the staff and on leaving received their comments on the study.

The study of DC 1 took place over a period of six months. The first two months of the study were spent observing the service and collecting documents and details of those using the service. In this setting all planned activity was based in one room, making observation of the service simple at a logistic level. During months three and four of the study, patient and carer interviews were conducted. In the final two months of the study I interviewed a variety of other stakeholders involved in the service. Table 4.2. provides details about the numbers and nature of these stakeholders. They were approached for interview in order to clarify issues that had been identified by patients as important to them but which they could not

explain fully. Interviewees were only interviewed on a single occasion. Immediately prior to leaving the service I spent a further two weeks observing it as a means of confirming the new construction. A total of 120 hours were spent observing DC1. Everybody that I approached to take part in the study in this setting agreed to be involved and duly gave consent, although one man requested that his GP was not informed about his involvement. Having discussed the implications of this decision on his part, I agreed to his request and he signed the consent form with this caveat. On one occasion an interviewee requested that the interview was not recorded and so I proceeded with the interview according to his wishes, simply writing up the interview when it was finished in as much detail as I could remember. As I came to the end of this case study I began to consider the value of a focus group to check the final construction with those who had contributed to it. I realised that whilst I had a clear idea about what elements of the service were most valued by its users and why this was the case, I was unclear about their value relative to each other. In part this was due to the fact that I did not have the time to return to those that I had interviewed in the early part of the study to gain their views on the constructions offered by others. I applied for approval from the local research ethics committee (LREC) to run a focus group to this end. However approval was delayed by the LREC to a point that many of the patients who had taken part in the research were no longer attending the service thereby making the plan unfeasible in this setting. This represents a weakness in the methodology in my view, but one that I could not address in any substantial way.

I spent just over five months in DC2 engaged in a similar process to that undertaken in DC1. The study commenced with observation and examination of documents, then interviews were undertaken with patients and other key stakeholders, interspersed with observation. See Table 4.2. for information regarding the number and nature of the stakeholders interviewed in this setting. I finished the study with another period of dedicated observation and a focus group. I only interviewed participants once, with the exception of the Day Care Leader

who was interviewed twice. There were some differences between the settings that demanded an alternative approach to collecting data. In DC2 for example, the participants sat in a variety of areas within DC2, rather than a single group as in DC1, making movement between the areas essential as a means of learning what happened within DC2 as a whole. I would tend to spend dedicated periods of time in each of the areas of DC2 over a period of a few days in order to achieve this overview. In addition the amount of time dedicated to observation of the service needed to be greater in DC2 to ensure that I had a chance to see its many different facets. It was open five days a week, each day providing something slightly different to the others and its provision included an outpatient service. In addition DC2 staff were involved in a number of meetings regarding patients attending the service that I felt were also important to observe. As a consequence a total of 220 hours were spent in observation in DC 2. The opportunity to include a focus group at the end of the study was also an important difference. A total of eight patients attended the group.

	Preliminary study	Study of DC1	Study of DC2
Number of interviews of patients attending the service	1	13 (including interviews 2 patients who attended from the inpatient unit)	14
Number of interviews with patients discharged from the service		1	0
Number of interviews with carers/family members		2	3
Number of interviews with staff working in DC	1	5	7
Number of interviews with volunteers attached to the service	1	4	4
Number of interviews with referrers to the service		5	4
Number of interviews with managers linked to the service	1	6	4

Table 4.2. Details of the interviews conducted in each case study

The point at which data collection finished in each setting was determined by a number of factors. Within broad constraints of time available for data collection, I was committed to remaining within each setting until I felt that I had achieved a joint construction of the service that participants could identify with and which encompassed the broad range of views that I had heard. This included time to search for data that offered alternative explanations of my findings, and elements of the service (people, incidents or views) that were inconsistent with the emerging analysis as suggested in the literature (Hammersley 1998; Lincoln & Guba 1985). In my plans to bring each study to a close, I also considered my impact on the service and its influence on me. For example my decision to leave DC1 was associated with a concern that I was going native, defined by Hammersley and Atkinson (1983) as "the danger of identifying with... members perspectives and hence failing to treat these as problematic" (p. 98). I became aware of this as I reflected on entries to my reflexive diary and left soon after this shift became apparent in an effort to minimise its effect on the data and its analysis. On my departure from DC1 and DC2 parties to mark my leave were arranged by staff members and volunteers. At this point, I also had the opportunity to thank participants for their help in the process of collecting data.

4.10. Analysis of the data contributing to the joint construction

As described earlier, data analysis was undertaken concurrently with their collection. A table describing the process of analysis of data according to each method of data collection is included as Appendix 9.

The recordings of the interview were transcribed verbatim based on the method proposed by Morse and Field (1996). Utterances such as "er" and "um" have not been included in transcriptions for ease of reading and in the light of my interest in learning participants' views, rather than studying the nature of the discourse itself. I transcribed the majority of the interviews myself as a means of becoming familiar with the data unless they were more than an hour in length when they were transcribed professionally. A list of symbols was devised which I used to

transcribe each interview, included as Appendix 10. The transcribed interviews were then anonymised and imported into NUD*IST, a computer software programme for qualitative data analysis.

Analysis took the form of the constant comparison method described by Lincoln and Guba (1985) and Strauss and Corbin (1990; 1998). This method requires that the data are fractured and conceptualised through a process of coding (ibid.). The different stages of this method used to develop the joint construction are depicted in Figure 4.7. Its aim was not to produce theory, as in grounded theory studies (ibid.), but to identify emerging themes from the data, as a basis for the emerging construction.

In creating the initial codes, the raw data were fractured and conceptualised. As such the interview was broken down into discrete elements which were identified with a name that stood for a phenomenon (ibid.). Some of the codes I used to sort the data would already have been created during the analysis of earlier interviews and others would be identified in response to new data. Each code would be assigned a brief description and to some I attached a memo – a note that contained my initial thoughts about the phenomenon. My choice of which data to code was based on learning about patients claims, concerns and issues in relation to the service that they were using. I also attached memos to each interview, in which I would record any comments about the analysis of the interview, my reflections on the process and the relationship between the interview data, the interviewee and their circumstances.

Having coded each interview I started to build substantive codes by merging those that appeared to be similar. In analysing the early interviews the initial codes developed were abundant in number, at one point exceeding 200 in total for DC1. Often one was very similar to another but I was reluctant to merge them prematurely, that is until more data from other interviews were available to determine their relationship to each other and whether it was important to

differentiate them. The rationale for merging particular codes was recorded in memos attached to the substantive code and also summarised in a separate account of the process as a whole, completed at the end of each period of data analysis in a separate document. It was the substantive codes that provided the "themes" proffered within the hermeneutic dialectic circle for critique by participants, and also served as the basis for discussion within the focus group. They were augmented by contextual data such as that derived from documents and observation of the service.

Stage 1 – Creating initial codes
- Code interviews line by line
- Use existing codes and new codes in response to new data
- Develop brief descriptions of codes to inform coding of new data

Stage 2 – Building substantive codes
- Examine the codes created
- Identify those that are the same and merge
- Describe the substantive codes, their contributing factors and consequences
- Create working "themes" for use within hermeneutic dialectic process
- Discuss with participants and integrate into emerging joint construction
- Present to focus group for comment and development

Stage 3 - Create categories
- Bring together substantive codes based on presentation of the emerging construction
- Describe each category
- Identify its contribution to the final joint construction

Figure 4.7. Process of analysing interviews to form joint construction

Categories were created once participants had agreed the key themes or elements of the joint construction in the interviews and the focus group. Categories brought together substantive codes and formed the basis of the written description of the joint construction. Memos were often attached to the categories providing detail of

the category, its contexts, how it related to other substantive codes and negative cases that were identified within the process.

Usually analysis, as thus described, followed after each interview conducted. On a number of occasions, the full process was not achieved prior to the next interview being conducted. In this event the analytical process was shortened until more time was available, and the detail of the interview (including its themes and questions arising) noted directly from the recording or transcription of the interview. The details were then discussed with the next interviewee as per the methodology to enable synthesis and critique of the emerging construction as each interview took place.

Appendices 11 and 12 provide details of the codes, substantive codes and categories created in relation to the claims made about DC1 and DC2 respectively as working examples of this process of analysis.

4.11. Presenting the joint construction

Chapters 5 and 6 describe DC1 and 2 respectively. They draw on themes developed within the hermeneutic dialectic process, informed by data collected via observation, examination of documents/other visual information and a focus group undertaken in DC2, as well as the interviews which serve as the main source of direct user comment.

The main body of each chapter describes the joint construction of each service accompanied by explanation as to the value of its various elements and the needs that they met in users of the service. This attention to how and why the patients constructed the service as they did is important according to Guba and Lincoln (1989) as a means of helping the reader clarify the meaning and the interpretations that can be drawn from the construction. In addition information is provided at the outset of each chapter regarding the operation of the service and its various contexts, deemed necessary for the purpose of transferability. This means

providing readers with sufficient detail of the service so that they can draw inferences that may apply in other settings (ibid.). The description of the joint construction is followed by a section of comment and discussion regarding the joint construction in relation to the research questions that have guided the current study. These represent the outsider view of the service that I presented to patients and others within the hermeneutic dialectic process for critique and development. In highlighting this perspective within Chapters 5 and 6, I make no claim of a superior viewpoint over and above that of other participants. Instead I present a commentary that is arguably the most informed on the grounds that I was the only participant to have heard the constructions of every one else who contributed to the construction. In separating this outsider perspective, somewhat artificially given that it was fed into the hermeneutic dialectic circle, I hope to make clear to the reader my contribution to the joint construction.

The descriptions of the services are interwoven with raw data collected in each case study, in an effort to establish that described by Stake (1995) - an empathetic understanding for the reader, conveying to the reader what experience itself would impart. These data have also been included as a prescribed means of establishing the validity of the research, in order that the reader can assess the degree to which the analysis and interpretations are supported by the data (Hammersley 1998). Any excerpts of data have been anonymised in keeping with the ethical principles underpinning the research, but their source is identified through the use of a code at the end of each section of data. The codes developed make it possible for the reader to ascertain their gender, which stakeholder group they belong to and the setting in which the data was collected. For example a section of interview followed by the code MP1.2 indicates that the participant was a male patient in Case study 1 and that this interview was the second undertaken with a patient of this gender in this setting. The text unit numbers were generated by NUD*IST during analysis of the interviews and enable the reader to identify from where they are derived in the transcription of the interview. Symbols used in the presentation of this data are described in Appendix 11.

4.12. Developing a proposition regarding PDC

Contention exists within case study research as to whether its findings are generalisable given the relatively small number of cases it normally comprises (Appleton 2002;Punch 1998). Even so, there is suggestion in the literature that it is possible (for example Punch 1998). Some writers go further and propose it a valuable outcome of this type of research. Simons (1996), for example, suggests that this is the very paradox of case study - that in studying the uniqueness of the particular, we are able to understand the universal. She believes that generalisation from case study can be achieved as a consequence of the holistic perspective of case study and its attention to detail (ibid.).

In practical terms Punch (1998) proposes two ways that case studies can produce results that have validity beyond the case depending on the purposes of the case study and the way that its data are analysed. The first is by conceptualising and the second by developing propositions. In this research I undertook the latter approach and suggest a hypothesis – that of PDC serving as a community for its users – to explain the value that patients placed on PDC. This hypothesis or proposition links the separate aspects of PDC that users of DC1 and 2 highlighted as beneficial, and is described in a way that enables others to assess its applicability and transferability, and hence its relevance in other PDC settings.

This proposition was arrived at by extending the process of analysis, a strategy proposed by Wolcott (1994) to interpret qualitative data. My decision to do this arose when examination of the two joint constructions revealed some remarkable similarities, pointing to the possible existence of a shared experience of PDC by users across services. I was interested to learn the detail of this experience and how it could be explained.

The data incorporated in the extended analysis was that which pertained to individuals' constructions of PDC and their experience of living with a progressive and life threatening condition, collected in DC1 and 2. It was drawn mainly from

data collected in interviews. In addition I referred to my observation notes, my reflexive diary and descriptions of the joint constructions relating to these services. I also revisited notes that I had made during the course of the studies in which I had identified incidents that were particularly illuminating about the service in my view or described aspects of the services that were highlighted repeatedly by participants. This action was based on a particular strategy proposed by Stake (1995) with regard to interpretation of case study. Whilst the data utilised were the same as those contributing to the joint constructions of DC1 and 2, the focus of my interest in the data had changed. Instead of seeking out areas of similarity and difference between the individual constructions as a basis for developing a joint construction of each service, I was now interested in learning the detail of those elements of PDC that individuals valued or disregarded, and how they related to each other and patients' life experiences. My approach to analysis was also different. I no longer confined myself to analysing the data within the case that had generated it; instead the analysis cut across the two cases included in this research.

In practical terms this analysis followed the process identified in Figure 4.8.

Figure 4.8. Process for developing a proposition regarding PDC
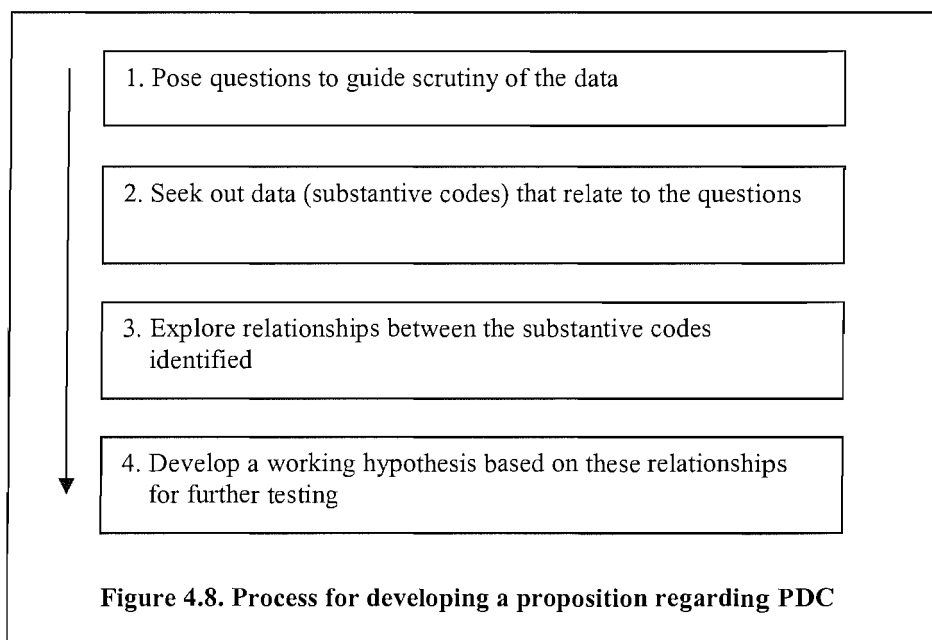
The questions posed in this exercise reflected the initial research questions and were identified as:

1. What experiences of PDC were shared by patients attending DC1 and 2?
2. What aspects of the service contributed to these experiences?
3. What were the benefits of these experiences?
4. How did they relate to their experience of illness?
5. Were there variations within the shared experience?

The substantive codes relating to DC1 and 2 were then scanned and loosely reorganised to reflect the questions that guided this analysis – experience of PDC, contributing characteristics, benefits of attending and experience of illness. This reorganisation was flexible and some codes moved from one group to another when their data were reconsidered in the light of the questions.

Those substantive codes concerned with experience of PDC, alone with data collected from other sources were then examined to develop some working ideas about common experience of PDC in both settings. They were then tested by looking at their fit with the substantive codes relating to patients' experience of PDC and the data therein. When I had identified two or three key experiences that I believed to have validity in both settings, I sought to establish links between these experiences and substantive codes grouped as "contributing characteristics". The same process of developing working ideas and then testing them was undertaken in relation to the remaining questions. The links that I made between codes were mapped, so that I could see how aspects of the service related to each other until a story emerged, as summarised in Appendix 13. Usually I worked with the data from one service until some pattern begun to emerge. At this point I would revisit the data collected in the other service to assess the degree to which the same pattern was present in that set of data too. Subtle variations within the shared experience were identified as I revisited the detail of the substantive codes related to patients' experience of PDC, in particular any concerns and issues that

were identified in relation to each service. The main substantive codes derived from the data collected in DC1 and 2 and their contribution to the emerging proposition of PDC as a community are described in Appendix 13. As the data were being analysed, reference was also made to the literature to explore aspects of the emerging interpretation, the process of analysis and a review of the relevant literature informing each other. The process was, at times, messy and subjective in nature, drawing explicitly on my experience of being part of PDC as well as data collected directly from patients. This according to Fontana and Frey (2000) is the nature of interpretation of this kind of data.

4.13. Summary of the chapter

This chapter has described the way that I conducted the research and the rationale for my decisions regarding this process. It provides details of the theoretical tenets of the research, how the research was conducted, and practical and ethical issues that I faced once the processes of data collection and analysis were underway. The importance of the chapter lies in helping the reader know how the findings described in the remainder of the thesis were arrived at, to enable assessment of the quality of the research. The following two chapters describe the joint constructions of DC1 and DC2 respectively. Chapter 7 describes the proposition regarding PDC based on the data collected in DC1 and 2 and Chapter 8 places this in context of the literature.

CHAPTER 5

DESCRIPTION OF DC1

5.1. Introduction to the chapter

This chapter describes DC1, a service that purported to provide a social model of PDC. It comprises three main sections. The first is an introduction to the service, its patients and those involved in providing the service. This is included to place the service in context. The main body of the chapter describes DC1 from the perspective of those using it. As such it provides detail of the joint construction of the service, developed by users of DC1 through a hermeneutic dialectic process. User views of DC1 are supplemented by information provided from other sources when this aids understanding of their viewpoints. The third section provides comment and discussion regarding the joint construction, based on the research questions that have guided the research.

5.2. Introduction to DC1

5.2.1. Introduction to the service

DC1 was part of a National Health Service hospice serving a population of approximately 800,000 people. Its services were comprehensive and specialist in nature, spanning inpatient, community, hospital based and bereavement provision. In addition an education centre linked to the hospice provided local, regional and national courses related to palliative care provision. At any one time the hospice would be looking after approximately 400 patients, of which approximately one-tenth would be attending DC1. Despite being based in the hospice, DC1 operated quite separately from the rest of the hospice most of the time. Input to DC1 by members of the wider hospice multi disciplinary team was rare, visits made to the service from this team numbering less than one a week for the period of the study. Similarly, although DC1 patients were usually cared for by the Community Palliative Care Team and could spend time on the inpatient ward, the working interface between the various services was limited. Staff members working in DC1

explained this separation on the grounds that the nature of their provision was quite different to that provided in other parts of the hospice. Those outside the service were unsure how welcome they were in the setting and often avoided it as a consequence.

DC1 had been set up some 20 years previously. Its early aims were concerned with improving the quality of life of patients on the hospice ward by offering diversion through pleasant activities and trips out. These early aims were still in evidence at the time of the study. They were underpinned by an empathic understanding by those involved in providing the service that living with a progressive and life threatening condition could be a wretched experience, and a belief that increased social support might serve to alleviate some of their suffering in this regard.

When DC1 was started, the occupational therapy team based in the hospice managed the service, a situation that continued for the next 16 years. At that point a PDC Leader was appointed and the service separated from the occupational therapy department. The first PDC Leader was a charismatic and visionary nurse who was keen to develop the service. She strove to develop increased awareness of the aims and value of DC1 within the wider hospice multi-disciplinary team and played a key role in developing plans that would increase PDC provision. However she left the service before DC1 moved to its new facilities and her plans to extend the model of care had not been implemented at the time of the study. Her successor had taken up the role some 12 months before the study begun and was in post at the time of the study.

At the point that the research begun the hospice had recently undergone a major capital development programme resulting in the refurbishment and expansion of its PDC facilities. About three months before I began gathering data in this setting DC1 had moved from its previous home in the day room of the inpatient unit to new and dedicated facilities in a separate building. This move represented a significant event in the life of the service and gave rise to a variety of feelings.

Whilst many involved in DC1 were very pleased with the improved facilities and the new opportunities they offered, others felt bereft of the relationship that they had enjoyed with staff and patients on the ward in the past. In addition it had led to some anxiety on the part of the managers of the service who were concerned that the new facilities were under-utilised, given the additional costs of maintaining them. At the time that the refurbishment was planned, it was envisaged that DC1 would expand in terms of the number of days that it was open each week and the scope of its care (hence commissioning this piece of research). In fact plans for expansion were on hold at the time of the research due to lack of resources available to support any new provision.

Other changes that the service faced were presented by the NHS reforms of the late 1990s. The hospice, of which DC1 was a part, was engaged in negotiation with recently formed Primary Care Trusts that would become responsible for purchasing its services and was also acting as a key player in the implementation of the National Cancer Plan at a local level. In DC1, however, there was little evidence of any awareness of these issues and even less regarding their potential impact on DC1 or how the service might contribute to them. A review of the documentation of DC1 indicated relatively little change in the service over the two decades that it had been in existence despite major changes in the surrounding political and economic climate during this period. It appeared that the service was exempt from having to adapt to a changing external environment, but no one seemed certain why this was the case.

5.2.2. Introduction to the patients attending DC1

About 30 patients used DC1 at any one time, spread over the three days each week that the service was open. Most of the patients attended one day a week, although a number would have liked to attend more often if they had been offered this option. Those that did attend twice a week described two quite different experiences of PDC on each visit as a consequence of the unique membership of each day. Most of the users of the service were living at home. One or two patients

at any one time attended from the inpatient ward usually for two or three visits in total.

During the period of the study nearly all the patients were over 60 years in age although the range of ages was great, spanning over 50 years. For some of the younger patients, being with older people was off-putting, particularly at the beginning and served as one of the reasons that patients either refused a place in DC1 when it was initially offered or stopped attending after their first visit. All the patients attending the service had a diagnosis of cancer, reflective of the policy of the hospice. However a proportion used the service for reasons that it might be argued were not directly related to their malignancy, although their diagnosis had accentuated their needs. Patients were referred to the service for three main reasons - social isolation, the need for respite care, and as an introduction to the hospice. Their carers/family members rarely visited PDC and had very limited contact with the service, amounting to no more than the occasional phonecall or note brought in with the patient.

5.2.3. Introduction to the team working in DC1

Three paid staff members were based in DC1 with sessional input from a paid aromatherapist, a paid chiropodist and volunteers. The charitable arm of the hospice funded a proportion of the paid posts. The PDC Leader headed this team. She took a lead in receiving and processing referrals to the service, communicating with the hospice multi-disciplinary team and its managers, and maintaining records and activity data related to the service. At the time of the study the Leader was relatively new in post, and for this reason tended to take many of her cues regarding the day to day organisation of the service from the Activities Organiser. The Activities Organiser had begun work in DC1 as an Occupational Therapy Helper some 17 years earlier and for this reason had an influential position within the service. Her work was concerned primarily with planning, organising and providing the activities offered in DC1, with assistance from the part time Nursing Auxiliary. The Nursing Auxiliary served as a link between the inpatient ward and

DC1, having worked on the inpatient unit for some years previously, and would often encourage inpatients to attend DC1, either for diversion or as an introduction to the service prior to discharge. She had only recently been appointed to DC1 at the time of the research.

Volunteers were a vital component of the team. They included drivers who provided transport for patients and drove the minibus on outings from the unit. In addition two or three volunteers would spend time in DC1 providing companionship to the patients and taking part in activities with them, assisting and encouraging as appropriate. On two of the three days that DC1 was open a further group of volunteers would be available to provide care to patients such as Reiki[6] or manicure. Finally a small number of volunteers provided specialist input to the Unit including help with art sessions. Many of the volunteers had worked in DC1 for a considerable period of time, some for many years on the same day each week. They were deeply committed to DC1 and its aims, and were diligent in meeting their obligations to the service and its patients.

5.2.4. The routine of DC1

Patients began arriving in DC1 at about 10 am. The majority came in from home, brought in by volunteer drivers. As patients entered the building they were met warmly by staff members and volunteers. Patients were offered a hug and kiss before they made their way to the circle of chairs set out in the main sitting room where they began the day. Their driver settled them into a chair of their choice, took their coat and offered them a drink. At this point most of the volunteer drivers left, although they were invited to stay for a drink if they wished.

Patients usually sat in the same place on each visit. As people arrived, the circle began to fill up, its members chatting and laughing with each other. Staff members and volunteers would position themselves around the circle, often choosing to sit

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[6] Reiki has been defined as "a method of natural healing" and "a form of energy healing, whereby the practioner places his/her hands upon the person to be healed" (Herron,D (2004).The Reiki Page. http/reiki.7gen.com/)

next to someone who appeared withdrawn or excluded from the conversation. In addition they would seek out individuals that they knew well, catching up on their news and imparting their own. This time of informal interaction as part of a group was repeated at other times during the day – for example before and after lunch and at tea time before patients went home. In the first sitting, following patients' arrival in DC1, a group of Reiki therapists would offer treatment. They would pass around the circle behind the patients, speaking briefly to patients over their shoulders as they delivered the care.

When everybody had arrived, the activities for the day began. Some days it might take the form of a concert or talk. Alternatively staff members within DC1 would organise a quiz. Patients remained seated as previously within a single circle. As the main activity got underway other services were provided simultaneously. For example patients might be offered a manicure or a foot massage as they engaged in a quiz or listened to a talk. They would also be offered a pre-lunch drink by one of the volunteers. One day a week patients moved into the art room for a creative art session during the morning. They were invited to sit around a large art table and were assisted in their artwork by staff members and volunteers. On occasions this session was led by the artist in residence. Otherwise dedicated volunteers took the lead.

Just before midday the activities would come to an end and patients would chat between themselves as they waited for the call for lunch. When it was ready they would make their way to the dining room, which was set out around a single large table. A housekeeper served out the food with help from staff members. Staff members and volunteers ate their lunch with the patients, people conversing across the table as they did so.

After lunch patients returned to their chair in the sitting room where they were served tea or coffee. One or two made their way to a bench situated just outside the front door or to the inpatient smoking room for a cigarette. Otherwise patients

dozed for the next hour or so or chatted between themselves. Staff members and volunteers would join them, engaging casually those who were interested in a conversation.

At about 1.30pm the afternoon activities commenced. One day a week this took the form of a trip out from DC1 in a minibus to a local attraction. On the other days staff members would arrange relaxation sessions, opportunities for reminiscence or a talk. When this finished, patients would be offered a cup of tea and then they started to prepare to leave. Their volunteer drivers arrived to pick them up, helped them out of their chairs and into their coats and collected their belongings. Many patients shared a hug and a kiss with the staff members and volunteers as they left. They would make their way out to the car with their driver chatting as they did so and waving goodbye to the other patients as they were driven off.

5.3. DC1 according to its patients and their families

According to patients, DC1 offered them an opportunity to relate to others. They could engage in reciprocal relationships that offered friendship and companionship over a prolonged period of time. Attending PDC enabled them to pass time, to feel cared for and supported and to enjoy a day away from home in a pleasant environment. These aspects of the service are described in further detail below.

5.3.1. A place to relate

The most valuable aspect of DC1 according to its patients was the relationships that they established in this setting. Nearly all of the patients identified the contact that they had with others as the most important aspect of attending the service. As such it served to counteract the loneliness and isolation that they were facing. For some, an underlying loneliness that they had lived with for many years had been made quite unbearable once they had been diagnosed with terminal cancer. Others described a new sense of isolation arising directly as a consequence of their diagnosis and their illness.

Crucial to this experience of re-engagement was the opportunity to meet others who had the same complaint. Joanna highlights this in her response to my question about the best thing for her about coming to DC1:

Joanna: Well, it's to come here and meet people with the same complaint…its an eye opener to meet people with other aspects of it and [see] how they cope with it. Everyone always seem to be able to accept their fate in a way, they are philosophical about it…but everyone suffers in some way or another. (FP1.1. Derived from Text Units 412-417)

The common experience of living with a progressive and life threatening condition overrode other differences between the patients. People regularly commented on the value of meeting others "in the same boat" (FP1.4 Text Units 66-67) and "going…the same sort of way" (FP1.5 Text Units 612-613) as a result of their shared diagnosis and prognosis. As such it gave rise to mutual aspirations as Anita, aged 93 years describes, when she explains the bond she shares with Jenny, a woman 50 years her junior:

Anita: (Jenny) is a young woman and I suppose I am the oldest but it doesn't matter……I think we are all looking for the same thing - as normal a life as possible in circumstances that are not normal. (FP1.2 derived from Text Units 162-180)

The shared experience of a terminal, advancing condition provided patients with new support which was often lacking in other settings. A patient called George highlights the value of relationships within DC1, when asked what he valued most about attending DC1. In so doing, he identifies how they differ to those established elsewhere:

George: [It's] meeting new people, nice people. Because some people, family even, may not respond. They may rather not know what is going on. (MP1.1. Text Unit 93-94)

Outside of DC1, people felt isolated as a consequence of their condition. Within DC1 they felt identified with others because of it. Those working in DC1 worked hard to encourage patients to become part of a group, based on their shared experience, some seeing the group experience as the most important aspect of the service. The Activities Organiser, Delia explains:

Delia: Keeping the majority of the day as a group works really well.... I actually think it is the group being together and the support that [the patients] have between themselves and with [the staff] that works. (FS1.1. Derived from Text Units 372-377)

The group that was created in DC1 was intimate in nature. There were rarely more than six or eight patients that attended each day and membership was regular. Despite frequent deaths of members of the group, it was experienced as having a comparatively stable membership. This was achieved through the existence of a small core of members who had attended the service for months or even years. Many of them were highly vocal, visible and influential in the service, serving to dominate people's experience of the service. For this reason their longevity of attendance in this setting eclipsed the loss of others who attended for much shorter periods. In addition the regular input of volunteers and staff on the same day each week contributed to a core consistent membership.

The group experience was facilitated by the seating arrangements in DC1 and its programme for the day, whereby patients, staff and volunteers spent a lot of time seated in a circle. This was large enough to allow everybody a place within it, yet small enough to allow its members to talk across it. When patients moved to the dining room for lunch or to the art room for creative art, this pattern of seating was replicated, all sitting around a large single table in both rooms. During the day there were various periods when planned activity ceased and patients, staff members and volunteers would chat informally to each other. It was an aspect of

the service highly valued in the light of the companionship that it offered its participants and the ensuing camaraderie that developed between them.

Patients quickly became identified with the group of people who attended on the same day as they did, this allegiance overriding any preference to change days, even if a change would have enabled them to gain access to other activities that they would have preferred. A patient called Colin, described this sense of loyalty, making a link between the experience of belonging to DC1 with that of belonging to a family:

Colin: No I wouldn't change [days]....I would feel odd about it because I've been with these people [who come on a Wednesday]. It's not [the fear of] meeting new people because I met different people when I first came. But it's, they feel like a family you know. (MP1.4 Derived from Text Units 183-189)

An important consequence of being part of this group for many patients was the renewed sense of belonging and integration that it engendered. Many of those attending the service felt ostracised from social groups that they had previously been part of as a consequence of their condition, and had become lonely and isolated for this reason. Alternatively they had withdrawn from relationships within which they no longer felt comfortable on account of their illness. In DC1 they could re-engage with people who understood their situation. By virtue of being with others who were similarly afflicted they ceased to feel different. They could feel normal again in this context, on the grounds that the majority of the rest of the members shared their diagnosis.

Furthermore, the group established in DC1 was one in which patients felt safe and protected from people who might respond negatively to their condition. It was as though a boundary had been drawn around the service, which served to limit movement in and out of it. Staff members within DC1 adopted a gatekeeper role

whereby only those who appeared sympathetic to the needs of those attending the service were invited to become part of it, others being denied entry or being asked to leave once their antipathy became evident. I first became aware of this aspect of the service during a concert performed by a new volunteer. It was of poor quality, and identified as such by all present. Furthermore its content was insensitive to the predicament of many of the patients, and its duration unacceptable given the fragility of most of his audience. After he had left, the Activities Organiser ascertained whether others shared her discomfort in relation to the concert and on learning that they did said that she would speak to him and reassured them that the event would not be repeated (Field notes dated 19.12.00). One of the patients described how this volunteer "was trying to build a little empire of his own and wanted everyone to conform" within DC1 but how he "didn't get a chance to succeed". (MP1.3. Derived from Text Units 316-323).

For one or two patients the commitment to the group experience in this setting served to deny individual needs and preferences. I recall, for example, the experience of Jenny, a young woman who attended the service with cognitive problems arising from a brain tumour. She found the quizzes and interactive group activities difficult to cope with as a consequence and felt happier working quietly on a piece of art on her own. On a number of occasions I observed her ask a member of staff if she could go and work in the art room, the response to which was a strong encouragement for her to remain with the rest of the patients. I recall a conversation in which she described frustration at the little say that she felt she had in what she did during her visit to DC1, resulting in a situation where her individual needs were often unmet.

5.3.2. A place of give and take

The relationships that were established within this group were informal, equal and caring in nature. They were often characterised by demonstrations of physical affection between members. Sometimes these shows were quite spontaneous; at other times they were part of a ritual, such as the hugs and kisses shared by staff

members, volunteers and patients that marked the arrival and departure of patients to and from the Unit each day. Patients placed high value on the physical affection that they received in this setting, a number describing a loss of physical contact, even with close family members, since their diagnosis. For one or two people, it was a new experience in their lives and one that they relished.

Those participating in DC1 would often give small gifts to each other, either as an expression of affection, or as a way of offering help. Volunteers and patients lent each other books for example once a mutual interest had been identified. Similarly patients would offer plants from their garden if they knew that a volunteer or staff member was developing theirs. Occasionally a patient would make another a present or bring in something that they knew a fellow patient needed, the value of these gifts enhanced by the shared knowledge of what it would have cost the person to make, find or remember. The experience of presenting gifts or making loans often served to enhance people's self esteem and sense of purpose. Reciprocally, the experience of receiving them was affirming.

This reciprocity was characteristic of the relationships established in DC1. Just as staff and volunteers were committed to caring for those using the service, patients were keen to offer support to their carers in this setting. A patient called Jean, for example, overheard the Activities Organiser talking about a problem she was experiencing in completing an assignment for a part-time course because she couldn't find the information she needed. When Jean left DC1 that evening she went to her local library in search of a book that she knew would provide this piece of information and brought it in the following day for the Activities Organiser. Another patient, Colin, described how he chose to have Reiki as a means of meeting the perceived needs of the therapists rather than his own:

Colin: [Reiki] not only does you good, I think it does the practitioners
           good..... It makes them feel that they are doing something I suppose,
           whereas in my heart of hearts I might think to myself, 'well, I can't see

any sense in this', but I don't want to upset anyone... give it a go, what have you got to lose?" (MP1.4 Derived from Text Units 327-332)

Staff and volunteers acknowledged the reciprocal nature of their relationships with patients, and enjoyed the experience of being cared for in this setting. A letter from one member of staff to the patients at Christmas time provides evidence of the high degree of reciprocity. The letter begins by thanking the patients for bearing with the staff team in the change of venue of DC1, and offers a wish that they feel settled soon. It continues:

> I hope that in some way coming to Day Care has helped you all in some small way [over the last year]. Coming to Day Care is some great way to work [for me]. And it is very, very rare for me ever to wake up with that Monday morning feeling because meeting and knowing you all is a real pleasure and I thank you for making my work such a pleasure. (D.136)

The reciprocity of relationships in DC1 offered patients a new sense of purpose associated with being able to make a difference to others. They were able to care for others, a role that had been frequently erased from their life as a result of their illness and the overriding desire of family and friends to look after them. In DC1 this opportunity extended to those with a formal charge of caring for them giving rise to a new sense of equality in their relationships. Jenny, one of the patients, described this experience and why it was so important:

Jenny: I don't like people feeling sorry for me....[In DC1] we are all on a par, everybody's equal. (FP1.3 Derived from Text Units 609-615)

This parity was often in marked contrast to the relationships patients had experienced with health professionals at other times in their illness, which had frequently left them feeling child-like and highly vulnerable.

5.3.3. A source of friendship and companionship

The relationships developed in DC1 varied in quality and character. For some patients, important relationships were established with particular individuals, affording them new and highly valued friendships. Often this was unexpected, but became a highly cherished component of the service nonetheless. The patient called Joanna highlighted the different sorts of relationships that she had developed in DC1 when she was asked what she most looked forward to when she attended DC1:

Joanna: Well, ..everyone is kind and happy and they greet you nice. And you
            get friendly with people like (Jane) [- another patient]. I must have
            known her for two or two and a half years I think. (Sharon) [-another
            patient] came later but somehow you do sort of make contact with
            some people more than others and I have done with (Jane), more so
            than that with (Sharon) for some reason. (FP1.1. Derived from Text
            Units 149-154)

Some of the patients simply enjoyed the companionship that they experienced in this setting, rather than friendships per se. The variety and number of volunteers and patients in this setting meant that patients could usually identify at least one or two people with whom they shared a common interest, helping them to feel comfortable and engaged with DC1. One of the patients, Dennis, described the value of volunteers for this reason:

Dennis: It's nice to have different types of volunteers [with] different ideas
            because you can find out, you come to realise 'Oh, I can talk to so and
            so about this'. You get to know that you can talk to a certain volunteer
            about a certain thing and then another volunteer about something
            else.....I try and pick the one that I think knows [the subject]... nine
            times out of 10 they do but it has happened that they don't know, [then]

they say 'Oh yes, so and so knows'. (MP1.3 Derived from text units
343-354)

Patients also valued the input of volunteers in the knowledge that they had chosen
to become part of DC1 and offered their services without payment. As a
consequence patients enjoyed a renewed sense of self-value and importance, an
experience that was enhanced when the volunteer was perceived as having an
elevated social status or a particularly fulfilled social life as one patient, Jack
describes:

Jack: You have the odd new person come in like (David) who has come into
           it ....very passionate about the job and you think of his lifestyle and
           you think 'Well, why does he want to come?'. Take (Janet) - her
           husband is an eminent surgeon and you wonder that again. Well they
           come because, of course, they want to be there and if they want to be
           there then they are going to do a first class job. (MP1.2 Text Units
           523-530)

Relationships in this setting were based on a unique set of unwritten rules that
guided how they were formed, conducted, and concluded. Engagement was
experienced as easy, patients feeling welcomed and part of the service almost as
soon as they started attending DC1. A patient called Sharon describes this
experience as she recalls her first day:

Sharon: I was made very welcome there, that's all I can remember and ... fitted
           in straight away. You didn't feel that you were outside because people
           were so friendly up there. As I say we are all in the same boat. So yes,
           ... having gone the first time I didn't come home and think well I can't
           go again. I started from there on in and looked forward to going [to
           DC1]. (FP1.4 Text Units 64-69)

During the period that patients attended the service they were invited to engage in close and supportive relationships. However these rarely extended beyond the service, patients being content to simply see each other for the period they were in DC1. Jack describes this unspoken rule:

Jack: You never hear......of anybody meeting up outside of Day Care. You don't hear anyone saying "Oh I met Marion last night and we went to the pictures" or " We went out together to the Pub" or "We went out as a couple". None of that, it is all Day Care, Day Care only which if you think about it in any other organisation or club that's a little bit strange, not strange, but different.....I never heard anything like that in five years. It was purely Day Care, end of story. (MP1.2. Text Units 249-258)

Furthermore, within the informal rules, a limit was placed on the amount of personal investment made by patients in the relationships created in this setting in the light of the imminent deaths of many members. Jack describes the process of learning to relate in this way:

Jack: When I went to Day Care there was a number of people I met who were smashing people, they really were, and for two or three weeks I got rather involved and made friends of them...I went up there one Tuesday [and asked] "Oh where's (Dennis) then today?" [and was told] "Oh, he went last night" and three more of them went one after the other and I found that very, very hard and difficult to cope with. And I had a period then of about three weeks when I couldn't handle it, I just felt that .... I wouldn't be able to go anymore because I couldn't handle this side of [DC1] anymore and then I thought 'Well, if I don't go, then we are back to square one here [at home]'. So I did force myself to go the next week... and....from that time on I have now learnt to hold myself back [and] I never really made friends.....On the whole

I...[would] keep myself to myself....I just held back. (MP1.2 Text
Units 223-240).

Although he says that he stopped making friends the relationships he developed in
DC1 were important to him nonetheless. This was evident in his sadness when
Jack was discharged from the service, which he assigned to the potential loss of
significant relationships. Like other patients, he described his relationships in DC1
as similar to those within a family, and comments about their loss with this
closeness in mind:

Jack: People in Day Care have really become my friends.... It's a hell of a
           wrench [being discharged] ... because you feel that your friends are
           being taken away from you for no reason, but that's not going to
           happen. I shall keep in touch without a shadow of a doubt and I mean
           that. They are damn good friends. They have really helped us out
           through these last few years. Because we have had someone to turn to
           and that's been important. (MP1.2. Text Units 725-731)

Unofficial criteria existed as to whose death within the group was acceptable.
Patients would consider how well or sick others looked in relation to themselves.
If another patient looked as well as they did, then they were not identified as likely
to die. If they looked less well, then their death was considered more of a
likelihood and accepted on these grounds. When someone died who other patients
had perceived to be similar or in better shape than themselves, this premise was
shaken and the death of the patient was felt to be untimely. The patient called
Joanna describes this scenario in relation to Jeff, a patient whose death she had not
anticipated and with whom she felt identified:

Joanna: (Jeff) used to come in a wheelchair but he was the life and soul of the
           party. He used to come with (Jane) ....and he just had you in fits all of
           the time and then one day he didn't come in - he had died overnight

and I think that shook us all because he didn't even look bad. That's the frightening part of it really because you think 'Well I don't look bad but will I go like that?'. (FP1.1 Text units 124-129)

When patients stopped attending the service, there appeared to be a relatively easy process of disengagement on the part of those who remained guided by another unwritten rule. Patients might ask initially about the missing person, but on hearing that they were more unwell and were therefore likely to die, would stop "remembering" the patient and focus instead on those attending the service. This process was not restricted to patients. Staff would often "forget" to tell people in DC1 that someone had died, their explanation for this being that their energy and application was directed towards providing a good day out for those still attending the service, rather than recalling those that had died. During the time that I observed the service I can recall almost no occasions when there was any discussion about patients who had died. Instead discussion focused on the present patients or past events in people's lives. It was as though there was an embargo on recalling previous patients, or perhaps a decision to forget them at the point of their death.

5.3.4. Somewhere forever?

A common issue raised within DC1 by its patients related to the question of discharge from the service. During the course of the study at least one patient was discharged from the service and it was suggested as a possible course of action to another. For these patients and those who looked on, this action was at odds with their perception and experience of the service. They believed that they had a place within a caring service for as long as they required it, and yet patients were being asked to leave DC1, apparently against their will. Their knowledge of the distress of others who had been discharged had coloured their view of the process, and made them concerned about its occurrence in their lives. Jack recalls the experience of a patient discharged a year previously as he considered his own discharge on similar grounds:

Jack: (Jeff) I suppose, really was the first guy ever [that I knew] that was

hit very very badly when they said to him 'Look, you haven't got

cancer, now, you can't come any more'. This hit [him] very, very

badly, which it did to me in the first instance, when it was said to

me 'The scans have been clear for about three or four years, we are

beginning to think that there is nothing there in the way of cancer'.

Of course, this is what happened to (Jeff), but because [PDC] had

become such a social part of his life, he found it very, very difficult,

and he is still finding it very, very difficult to accept. I spoke to him

[a few months ago] and he is very depressed. He was a happy-go-

lucky sort of guy and he really looked forward to his Tuesdays

(MP1.2. Text Units 386-391)

For Jack, the lack of evidence of advancing disease seemed something of an
irrelevance in any consideration of whether he remained within the service or not:

Jack: [The initial suggestion that I stop coming to PDC] hit me rather

hard. Now it only hit me hard in so far as I - it was nothing to do

with me actually [or] my feelings, it was for [my wife], because I

could see this Tuesday break [that my coming to PDC offers her]

going away. Because nothing had changed in my case, I mean as far

as I was concerned, I may not have..cancer [now] but it was

certainly cancer that caused the problems and that problem [is] still

there. (MP1.2. Text Units 315-325)

The ambivalence that he and others described was exacerbated on the grounds that
the proposal was linked to a review of their condition – a rare event and not one
undertaken for all patients. Furthermore when patients sought information about
the process of discharge, staff members were unclear about the reasons why one
patient may be discharged whilst another was not. The patient called Sharon

describes the experience of learning of her possible discharge, and her associated confusion and distress arising from this:

Sharon: [The Day Care Leader] said "it's six months [since your last review]". I didn't think it was quite six months ago since she took me in the office up there and said 'We've had our usual monthly meeting'… [at which the hospice doctor] thought perhaps I didn't need to go there anymore…Of course the way that it was thrown at me I got quite upset about it….as far as I knew nobody else had been spoken to up there….And then last week…. (the day care leader) approached me again and said 'We are reviewing you, your six months review' and the way that she put it, it sounded as though they were going to assess me as to whether I still needed to go there again…. She phoned me [here at home] at tea time on the Thursday and said … 'I need to speak to you about your six months review'. She said 'I thought I would ring you to give you a week to talk things over with your family, your husband and that' and I said 'Well you know how my family feel about [DC1]…'. 'Oh yes, but I thought I would give you a week to mull it over'. So that was the conversation over the phone, so yes what would you take from that? That they were perhaps reviewing you as to whether you need to go there again…. That day [when] I got so upset ..there…was [another patient] that came out to me, one of the other ladies, and we were talking about it and she said 'I can't understand it because I have been here a couple of years and I've never been reviewed on a six monthly basis', so I really wasn't sure what was going on up there and it was a bit unsettling…And when [my home care nurse] came out which gave me an opportunity to talk…. my husband was in here with me and like he said that's one day of the week he gets four and a half hours off that he can basically do as he likes because now he really has to cope with a lot here. …it all falls down to my

husband to do everything, so like I say [DC1] just gives him one day when he can just think about himself and do what he likes...I suppose in a way I've got reliant on there....I would [also] miss it very much because of the friends that I have made up there...we enjoy one another's company, we enjoy the things we do....

(Derived from Interview with FP1.4. Text Units 78-187)

According to the staff this problem related, in part, to the fact that there was no working policy regarding discharge, even though one had been drafted some four years earlier. The problem also arose from staff members' ambivalence about the process of discharge. In their view discharge from DC1 was rarely appropriate, a stance sometimes at odds with that held by medical consultants who had overall clinical responsibility for patients attending the service.

5.3.5. An important pastime

Attending DC1 was an important pastime for its patients. Many of the patients that I met described a series of losses related to work, hobbies or social activities as a consequence of their illness, which had left them with time on their hands. Others felt that they were biding time until they died and looked for new ways to fill this period. In contrast, for people whose lives were not characterised by loss, attendance in DC1 had little or no value. A lady called Yvonne who discharged herself from DC1 described a full and active social life, some of which she had to forfeit to attend the service. As a consequence her discharge was something of a relief on the grounds that:

Yvonne: "I could go out to lunch on a Thursday [again]" (FP1.8 Text Unit 290)

Patients who attended the service and sought help to pass time placed value on the routine of the service and its activities, as well as the relationships offered within it. These various components of the service lent patients renewed structure,

purpose and hope to their lives, aspects which had often been lost as a consequence of their condition. The patient Toni highlights this need:

Toni: I need a purpose.... Any purpose I've got is stopped by my myeloma, by my body. I used to be very active. I had enough energy for two people and a lot of drive. [Losing that] is quite a bitter pill to swallow. (FP1.5 Text Units 213-219)

The routine of DC1 was an established one, with little variation from week to week. Patients would anticipate with pleasure their time in DC1 in the knowledge of what they would be doing. They enjoyed the structure offered within the day and its constancy. For many these were comforting factors in the light of the many changes and uncertainties that they faced in relation to their illness. Within the routine patients were encouraged to take part in a variety of activities which served as the focus of each day. These offered an experience of being busy reinforced by the language of the unit concerned with achievement and purpose, and the work style of staff members who always appeared to be on the go. For some patients this aspect of the service was highly valued. The patient Anita, for example described, in appreciative terms, her approach to the creative arts session:

Anita: You work, everybody works, there is nobody [that] fiddles. Everybody wants to do something, you see. (FP1.2 Text Unit 512-513).

In spite of the emphasis on activity in this setting many of the patients "did" very little, watching staff and volunteers do it instead. As they did, they lived vicariously through others. They would watch the staff and volunteers involved in activities and in this way share their enthusiasm, energy and sense of purpose.

Talks and concerts were offered on a regular basis as part of this routine. Visiting speakers who were willing to give their time free of charge would provide them. They varied in quality and were often repeated, but patients rarely complained

about this, grateful that the speakers were prepared to come and entertain them. For many, the relationships that they established with the speakers was the most important part of this activity, as the patient Jack indicates in his description of talks he had heard:

Jack: Invariably we would have somebody come in [to speak to us]. We became more friends than I would call speakers. I mean the guy from the Customs and Excise, he came so many times now it was always a good laugh whenever he come. He would say, 'I was going to bring the sniffer dogs up today, but the amount of bloody drugs there is round here, I daren't bring them in here'. There was always a lot of banter and it was all good stuff. (MP1.2 Text Units 469-474)

Whilst one or two patients described the talks as boring, this negative response was counteracted by the knowledge that the Activities Organiser would have gone to a lot of trouble on their behalf to find the speaker. Notably, none of the people who described them as boring considered giving up DC1 as a consequence of their disappointment in this regard. Instead it was simply an aspect of the service that they found more tedious than others and one to be endured in order that they could continue to benefit from other aspects of the service.

The trip out each week was popular with patients, particularly those who found it difficult to leave their house. The trips outs served to broaden their narrowed horizons and were highly valued for this reason. Patients that attended on the days when the trip wasn't available often commented that they would have welcomed an opportunity to go out more. On an occasional basis special trips were also organised from DC1 to a venue that was unusual or normally inaccessible to the general public. Patients enjoyed these very much on two accounts; first, they were aware of the lengths that the activities organiser would have gone to in organising it. Second, they relished an opportunity to experience something new. This was important in the light of the many endings that they faced. A patient called Dennis

recalled with pleasure his experience of having Christmas lunch in a smart local hotel, hosted by DC1:

Dennis: The whole lot was impressive it was. Not having been anywhere like that before in my life. I had never been anywhere like that before. I phoned up my sister from there on the mobile and told her. I said to her "You will never guess where I am ringing you from" and she said "No" and I told her and she said "You jammy whatsit!" (MP1.3 Text Units 538-542)

Similarly a volunteer, Jane, described the experience and thoughts of a young woman called Gill, normally confined to a wheelchair, who was being taken round a harbour in a boat at high speed by a group of Marines:

Jane: [Gill] suddenly thought 'Oh God, I am going to lose my wig' and then [she] thought 'It doesn't matter. I'm having such a wonderful time'. And she got off and said 'I never thought I would do anything like that again….That was great. My life is still, can be exciting and I had given it up'. (FV1.3 Derived from Text Units 95-100)

The outings provided something for patients to look forward to and also offered an experience quite separate from their illness that they could discuss with their families. Professionals familiar with patients' home environments often reported situations where any conversation at home had become focused entirely on the patient's illness and its consequences. Coming to DC1 and taking part in outings and activities gave patients something new to talk about at home, thereby changing this focus.

The creative art sessions offered one morning a week were particularly important to many of the patients in the light of the opportunity they provided to learn new skills. Patients would practice these skills in DC1 and at home, the art providing a

new focus within their lives and filling gaps left by hobbies and jobs that patients
could no longer pursue. The creative art sessions were not competitive and were
designed to accommodate the limitations of individuals imposed by their
condition. Toni, one of the patients who attended the creative art group describes
this approach with approval:

Toni: [DC1] is uncomplicated and very elastic which means that if you're
            not feeling up to it then you can just sit and watch if you want to. If
            you are not feeling energetic or terribly well, then you can just doodle,
            anything is accepted, nothing is criticised. Fair enough, we might have
            a joke if someone has done nothing, but go around in little circles.
            Someone might say 'You've enjoyed yourself today haven't you?'. No
            edge,..no bitching or anything like that at all. No edge on anybody.
            (FP1.5 Text Units 541-548)

As a result people felt comfortable in this context even if they had never done any
art before and were often surprised by what they could achieve. However the
uncritical nature of the activity was, for at least one patient, a patronising and
unfulfilling experience. Yvonne, a patient who later discharged herself from the
service explains:

Yvonne: ...They tend to treat you as if you were five. I'm not an artist at all, but
            I did my bits and pieces [of art] you know, and they would say to me
            'that's lovely!' And I'm not so silly that I can't see what it's like. If
            they'd laughed with me and said, ' You're not much good, are you!', I
            could have taken it better. (FP1.8 Text Units 49-53)

A key benefit of attending these sessions was the diversion from illness that they
offered patients who attended the service. In a letter sent to a local newspaper
where patients described the essential value of the creative art session to them, this
was a recurring theme. One of the letters stated:

We come to these classes because we can forget our cancer for a short while. (Derived from Document 1.40)

Another person wrote:

It is a very safe place to learn art and craft in relaxing surroundings. My artwork…is a learning curve which makes me forget my problems and encourages me to do artwork at home. It has given me more confidence in myself and I have made friends in attending the centre. (Derived from Document 1.40)

This offer of diversion was important for many of the patients using DC1. They were commonly those who were preoccupied by their condition and sought respite from their anxieties in relation to it. George describes this scenario:

George: With these complaints I think you need to keep yourself occupied, if not physically at home, you need to be doing what you can…If for instance you just sit and watch television you start watching something that isn't very interesting…your mind goes off it, and you start worrying about your problem and it's silly, it doesn't do any good at all…..Once you have got [cancer], it is always in your mind….. whereas if you have got flu or you break your leg, you know you are going to get better but when you are terminally ill it is a little bit different but if you can take your mind off things and occupy yourself then it makes a big difference (MP1.1. Derived from Text Units 47-63)

To achieve this time off from anxiety about their condition, patients often chose not to discuss any new problems that they were experiencing whilst attending the service for fear of destroying the opportunity for escape that the service offered. Instead they would wait until they went home to gain access to help, even if this

action resulted in a delay in treatment. As a consequence patients felt liberated from their condition for the period that they were in DC1. I heard one patient comment that she attended DC1 to have a day off from her illness. For many it offered rare time when they were not cast in the role of a sick or dying person – a position from which they often felt unable to escape.

As well as serving to divert attention, the art sessions offered stimulation, something for patients to look forward to and plan for. This element of participation was important for those who felt they had no long-term future to anticipate as a consequence of their condition. The patient called Anita described this changed temporal perspective and the value of creative art in this context:

Anita: Now then, a person such as I am has no future to plan for...there is no point in talking about the future because ....you have got no future to think out or to plan [for]....no future and you become a bore if you are always talking about the past.... so that something [that] kept my brain alert, something new, water-colour ...offered an escape route, let's face it, something that I was capable of planning what to do next week. As simple as that. And you see going home on a Thursday afternoon [after creative art]... you think of all that you have tried to do, where you've failed and where you have managed and you see you have got something in your head that is still alive whereas the future is blank, the past is gone. (FP1.2 Derived from Text Units122-141)

Most importantly it enabled her to reinstate aspects of herself that she felt had been lost:

Anita: [In this setting] I wasn't just somebody to have their bottoms wiped and to be kept clean. I still had a brain. (FP1.2. Text Units 82-83)

In addition to these planned activities, DC1 provided something quite unintentional for its patients. The patient Toni, for example, described how she would use the activities provided within DC1 to vent her frustration associated with her illness. This was achieved as she "cocked a snook" *(FP1.5 Text Unit 137)* at those in authority, usually without their awareness. She recounted one particular art session in which patients were being encouraged to do collage. She described her approach as "carnage" instead, and described how she used the shavings and other bits of rubbish that she found in the trays rather than the sequins provided to develop her picture. She called her picture "Waste not, want not" and drew quiet pleasure from the responses of staff and volunteers who were complimentary about her work, and apparently unaware of her sense of anarchy in its development and presentation.

5.3.6. A place of support and care

Patients attending DC1 described a positive experience of feeling cared for. The sense of being cared for was a consequence of belonging to the Unit, rather than the receipt of specific elements of care such as bathing or dressings. In belonging to DC1 patients felt that they mattered to others involved in the service. This was reflected in a comment made by the patient Anita who described the essence of the service as being the fact that:

Anita: There is always people here to greet you....They are always
            there.....they are always there. (FP1.2 Derived from Text Units 307-
            314)

Her sentiment was reflected in a comment made by a staff member who suggested that the core of DC1 was:

Michelle: The care, just that you care. (FS1.2 Text Unit 393)

How this care was provided was a finely balanced act, reflective of the seemingly paradoxical needs of the patient. Although patients were forced to face new and increasingly debilitating aspects of their illness, they craved normality and an opportunity to forget that they were ill. In the majority of cases these requirements were met. Patients described care that was alert and insightful to their "real" needs whilst at the same time allowing them to maintain a façade of normality. One man described this approach at the point that he arrived in DC1:

Colin: When you walk in .., these women and nurses are shrewd enough to know how you are, they are able to spot you coming out of that car or you come in the door and its 'How are you?' and you say 'Oh, well, I'm like I am' and sometimes they turn around and say 'You aren't all that smart are you?', so they can tell, whether you are... well not playing a blinder with them but being more conservative with the truth than you should be. But I think if you come in and say 'Bloody hell, I feel terrible' it makes everybody, it drops them straight away doesn't it? (MP1.4 Text Units 528-536)

Similarly staff members and volunteers assumed different roles in relation to the individual patient depending on the patient's needs at any one time. The patient called Dennis described how staff shifted between treating him as a friend "pulling your leg and having a little joke" (MP1.3.Derived from Text Units 214-219) and responding to him as a patient that might look to professionals for help - "There is the more caring side of them...they try to look after you" (MP1.3. Derived from Text Units 214-219). He approved of these different approaches on the grounds that he felt cared for when he felt low and vulnerable, whilst also having the opportunity to have fun when he felt stronger. Other patients shared his approval and became part of this spectrum of care, moving between harmless banter between themselves to spontaneous displays of support and compassion when a fellow member appeared to be suffering.

This sense of being cared for was enhanced by the provision of services that were additional to what patients expected from a healthcare setting. The offer of Reiki, massage, hairdressing and manicure in DC1 were such services. These were described as "added extras" by one patient (FP1.1. Text Unit 158), and "the things that people really want" by another (MP1.2 Derived from Text Units 617-619). As a consequence of their provision patients felt cared for, pampered and special without undue attention to their illness or symptoms.

5.3.7. A day out from home

A valued aspect of the service was the day out that it offered its patients. Many of them were imprisoned in their homes by the debilitating nature of their condition and were only able to come to DC1 because transport was provided for them. The patient Sharon describes such a scenario, within which the trip to DC1 served as the only regular opportunity for her to leave home:

Sharon: I don't go out very much unless my daughters take me because I can't go on the buses any more and if I go long distances I have to take my wheel chair which you can't on the buses. So really I am tied to the house and you know it is one day a week I really look forward to going out - and the fact that transport is supplied- we haven't got a car and haven't ever owned a car because we don't drive, so... I really look forward to going up there. (FP1.4. Text Units 156-162)

This experience of imprisonment had important implications for patients and anyone caring for them at home. Referrers to the service repeatedly described occasions when they were faced with families at risk of breakdown as a result of the impact of the illness on life at home, demanding that patients and their families had time away from each other. They would seek a place in DC1 for these patients to give family members a break from caring, and patients a break from home and those that they lived with.

Some of the carers that I met during the course of the study described an enormous sense of burden in relation to this role. They felt responsible for managing, not only the physical needs of the patients, but also their complex psychological and social ones. Carers described a pressure to compensate for the reduced opportunities in the sick person's life, such as getting out, finding new interests and meeting new friends. One carer described candidly the challenges of this role. He described it as a "job", concerned with "managing [his wife's) week and life to get the maximum quality out of it" on her behalf (MC1.1. Text Units 341-343). He talked about the importance of trying to balance meeting her needs within limited resources, including those arising from his own needs and limitations. For him and other carers, seeking respite from care of their loved one was an experience accompanied by guilt and some shame. For this reason, it was important that the patient enjoyed their time away from home and was looked after in an environment that was caring, nurturing and safe.

Some patients were aware of the demands their illness placed on their family members and for this reason valued the chance to come to DC1 on the grounds that it reduced their own sense of burden. Jack, who had attended DC1 for four years highlighted this as the main reason for attending. He recognised that his illness had resulted in significant changes in both their lifestyles and he was pleased to attend DC1 in order to give his wife Daphne some time off:

Jack: What (DC1) was doing from square one was giving (Daphne) a one day away from me, a day that I could go [out], she could do whatever she wanted to do with no fear of being phoned or whatever. ...It just gave her space. She has had a life long friend, they used to meet when they finished work and (Daphne) has known her for the last 40 years and so [Tuesday] was her day when she always used to go out with her.... [DC1] allowed her to do that, but it was the only time that we were ever away from each other. As I said, when you go from almost

never [being at home] to always being [at home], her life style had to change as much as what mine did. (MP1.2 Text Units 189-203).

As a consequence he was quite unconcerned about the quality or relevance of the activities provided in DC1, focusing instead on its value in providing respite care:

Jack: Whatever they gave us… didn't matter to me because I thought 'well that's fine, today is good, next week won't be so good, but that vital ingredient of coming away from home is going to be the same'. That never changes. (MP1.2 Text Units 566-569)

A small number of patients used DC1 as part of a larger package of respite care. One woman, for example, needed care 24 hours a day and coming to DC1 was part of this provision, albeit for a maximum of nine hours a week. Both she and her husband were conscious of its invaluable contribution in this respect and as a consequence were anxious about possible discharge. Given the length of her attendance that was in excess of four years, this presented a real dilemma for the professionals working in DC1. They were aware of the needs of this patient and her husband, but also faced questions from other members of the hospice multi-disciplinary team as to whether she should be discharged given the length of her attendance.

5.3.8. A pleasant place to be

The milieu of DC1 was an important backdrop to the relationships, activities and care on offer in this setting. It was experienced as welcoming and friendly, assisted by its homely and informal nature. In this setting neither the staff nor volunteers wore uniforms, although elements of a clinical setting were evident such as height adjustable tables and footrests, similar to those that might be found in a hospital ward. Patients were untroubled by this and for some the reminder that they were attending a hospital-like service was reassuring. One of the patients George was a good example. He suffered from distressing panic attacks associated with feeling

breathless and had become increasingly frightened to leave his home for fear of being separated for any period of time from his oxygen supply. When he was invited to start attending DC1 he was anxious as to whether he would cope, and only came in the knowledge that skilled medical help was at hand. However, like many of the patients that would only come to DC1 in this knowledge, he never actually sought or needed this help whilst attending the Unit.

The atmosphere of DC1 was an optimistic one, even when people felt unwell. They were buoyed by the attitude of all involved in the service who were committed to making the best of their situation, at least for the period that they were in DC1, and they would contribute to this by making an effort to minimise their own distress. The patient called Anita saw the optimistic environment as one of the most valuable aspects of the service given her need to forget her illness and its consequences, at least for the time that she was in DC1. She believed that patients played an important part in creating it:

Anita: The attitude of everybody is so positive, there isn't a negative attitude amongst the people in there. There's nobody tell you how poorly they felt even if they have felt poorly. It's positive, that's the word to use about a place like this..It's got to be positive. You mustn't look at the scars. (FP1.2 Text Units 342-345).

Similarly staff were committed to ensuring a light and cheerful milieu. One member of staff commented to me that her main criterion for evaluating the quality of DC1 on a day to day basis was whether she felt that the patients were happy. The use of humour in this setting was characteristic of the service, the jokes often derived from an effort to redefine elements of illness when it was impossible to ignore them, so that they became amusing rather than tragic. The patient called Jack valued this approach as a means of managing his symptoms:

Jack: When you are trying to fight the disease you fight it whichever way you feel you are able to. To have to sit down and listen to someone

else about a bad night, or that the [painkiller] didn't work - I don't think

I wanted that…..The big thing about Day Care as far as I was

concerned was that people laughed at their disease. Not many people

were in tears at Day Care, they always laughed at their

symptoms….That's how people are. When they lost their hair through

treatment etc. it was always a laugh: 'What are you wearing a wig for?

You don't half look stupid in it'. No body minded, no one took any

notice of it. (MP1.2 Derived from Text Units 626-650)

This positive and light-hearted environment offered relief for patients who sought
escape from fear about their condition. This was particularly true for patients
attending from the ward who were terrified by the images of serious illness, death
and dying that they were confronted with in this setting. One such patient called
Deidre articulated this as she described the value of DC1 for her:

Deidre: It was nice to get out of the ward for a little while….[On the ward] I

             see a couple of patients very ill and I used to sit and think 'Well, that is

             going to be me one day' (FP1.7 Derived from Text Units 28-35)

However, whilst there were attempts by all involved in DC1 not to dwell on their
illness, it was a regular item of discussion particularly on an informal basis. The
key to this apparent paradox lay in the fact that patients were in control of the
decision about whether they chose to discuss their illness or not. One of the
patients called Toni explained:

Toni: I think [DC1] is a good way to escape 'the big C', because out there in

            the wild, there is a morbid aura around cancer……You can get away

            from that [in DC1] because…you can say how you are feeling

            today….And it is accepted if [you] want to talk, and if [you] don't want

            to [you] won't. (FP1.2 Derived from Text Units 613-622)

The "Big C" as Toni described her condition was one which gave rise to a variety of reactions in people when they became aware of it, many of which she felt were negative and destructive. She talked about the distress that her cancer caused in those that were close to her and the distaste that it gave rise to in others. In DC1 she felt that she did not have to worry about people's reactions or defend herself in relation to them. Instead she found a new sense of safety in the knowledge that people here could cope with her condition and would take their lead from her as to whether she wanted to discuss her illness or its consequences. For many patients this gift of autonomy represented a significant difference between life in DC1 and their experiences at home, where issues concerned with their illness were dominant in any discussion.

The uplifting nature of DC1 was facilitated by the lack of attention to people's disabilities in this setting. The physical layout of the service helped in this regard. All facilities were easily accessible to people with relatively little help and when assistance was required it was offered in a way that was unobtrusive and unremarkable. Furthermore within this context, many of the problems experienced by particular patients were common to many, effectively making them unexceptional. As a consequence patients were able to feel normal again.

The pleasant and optimistic atmosphere of DC1 was noted by referrers who would use the service as a gentle introduction to hospice care for some patients. Whilst their aspirations in this regard were often met, in that patients quickly settled in this setting and appeared less frightened by the prospect of a transfer to the inpatient unit in the event that their condition deteriorated, some patients did not see referral to DC1 in the same way. Many that I talked to described their initial contact with the service as highly disturbing as it forced them to face the fact that they needed hospice care and as such were terminally ill. The patient called Joanna described her first day, highlighting her shock at finding herself in this setting, surrounded by people who were terminally ill:

Joanna: I was just in a state, crying all the time and then I was physically sick
            and I just didn't know what I was doing here. I could not believe that **I**
            was here, this place had a reputation that you go in and never come
            out….. the actual fact that **I** was there…And seeing all these other
            people….. other people looked so much more ill. (FP1.1. Derived from
            Text Units 40-55. Emphasis added to reflect the style in which this
            comment was made)

However this experience improved, and Joanna was quickly able to identify some
of the benefits of attending the service. She goes on:

Joanna: But as time went on I just looked forward to Wednesdays every week
            and I like coming and it has really opened my eyes to see…. As time
            went on you get to know other people. (FP1.1. Derived from Text
            Units 59-66)

Introduction to hospice care via DC1 also had value for relatives in the event that
admission was required. The husband of a young woman who attended DC1
describes the difference that attending DC1 made to their experience of being
admitted to the hospice inpatient unit:

Husband: We've had I would say about …four major crises, that is 'this is an all
            night vigil from which (my wife) might not be there in the morning'.
            Three of those have been at (the hospice) and it can't be understated
            that they are very traumatic. And its been much better in [the hospice,
            than the general hospital] because you are surrounded by all these
            friendly faces…you get to know the people you see in Day Care. And
            when [my wife] recovers and rallies around, whilst she is staying
            in,[she can] slide into Day Care at the same time during the week
            which aids recovery. (MC1.1. Text Units 74-81)

5.4. Comment and discussion

My view of the emerging construction was offered to participants for their comments as part of the hermeneutic dialectic process and either incorporated into the joint construction, reviewed or rejected according to the participants' response. My thoughts regarding the joint construction that participants agreed with are described in this section, based on the research questions guiding the current study.

5.4.1. The nature of DC1

DC1 was essentially a source of social support. This support was offered in the form of a group to which people with progressive and life threatening conditions could belong. It comprised patients who shared this condition and professionals and volunteers who were committed to their care and well being.

The provision of a group in this setting reflected the belief of those working within the service that being part of a group and the relationships and experiences therein would improve the quality of life of its members. It guided decisions about the activities provided within DC1, the use of its physical facilities, the routine of the day and how care was delivered. For this reason activities were collective, the arrangement of chairs was circular, the facilities used in DC1 were those that were communal in nature, and the routine concerned with providing opportunities for patients to interact informally. Any care that was available in DC1 was offered to patients as part of this group. Rarely would anyone be seen on a one to one basis outside of the group even if the care was intimate in nature. In these instances the therapist placing more importance on patients being part of the group than providing the treatment in a private area. Patients actively contributed to the life of the group and helped to perpetuate it on the basis that it met many of their needs. They derived particular value from the relationships that were established within it and their identification with the other members.

The group itself was bounded. This served to restrict movement in and out of DC1 and in so doing, preserved the experience of safety within the service for its

members by keeping those who could not relate to people with terminal and advancing conditions outside of the service.

The empathic relationships of DC1 were ascribed great importance by users of the service. They were experienced as accepting, caring and equal in nature. However, they also served to offer the service a complexity. For example patients were reluctant to be discharged from DC1 even if discharge was offered on positive grounds of remission or cure from serious illness because it represented expulsion from the family. Similarly, the identification of members with each other resulted in a lack of regard for any formal boundaries in their relationships.

The activities, particularly the creative art sessions and trips out served to broaden the narrowing horizons of those facing a terminal illness. The activities and care offered in this setting were finely balanced to accommodate both the aspirations and limitations of the patients. When the balance went awry or patients were pushed beyond their ability, many of the benefits of DC1 were lost. Staff and volunteers usually achieved this balance as a consequence of their close relationship with those using the service, which gave rise to a tacit knowledge of what patients required from the service. As such plans for care drew little on formal policies and procedures and more on what individual staff and volunteers felt to be "right" in the circumstances.

The relationships and activities offered within DC1 were enhanced by the homely and undemanding milieu of the service and the practical support on offer in this setting. For example, the lifts offered by volunteer drivers to patients served to make the service accessible to those who would have otherwise been unable to attend.

5.4.2. The value that patients placed on the service

Patients using the service were very positive about it in the main. In joining the group that existed in DC1 they could anticipate a day out from home in an upbeat

and homely setting where ill health was denied a prominent position. They were given an opportunity to experience life, albeit for the short period of time that they were in DC1, as they had known it in the past. As such they felt liberated from the imprisonment in their homes imposed by their illness, they could feel optimistic again and were able to deny the reality of their terminal condition. They could meet others who understood their predicament and engage in activities which were absorbing and stimulating. In addition they could experience renewed autonomy regarding their illness and its management. As a consequence of attending DC1 patients experienced a sense of purpose, they enjoyed new goals and aspirations, a renewed belief in self and a sense of belonging. In this setting they were confident that skilled care was available to them if they required it, but in the meantime they could enjoy time off from their illness and a belief that they were normal again.

The few concerns expressed about the service related to the lack of attention to individual needs of patients and the limited access they had to other specialist services. It would seem that the emphasis on providing a group experience in this setting could serve to deny the individuality of its members. Patients who found this particularly difficult were those who were keen to pursue individual interests whilst attending the service. One or two patients also raised a concern regarding the limited opportunities afforded to them to identify specific goals for their care and review their progress accordingly. The patients who identified this shortcoming were those who still sought improvement in their condition.

5.4.3. The needs met in patients and their families by the service

DC1 addressed a major need in its patients – that of a disintegrating or lost social network within their lives. Its users were people whose social support had been shattered by the knowledge or experience of having a progressive and life threatening condition. They were commonly people who were socially isolated and felt imprisoned in their own homes. For many, their illness was a dominating influence in their lives, leaving them preoccupied and anxious. Some of the patients felt that they had outlived their expected lifetime and were now simply

biding time until they died. In this event they had disengaged from relationships of value and felt that family and friends had disengaged from them. These people looked to DC1 to help alleviate some of their loneliness arising from this situation.

It is notable that patients' carers received relatively little support from this service, evidence for which lies in the relative lack of comment within the joint construction regarding the role of DC1 in meeting the needs of this user group. With the exception of providing limited respite care, there was no attention to the remainder of their needs. This was highlighted by carers as a limitation of the service. It is also notable that patients' other needs such as physical symptoms of their illness were rarely addressed in this setting, patients seeking help from other sources for problems such as these.

5.4.4. The consequences of attending the service for patients

As a consequence of attending DC1 patients could redress the losses experienced in their social lives arising from their condition. They could reconnect with people and in so doing feel engaged at a societal level. This offered an experience of normality - instead of feeling different from everyone else, they could identify with others again. In addition they were able to hold onto some aspects of their self and even rebuild elements that had been lost through loss of purpose and self-value. This enabled them to feel hope again.

5.4.5. How the patients' construction compared with that of other stakeholders

The degree to which the detail of the construction developed by users of the service resonated with the views of other stakeholders varied depending on their relationship with the service, and specifically the nature of their interaction with users of the service.

The user construction resonated most closely with that belonging to staff members and volunteers working in the service. This was a consequence of their close

relationships and the empathy established between them. One of the nurses working in DC1 describes the purpose of DC1 in very similar terms to that described by patients in the joint construction:

> [DC1 is about] showing people that they are not the only ones with the illness. The fact that they can meet other people and talk with other people about their illness. The humour, sometimes is hilarious, isn't it and we laugh with them, to let them know that people can laugh with them, not at them, with them. And I think that is very important. That they can come and they can feel that they haven't got to keep talking at home about it but they can come here and talk as freely as they can and I think, if they can come and do that…that relieves a little bit of pressure from home. And to feel that they have got something separate from home for themselves as well. That doesn't involve anybody else in their home or family, that's specially just for them. And it is like a club isn't it. It is like an elite club, you are allowed to come to (FS1.2. Text Units 55-66).

It is notable that the claims of many of the volunteers working in DC1 in relation to the service were similar to those of patients. Whilst volunteers' reasons for enjoying DC1 were different to the patients (arising from retirement, bereavement or children leaving home for example), their reasons for joining the service were similar. Clive, one of the volunteer driver highlights this resonance in his description of what being part of DC1 offers to him:

> [Coming to Day Care] gets me out of the house. It gives me something to do and I meet people (MV1.1 Text Units 118)

Managers of the service that I spoke to identified similar claims for the service on behalf of its users but the relative importance assigned to the claims were different. For example, although managers acknowledged the role of DC1 in providing

diversion for patients from their illness, they did not see this as particularly important. Instead they were keen to see staff members paying more attention to patients' symptoms. They felt that this would represent good use of resources and skills and that it might have a cost benefit for the hospice as a whole by reducing the uptake on other palliative care services. One of the doctors describes his vision for this service:

> Well I think we ought to look at the medical, at a more medical model, although there are all sorts of problems with it and I don't think it would be that difficult to do... I would have thought that is probably what we should look at and providing some sort of service for some of the areas that we seem to have to admit people for like as I say, tapping their ascites and so on. And in some, an intensive review of symptoms. You know we admit some patients for pain control, knowing full well that over the period of time that we are going to be doing it is probably not long enough. If we had a period with somebody coming for day care, and being reviewed and I do feel that there are some areas of pain control which actually require medical input rather than home care, nursing input as well and probably require the kind of supervision that we could provide and I think those are things that we could do well. (MS1.1 Text Units 261-277)

Without this input, it was suggested that the service be offered in a less specialist setting. One manager posed a question regarding the place of DC1 in a specialist palliative care setting, given its current focus on social support:

> I don't really understand how it does fit [into specialist palliative care]. I know it is there as part of our service but why is it different from any sort of elderly care day care facility that is provided in the local community centres? My mother is 79, she doesn't have cancer but she may well like to go to a day care and get lots of benefits which could

be proven to show that it is good for the holistic person at that age.
What is special about this palliative day care [over and above other day
care services]? (MS1.2 Text Units 91-99)

Underpinning their suggestion was a belief that DC1 was a luxury service, an
"added extra". This is reflected in the reported views of the purchasing Health
Authority, according to the business manager of the service:

> [Day-care] is not perceived by the health authority as a priority. It's a
> "nice to have" but nobody is banging on the drum saying "we must
> have day care out there". I mean it's soft isn't it. Its not new cancer
> drugs. (MS1.2 Text Units 58-61)

This viewpoint contrasting strongly with the views of patients, staff members and
volunteers based in DC1 itself who saw it as an essential means of helping patients
cope with their diagnosis.

5.4.6. How the patients' construction of DC1 relates to the literature

The joint construction of patients in DC1 supports many of the existing findings in
the literature regarding PDC. It would suggest that social models of PDC exist, if
this classification refers to the offerings of the service. Even so, DC1's exclusive
provision of social support is somewhat unusual when compared with the services
that have been studied through survey or observation which incorporated other
forms of care as well as social support (Copp et al 1998, Douglas et al 2000,
Higginson et al 2000). Its other characteristics such as size, availability and
reasons for referral are similar to other services studied (ibid.), although it would
appear to provide a much smaller number of places per week per 10,000
population that it serves, than the level identified in the study by Higginson et al
(2000) (0.375 in DC1 compared with 1.77 identified in the literature). It is also
more limited that other services in its support to carers. Its lack of input from a

team of multi-disciplinary professionals may also serve to differentiate it from other NHS PDC services, such as those described by Copp et al (1998).

In terms of patient experience it reflects the research reported to date related to PDC and serves to add structure and process to that reported. It supports the findings of Goodwin et al (2003) who describe how those attending the service valued the opportunity to meet other people as a means of improving their quality of life. In so doing it serves to reinforce their suggestion that future studies evaluating outcomes of PDC need to consider adding items of social contact or support to quality of life measures. The nature of this social contact elucidated in the qualitative element of their study (Goodwin et al 2002) is also prevalent in the patients construction of DC1. Goodwin et al (ibid.) stress that this meant more than just socialising. It meant talking to people who understood; engaging in important relationships with staff and volunteers; enjoyment of the various activities offered in PDC and getting out of the house. Characteristics of DC1 which contribute to this, such as shared experience, a friendly and relaxed atmosphere, time to talk, diversion and something to look forward to are also identified by Hopkinson (1997) in her phenomenological study. The nature of the diversion offered in DC1,which enabled people to forget their illness and feel normal again resonates strongly with the alternative reality described by Lawton (2000).

The experiences of patients using DC1 of having a progressive and life threatening condition are reflective of those described in the literature, in particular those that are negative in nature. Those experiences that were prevalent in the patients attending DC1 included the dominant fear of death, an erosion of self as a chronic and isolating aspect of the condition, feeling stigmatised and that of social death (see Section 2.9.4. of Chapter 2 for more details).

5.5. Summary of the chapter

This chapter has described how patients constructed DC1. According to its users it provides valuable service which offers an opportunity to engage with others, a pleasurable way to pass time, and care and support within an agreeable environment. This provision is highly valued by those whose social network is disintegrating. Comparison with the literature suggests that this service shares characteristics with other PDC services that have been described in the past. This would suggest that the joint construction described in this chapter could be valid in other settings. The degree to which the joint construction is similar to that belonging to DC2 is considered towards the end of the next chapter.

CHAPTER 6

DESCRIPTION OF DC2

6.1. Introduction to the chapter

This chapter describes DC2, a service purporting to provide a medical model of care. The chapter has been structured in a similar way to Chapter 5. The first section of the chapter introduces the service and provides contextual information, the second describes the joint construction of the service as developed by its users, and its final section considers the construction in the light of questions posed at the outset of the research. Within this section, comment is also offered regarding the similarities and differences noted between DC1 and DC2.

6.2. Introduction to DC2

6.2.1. Introduction to the service

DC2 was part of a hospice operating within the voluntary sector, which served a population of 130,000 people. It had been established in the early 1980's and comprised an inpatient unit of 14 beds, an outpatient service and PDC. In addition it had close working links with a palliative care team serving patients at home and in the local hospital, who were managed within the NHS but whose office was based within the hospice.

The hospice prided itself on serving its patients on the basis of need rather than disease category. As a consequence it cared for people with a variety of conditions, contributing to the continuing care of patients with progressive and life threatening illnesses and others needing specialist symptom control. It sought to achieve this through the provision of skilled care and a caring environment as a means of improving their quality of life. It had a clear commitment to serving its local community, the needs of which took precedence over trends in health and palliative care provision in any policy development for the service.

DC2 was an integral part of the care offered by the hospice and as such worked closely with the hospice inpatient unit and outpatient clinics. These services were based in the same building and patients moved regularly between them in response to changing needs. The working interface between the inpatient unit, PDC and the outpatient clinics was an effective one, maintained on a daily basis by a hospice-wide multi-disciplinary team meeting at which current patients and their progress were discussed. In addition the nurses from DC2 provided input to the outpatient clinics, working with a medical colleague from the hospice to assess and review patients using this service.

The integral role of DC2 within the hospice was reflected in its generous share of hospice resources. Development of the service had been supported over the years by the Senior Management Team (SMT) and the trustees of the hospice, who believed it had a vital role in the provision of palliative care for the population that it served, investing in it accordingly. Members of the SMT had a good working knowledge of DC2, the chief executive visiting the service most days and the medical and nursing directors attending the daily multi-disciplinary meeting of which Day-care was a part.

DC2 was founded in the early life of the hospice. Initially it was a small and informal service run from the homes of volunteers who offered patients social support and a pleasant day out from home. Four years after the hospice came into being, a dedicated PDC unit was opened, enabling the service to extend its care to more patients. At this time its emphasis of care remained focused on the social needs of the patients. In the early 1990's a PDC Leader was appointed to the service. According to staff members working in DC2 at the time, the new post holder brought to the post a clear vision of what PDC could achieve and she immediately set about implementing it. She created new posts within the staff team and began to develop a clinical role for the service, thereby facilitating a shift in the model of care from what had essentially been a social club to one that also addressed physical, emotional and practical needs. The numbers of patients using

the service increased dramatically and the changes in staffing levels and skills that she implemented meant that patients with greater nursing needs could be accommodated within the service. The facilities had to be extended physically to accommodate the increased activity, but they remained inadequate, and their redevelopment was part of new plans to extend the hospice. The first PDC Leader left the service a year before the study of the service commenced. However her contribution to the service was still very much in evidence and patients, staff members and volunteers would regularly comment on the impact she had made to DC2 in the seven years that she had been there.

6.2.2. Introduction to the patients

DC2 looked after about 70 patients at any one time, which represented about a third of the total number of patients under the care of the hospice. The service was open five days a week, accommodating between 15 and 20 patients a day, expanding as necessary to meet new demand for the service. As a consequence there was no waiting list for the service during the period of the study, even if demand for it was high.

Patients' pattern of attendance varied according to their reasons for using DC2 and their personal preferences. Some patients attended one, two or three days a week, whereas others attended only fortnightly or monthly. On occasions a patient's attendance in DC2 would vary from week to week to accommodate specific needs. For example one of the patients that I met, normally attended the service two days a week but had started to come each day the service was open for a period of a month following the death of his wife. This amended pattern had offered him additional support as he struggled to cope with his bereavement.

The majority of patients attending the service were 70 years or older. A minority were in their 40s, 50s or 60s. All the patients that I met during the course of the study, except one, were white. Ninety percent of the patients using the service had a diagnosis of advanced cancer. The remaining ten percent included people with

conditions such as motor neurone disease, multiple sclerosis and multi-system atrophy.

Patients were referred to DC2 for two main reasons. The first was for social support in the face of social isolation. The second was for ongoing surveillance of the patient's condition, and treatment of new problems as necessary. Patients referred for this reason were usually those who referrers identified as likely to experience additional problems as their disease progressed. In addition patients would sometimes be referred to DC2 as a means of providing respite care for their family carers. However this was usually a secondary rather than a primary reason for attendance.

Patients attended the service for variable lengths of time, most people only ceasing to attend at a point when they became too unwell to come to PDC, or after their death. A small number of patients discharged themselves after one or two visits on the grounds that PDC was not for them. Nearly three-quarters of the patients using DC2 at the time of the study had attended for less than a year. However, there was a small core of people who had been coming for much longer, some in excess of 10 years. In addition there were a small number of people who used the service on an intermittent basis just for one or two visits. They were well known to the PDC team through the outpatient clinics and would contact DC2 in response to a new problem or the desire for additional treatment. Often they were never placed formally on the books of DC2 although staff members were committed to extending care to them and would accommodate them in the service to achieve this.

6.2.3. Introduction to the DC2 team

Five staff worked in DC2, the team comprising a PDC leader, two staff nurses, a PDC helper and a nursing auxiliary. The PDC Leader was a senior nurse who had been appointed approximately one year before the study began. She oversaw the work of DC2 and liased with families, colleagues working in the hospice and the

community on behalf of patients receiving PDC. She was also responsible for producing management information regarding the activity of the service. The staff nurses provided a variety of clinical procedures for DC2 patients including venepuncture, intravenous treatments, blood transfusions and dressings. In addition they and the PDC Leader would provide nursing input to the outpatient clinics which were also attended by a hospice doctor. The nursing auxiliary working in DC2 was responsible for bathing patients who attended the service. Usually these patients attended for other reasons, but on assessment help with bathing was identified as a need, which DC2 then sought to provide. In addition the nursing auxiliary co-ordinated patients' food requirements with those working in the hospice kitchen and would assist the PDC helper in her work. The PDC helper was responsible for organising the activities in DC2, helping patients to participate in them and supporting the volunteers who contributed to these activities. All the staff members, whatever their role or grade took responsibility for reviewing patients' conditions and identifying any new needs or problems that they were experiencing. This was done as they went about their work - during informal conversations, by watching patients interact in DC2 and listening to the comments of fellow patients, volunteers and family members. If new needs were identified then action would be taken, usually by the PDC Leader or one of the staff nurses to formally review the situation to identify additional help required to alleviate the problem.

In addition to the staff team attached to DC2, patients attending the service also had access to the wider hospice staff team comprising medical staff, professions allied to medicine, counsellors, chaplains and a care manager. These professionals tended to become involved in the care of the patients at the request of the PDC staff in response to a specific problem or need. However, such was the layout of the hospice that they would often pass through the Unit as part of their daily routine and on talking to one of the patients might notice a new problem and initiate some involvement on these grounds.

Volunteers played a major role within the service, usually helping at a practical level. Many of the patients were driven into DC2 and taken home by volunteer drivers. In addition volunteers working in the Unit provided beverages and helped with meals. A number of volunteers provided a "pampering service" that included manicure, hand massage and make up services each afternoon. Others provided art classes, aromatherapy, or musical recitals. Within the service, volunteers were encouraged to work as active members of the care team, noting any changes in the patient and communicating any anxieties that they had about individual patients to the staff. In turn staff members took their comments seriously and acted on them. The PDC team would often rely on volunteers to take messages to and from the families when they collected or dropped off patients at home.

6.2.4. The routine of DC2

DC2 began at 10am each day when patients would begin to arrive and make their way to the main sitting room of DC2. Most patients were brought in by volunteer drivers, either in the volunteer's own car or one of the adapted vehicles owned by the hospice. Others drove themselves or were brought in by relatives. They would be met by volunteers, settled in the sitting room and offered a drink. As they waited for others to arrive, the patients and volunteers would chat between themselves. Sometimes they would embark on the crossword which the PDC Helper had prepared beforehand. Alternatively they might start work on a painting, drawing or piece of needlework that they were completing over a period of weeks which had been put out, in the seat that they normally occupied, in anticipation of their arrival along with any materials that they required. Some of the volunteer drivers joined the patients in the sitting room for a cup of coffee before driving home.

At about 10.30 am. the staff team would emerge from the office where they had been having their morning meeting. This was the forum at which they discussed patients they were expecting to attend the service and their various requirements for care. The staff members would make their way towards the patients, chatting

and laughing with people as they did so. The nursing auxiliary would make her way slowly and systematically around the group kissing each patient and saying hello. The staff nurses would set about their work organising the clinical treatments required. The PDC Helper would approach those preparing for the art session, whilst the PDC Leader approached individuals whose condition the team had decided needed review during the day. In the meantime patients and volunteers would chat between themselves, sharing magazines, photographs, stories about their families and any other news that they had.

The majority of the morning was taken up with a mixture of clinical treatments, baths, and visits from members of the hospice multi-disciplinary team such as the physiotherapist or chaplain. In addition patients would undertake a variety of creative activities which they would leave and return to if they needed additional care. The PDC Helper would identify those who were new or who appeared at a loose end, inviting them to identify any particular creative interests that they had, which they might wish to pursue whilst in DC2. In the meantime she guided, supported and finished off work that patients were in the process of completing, so that they could take it home at the end of the day. The morning would be interspersed by the arrival of regular visitors to DC2 including the hospice chief executive and volunteers working in other parts of the hospice, who would walk around the unit and chat to people who they knew. A raffle was organised, the prize for which was often donated by a patient. At about 11.30 am patients were offered a drink before lunch which was served by the volunteers. Just before midday patients would make their way slowly to the dining area, assisted by staff members and volunteers if required.

The dining area was made to look attractive and homely. Volunteers would lay up a number of small tables to accommodate those expected for lunch. When it was ready, they joined the patients for the meal and were served by the staff members. Lunch was a convivial and relaxed affair. People chatted with each other and the

volunteers sitting at their table. Food was served according to personal preference and any particular requirements accommodated wherever possible.

After lunch patients made their way back to their chairs and many would doze or read for the next hour or so. Others worked on word puzzles or the crossword with help from the volunteers. They were offered a hot drink whilst they did so. At this point the staff team would come together and eat their lunch, during which time they discussed any concerns that they had about patients attending the service. When these existed, they would agree changes to a patient's care package such as an increase in PDC attendance and additional help required at home, to be organised by the PDC Leader and the staff nurses after lunch. Commonly appointments were made for patients to see the hospice doctor, volunteer drivers were mobilised to pick up new prescriptions for drugs, new referrals were made to community nursing teams and additional equipment sought for the patient to take home with them as part of this activity.

Between 2 and 3pm patients might continue to work on their art piece, or they relaxed and chatted in the sitting room. The team of volunteers offering pampering services and massage would arrive and offer their services to the patients, happy to work with anyone who expressed interest. In addition patients with new problems would be invited to see the hospice doctor with a view to changing their treatment or admitting them to the hospice. At some point, the nursing auxiliary would seek out the patients in turn to discuss their food requirements for the next week. As she did so she would chat with them, checking that they had received all that they required from their visit to DC2. At the same time patients attending the outpatient clinic attached to DC2 might be introduced to staff members, volunteers and patients if they were considering attending the service.

At 2.45pm patients were offered another cup of tea. Volunteer drivers who were arriving to take them home sometimes joined them for this. The PDC Leader would walk around, checking that patients were aware of any changes to their care

that had been arranged on this visit to DC2. As patients left the Unit at about 3 p.m. they would say good bye to the staff team, some kissing and hugging members as they did. After they went, staff members would record their progress in their notes, make final phonecalls to colleagues within the hospice and community and tidy the unit in preparation for the next day.

6.3. DC2 according to its patients and their families

Patients attending the service described it as a family of friends in which they could find care, assurance regarding the future, recreation and hope. It enabled them to enjoy a day away from home in a pleasant setting. DC2 also served as a source of support for carers. These are described in more detail in the following section.

6.3.1. A family of friends

Relationships made in DC2 were central to the value that patients placed on the service. Nearly all the patients interviewed spoke very positively about the opportunity to meet new people in this setting and the subsequent companionship enjoyed with other patients, staff and volunteers.

For some patients important friendships were established in this setting, many with fellow patients who used the service. In coming to PDC on the same day each week patients were able to get to know a small and relatively stable group of people, who they looked forward to seeing on each visit. The relationships that they formed were facilitated by the routine of DC2 which allowed for extended periods during the day when patients were able to sit and chat to each other. They were also enhanced by a familiarity that developed between members as a consequence of sitting near to each other every time they attended DC2.

The value of these relationships to those attending DC2 is highlighted by a patient called Rhoda, who was grateful for her condition on the grounds that it had given

her access to DC2 and the relationships therein. For her a lifetime of isolation and loneliness was amended in this setting:

Rhoda: I had no friends before. Not because I didn't want friends but I was, I used to be home with my mum and dad and sort of a home bird. That's why I didn't think I was going to like it up here but of course when I came I thought it was lovely.......I tell you something. Having cancer has enriched my life. It's a funny thing to say but it has because had I not had cancer I would never have met all these people. I would never have come out of myself to be able to talk. (FP2.10 305-315)

For some people the relationships offered in DC2 served to replace those that they had lost as a consequence of their illness. Often patients had withdrawn or felt excluded from relationships that had been important in the past, leaving them feeling isolated and alone. A patient called Steve, described an experience of rejection, which felt particularly painful in the context of small village life:

Steve: I met a chap in the village who more or less stepped off the pavement to walk around me. And I said to him 'it's not catching you know' . I said 'I've got it and I'm stuck with it'. People can't handle it. As soon as someone mentions cancer, then the shutters go up. (MP2.2. Text Units 206-210)

In DC2 this situation was remedied to some degree. People accepted him for who he was and he felt confident of being accepted and valued.

Steve: That is the most important thing of the lot. That you come here and you are a person. You are somebody. You are important. I don't mean that in a pompous sense, but everyone is treated in exactly the same way whether they are nice or extremely bloody

difficult....You matter, you are a person. (MP2.2 Derived from Text Units 261-265)

This patient looked forward to seeing a particular group of people each week who were nicknamed 'The Famous Five' in the light of their attachment to each other. They sat together on each visit and assisted each other according to their relative abilities and disabilities. They were unified in the knowledge that they shared a common diagnosis of advanced illness, giving rise to a powerful sense of camaraderie between them.

This experience was common to other patients in this setting too. They talked about meeting "kindred spirits" (FP2.1 Text Unit 49) and being with those that were "in the same boat" (FP2.7 Text Unit 90) as they described their relationships in DC2. As a consequence of them, they were able to feel normal again, on the grounds that they were one amongst many who shared the same condition in this setting.

The kinship that they felt was family-like in nature. Doris highlights this in her response to the question about what she most valued about coming to DC2:

Doris: I think just coming here and being one of like a family group. Even if you don't see [other members] outside [of the service], at least you are here and they take such care of you and they will talk to you and they simply seem to know when you need to talk a little bit and they are very kind. And I just love it because it is like a family, which I suppose I miss very much. (FP2.9 Text Units 202-206)

For this reason she described coming to DC2 each week as similar to being "at home again - you are back" (FP2.9 357), where relationships were familiar, warm and welcoming.

Another patient called Dave described DC2 as a community. He ascribed value to it on the grounds that many of the other social groups that he had been part of in the past were no longer available to him. This characteristic of the service was identified as he considered the question of discharge from it:

Dave: If I was told that I couldn't come any more I would be devastated because it's a kind of extra community that has been created and to have that happen when you know you are in the later stages of your life is just amazing. You think that you have got to the stage where you have had your life and all your different experiences, social connections and so on are coming to an end, to have this, to come to a place such as this and as good as this is simply amazing. (MP2.1 421-428)

The community he described included staff members and volunteers as well as patients. Patients regularly commented on the equality of relationships in this setting, seeing staff members as friends rather than formal carers. Patients felt that staff and volunteers were "handpicked" for the job (MP2.1. Text Unit 113) and were confident that in the unlikely event that a staff member did not work at the standard expected, they would not remain part of the service. Compassion and concern on the part of the staff underpinned their friendships with patients, based on an understanding of what patients were going through. This empathic response was highly valued by patients as Doris highlighted:

Doris: I trust everybody here and you sort of feel that.... you have got a place of safety to go to who understand and who give you support and even if you break down and cry they fully understand how you are feeling. You can literally be yourself, you know. You don't have to put on a face about it and they know you are frightened, they know you are scared about everything and even though they haven't got it, they have got a lot of experience of it. (FP2.9 Text Units 435-441)

The comprehension by other members of the patients' predicament was key to enabling people like Doris to cope with the news of their terminal condition:

Doris: [Hearing that I had cancer] was a terrible shock naturally because it always is, but they were so kind here and so loving and understanding that it put me at my ease straight away and they couldn't be more caring….I think it does you good [to come here] because all the other [patients] are in the same boat so you have all got something that you can talk about. And although we lose people and its terribly sad at least we can all feel it together and talk about it together, which is a good thing I think. (FP2.9 Derived from Text Units 41-49)

The sense of safety that she feels in this setting was reiterated in a painting, which hung on a wall in DC2 and which had been presented by patients attending the service to staff members and volunteers working in this setting. It served to mark their gratitude for the care that they received, conveyed in a quotation included in the picture which read:

Friendship is the inexpressible comfort of feeling safe with a person having neither to weigh thoughts or measure words

One characteristic of the friendships that patients experienced in this setting was their reciprocity. Patients cared deeply for staff members, and were concerned for them when they were ill or facing difficulties. They regularly brought in gifts for the staff team or their children and were interested to know their lives outside work. Staff encouraged this by bringing in personal photographs, sharing stories about their family life or by inviting members of their family to visit the Unit.

Whilst the relationships of DC2 served as a major contributor to the enjoyment of the service and as such were deeply valued, they could result in a profound sense

of loss when people attending the service died. Steve highlighted this as he looked back on the years that he had attended DC2:

Steve: It's been heart breaking in some ways because you lose a lot of good friends which is very very sad. I.... lost one friend two or three weeks ago.... That really really got to me. (MP2.2 19-23)

Other patients, like Lilian, talked about the fear they experienced as they witnessed deterioration in others, often giving rise to anxiety about their own future:

Lilian: I don't like seeing people very ill, it's upsetting I think when you see the change in them. That's when I feel quite upset, but that's part of life isn't it and you can't ignore that sort of thing. It could be me, it could be any of us. But still. It is just sad for them really. And that can be distressing. The people you see seem quite well and then suddenly they are looking awful. That is an upsetting thing but it doesn't seem to happen too often. (FP2.6 226-233)

Staff and volunteers were aware of these feelings and would amend the DC2 policy regarding news of a patient's demise to accommodate the experiences and requirements of individual patients. The policy stated that patients would only be informed of a death if they asked about the deceased person. However if staff members were aware that two patients had enjoyed a particularly close relationship in the past, they would make an effort to warn the surviving patient of the death of their friend as soon as they arrived in PDC and make time available to comfort them afterwards. They did not wait for news of the death to be learnt from other sources such as the newspaper or the volunteers. In the main, discussion regarding deceased patients was open in this setting, with staff, volunteers and patients acknowledging their feelings of loss. However, this openness was tempered by an unspoken but shared acknowledgement of the inevitability of this outcome and a commitment to look forward, despite the sadness this event generated. For this reason, patients often talked about the loss for a short time after

the death had become known and then moved on, subsequently referring very little, if at all, to the patient who had died.

This effort to move on was assisted by balancing the negative experiences of attending the service, such as the regular loss of friends against the benefits of DC2. Dave explained this process:

Dave: I think we all suffer from losing friends, I have had a very bad time....because we've lost some extremely good friends and that does hit you hard and there is no escaping that at all, but you have got to live with it, otherwise you would end up in the funny farm. It is as simple as that......I think you have got to balance it. There is 99.999% that is good and there might be .01%, but you disregard that. (MP2.2 366-378)

As a result most people continued to attend, only one person that I met during the course of the study choosing to stop attending on the grounds of the death of other people attending the service.

6.3.2.   A source of care for patients

A highly valued element of DC2 was the care that patients received in this setting. It took a number of forms, ranging from highly skilled palliative care to practical support and basic nursing care depending on the patient's needs. This range of provision was designed to reduce the inconvenience and distress associated with having a life threatening condition wherever possible, staff often working proactively to identify and address any new problems to avoid them becoming a dominant feature in the patient's life. On a day to day basis, a variety of treatments and care were on offer in this setting including intravenous drug infusions, blood transfusions, baths and dressings. Social and creative activities took place in the same area, often side by side, an aspect of the service which patients did not appear to find in any way remarkable, as a patient called Daphne suggests:

Daphne: You get not to notice it. I mean when I first came I was having a drip and it is only because my veins are not very good that I now need to have tablets instead of the drip but it is just another form of the same treatment......You just accept it as being normal. (FP2.2 Derived from text units 74-83).

Care in this setting was concerned with a range of needs that spanned those that were physical, emotional, social or spiritual in nature. This approach to meeting the multi-faceted needs of the patient was highly valued by those using the service. The same patient reflects on this aspect of the service and describes how it served her:

Daphne: I think that [other patients] do enjoy coming because it is a day out [as I do], but of course another advantage is that when one comes, there is very discreet supervision sort of medically as well as the people's moods and if there is anything that needs attention, then it will be seen to. For example, a long time back now, when I wasn't so well, I had a very painful heel and it was caused by pressure in bed.... Well I could hardly walk when it came to Tuesday for coming here and so I immediately mentioned it, and I was seen by the doctor and they gave me one of these boots...and it was better within a couple of days. Now that is a very small example, but instead of having to phone up the local medical centre and wait several days before being seen and not necessarily getting a piece of equipment or what one really needs. You see it is so much easier when one comes here with a minor ailment [because] they really cope with everything. (FP2.2 Text Units 281-295)

Practical needs of patients and their carers were also attended to in this setting. For example DC2 would arrange hospice transport for patients to attend hospital appointments even when this appointment was unrelated to the hospice and fell on

a day that they were not attending the Day Unit. Similarly when the hospice doctor prescribed someone a new drug a volunteer driver would often take the prescription to a pharmacy prior to taking the patient home to get it made up if it was known that the patient experienced problems getting out of their house. This particular form of support was vital for some patients whose ability to care for themselves was severely restricted. The patient, Dave, who had motor neurone disease that had affected his upper limb movements highlights this as he comments on the care provided by volunteer 'pamperers':

Dave: The ladies will come and tidy your nails. I need mine done because I can't cut mine you see, so they just wander around and they will look at you and say "Nails this week?" and I'll look down and sure enough, it is time for nails. They have got a knack of knowing when you need the help. (Comment by MP2.1 in the Focus Group. Text Units 76-80)

He was particularly appreciative of this service given that the practical difficulties he encountered as a consequence of his condition were at the heart of his frustration and distress associated with his illness.

In this setting staff members and volunteers worked hard to develop an intimate knowledge of the preferences of each patient. Patients' conditions were assessed on each visit and time was always made available for any patients who wished to talk to staff members about a problem or fear that they were facing. As a consequence, patients felt assured of care that would address any problems that they were experiencing, even if they hadn't felt able to mention them. Dave describes this experience:

Dave: It is the sense of safety, that's the biggest thing for me [in coming to Day Care]. I feel when I come here that if there is any problem I only have to mumble about it and they take it up for you...[here] people are keeping an eye on you. (MP2.1 Derived from Text Units 124-136).

Staff members would tailor their response to individuals according to their knowledge of the patient's personal preferences. I recall for example their care of a patient called Fred who was stoic in the face of his illness and anxious about any changes in the management of his condition. He began to suffer increasing pain, despite changes in his medication and the medical team proposed that he be referred to an anaesthetist for advice regarding alternative pain relief. Fred was reluctant to visit the local general hospital for this appointment and worried about what the anaesthetist might propose. In the light of this, the staff in DC2 arranged for the anaesthetist to assess him in DC2 with the staff from the service present to offer support to Fred during discussion and afterwards.

The care on offer in this setting sought to normalise the experience of illness wherever it could. This approach did not serve to minimise the profundity of the experience; instead it was concerned with lessening its impact on the patient's life. This aim was reflected in the informal approach of the staff members and volunteers to their work in PDC. As a result the skill and expertise of those involved in the service was often understated, although patients were aware of both elements and were grateful for their presence, as described by the patient called Lilian:

Lilian: They don't keep mentioning illness, you don't mention it much to
            them, we feel normal. Your illness is in the background unless you felt
            ill when you could go to anyone. I think that's a nice thing. It's not an
            atmosphere of illness is it? (FP2.6 Text Units 177-180)

However this approach was sensitive to the requirements for care by those who could not ignore the consequences of their illness as the same patient highlights:

Lilian: [Day care] doesn't make you feel like you are on your way
            out...[Those within the service] don't treat you like you are

> fragile…but if you need that help…with people who are really frail
> they are very gentle and kind. (FP2.6 Text Units 516-519)

The confidence that people such as Lilian felt in this setting was reinforced by the knowledge that they would be referred to the inpatient unit for admission if their problems were too severe for them to remain at home. This provision was situated close to DC2 and patients attending the service would often visit the inpatient unit when friends from DC2 were admitted. As a consequence many were familiar with it, and were relatively unworried if the suggestion of admission was made.

The care available in this setting extended beyond the period that patients were actually present in DC2. Staff members and volunteers were dedicated to providing a flexible service for their patients to ensure that their needs were met wherever possible. They were happy to be approached in the event of a new problem even on days when the patient was not attending the service in recognition that the patient's condition could change unexpectedly. During the period of the study a number of patients called into DC2 on days that they did not normally attend the service, seeking help in response to a new and distressing problem. Staff members were highly responsive when this happened, often supporting family members in these times of crisis as well as responding to the needs of the patient. In this event, they would adopt a central co-ordinating role, organising care from primary and secondary care teams as well as hospice colleagues to ensure that the patient could remain at home if this was what they wanted with additional help and support. This co-ordinating role was reflected to a lesser degree at other times too, when staff members noted a gap in the ongoing care package received by patients and believed that their wellbeing could be improved with additional input, which they then sought to arrange.

As a consequence of the nature of this care patients enjoyed a highly attentive and effective service in their view. In addition they felt valued as a consequence of the

attention that they received, and confident that they and their problems mattered to those involved in the service.

6.3.3. Assurance regarding the future

The support offered within DC2 was not only concerned with the present needs of patients, but also those that they might experience in the future. For this reason, patients and their carers were taught aspects of self-care in anticipation of new needs. As a consequence patients in this setting experienced a sense of security about the future, despite it being an uncertain and frightening one. The patient called Dave described how coming to DC2 had allayed his fears related to his anticipation of the next few months, in particular those relating to his death. He felt confident now that he would not suffer in the light of the support offered to him by PDC:

Dave: Once you have experienced time here you realise that if you are in trouble you are going to be looked after. You are not going to suffer any pain, this is the main thing and my only concern really, is pain and the route by which you [die]. That's the only thing that has ever really concerned me and I feel that here you have got so much assurance that you won't suffer.... I don't feel any fears really and to see anybody else in trouble I feel the same thing for them. (MP2.1 Text Units 311-321).

Some patients actively sought a place in DC2 as part of their own plans to manage their future. A patient called Jeff joined PDC as a means of ensuring access to specialist care as his condition deteriorated. He explains:

Jeff: I had realised ... that here [at the hospice] they were the experts in palliative care and I decided that if a time came when I couldn't be looked after at home then I would much prefer to be looked after here where they know what to do properly, and so that was why I wanted to get to know this place... It was just one day in the summer this year,

that a friend was taking us to [the shops] and she said "Would you like to see the hospice on the way?" and I said "Yes please" so we drove in and we just sat in the car and she said "Would you like to go inside?" and I said "OK, I'll just go inside and see if we can get some information" and so that is what happened. I came in and I talked to [a staff nurse] for quite a while and she said "The best thing is to get your name known here, to get on the books so to speak", and so she arranged for the consultation with [the hospice consultant] and the rest flowed from there. (MP2.4 25-39)

Such efforts by patients to prepare for their future was assisted in this setting by the knowledge that they were unlikely to be discharged from the service unless they requested to leave. During this time their needs and care were regularly reviewed and adjusted in the light of any new problems they were experiencing. As such the service was particularly valued by people who were frightened of having to cope alone with their situation. These included patients who had recently been discharged from the inpatient unit and were concerned about leaving an environment where they felt safe, sometimes for the first time. It was also valued by those who had experienced problems in the past and were frightened as they anticipated the future. Dave was one such person:

Dave: [DC2's] given me a sense of security in that I know that I am never ever going to have to suffer the sort of pain that I had right at the beginning because day or night I can always get hold of somebody. There is always somebody at the other end of the phone and I could say "help" and I know I shall get help...... It's a life line. (MP2.2. Derived from Text Units 157-163)

Very rarely, discharge from the service was deemed appropriate for patients attending DC2. I met one such patient during the study. He had been diagnosed with advanced cancer of the oesophagus and was referred to the hospice in the

light of this. However examination 18 months later revealed no evidence of malignant disease. In the light of this it was proposed he be discharged from DC2 and this plan was discussed with him. It was agreed that he be discharged some six months later with reducing levels of attendance during this period to enable him and his family to get used to this change in care. This was acceptable to the patient, although he expressed concern about how he and his family would manage the transition.

6.3.4. A place of recreation

An important component of PDC was the activities organised by the PDC Helper. In the main these comprised art and crafts, the nature of which varied in response to the level of skill, time available and preference of individual patients. Patients would normally work at their own pace to complete individual pieces of work often over a period of weeks or even months.

For some patients, undertaking art and craft work in this setting provided an opportunity to maintain an old interest. This was particularly important for individuals who found it difficult to achieve this otherwise because of their advancing illness. One patient for example had started attending the Unit because it offered him the opportunity to continue painting with assistance, a hobby that he had enjoyed in the past but was finding it increasingly hard to do at home alone. For other patients PDC provided an opportunity for them to learn new skills. Many of the patients were delighted with what they could achieve, particularly when they had not done anything similar before. The selection of activities on offer in this setting facilitated this process. They could often be completed in a fairly short period of time and required little or no skill, whilst still achieving a pleasing end product. One of the patients called Jan describes this experience in her explanation of why she considered DC2 to be a "wonderful" occurrence in her life:

Jan: Well…they teach you things. I mean art. I never thought that I could
              do art and yet I am thoroughly enjoying it. Needlework [that I have

done in the past] was on the fringes of putting a patch on, …not like I am doing now. And things like that which I never thought that I would be doing. It's fantastic. (FP2.3 Text Units 44-47)

Another popular activity on offer in DC2 was word games, photocopied each day from a newspaper. Often patients would share answers with each other and grapple with clues collectively, involving staff and volunteers in the process. For some patients it was important to complete all the games without a mistake; others would attempt the first few clues of a crossword and give up soon after. Regardless, it was a regular part of the routine of DC2 and one that was greatly enjoyed.

Patients could do something quite different if they preferred. For example one patient was keen to undertake "jobs" whilst in the Unit and consequently undertook routine administrative tasks such as sorting moneybags whilst attending DC2. Another patient prepared new files for the medical secretary on a regular basis. Both individuals were keen to make a contribution to the hospice, deriving a strong sense of purpose as a consequence. Rhoda explains the value she placed on being able to help the medical secretary:

Rhoda: I feel that if I am coming here [and] I do that…it's a help. It helps the office and it's something useful…. I would rather have something to do that is useful and I finish, rather than just make something to keep me occupied. I like an end product and I like a purpose to it. (FP2.10 451-457).

Whilst patients were encouraged and supported in learning new skills, there was no pressure for them to do anything if they preferred not to do so. Consequently some patients spent the majority of the day "doing" very little whilst others were involved in a high level of activity throughout their visit. For some patients these

activities combined with the opportunity to engage in idle chat offered valuable diversion from their condition that was otherwise dominating.

Once or twice a month patients were invited to go on a trip from DC2 in a minibus as part of a small group. The opportunity to take part in this activity was made available to those who staff knew could not leave their houses at other times, although the invitation was extended to others if there was enough space on the minibus. Whilst there was only a small uptake for this particular activity from the group as a whole, a number of patients felt that they would have enjoyed more trips out, given how trapped they felt in their homes when they were not in DC2. They relished the change in scene that the trip out offered and its break from routine as Amy describes when she identifies an aspect of the service that she would like to see amended:

Amy: Well sometimes I do wish that they would take us out more often because we don't go out an awful lot. I doubt if it's once a month but that would be nice because I haven't a car so I can't get out and having had polio I can't walk a lot, so I am quite pleased....It's lovely to me if somebody takes me out in the car and we go out and see the sea. ...It was lovely the other week, they took us down to [the harbour] where you could see the shipping... and that was really nice....It gets you out of this environment.....I hate it when people say 'Oh I can't do that because I have a pain' and 'I can't do that'. If you have got a pain you want something to interest you so you forget that you have got one. I don't believe in sitting down to think about how you hurt. (FP2.5. Derived from Text Units 205-216)

6.3.5. A place of fun and hope
DC2 was experienced as a place of fun for most of the people using the service. This aspect of it was created and sustained by patients, staff members and volunteers alike. Staff members were light-hearted in their approach to work,

regardless of the demands it made on them, and their humour was infectious. Patients enjoyed the antics that they engaged in and would often share in their laughter, an element of the service that did not appear to be at the expense of opportunities offered to patients to talk about more serious aspects of their illness or any sadness which they felt. Whether their participation was active or vicarious, it offered patients a sense of optimism as the patient called Doris described:

Doris: Everybody is laughing and going about their work and….you never see anybody getting worried or upset or anything like that. They simply carry on gradually and normally and that makes you feel that you can carry on like that too. (FP2.9 Text Units 365-368)

Some patients made their own fun too, particularly when they had become part of a small group of people who met regularly, staff members and volunteers often serving as the butt of their jokes. This atmosphere gave patients a lift in mood, many describing how this experience contrasted strongly with the oppressive nature of their illness in other contexts. One patient suggested that it was the "little cheeky jokes, this is what keeps us all going" (MP2.1 Text Units 420). This was reiterated by another in his comment that it was "The humour, the repartee [that keeps us alive]. Perhaps we are sometimes a bit coarse [and] rude but it is all good fun" (MP2.2 Text Units 406-407).

When patients felt unable to enter the fun of DC2 they could find peace and solitude here too. There was no demand that they were part of the high-spirits if this did not reflect their mood. When this was the case patients felt able to retreat into themselves, and often found comfort from fellow-patients, staff members and volunteers, DC2 serving as "a haven" in this respect (MP2.2. Text Unit 177).

DC2 was a place of hope despite the gravity of the situation that most patients faced. This sense of hope did not seem naïve and it did not jeopardise the opportunities that existed for patients to discuss any concerns that they had relating

to their illness. Instead it was concerned with ensuring that people lived life to the maximum of their ability and were able to meet their goals wherever possible. In part, staff facilitated the sense of hope that patients enjoyed. The physiotherapist, for example, had a central role in helping appropriate patients to regain confidence and independence as she worked with them to maintain and improve their mobility. Similarly the medical staff would often encourage patients to anticipate the future with confidence as they demystified elements of their illness. Other patients also contributed to this sense of hope by demonstrating that they could cope with situations that were perceived as dire, with the support and help offered by DC2. Patients would derive a sense of perspective from seeing people worse off than themselves and felt hopeful when they were able to witness improvement in others. A patient called Laura described the environment of DC2 as an optimistic one for these very reasons and explained how her hope was derived:

Laura: Well if [Don] is worse off than me and he is still happy then he has still got something hasn't he? Do you know what I mean? He's a good example and a good example to everybody. Because it must be dreadful sitting there. He can't even close his mouth properly. …..
There is not much that that man can do and yet he sits there and waves to you and if he can do it, so can I. I mean some of those people, like [Jan]. I would have given up I think ages ago but she never does which is an inspiration to people like me, who think they might. (FP2.1 373-381)

6.3.6. A day out from home

Coming to DC2 offered patients a day out from home. It permitted patients to leave their home environment on a regular basis, which transpired to be as important for those living with families as it was for those living alone. The transport facilities provided by the hospice, which included adapted vehicles, enabled patients who would have ordinarily been imprisoned within their homes to come to the hospice. The determination of volunteers and staff members to

facilitate a day out for their patients further increased the chance of offering this benefit to individuals, even if they were profoundly immobile. The majority of patients attended for a full day, but a minority only came for part of the day if this was all that they could manage. Staff members and volunteers would work flexibly to accommodate these variable needs and limitations, confident that time away from home was highly therapeutic, even if only for a short period.

Having time away from home was valuable to patients for different reasons. For some, it was the company that they enjoyed during their time in DC2. For others it was the break that they had from members of their family. Still others enjoyed the knowledge that their carers had some time off from caring for them whilst they were attending DC2. For a few it was simply a change in scene from one where they spent the majority of their time and a break to the monotony of their week.

The majority of patients attended on a planned and regular basis, an aspect of the service that they highly valued on the grounds that it provided structure to their lives. Coming to the Day Unit often served as something for patients to look forward to and provided a shape to their week, the patient Dave explaining:

Dave: Coming here provides, it's a highlight. It breaks the week up otherwise the days go on and you don't know whether it is Christmas, Easter, Saturday or Monday. (MP2.1 85-87).

6.3.7. A pleasant place to be

DC2 was a pleasant place to come to, largely as a consequence of its comfortable physical environment and its happy and easy milieu. Staff members and volunteers were hospitable and the routine of Day Care was informal and undemanding, despite some formal elements such as staff uniforms. Patients would seat themselves in various parts of DC2, depending on the degree of company and stimulation they required. Staff would accommodate their preferences even when these were unusual. For example, a man who attended DC2 never came into the

areas formally assigned to the service. Instead he chose to spend the day in the reception area, and would chat to the volunteer on the reception desk as he watched people coming and going from the hospice. Staff members from DC2 would go to reception to find him to talk to and volunteers took his refreshments out to him, rather than expecting him to join the group in the sitting room to benefit from their input.

6.3.8. A source of support for families

Support that was provided by DC2 reached beyond the patient to their families. Relatives of patients would sometimes come into DC2 in search of advice, information or informal support. Staff members and volunteers were highly responsive to these needs, referring them to other departments within the hospice if they felt these needs could be better met elsewhere.

One element of support offered to carers was some time off from the demands of caring, when the patient attended the service. Many of the carers whose relative came to DC2 to enable them to have a day off from caring were ambivalent initially about accepting this provision. In their minds it posed a question regarding the adequacy of the care and they felt guilty needing a break from caring. However, as Janet, Don's wife explains, the pleasant milieu and the benefits of attending served to persuade her otherwise:

Janet: At first, I resented [Don coming here] because I felt "why does he have to go to the day centre, I can do what they can do at the day centre", but... after a little while, Don was so happy at the day centre and it gave him a purpose ...And then I realised that I was benefiting from him coming up here and I felt a lot better, and for three days a week I could do my own thing whilst he was away. (FC2.1. Text Units 40-48)

In addition staff were supportive to patients' relatives even after the patient had died. Often bereaved relatives would come and visit Day Care and were welcomed by staff members, volunteers and surviving patients alike if they did. On one occasion, the Activities Organiser finished sewing a cushion started by a patient who had died unexpectedly, in the knowledge that the patient was making it as a present for the son of her best friend. She later arranged for this friend to come and pick it up in the knowledge of what the gift would have meant to the three of them.

6. 4. Discussion and comment

My views regarding the emerging construction of DC2 were discussed with participants and based on users' responses to them were incorporated, amended or disregarded. The following section highlights those that patients and families/carers felt were valid, based on the research questions identified in Section 4.2.

6.4.1. The nature of DC2

DC2 provided holistic care to patients living at home, operating as an integral part of a hospice service. It was committed to meeting the multi-faceted and myriad needs of people with progressive and life threatening conditions and their families/carers and drew on a wide pool of expertise within and without DC2 to achieve this.

At the heart of its provision was a commitment by all involved to improve the experience of people who were affected by this condition. They believed that this would be achieved by attending to the physical consequences of an advancing illness, by addressing the social needs arising from having a terminal illness and by serving the practical needs of patients and carers related to the disabling consequences of their condition. Emotional needs of patients such as low mood and anxiety were addressed less directly by attending to their other needs. Those involved in the service were highly attentive to changes in their patients'

conditions, meeting on a regular basis to discuss the changes and how best to respond to them.

DC2 served as a family to which patients and others could belong. Relatives and carers of patients were often part of it, as were staff members and volunteers. As part of this family patients could expect to feel affection, concern and commitment from other members. In addition they were able to be involved in the life of the service and were able to care for others within it.

It also served as a major source of help, advice and support for patients as they attempted to cope with the consequences of their illness. As such the service often served as the hub of its patients' care packages. This help was easily accessible, highly responsive and skilled. This reputation gave rise to self referrals of people who were concerned to secure skilled and attentive care as their disease advanced, even if they were relatively well at the time of referral. On occasions this care extended beyond the provision of palliative care to that commonly undertaken in primary care. For patients this was an added bonus, even though it raises a question in my mind about its appropriateness.

Attendance in DC2 offered patients a valuable day out from home. The environment of DC2 was experienced as hospitable, friendly and undemanding, where patients could find fun and comfort. The day out was enabled through hospice transport, even for people who were wheelchair bound.

6.4.2. The value that patients placed on the service

Patients using the service were very positive about it. It served as a central tenet of their care offering immediate help in the event of any problems and security about the future. In addition attending the service offered new friendships, opportunity for creativity, and liberation from the constraints of a progressive illness. Elements that were identified as particularly important to patients were the relationships established within the service which they experienced as empathic,

supportive, companionable and at times inspiring. For some people the relationships evolved into important friendships. Patients engaged with fellow-sufferers, the staff members and volunteers in a reciprocal manner. The service took on a family-like quality as a consequence of these relationships and was highly valued for this reason. Patients also valued the activities on offer in DC2. These were experienced as creative, individualised and highly satisfying. They provided stimulation, diversion and new opportunities. Help was always available to those who were struggling to complete their chosen activity, to enable them to achieve their goals wherever possible. The availability of physical care, including symptom control was important in this setting. Patients felt confident that any new symptoms that they had would be met in this setting given the priority that staff members afforded this aspect of care, their related skills and expertise and their access to other hospice services and personnel in the event that a problem was particularly complex. These various elements of the service were provided in a setting which patients experienced as comfortable and friendly. In addition they were enabled by the provision of practical help, including transport to and from DC2 for those who could not drive.

I heard only a few concerns about DC2 and was not alerted to any issues. Patients explained that the service was straightforward and transparent in its operation. If they ever had any queries about its provision they were able to approach a staff member who would address their question in a way that left no doubt in their minds. If there was something that a patient disliked or disagreed about in relation to DC2 this was addressed by the team as a matter of priority. The concerns identified by patients were far outweighed by the positive aspects of the service and as such were considered relatively unimportant. Given this, patients explicitly requested that attention was not drawn to them within the joint construction.

6.4.3. Needs in patients and their families that the service met
DC2 addressed a variety of needs in its patients. Like DC1 it served to replace a social network of support in people who was disintegrating as a consequence of

having a progressive and life threatening condition. Sometimes the loss of this network had arisen in members of DC2 as a direct result of their illness – either people had withdrawn from them on learning their diagnosis or they had withdrawn from relationships for fear of being rejected. Alternatively this network of support was already weak, and was easily destroyed by the impact of the illness and its and manifestations. As a consequence patients were socially isolated, lonely and felt understimulated.

The service also addressed patients' needs and concerns related to the physical effects of their condition. Patients using DC2 were often people who had experienced physical problems arising from their illness, including those that were highly distressing in nature. Alternatively they were people who were fearful about suffering in the future. For this reason they sought a service that offered regular review of their condition, easy access to treatment and care and assurance that any new symptoms that they experienced would be quickly and effectively addressed.

In addition, DC2 met needs that were practical in nature. In so doing, the service reduced the impact of lost abilities that patients faced. Commonly this loss had given rise to frustration, feelings of inadequacy and an unwanted dependency on a variety of agencies and individuals.

6.4.4. The consequences of attending the service

As a consequence of attending DC2, patients were able to derive pleasure in the present and feel secure about their future.

Their pleasure arose from the opportunity to engage with people who understood their situation, the chance to be involved in a variety of activities and the offer of time away from home. This provision gave rise to a number of outcomes. Patients felt reconnected with other people and normal again as a consequence of being with others in a similar situation. They felt cared for and important as individuals, and had new self-esteem arising from the knowledge that they made a difference

to the lives of others. They enjoyed a sense of purpose, new skills and interests and a focus for their energies and creativity as a consequence of the activities. Being away from home offered a sense of liberation and an alternative experience of the day that they could take home with them when DC2 ended.

Patients' security about the future lay in their belief that DC2 would find any help that they needed as their condition deteriorated. They were confident that the staff members in DC2 were innovative, attentive and skilled in their care, and were certain that if they needed additional care, then they would be transferred quickly and seamlessly to the hospice inpatient unit or specialist community services. They knew from watching others that care at the end of their lives would be sensitive and effective. For this reason many patients felt able to cease worrying to the same degree about what lay ahead, and were able to focus on enjoying the present instead.

6.4.5. How the patients' construction compared with that of other stakeholders

In general there was high resonance between the patients' construction of DC2 and constructions described by other stakeholders, this resonance being most evident in relation to the constructions developed by those working in the setting. This is explained by the close relationships established between patients, volunteers and staff members in which staff members and volunteers were committed to learning the perspective of those using the service as a basis for the care that they provided. They sought to learn how individual patients experienced their illness and what needs it gave rise to, tailoring their approach to the patient accordingly. This was at the heart of the individualised care that was characteristic of this service and at the source of its value for many of its users as the Day Care Leader describes:

> The value of it - that we are able to identify with the individual what
> their needs are really and that is not just to do with symptom control
> [but] the full range of emotional needs, social needs, all those types of

things and....to support them in their difficulties, and just be alongside
but not in their face either (FS2.1. Text Units 7-11)

Similarly, the constructions of DC2 held by managers of the service and those in
senior positions within the hospice, such as the medical and nursing directors
tended to reflect the patient construction identified in the study. This similarity
arose from their close working relationships with the Day Care Leader and her
team who communicated to them the needs and preferences of the patients. It was
also a consequence of a hospice wide commitment to acknowledge and respond to
the individual requirements of patients wherever possible, within which it was
recognised that DC2 had a pivotal role. The chief executive explains:

> Day-care is an integral part of [the hospice]... the in-patients [unit]
> couldn't function without the day-care. So it's not either/or and
> certainly when I am talking to people I always say, and in things which
> we write, I always put that patients are supported in the most
> appropriate way through out-patient, day-care or in-patient care. And
> the fact that the patients may move between the various parts of the
> service according to their clinical needs. (MS2.1 Text Units 137-143)

As a consequence DC2 enjoyed the strong support of senior managers and
clinicians working in this setting. It is notable that even when the construction of
such stakeholders varied from that of the patients, this had little impact on the
organisation of the service, because of the force of the commitment of others to
respond to patient needs and preferences. For example, concern was raised by the
medical director regarding the central role of DC2 in the general care of its
patients, particularly when this care trespassed into the domain of primary care. He
explains:

> I've tried to insist but failed I think that we don't try and take on every
> problem that everybody has, and I have to keep reminding people that

they actually still have GPs and we shouldn't be seeing them for the ingrowing toe nails and all the spots and things like that, that actually that's not our role and it is inappropriate to deskill the GPs.... I don't think that it is a huge problem, but I think it is fair to say that....when I am here by myself far fewer people get seen because [the other hospice doctor] is a bit more approachable whereas I will say "No I am not seeing them today, it is a GP job". (MS2.3 Text Units 237-247)

However, even when it was highlighted as an aspect of the service in which there was not consensus, there was no attempt within the organisation at resolution or change in provision. This was, first and foremost, because it was in keeping with patients' preferences and also because it was not deemed a matter of concern by most primary care teams. As a consequence, this pattern of provision continued, in spite of the views and efforts of what might be identified as a key stakeholder, reflective of the commitment of the service to meet user needs and wishes.

6.4.6. How the patients' construction of DC2 relates to the literature

DC2 shared many of the characteristics of PDC services described by Copp et al (1998) and Higginson et al (2000) in their surveys of other PDC units. Based on their findings, its activities were similar to those provided by other PDC services as was its team composition and its commitment to meeting carer needs as well as those of patients. However the large size of the service is notable, particularly when considered in relation to the size of population that it serves. Compared to the 1.77 places per week per 10,000 population that Higginson et al (ibid.) describes, DC2 provided over four times that number, based on its weekly provision of up to 100 places a week. This generous allocation of places is likely to have contributed to its ability to provide a place for a patient within a few days of referral. It would also have enabled its offer of a place to patients for as long as they required it without consideration of discharge from the service for those who had attended for long periods in a stable condition. The service cared for patients with diagnoses that did not appear to be accommodated by other services

described in the literature, for example multiple system atrophy and multiple sclerosis. Otherwise its proportion of cancer and non-cancer patients was similar to other PDC services included in these surveys.

Although the service purported to provide a medical model of care (PDC Leader, personal communication, 2000), its provision was multi faceted, reflecting a commitment to a variety of needs including those physical, emotional and social in nature. This would support the suggestion of Higginson et al (2000) that PDC is multi-layered rather than unidimensional in emphasis. Its regular provision of blood transfusions, biphosphonate infusions and other similar treatments would seem to differentiate it from other services, if the findings of Copp et al (1998) which suggest that this is relatively rare in other PDC services are still relevant. Its provision of a service for individuals tailored to their individual needs resonates with the service described by Hopkins and Tookman (2000), although the emphasis of care is not exclusively concerned with rehabilitation.

6.4.7. How the construction of DC2 compares with that of DC1

There are striking similarities between the construction of DC1 and that of DC2. Patients in both settings found somewhere to belong, on the basis of their illness. Within DC2 they could meet others who shared their experience of living with a progressive and life threatening condition or were empathetic to their situation. Many patients found new friendships whilst attending the service and derived much that was positive from these relationships. In addition coming to DC2 on a regular basis offered them a day out from home and opportunities for recreation and fun. This provision was available in a setting which was homely and comfortable, but also one in which skilled help was at hand if required.

Patients attending DC1 and 2 reported many of the same benefits. They enjoyed the camaraderie that DC2 engendered between its members, the sense of being cared for and the opportunity to have time off from worrying about their situation. They felt accepted and safe in this setting and enjoyed a new sense of self worth.

Being part of the service offered patients new hope and purpose, despite coming to the end of their lives. Those that placed most value on these benefits were people whose social support was inadequate, which left them feeling isolated at a point in their lives when they most needed to feel in communion with others. Patients using DC2 described many of the same experiences of living with a progressive and life threatening condition as people attending DC1which had led to this isolation including feeling stigmatised, being socially dead and losing a sense of self.

A difference between DC1 and 2 related to the scope of care available in each setting. In DC2, staff members and volunteers were committed to meeting a broad range of needs in their patients, an aspiration which could be achieved as a consequence of the size of the staff team, their specialist skills and DC2's close working relationships with other hospice services. As a result, patients in DC2 could enjoy close attention to their physical and practical needs as well as those that were social in nature. One consequence of this was a sense of security about the future as well as enjoyment of the present. This sense of security was also derived by those attending DC2 from their belief that they could remain part of the service for the rest of their lives if necessary. Many patients in DC1 would have liked the same reassurance, but did not feel confident in this respect. This was not necessarily related to the number of discharges that took place in DC1 compared to DC2. In fact, during the course of the research, there were similar number of patients discharged from both services. The difference seemed to relate more to the process of discharge in each setting. That which was adopted in DC1 appeared to result in much greater levels of fear and some loss of autonomy, not only on the part of those leaving the service, but also those that remained part of it.

Another difference between the services related to how personalised the care was in each setting. In DC1 the emphasis of care was concerned with being part of a group – at a cost of ignoring individual needs if necessary. In DC2, by contrast, staff members and volunteers were most keen to meet the needs of individuals, and they would sacrifice the group experience if necessary to achieve this aim. This

enabled those attending DC2 to work towards individual aims and goals, which could be directed towards adaptation to their illness if they wished.

6.5. Summary of the chapter

This chapter has described DC2 which was a service highly valued by its patients. Like DC1 it played a central role in providing them with much needed social support through its relationships and activities, facilitated by its practical support and enhanced by its informal and comfortable milieu. Unlike DC1 it offered a high level of physical care, including symptom control, and played a central role in shaping the care package that patients received at home as well as in DC2. The benefits for patients were arguably greater as a result. A review of the characteristics of DC2 in the light of those described in the literature relating to other PDC services suggests that it is similar in many ways, which may mean that the joint construction has validity in other settings too.

Despite some differences, there seemed to be a high degree of commonality between the constructions of DC1 and 2. As a consequence I returned to the data collected in both settings to consider the nature of the commonality. This is described in the next chapter in the form of a proposition that suggests that PDC serves as a community for those involved in the service.

CHAPTER 7

A PROPOSITION REGARDING PDC

7.1. Introduction to the chapter

This chapter describes a proposition regarding PDC based on patients' experience of DC1 and 2. It identifies PDC as a community for people with a progressive and life threatening condition. This is based on the comments of patients attending DC1 and 2 regarding their experience of PDC, my observation of these services, and my experience of being part of them as a participant observer. Where appropriate the literature has also been consulted to develop various aspects of the proposition. It is presented as an hypothesis, and requires to be tested in other PDC settings. Within the proposition some reference is made to data collected in DC1 and 2 to illustrate its detail.

7.2. Identifying community as the focus of the proposition

When I started to explore the shared experience of PDC by patients attending DC1 and 2, the idea of community quickly began to establish itself as a central tenet of this experience. In both settings many participants identified PDC as a group to which they could belong, offering them an opportunity to meet with other people who had similar needs and with whom they could identify. My own experience of being an observer in DC1 and 2 supported the presence of a group. This group was referred to in a number of ways – as a family, a club and as a community. Key to its value was the relationships that members of the group established with each other.

Within the literature, community has been described as a group of people who have something in common (Crow & Maclean 2000), a definition that is highly applicable to the group created within PDC based on the shared experience of its members of living with a progressive and life threatening condition. The relationships that they develop with each other serve to differentiate this

community as one of attachment (Wilmott 1986), as opposed to those based on shared interests or geography.

7.3. Introducing the community

The PDC community comprises people with progressive and life threatening conditions. It may also comprise family members, and staff and volunteers working in this setting. Many of these are drawn to PDC having had some experience of living with a progressive and life threatening condition, either in the past or present. It is notable that in DC1 and 2 a significant proportion of the volunteers had been involved, at some point in their lives, with someone that had suffered from a progressive and life threatening condition. This had provided them with an affinity and commitment to others in a similar situation. Other members, such as staff members are particularly interested and committed to working with this specific group of people, their condition and its implications serving as a chief motivation in their work.

Attendance in PDC brings these people together as a group. All its members are aware of the difficulties of living with this condition, they are supportive in this context and are committed to amending this experience for themselves and others wherever possible.

The community of PDC is a bounded one, the boundary serving to separate and thereby protect members of the community – the insiders, from the rest of the world – the outsiders. It is easily traversed by those with a diagnosis of a progressive and life threatening condition and also by staff and volunteers who exhibit a commitment to meeting the needs of such people. Otherwise entry to the community is more difficult, and only possible when granted by gatekeepers of the community, usually members of staff. This characteristic of the community is important for people who are frightened of being misunderstood and mistreated as a consequence of their condition, and seek refuge from those who could inflict this upon them. In the event that someone becomes part of the community who does

pose such a threat they are expelled by staff members, with the support of the rest of the community.

7.4. Joining the community

For people with progressive and life threatening conditions, joining the community is a straightforward and comfortable process. There is a commitment within the group to make newcomers feel welcome, and efforts are made to engage the newcomer in discussion and activities. Aside from the criterion of having a progressive and life threatening condition there are few other criteria that determine whether someone can join the community. Usually patients are invited to come and take part in the service in the first instance, as the basis for the decision as to whether they remain part of it or not. As such this visit serves as an opportunity for them and those within the service to assess the fit between their needs and the support available in this setting. In DC1 and 2, patients usually determined for themselves whether they wished to continue attending the service, staff members concurring with their decision. In this way membership of the community is self-selecting.

7.5. Being part of the community

Once in, patients find a setting in which they feel safe, accepted and understood. They are with others who understand their predicament and have similar aspirations. Their common experience of having a terminal and advancing condition serves to override differences between them such as age and professional background that might, in other settings, serve to differentiate individuals. It also gives rise to common aspirations for the time that they are present in PDC. They want to be treated as normal, to be freed from a preoccupation of their illness and to be made cognizant with their abilities rather than their disabilities. Many patients seek an alternative experience of life, within which they can continue to aspire to a future, find fun and engage in new relationships despite their proximity to death. This opportunity is often unavailable

at home or in any other setting, in which the individual's illness dominates how other people relate to him/her and how his/her life is organised.

In joining PDC patients become part of a group of people who meet on a regular basis. The service is organised so that the same set of patients, staff members and volunteers meet on each visit to PDC wherever possible. Whilst there is a small turnover of patients (through new referrals or discharge and death), a core of patients remain for weeks, months or even years, enabling members to get to know each other well. Volunteers and staff members who commonly work in the same service for long periods of time augment this stable nucleus. In the majority of cases patients are offered a regular and dedicated place within the service for as long as they need it, providing a permanency, security and stability in an otherwise rapidly changing and uncertain existence. They are made to feel an important part of the life of PDC through the physical demonstrations of affection directed towards them, the expectation that they will attend on a regular basis by the other members, and efforts made to identify and respond to their individual preferences.

Regular attendance of PDC enables patients and other members of the community to establish important relationships. They are the essence of the community and give rise to its benefits. They are established between patients, staff members and volunteers and are deeply caring in nature. These relationships are empathic, generous and often demonstrative. They are also highly informal in nature. Members of the community relate to each other on first name terms, engaging in light-hearted banter and chatter for much of the time that they are in PDC. Generally there is widespread acceptance of individuals' idiosyncrasies engendering a sense of acceptance in this setting, regardless of changes in appearance, behaviour or ability that would otherwise render them a sense of being abnormal or different. Relationships between members are highly reciprocal. Members extend care and support to each other regardless of formal differences in status within the service, confident that they can improve the wellbeing of other members through their offer of affection and help. Some members of the

community develop new friendships as a consequence of attending the service; others simply engage as companions for the period that they are present in PDC. For many, the group of people who they meet in PDC becomes a substitute family for them. The mixed membership of the community, incorporating a variety of volunteers, as well as staff members, patients and even carers, means that there is normally someone for everyone to relate to in this setting, despite a variety of backgrounds, interests and social needs. These relationships are guided by unspoken rules regarding engagement and disengagement that reflect the needs of the community, particularly those arising from the frequent deaths of its members. The rules encourage easy engagement of new members, an experience of intimate and substantial relationships for the period that people are in PDC and quick disengagement by survivors in the event of a member's death or departure from the community. New members learn the rules by watching other members relate to each other and by gauging the response of the community as they begin to relate to others in this context. A lack of commitment by a member to observing the rules and perpetuating them renders them 'outsider' status, and as such they are at risk of being expelled.

Within PDC patients engage in an existence which is highly communal in nature. Most of those involved in the service sit and chat with each other for much of the day, eat and drink together, and engage in many of the activities as part of a set. The physical layout of the service and its routine encourage individuals to relate to each other as members of a group, patients and others often making efforts to draw those on the periphery of the group to become part of its interaction, and thus part of its life. Roles exist within PDC for its members encompassing a wide range of tasks and abilities. As people take these on, they become an integral part of the community and feel that they are contributing to, as well as taking from, this entity.

In addition patients engage in an "alternative reality" created and sustained by those involved in the service. The term "alternative reality" is borrowed from

Lawton (2000) who uses it to describe a PDC service she studied that had diverged from its formal objectives to meet the subjective needs of its patients. As such it offered a place where the harsh experience of being terminally ill for patients was ameliorated through its provision of ongoing psychosocial support. It was characterised by a light-hearted, homely and convivial atmosphere protected from the outside world by the boundary of PDC. Its activities, values, perspective and relationships enabled people to place distance between themselves and their death, to diminish the impact of their illness and redefine their sense of self.

In the community this reality is adopted and perpetuated by its members who recognise its benefits to them, and who find solace in its alternative experience of ill health and dying. As a consequence they are committed to a light-hearted atmosphere despite the gravity of their situation, to forgetting about their illness regardless of its dominating position in their lives and to looking forward even though they face premature death.

7.6. Leaving the community

Patients usually leave the community when their condition deteriorates to such a degree that they cannot cope with the demands of travelling to and from PDC or its routine. Alternatively they continue to attend right up until they die. A few patients attending the service are discharged on the grounds that their condition has not continued to advance and their disease is stable. This is commonly intended as a liberating action to enable patients to reject their identity of someone who is dying. However as described later in the chapter, it is not always experienced as such by patients, who can find the idea of discharge difficult to understand and accept. A few patients discharge themselves from PDC on the grounds that it is not the right setting for them. In the context of community life this can be hard to achieve, for reasons described in Section 7.9.

7.7. The offerings of community life

As a consequence of belonging to the PDC community, patients can enjoy the following offerings.

First, they can engage in relationships with people who understand their predicament. Being part of the community offers patients the opportunity to meet with people who share their condition and can identify with them for this reason. They are also invited to engage with staff members and volunteers who have a particular interest and commitment with this particular group of patients. This empathic response enables patients to feel confident in these relationships. They are assured of acceptance and understanding and no longer feel at odds with people who cannot relate to their situation. They can engage at a social level without fear of rejection on the grounds of their illness and in so doing, begin to rebuild a social support network that has commonly been lost on learning their diagnosis.

Second, it offers a renewed sense of normality. In this setting the experience of having a terminal and advancing condition is the standard and patients can meet others who face the same predicament. In so doing, they cease to feel abnormal as a consequence of their diagnosis; instead it serves to bind them with other users of the service. The consequences of their illness are often shared by fellow members of the community, thereby reducing their potency as an attribute that differentiates them from other people. For example, the changed temporal perspective held by patients who know that their future is truncated by their likely premature death is not one that is shared by the majority of people outside the community. As a consequence it puts them at odds with their family and friends and serves to separate them from the rest of the world. However, within the community of PDC the changed temporal perspective - that which has a limited future - is the norm.

Third, members of the community enjoy renewed purpose and structure in their lives. Community life is built around the routine of PDC, its events and activities.

These are tailored to meet the limitations of people with a progressive and life threatening condition and are easy for people to take up or drop according to how they feel. They are often creative in nature and provide new opportunities for members. As such they serve to provide those involved in the service with hope and optimism and an illusion of being at the beginning of something rather than at the end – a perspective that is a stark contrast to their beliefs about their lives in general. The sense of purpose engendered in this setting relates to the opportunity afforded members to care for others within the community, to become involved in a variety of activities that benefit themselves and others, and to partake in deeds that serve as a substitute for work. In so doing they derive satisfaction from their achievements and enjoy the experience of having a specific project or goal to work towards. Some are simply grateful for the experience of being busy again, in so doing replicating aspects of past life.

Fourth, patients receive care and support in response to their needs. At the heart of community life is the commitment by all involved to meet the needs of its members. These subjective needs shape the community and determine its priorities. Whilst many of these needs are complex, the nature of the community is such that they can be accommodated. For example the mixed membership of the community enables the service to meet the myriad and varied needs of its members. In addition members' affinity with each other ensures a sensitive response to people's wants. Furthermore, their commitment to care for each other is valuable both for the provider and recipient of this care, providing new self-worth for the former and an attentive, supportive environment for the latter. Where the needs of the patients are reflected in those of the volunteers and staff members, the service is even more responsive as a consequence of the identification of members with each other.

Fifth, patients enjoy time off from their illness as a consequence of being part of the community. In disregarding their illness for the period that they are in PDC, patients are not denying that they are terminally ill; instead they are seeking to

limit its dominion in their lives by shutting it out for a limited period. One facet of the service that enables this is the provision of activities in this setting that serve to divert the attention of patients away from themselves and their condition. Patients who are highly anxious about their illness and its implications find particular relief in this regard. Another facet of community life that enables patients to forget about their condition is the provision of an environment that focuses on patients' abilities rather than their disabilities. This may happen at a physical level, where efforts are made to limit the demands made on individuals, thereby enabling them to forget the help they need in relation to the activities of daily living. It may also occur at an emotional level as patients determine the degree to which they address aspects of their illness whilst in PDC. Those working in this setting take cues from the patient as to whether they offer intervention for the problems experienced by the patient, giving patients autonomy in this regard.

Sixth, the alternative reality of the community provides patients with new optimism about their condition. It is derived from the commitment of members to create and sustain a milieu that is positive, within which patients can forget their illness for the day and engage in a frivolity that belies the enormity of what they face. To achieve this, death is "managed" in this setting. As such the community operates in a way that diminishes the impact of the frequent deaths of fellow members on survivors, focusing instead on relationships that are live and current. The optimism that some members feel is also a consequence of the opportunity afforded them to amend their perception of their situation as they compare themselves to other members of the community. Commonly they meet others who they perceive to be worse off than themselves, a situation that offers them comfort and encouragement. Their relative position of being more well than others allows them to distance themselves from their impending death on the grounds that there are others who are likely to die before they do within the community. It may also serve to help them manage their condition more actively, as they learn to manage aspects of their illness by watching others cope with similar problems, thereby offering them a renewed sense of control in relation to their illness.

7.8. The positive consequences of belonging to the PDC community

The consequences of belonging to the community are positive in the main. As Chapters 5 and 6 reveal, patients in DC1 and 2 highly valued the experience and attended for as long as they were able in the majority of circumstances. The offerings of community life give rise to the following positive consequences:

7.8.1. Retaining membership of the social world

The offer of a social group to which people with a progressive and life threatening condition can belong is an aspect of PDC provision that is particularly valued by its users. The community of PDC is a place where those with a progressive and life threatening condition can meet new people and establish relationships of substance. They can make a difference to the lives of others and enjoy the richness of social life that embraces people with a variety of experiences and attributes. They are encouraged to adopt vital social roles within this context and believe that they are important to others. Whilst in PDC they engage in recreational activities and are able to claim new social experiences which they can then share with their families. Most importantly they feel an insider in a group that they can attend regularly, and which for many serves as a "date" in an otherwise empty social diary. Many of these opportunities are only possible within the context of the community of PDC which operates in a way that acknowledges and accommodates the limitations of people with progressive and life threatening conditions, particularly those associated with making and sustaining relationships towards the end of life.

7.8.2. An experience of living rather than dying

Those belonging to the community of PDC can enjoy an experience of living with their illness rather than dying from it. This is a subtle but vital shift in perspective in relation to their condition that is enabling and liberating. It permits individuals to place value on the present and to anticipate a future, even if it is shortened, within which they can re-engage with aspects of their lives such as relationships and hobbies that they enjoyed prior to becoming ill. This more optimistic

viewpoint is achieved through the alternative reality of the community. Within this reality, patients are able to forget their illness and its consequences, they are encouraged to feel more positive in relation to their condition, and they can be productive and purposeful in their efforts. The experience of being with many others who have similar conditions reduces their experience of feeling abnormal and helps them to realise that there are others in worse situations than themselves which, for many, is both humbling and encouraging. For some it is also comforting on the grounds that there are others that are probably closer to death than themselves. The community of PDC helps to create the belief that people are living rather than dying through its provision of new opportunities for its members which are carefully designed to accommodate the limitations of the members whilst broadening life experience, creative abilities and interests in those using the service. By providing regular places and transport to and from PDC if required, the community offers emancipation for many of its members who commonly feel imprisoned and overwhelmed by their condition and its implications at home, where its reality is most apparent. Finally being part of live and vibrant relationships established between the various members of the community serves to inject life into individuals who otherwise are part of relationships that are dying, and as such feel reflective of their own situation.

7.8.3. A positive sense of self

Belonging to the community of PDC can enable its members to retain a positive sense of self, or to regain it in the event that it has been damaged or lost. The term "self" as used in this context draws on a definition provided by Charmaz (1999) which identifies self as both product and process. Thus the self-concept is a relatively stable organisation of attributes, feeling and identifications that the person sees as defining themselves, which may change in response to emergent events. Loss or disintegration of self relates to the experience of people with chronic conditions and similar, in which they witness their former self-images crumbling away without the simultaneous development of equally valued new

ones (Charmaz 1983). According to Charmaz (ibid.) this gives rise to a fundamental form of suffering.

This is an experience shared by people with a progressive and life threatening conditions as described in Section 2.9.4. They believe that, as a result of being terminally ill, they have less value in the eyes of those around them and society more generally causing their self worth to plummet. This experience is exacerbated for some when their perception of self is at odds with how others see them and when they believe that they are different from everyone else (who are seen to have value) as a consequence of their illness.

The community of PDC helps with these beliefs and experiences in a number of ways.

> It serves to increase an individual's self-value. The community is a welcoming place that seeks to engage its new members on the basis that they have something valuable to contribute to the service. The community provides opportunity for positive interaction between members and encourages individuals to adopt roles and care for each other, thereby serving to boost feelings of self worth. This is further enhanced by the care that individuals receive in this setting from other members.

> It offers an environment in which the person who has a progressive and life threatening condition ceases to feel abnormal. In this context they are no longer on the margins but part of the majority.

> It serves to lessen the downward revision of self worth often experienced by individuals as they consider their value to their friends, families and the other communities in which they live. It does this by providing an alternative point of reference that is affirming and positive for the individual member. Those involved in the service know that they are valued in this context. Patients are

aware that the community does not simply tolerate their condition but in fact exists because of it. They know that they are important to others in this setting and believe that they will be missed if they do not attend. People want to know their story and are keen that they feel an integral part of the service. In this way the community anchors their sense of worth, and protects it from being destroyed by those outside the community.

7.8.4. A sense of control

The community allows patients to regain some control over their illness. Often their condition has become a force in its own right, dominating their lives at physical, emotional, social and practical levels. Family, friends and professionals often exacerbate this situation by seeking to influence how the person manages their condition and the problems arising from it. In so doing, they deny the patient any autonomy in the way that they cope with their illness. The community of PDC, by contrast, makes few overt stipulations about how people cope with their individual situation and problems. Patients in this setting make their own decisions about the degree to which they discuss their illness and what help they seek from those within the service. They watch others coping with various problems and learn vicariously, at a speed and degree dictated only by them, about what the future may hold for them. In this way they become familiar with the consequences of their condition at a pace that they can cope with, and are able to make contingency plans to address additional problems that they might be faced with if they wish. Within the alternative reality of the community they are encouraged to laugh at some elements of their condition, an activity which allows them to reframe its impact on their lives and thereby deny its domination over them. Staff members and volunteers take their cues from patients as to what degree of help they offer patients, which is reassessed regularly to accommodate oscillating requirements. Finally the community operates in a way that enables its members to feel confident about seeking help if they require it. They learn quickly about how to gain access to care if they need it, other members of the community advising

and modelling an approach that enables the patient feels some control in their treatment plan.

7.9. Negative consequences of belonging to the PDC community

Community life can be experienced in a less positive way for those who do not require the alternative reality of the community or who cannot engage with it. Alternatively membership of the community can give rise to uncomfortable feelings for people who find themselves denied the opportunity to remain part of it.

People who do not require the alternative reality offered by the community are commonly those who are able to integrate their illness and its implications into their existing life style. Characteristically, they have strong networks of support, they are able to pursue previous interests, their illness has done little to dent their view of themselves and they still consider themselves to have a future. In being referred to PDC, they are being invited to join a community that seeks to integrate them but can only do so if they are willing to become part of this alternative reality and contribute to its life. To do so, they must adopt a new perspective on the world held by those within the service. If they are unable to do this they feel something of a misfit and struggle to reconcile their original perspective of themselves and their condition with that held by other members of the community. This discomfort continues even when they make the decision to leave the community. Often this is difficult to enact – other members are keen that they remain within the community in order that they feel the same benefits that others have enjoyed, they feel guilty about rejecting the kindness of those within PDC, and they are concerned that they are letting fellow members down. In addition their decision may receive little support from family members or carers at home who benefit from their attendance in PDC.

Individuals who cannot engage with the alternative reality of the community are often people whose condition is sufficiently disabling, advanced or dominating

that they are unable to become an active member of the group that is the basis of the community. They are those who cannot adopt roles, learn new ways of relating, enter into the fun and frivolity of the setting or become involved in new activities. For this reason they remain on the periphery of the community and are exposed to its harsher realities (such as the unremitting deaths of fellow patients) without the means of coping with them that are provided by the alternative reality. In this event, the experience of being part of the community can be a highly distressing one and one that can only be avoided by ceasing to attend the service. As an example I recall meeting a woman who had suffered a recent stroke. She had attended DC1 in the past and according to the staff had enjoyed the service at that time. Since her stroke, however, she found it hard to engage with any of the members and was unable to be part of the group as she was required to remain in a wheelchair at all times. She spent much of the day crying and appeared distressed. It seemed that the experience of being back in PDC with limited abilities was a stressful and unhappy one, and one from which she derived little or no benefit.

Individuals who are unexpectedly denied the opportunity to remain part of the community can suffer too. This situation arises when patients are faced with discharge from the service, even though they still wish to attend. It reflects their belief that their place within the community is theirs for as long as they require it, a position that is suddenly challenged by the suggestion that they leave PDC on the grounds that their condition no longer warrants care from this service. Furthermore, there is often little negotiation around the issue, and patients feel forced to leave against their will. In this process patients must leave the alternative reality of the community that they have adopted as their own; they are being cast as "outsiders" of a group that they had considered akin to a family; in addition the experience of autonomy that the community has offered regarding the management of their illness is now denied to them. This experience can be disempowering, painful and hard to understand, particularly in the short term. Patients that I met in the research who had been discharged from the service saw this process as an expulsion from the community. Some described a residual anger

and disappointment with the service, and were often unable to appreciate the opportunities afforded by this decision that others identified on their behalf. Furthermore they were often unable to reintegrate into the world outside PDC given their dependence on the alternative reality and their belief that they no longer belonged in the bigger world, given their previous diagnosis of a terminal condition. Their pain and fear associated with leaving the community was usually communicated to other members who would lobby on their behalf for some reprieve of this plan.

7.10. People who benefit from being part of the PDC community

In general people who benefit from belonging to the PDC community are individuals whose social being is disintegrating or has been lost. Often this breakdown is associated with social isolation arising from physical or emotional limitations imposed by the person's illness. It may also be a consequence of feeling stigmatised as a result of having a progressive and life threatening condition, or of being preoccupied with the condition to such an extent that individuals can no longer related to anyone or anything else in their lives. Loss of social self may arise from the experience of being socially dead in advance of biological death. Patients that I met in this situation felt that they had lived too long following their diagnosis of a terminal condition. This situation is one of limbo – one in which the patient and those close to them anticipate death but it is longer coming than expected. As a consequence families and friends withdraw and make plans for a future in which the patient has no future. This can be an intensely lonely experience and a highly devaluing one for individuals who can no longer look to these relationships for affirmation as to their value.

7.11. Variations within the proposition

Within the proposition, subtle variations exist in relation to individual PDC services, arising from their particular characteristics.

The first relates to the degree of holism of care provided in this setting. Most of the patients using PDC present with myriad needs spanning the physical, emotional and practical consequences of their illness in addition to those that are social in nature. For this reason, being part of a community that only addresses social needs represents a potential shortcoming in the service. This weakness in community life is avoided when members of the community bring a variety of skills and expertise, including those that address physical, emotional, spiritual and practical needs. As illustrated in DC2, holistic care within PDC requires a staff team that is large enough to offer these diverse abilities. It is facilitated by a close working relationship established between PDC and the rest of the hospice where additional help can be sought. In addition this provision is enabled by a working routine that enables staff members to regularly review the progress and needs of those using PDC, calling on the advice and input of colleagues to address these as required. Where the service plays an active role in co-ordinating the care of its patients, it can make quick and effective changes to their care plans in response to new needs.

As a result of this pattern of provision, patients can enjoy a strong sense of security arising from their attendance in PDC. They believe that they will receive specialist and comprehensive help from PDC in relation to any problems that they might experience from their illness. They are also confident that staff members and volunteers in this setting will make changes to their care package quickly and effectively as required. This serves to reduce their fear about what the future might hold, addressing in particular any concerns about suffering from uncontrolled symptoms as they approach death. When patients believe that they can remain within PDC up to the point of their death, this experience is enhanced.

The second variation concerns the place of the individual within the group. Within community life observed within DC1 and 2, there appeared to be an ongoing tension between meeting the needs of individual members within the community of PDC whilst also ensuring a group experience. When the group experience takes

priority, then the individual preferences and requirements of members may be lost. The routine of the group may be too rigid to accommodate personal wants, and individual treatments may be assigned relatively little importance. When individual needs are given preference, the group experience may be sacrificed. In this case the routine and organisation of activities focuses on the different needs of people rather than their shared requirements. The interest of staff members on individual preferences enables members to work towards personal goals, including those that are concerned with adaptation to illness, rather than diversion from it. Even when diversion is sought, individualised care may make this activity more meaningful. It offers a sense of control and a basis for anticipating the future, even if it is only on a short-term basis. However the sense of camaraderie may be less, and members may feel more isolated in their illness, even whilst in PDC, in the event that the group experience is compromised.

Thirdly, membership of the community may differ. As demonstrated within the current study, the degree to which relatives, friends and informal carers are invited to join the community varies between the service. This has implications for the level of support that they can expect from this source and how involved they become in this aspect of the patient's care.

7.12. Summary of the chapter

This chapter has outlined a proposition drawn from the study of two PDC services. As such its validity is uncertain, and further testing to ascertain its relevance in other settings is needed. It proposes that PDC serves as a community for people with a progressive and life threatening condition, and in doing so meets a variety their social needs. Its members derive much that is positive from belonging to this community and it is a highly valued service as a consequence. However, as the chapter portrays, the community is a complex entity that requires skilled creation and sustenance; in the event that this is not available the community can serve as less beneficial or even harmful to its members. Finally the chapter identifies some subtle variations within the interpretation that increase or decrease the benefits of

belonging to the community for its members. How this proposition fits with the literature is the subject of the next chapter.

CHAPTER 8

THE PROPOSITION IN CONTEXT

8.1. Introduction to the chapter

This chapter places the proposition in context. It establishes links between the proposition and relevant literature including that concerned with the concept of community, the experience of dying and therapeutic elements of care. Although the concept of PDC as a community is not described in the literature as such, the literature serves to support the proposition and its detail in a number of ways. In turn, the proposition adds to the literature, particularly that concerned with PDC and the place of this service within palliative care. These relationships are described in this chapter.

8.2. The value of community for people on the margins of society

Review of the literature suggests that community life has value for people who are on the margins of society, as a consequence of illness, impairment or social change. Higgins (1980), for example, provides a description of a community for deaf people which is valued by its members for many similar reasons as those held be members of the PDC community. Its deaf members felt that they did not fit in a hearing world, and for this reason were outsiders in this context. By joining the deaf community they could find a new environment in which they derived a sense of belonging and could identify with others. Similarly an old age community described by Hochschild (2000) comprising widows living in sheltered housing provided new purpose, friendships and fulfilment for its members. They were people who were retired, whose families were grown up and independent, and who faced a time of "problematic" social change (ibid. p.249), similar in their potential social isolation to many of the members of the PDC community.

8.3. Characteristics of community life

There are characteristics shared by the community of PDC and other communities identified in the literature. Those that are termed "therapeutic" in the literature

have particular resonance in many respects. As such they characteristically focus on the quality of relationships, and the communication and interaction between members as a basis of the care that they offer (Kennard & Roberts 1983). In addition they are small and cohesive in character, and are places where "therapeutic decisions and functions are shared by the whole community and where the status differences between staff and resident are greatly reduced though not abandoned" (ibid. p.6). They commonly exist in an informal and communal atmosphere, within which there is shared responsibility for maintaining and running the community (ibid.). They are underpinned by a belief that patients have therapeutic value for each other, achieved through their interactions (ibid.). Communities which are particularly similar to the PDC community are those that have a social emphasis, such as the Camphill Village Communities for people with learning difficulties. As such they enjoy many of the therapeutic elements described above, but do not call upon group work within a psychodynamic framework and a focus on the interaction of members and the nature of their relationships as the basis of therapeutic intervention as true therapeutic communities would (ibid.).

8.4. Reasons why the PDC community is valued by people with progressive and life threatening conditions

The literature serves to identify reasons why the PDC community is valued by people with progressive and life threatening conditions.

First it suggests that the community of PDC could serve to plug a gap that exists in modern society. Young and Cullen (1996), who undertook a study of 14 dying people and some of their carers highlight the loss of community in modern society as a key reason for the pain experienced by dying people and their survivors. As they reflect on what was missing from the lives of the people who they studied to ensure a good or better death they suggest that " They are almost all lacking, and we think wanting, the presence of a wider community of people... A hospice, even well run hospice wards, as temporary communities can give something of this

sense but they cannot be the same as more durable communities to which the dying and the bereaved can belong long before and long after the death" (ibid. p.182-183). This gap in modern society means that the dying person and their carers are faced with intense and private feelings that are undiluted. In other words, they have no access to the comfort of human companionship offered by communities in the past (ibid.). Whilst the PDC community is not an adequate substitute for the long term communities that Young and Cullen (ibid.) describe, it could serve to provide some of the "softening, meliorating and transformative effect" (ibid. p.182) of community life on death, which they yearn for on behalf of those they studied. The absence of community life in modern society is also noted by Murray et al (2003) who compared the experience of dying in developed and developing countries. Their research suggests that the psychosocial needs of patients dying in the developed world were largely unmet, whereas the same needs in people dying in the developing world were addressed by being part of local community life. By implication, there is a place for new opportunities for the dying to engage in community life, as a means of addressing their psychosocial needs.

Second, the literature suggests that dying people have social needs that are difficult to meet in the context of ordinary life, and which may be more effectively met in a community created specifically for people with progressive and life threatening conditions. It describes a paradoxical situation within which people who are dying are often lonely and estranged (Elias 1985), yet they have a profound need to engage in meaningful relationships and remain part of a social world (Herth 1990; McNamara 2001). As described in Section 2.9.4, the loneliness of dying arises from the experience of "social death", where the person is treated as already dead despite being clinically and biologically alive (Sudnow 1967). It is also the consequence of the stigmatising effect of conditions such as cancer (Goffman 1963; McNamara 2001; Sontag 1987), changes in relationships between the sufferer and their significant other(s) (Exley 1998; Germino et al 1995; Lawton 2000) and the distance placed between the living and the dying in modern society

(Bauman 1992; Lawton 2000). The pain that results has a longevity and degree of excruciation that is notable – portrayed by McNamara (2001) as a process in which "the individual alone, and in terror, shatters" (p.1). Lawton (2000) highlights the degree of suffering as she considers the experience for people of "living too long" (p.154). She draws a parallel between the terminally ill patients she studied who suffered "social death" and Holocaust survivors whose suffering was long-term and continued well beyond the end of the Second World War. Citing the work of Langer (1996), she describes how these survivors became suspended between life and death – a place of limbo- in which part of their self had been lost at the time of the mass murder of fellow Jews and had never been recovered. Muzzin et al (1994) suggest that this experience of suspension between life and death is intolerable given the incompatibility of life and death. In the face of this suffering McNamara (2001) suggests that what is most valued by the dying person is the offer of a place in a social world - "while we are dying it is imperative that we, in a small way, are part of social life" (ibid.p.1). Others echo this requirement. Herth (1990) for example, highlights the need by people who are terminally ill to engage in meaningful shared relationships with others. This offers a means of finding hope. When such engagement is achieved, people can face the shortness of their lives constructively and move beyond their current predicament toward new awareness and enrichment of being (ibid.). The opportunity for such engagement is provided within the context of the PDC community through its social milieu, routine and regular membership. In this setting people may remain engaged with others, even if they are perceived by themselves and the rest of the world to have lived too long. They become an important part of this social world, which not only accepts them but also exists to provide for them. This realisation, according to the literature, gives rise to hope, arising as a consequence of being treated as an individual of value (ibid.).

Third, the literature suggests that people with progressive and life threatening conditions may cease to feel accepted in the social world within which they have engaged in the past and for this reason value the opportunity to become part of a

community set up specifically for them. This change in status arises as a consequence of the stigmatising impact of conditions such as cancer, which are perceived to be "morally, if not literally contagious" (Sontag 1987 p.10). For this reason there is a desire on the part of those who do not have the condition, to avoid meeting those that do (Goffman 1963). By the same token, the stigmatised individual seeks to avoid meeting with the person deemed normal for fear of rejection (ibid.). The subsequent lack of social contact for the stigmatised individual often leads to feelings of suspicion, depression, hostility, anxiety and bewilderment as they are denied the feedback afforded by daily social intercourse (ibid.). It is also likely to result in profound social isolation. This situation is only changed when the stigmatised individual meets "sympathetic others" (ibid. p.31). They are those who either share their stigma or whose experiences have made them sympathetic to the problems that the stigmatised individual faces. In the PDC community, the stigmatised, as described by Goffman (ibid.) are the patients (in the main) whose progressive and life threatening condition renders them abnormal and unwelcome in a world in which the majority of its members wish to deny that death exists (Mellor 1993). The 'sympathetic others' are the staff and volunteers, who by virtue of their job, or life experiences, have particular insight into the lives of people facing a diagnosis of advancing disease from which they will die. In belonging to this community and engaging with those within it, the stigmatised individual is able to find acceptance and normality, experiences denied to them in other settings.

Fourth, the literature suggests that community life, established on the basis of a shared experience of dying, has a valuable and almost unique place in the context of modern society, in which death has been sequestrated (Lawton 2000; Mellor & Shilling 1993). This serves to deny those that are dying the opportunity to become familiar with the phenomenon, and in so doing lessen their fear associated with their own death. For this reason, the provision of a setting in which issues concerned with death and dying are acknowledged may be valuable for those that face this predicament. This sequestration is linked to the values of modern society,

such as those concerned with youth, vitality and the future (Mellor & Shilling 1993), which are at odds with the experience of dying. The values of the PDC community are diametrically opposite to these, and as such are affirming of those that are nearing the end of their lives.

Fifth there is a group of people whose lives are dominated by the experience and consequences of their condition. These people often feel defeated by their disease. They are not the heroes described by Seale (1995) or Exley (1998) who are determined to fight their illness and find meaning within it. They are those who wish to be rescued from the domination of their condition. They seek a "safe retreat" (Lawton 2000 p. 53) in which the proximity and potency of death is reduced. This shelter or haven is provided by the alternative reality of the community of PDC.

8.5. The detail of community life

The literature supports elements of community life described within the proposition, in particular its relationships, interaction and alternative reality. These are described below.

8.5.1. Relationships within the community

Within the proposition, particular value is placed on the relationships established in this setting. They are perceived to have therapeutic value, a concept identified in the literature as one of healing, even within terminal illness (Hockey 1993). The literature confirms the value of their intimate, accepting and companionable nature as described in the proposition. It also backs up the suggestion that they serve to replace those that have previously been offered by family and friends.

The value of intimate relationships in care settings is well documented in the literature. De Hennezel (1998) proposes that such relationships between care giver and patient are highly positive on the grounds that they are enriching and valuable for all concerned. Drawing on the work of Barnard (1995) she suggests that they

"open up both the caregiver and the patient to the possibility of feeling related, of finding meaning, hope and even joy amongst great suffering" (De Hennezel 1998 p.56). In this relationship both parties can acknowledge feeling powerless and vulnerable in the face of death. Raudonis (1993) highlights the importance of reciprocity, openness, care and acceptance in her description of empathic relationships established between hospice nurses and their patients. Her study suggests that these relationships result in the improvement and maintenance of patients' physical and emotional well-being, as patients feel acknowledged as individuals and people of value. The importance that Raudonis places on reciprocal and caring relationships is reiterated by Gullickson (1993) who believes such relationships can provide terminally ill patients with new optimism about their future. These relationships offer a "future of possibilities" (ibid. p.1390) despite the nearness of death, effectively transforming a period of waiting for death to one of richness and opportunity.

The accepting nature of the relationships within the community is also discussed in the literature. It is an acknowledged part of professional companionship that has been described in the literature, giving rise to hope in the terminally ill (Herth 1990). Campbell (1984) sees it as an integral element of the moderated love that he identifies between care professionals and their patients. This relationship offers companionship characterised by a "closeness which is neither sexual union nor deep friendship. It is a bodily presence which accompanies the other for a while…..The good companion is someone who shares freely, but does not impose, allowing others to make their own journey" (ibid. p.49).

The personal nature of relationships within the PDC community identified by patients is also noted by researchers. Lawton (2000), for example, suggests that PDC may serve as a surrogate family within which patients are able to forge close personal ties with other people, thereby preserving the exterior aspects of self. In her consideration of the importance of PDC for those she observed in her study, Lawton (ibid.) suggests that people with life threatening conditions are often

unable to relate to their real families for a variety of reasons, including a changed temporal perspective of life that is no longer in synchrony with those around them. As such they have no future to anticipate and the past becomes increasingly important. For this reason, the surrogate family of the community is important, even for those who apparently exist within a family network.

Whilst the relationships of the PDC community are family like in nature, they do not offer the intensity or burden of those established between patients and their true families. For some patients within the communities of DC1 and 2, this was a relief as they struggled to cope with their concern and sense of burden in relation to their families arising from their illness. Exley (1998) describes how the terminally ill patients she studied sometimes preferred to discuss their illness with people other than family on the grounds that these individuals were unlikely to feel personally wounded by the content of their discussion. For similar reasons, patients who I met would often choose to discuss aspects of their condition with others in PDC. They were confident that people in this setting would understand and accept what they were saying, but were unlikely to be damaged by the conversation, however harsh in nature.

8.5.2. Interaction within the community

The community of PDC is a comfortable one in which to belong. It accommodates limitations in people arising from their condition and is generally very positive and accepting of its members. Shaver (2002a) describes how, in the face of death, people often undergo damage to their sense of self resulting in intense feelings of loneliness, fear and anxiety. He suggests that this suffering can be effectively addressed through the therapeutic interventions of reflective listening, validation, respectful presence and unconditional love, giving rise to someone who feels cherished, peaceful, connected and has a sense of wellbeing. According to Shaver (ibid.), this facilitates the innate ability of an individual to move towards a more cohesive and integrated sense of self. His prescription for those whose sense of self has disintegrated resonates with many of the characteristics of the PDC

community and the care offered therein. This is concerned primarily with being with others rather than helping individuals correct specific problems or achieving particular goals. Whilst this could be seen as a shortcoming of the service, particularly by those that seek measurable outcomes and observable improvements in patients, Shaver would argue that it is serving a much needed and difficult role, leading to psycho-spiritual healing and growth.

Part of the interaction between members of the community is concerned with comparing their relative conditions. Those within the community would often compare their situation with that of other members and note with some relief and gratitude that there were others whose condition appeared worse and therefore likely to die before them. They derived encouragement from seeing others cope with problems that were greater than their own and felt humbled by the courage of others who faced troublesome or distressing scenarios. This activity of comparison has been noted by other researchers (for example Exley 1998) who suggest that it contributes to patients' sense of wellbeing and a belief that they are more fortunate than others in similar situations.

8.5.3. The alternative reality

The alternative reality of the community is vital for some of its members. Lawton (2000) suggests that this reality is essential to enable people to reinstate their personhood which has been lost as a consequence of their isolation, disengagement and physical dependency arising from an advancing terminal condition. Within the alternative reality that she noted in her research, patients in PDC were able to feel normal again and aspects of self that had been diminished in other settings were recovered in the social world of PDC (ibid.).

The alternative reality that develops within the PDC community arises as a consequence of the shared work of staff members, volunteers and patients to keep death at bay. They seek to create and sustain its positive milieu, and protect it from aspects of dying that could serve to erode it. Lawton (2000) describes how the

"alternative reality" that she observed in PDC was dependent upon a mediating
and filtering role undertaken by staff particularly with regard to death. Jarrett and
Payne (2000) in their investigation of nurse-patient communication in a cancer
care context describe how patients and staff jointly contributed to talk that was
optimistic and hopeful in nature. They believed that dwelling on negative aspects
and being pessimistic could be unhelpful. Exley (1998) notes how the terminally
ill cancer patients she studied would avoid talking about their illness to reduce the
opportunity it afforded to take over or fill their lives. In this way they were able to
maintain more normal social interactions, and retain aspects of their identity
outside of their illness. Some structural aspects of community life also assist this.
A commitment exists, for example, to provide ongoing roles within the community
that survive the death of those that take them on. According to Hochschild (2000)
who studied an old age community and noted a similar process, this aspect of
community life served to create a feeling of permanence despite the ongoing loss
of members.

Skeptics of the service might argue that the apparent denial of death in this setting
does not allow patients the opportunity to face the reality of their imminent demise
and to undertake the preparation that is required to ensure the "good death", as
described by Kellehear (1992) for example. They might also suggest that imminent
death is something to be confronted rather than ignored, in order that people can
find meaning and locate value in the experience of dying (as, for example,
described by Hinton 1984). What is important to note in the context of this
research and its proposition, is that the impetus in DC1 and 2 to provide
opportunity for patients to be diverted from worrying about their illness and
forthcoming death came from the patients themselves. Those that I met in the
research, actively sought diversion from their illness and displayed considerable
pleasure when their illness no longer dominated their thinking, even for the short
period that they were in PDC. They had no desire to discuss their illness or its
consequences, a finding similar to that reported by Kellehear (1992) who describes
how a substantial proportion of the 100 terminally ill interviewees in his research

had no desire to talk to anyone about the subject of death or dying. Moreover they wanted to place distance between themselves and their death, a strategy also noted by Langley-Evans and Payne (1997) in their study of social talk in a PDC setting. Staff members and volunteers within the PDC community were aware of these preferences in the majority of patients that they cared for and shaped the service accordingly. Lawton (2000) describes such a process based on her study of a PDC unit which had diverged from its formal objectives to provide a new social world to meet the subjective needs of its patients. It apparently ignored its formal aims of the service concerned with providing a short-term rehabilitation programme in favour of providing a haven or retreat for its patients in which they could feel normal again and "live with their cancer" (ibid. p.40).

Thus, the alternative reality ascribed to the PDC community within the proposition and described in the literature does not so much seek to deny death, as to make it a manageable concept for those that face it imminently. Hockey (1990) who undertook an anthropological study of death in a hospice and residential home suggests that death was addressed in the PDC Unit she observed, but in a subtle way through the blurring of spatial and temporal boundaries. She was confident that in this setting patients could consider their future demise and acknowledge the death of patients around them but at a pace and depth determined by themselves, often amidst laughter and other activity that diluted the grave nature of these thoughts.

8.6. The negative consequences of community life

Members of the PDC community feel very attached to it, a common aspect of community life (Crow & Maclean 2000). Whilst positive in the main, the attachment that members have for the community can make the experience of leaving it a difficult one, particularly when their leave has been initiated by others. Even when professionals within the setting believe that discharge from the service is a positive step for the patient particularly when it represents a change in disease status, the patient may see it differently. This research suggests that patients

viewed discharge as expulsion from the community and rejection by people who have come to represent family to them. Literature concerned with discharge from PDC reflects the experience of those patients that I met who were both affronted and frightened by the prospect of discharge. Johnson (2001) describes how patients attending her service were often upset at being asked to leave PDC, using terms such as "being thrown out" (p.4) to describe their discharge from a previously safe and secure setting. In his study of a deaf community Higgins (1980) observed that members' identification with the community was permanent, even if their degree of impairment changed. This was similar for some people attending PDC. Patients discharged from PDC on the grounds that their condition was stable often yearned to be part of the community for extended periods after discharge despite this "good" news of remission from advancing disease. Like those who are deaf, they continued to see themselves as terminally ill regardless of changes in their condition identified by professionals, and consequently found it hard to establish relationships with those who didn't share this identity.

8.7. Variation within the proposition

One variation between the two communities studied in this research relates to the place of the individual within the community. In general terms some relinquishment of individuality for the benefit of the community is considered essential in order for any community to function effectively (Crow & Maclean 2000). Even so, the attention afforded to individual needs and preferences varied between the communities established in DC1 and 2.

Evers (1981), who examined the patterns of work organisation in long term geriatric wards, provides some pointers as to why this might be the case. She identified two care routines created by the staff – minimal warehousing and personalised warehousing which differed according to the degree of personalised care available to those resident in these settings. The term "warehousing" in this context is used to describe the application to patients of care routines that are predicated on implicit definition of patient need couched in terms of physical

problems and dependency. Whilst neither routines are ideal, the personalised warehousing careers of patients in long term elderly care are to be preferred. Evers (ibid.) suggests that the crucial differences between the routines related to how the work was planned and the relationship of the Unit and the wider multi disciplinary team of the hospital. Within personalised warehousing wards the ward sister would regularly do a round of the patients, review each patient and identify any particular needs or tasks they defined as necessary. Thus, even within a ward routine, care was individualised. In the same wards, the care of long-term elderly patients was acknowledged as valuable by the consultant geriatricians, reflected in the high level of attention that they offered these patients, despite their chronic nature. In addition they were highly responsive to requests for help and advice by the nurses working in this setting, and actively supported them in seeking the input of other professionals to enable patients to retain or rebuild their abilities. Whilst the patient group considered in Evers's research is different to those attending PDC many of the characteristics of the two care approaches are reflective of the approaches to care observed in DC1 and 2, that offered in DC2 being more individualised than that provided in DC1. For example the staff team in DC2 met on one or two occasions each day to review their patient needs and amend their care plans accordingly. They were confident of the support of the medical and other staff in the hospice in relation to the care of their patients and knew that their service was considered a vital and central component of the care of the hospice as a whole. In DC1, the staff team met less regularly, and care of individual patients was rarely amended even when staff considered their needs and the degree to which they were being met in this setting. This particular staff team experienced isolation from the rest of the hospice multi-disciplinary team on a daily basis and the medical staff within this team rarely visited patients in PDC. Those working in DC1 lacked confidence about the value assigned to DC1 by those outside it, including managers and senior clinical staff. Their suspicion in this respect was substantiated in my discussion with these stakeholders, many of who were unsure of the benefits of the service either in terms of meeting patients' needs or enhancing the care provided in other parts of the hospice.

The current study suggests that when care is individualised, patients enjoy a sense of security about the future. According to Evers (ibid.) and the findings of the current study this experience is facilitated by a close working relationship between the service and other palliative care provision. In the past a close working relationship between PDC and other hospice services has been prescribed on the grounds that it is reassuring and convenient for patients (Wilkes et al. 1987). This research would reinforce the value of this relationship, given the security that patients in DC2 experienced on knowing that they could be easily admitted to the inpatient unit in the event that their condition deteriorated. This has implications for PDC services who work in isolation from the rest of the hospice, including those separated geographically, and those that are stand-alone, effectively denying them any organisational link to inpatient palliative care beds (ibid.).

Another consequence of the care approach encapsulated in the description of personalised warehousing by Evers (1981), and illustrated in DC2 is the opportunity it affords to shape the care that a patient receives. DC2 effectively operated as the hub of its patients' care. Most people attending the service engaged in review of their condition each time that they visited PDC, giving rise to changes in the care that they received as necessary. They valued this aspect of the service, believing that any new needs they had would be addressed in a timely and effective way. This was borne out in experience, patients being referred quickly and effectively to other services as required. Tookman and Scharpen-von Heussen (2001) identify how a monitoring role in PDC increased the number of admissions to the inpatient unit, a pattern also observed in DC2. This is counter to the rhetoric in the past regarding PDC which has suggested that the service reduces the need for inpatient care through its provision (Stevens 1996). In the past, claims have been made about the contribution of PDC to a seamless service for its patients, on the grounds that the service enables a patient to move easily between home and hospice care as required (Fisher & McDaid 1996a). The current study challenges this claim in so much as it suggests that PDC may serve as either the hub or a spoke in their patients' care. For this reason staff within this service may or may

not be involved in facilitating changes in care, according to the importance they place on regular review of their patients' conditions.

The second variation in community life relates to the scope of care offered in each setting. The variations in care provision noted between the communities of DC1 and 2 may be linked to the different layers of activity which Higginson et al (2000) identify. Utilising their descriptions, it would seem that the community in DC1 offered a base layer of social support, overlaid with creative and therapeutic layers. The community in DC2 offered the same base layer with additional layers offering medical help, symptom control, artistic and creative activities and complementary therapies. As the current study demonstrates, patients' experience of PDC and the degree to which it meets their needs depends on the layers of activity that exist within a particular service. The holistic approach to care evident in DC2, which was reflected in the various layers of activity seemed to be of particular benefit to patients as they struggled to cope with the myriad demands of their condition. A multi-dimensional focus in relation to PDC has been identified to PDC in the past (Birch et al. 1997) and may explain the wide range of activities and care identified in previous surveys of PDC services (Copp et al 1998; Higginson et al.2000). One of the additional layers of activity in DC2 which patients placed particular value on was that of symptom control. This finding could challenge the proposal of Goodwin et al (2002) that PDC be provided as less specialist satellite services, if her suggestion would result in the loss of specialist symptom control skills in this setting.

The third variation concerns membership of the community and the degree to which families/informal carers were invited to become part of it and thereby benefit from its offerings. Research by Pottinger (1991) reveals a need in relatives caring for terminally ill people for emotional support, specifically the opportunity to discuss treatment plans, the patient's condition, their fears, a chance to express their feelings and to be comforted. These opportunities were not available to the families and carers of patients in DC1. Whilst they sought this help elsewhere, for

example from nurses working in the Hospice Home Care Team, the lack of support for these stakeholders was perceived to be a shortcoming of the service by some family members with whom I spoke. By contrast relatives were welcome within the community of DC2 and their inclusion did not appear to be to the detriment of the patients attending the service. The comfort afforded them, particularly as the patient's condition started to deteriorate and after their death was notable, reinforcing the findings of Pottinger (ibid.).

8.8. The literature regarding PDC

Many of the benefits of belonging to the community of PDC described in this research have been identified in previous research that has sought to understand patients' experience of PDC. Reference is made, for example to the milieu, relationships and activities within PDC, giving rise to increased self-esteem, social integration, autonomy, hope and reduced isolation (Hopkinson & Hallet 2001; Kennett 2001; Kennett 2000). According to the literature, patients place particular value on feeling wanted and cared for in this setting (Martlew 1996). The work of Langley-Evans and Payne (1997) identifies PDC as a mutually supportive environment for discussion about death, illness and cancer. This is confirmed by Goodwin et al (2002) who highlight the social value of PDC, in particular the opportunity to meet people, "meaning not just talking and socialising, but also meeting people who understand" (p.561).

The proposition that PDC serves as a community provides a framework which links these benefits and identifies the components of the service which give rise to them. It places particular importance on the opportunity provided by PDC of a place where people with common needs arising from advancing and terminal conditions can come together as a group and engage with each other. This finding may challenge the suggestion of Clark and Seymour (1999) that PDC services providing long-term social support be delivered at less cost by non-specialist services if patient opinion carries more weight than the need to reduce costs. Their option would effectively deny patients the opportunity to be with the "sympathetic

others" to which Goffman (1963) refers, if by "non-specialist" they mean services such as elderly day-centres and luncheon clubs which serve people with a variety of needs and conditions. The proposition also highlights the complexity of PDC in its identification of its work as a group within which the relationships and interactions are vital to the benefits of its users. This is a relatively new slant on the service and builds on the suggestion that PDC is complex made by others (for example Myers & Hearn 2001). In so doing, it challenges the original view of PDC as a simple service to provide (Wilkes et al 1978). It also presents some cause for concern given previous findings that some services are run by individuals with few or no formal qualifications (Copp et al 1998).

The research of Goodwin et al (2002) considered whether patient perspectives of PDC varied between services purporting to provide different models of care. The authors were interested to note that the most important thing for patients about PDC was the opportunity to meet people regardless of whether the service was based on a social, medical/social or medical/therapeutic model of care. These findings are reflected in this research and its proposition. The community existed in both DC1 and DC2 with only minor variations despite claims by staff members in these settings that they operated according to different models of care. As Goodwin et al (2002) state, previous differentiation of models of PDC (for example that proposed by Eve & Smith 1994) has been based on health professionals' definitions rather than patients' experiences of the service according to who works in them and how the service is delivered. Their findings and mine suggest that professional differentiation of PDC services does not reflect patient experience of them. These two pieces of research also suggest that the social aspect of PDC inherent in the experience of being part of the PDC community is the most important element of the service from the perspective of those using it, irrespective of who is involved in providing PDC and its emphasis of care.

The effectiveness of PDC is a question posed recurrently in the literature (for example Spencer & Daniels 1998). This is, in part, due to the lack of evidence

available regarding the impact of the service on its users. It has also been attributed to the use of inappropriate measures to gauge the effectiveness of PDC given the lack of knowledge about users' perceptions of the service (Goodwin et al 2003). Tigges (1993) proposes indicators of quality of life for use by hospices that would reflect many of the offerings of the PDC community. For example he suggests indicators that are concerned with the alleviation of feelings of helplessness, hopelessness and uselessness within individuals that are dying rather than those that focus exclusively on the provision of symptom control, care and support. The findings current study would suggest that PDC would be evaluated in a more positive light if the criteria proposed by Tigges (ibid.) were used to measure its impact. In so doing, the opportunity provided to community members to find purpose, status, recognition, to feel valued and important and to experience choice and autonomy and achievement would be recognised. This suggestion does not negate the importance of symptom control, support for carers and similar provided within PDC; instead it places these offerings in the context of the consequences of living with a progressive and life threatening condition for patients and their families/carers.

8.9. The proposition in the context of palliative care

This research reveals an important role for PDC in supporting patients at a social level as they strive to cope with having a progressive and life threatening condition. For this reason PDC provision would seem to be a vital component of palliative care, given the commitment of this speciality to treat the person with a progressive and life threatening condition holistically, with attention to their social needs (World Health Organisation 2002). This has been emphasised in a policy briefing paper produced by National Council for Hospice and Specialist Palliative Care Services (2000) on the concept of "psychosocial" in palliative care which urges recognition by practitioners that the meaning, experience and expression of terminal illness by sufferers is shaped and influenced by the social fabric of their lives. The paper suggests that attention to this fabric is essential if palliative care is to be fully effective, and it makes a number of key recommendations in relation to

this provision to ensure people's social needs are identified and addressed. One of these stresses the importance of addressing the broad social contexts within which patients and families live their lives. Another emphasises the importance of considering social aspects of care, which the authors suggest is currently masked by consideration of psychosocial needs as a single entity, rather than two different sets of requirements. The value of attending to social needs is highlighted by a recent article by Kelly et al (2003) which identifies factors that contribute to a wish in some terminally ill cancer patients to hasten death. These include the experience of demoralisation that encompass feelings of hopelessness and loss, feeling a burden to others and having fewer social supports. The community of PDC would seem to be able to offer much to these patients if they were to have access to it. For this reason, the tentative place of PDC in the guidelines from the National Institute for Clinical Excellence regarding supportive and palliative care (National Institute for Clinical Excellence 2004a) are concerning as they may leave the service vulnerable to reduced funding, when scarce resources are allocated on the basis of existing evidence of effectiveness.

8.10. Summary of the chapter

This chapter has considered the proposition that PDC serves as a community in the context of the literature. It highlights the value of community life for people on the margins of society, such as those who are dying, and confirms that key characteristics noted in the PDC community also exist in other communities. It identifies literature that endorses the value of community life The literature helps to clarify why community life is valuable for people who have a progressive and life threatening condition and offers insights regarding its particular offerings. Review of the proposition in the context of the literature suggests that it builds on existing knowledge regarding PDC and adds to the limited evidence that exists regarding the important role held by the service in providing social support to those that have a progressive and life threatening condition. Even so, the proposition requires further testing, a recommendation made in the final chapter.

The next chapter offers my reflections on the current study and its findings, including their relationship to the literature.

CHAPTER 9

REFLECTING ON THE RESEARCH

9.1. Introduction to the chapter

This chapter describes my reflections on the process of undertaking this research and its findings. It provides an opportunity for me to stand back and make some comment on the findings of the research without jeopardising the main aim of the research – that of describing PDC from the perspective of those using the service. It also makes explicit my relationship with the research and how I have contributed to it, an essential component of qualitative research (Peshkin 1988).

Within the chapter I consider the findings of the research, then identify its strengths and weaknesses. Finally I contemplate the contribution that I, as researcher, made to the research and that which it has offered to me. In writing this chapter I have drawn on my reflexive diary written during the period of the research, and a second diary which charted the process of collecting data and changes to the methodology that were implemented in response to issues and problems that arose during data collection. I have also revisited notes that were made at various stages in the research when I would seek to stand back from the minutiae of data collection to consider my findings in their wider context. As I ponder on their meaning for care professionals, managers and planners of palliative care services I have drawn on my own experience of these roles in the past.

9.2. My reflections on the findings of the research

9.2.1. PDC – a valued service by those using it

The findings of this research suggest that PDC is a valuable service from the perspective of those who use it. They evaluate it in positive terms and are clear that the service meets vital needs in them that are not addressed elsewhere.

These needs are commonly those that are social in nature. They are met in PDC through the provision of a community to which they can belong. It offers new social support and a network of friendships, which commonly serve to replace aspects of their lives that have been destroyed as a consequence of their illness. Patients that benefit from being part of the community are people whose network of social support is disintegrating or lost. In joining PDC, the social fabric of their lives is strengthened, enabling them to retain or regain some aspects of self that have disappeared as a consequence of their illness. The social benefits of attending PDC are derived primarily from the relationships that patients establish with others within the community who either share their condition or appreciate their situation. It is also a consequence of the alternative reality created within the service, which they can become part of. These elements of PDC are available regardless of the purported model of care of the service, and differences in the composition of the staff team working in this setting.

Patients' value of PDC is enhanced when care offered within the community has a holistic focus. In this research the patients who had access to skilled symptom control, practical support and basic nursing care were able to derive even more from the community. In addition it served their families and carers. This provision served to reduce many of the anxieties experienced by patients related to the consequences of their illness and their future, and in so doing, enabled them to engage more fully with community life and its relationships. It is interesting to note that patients' value of symptom control was not reflected in the findings of Goodwin et al (2003) regarding the effectiveness of symptom control in this setting. This apparent disparity would benefit from further exploration to ascertain appropriate outcome measures for this activity according to users. It is also interesting to note the different approaches of DC1 and 2 in relation to meeting needs of patients that might be deemed to fall outside the arena of palliative care. In DC1, the responsibility for basic nursing care, practical support and ongoing medical support lay with the primary care team and social services. In DC2, those within the service provided much of this, on the grounds that it was more

convenient for patients and responsive to their needs. Patients supported this approach in the value that they ascribed to it.

In my view these findings have some important implications.

First, they highlight the importance of PDC for people with progressive and life threatening conditions, particularly people whose social being is at risk. This clarification helps to identify who will benefit from attending the service. They are those who have become disengaged from social networks and relationships that have supported them in the past. In addition the findings suggest that PDC is a service which cannot afford to be cut even in a context of scarce resources given the importance that users place on PDC. The research suggests that PDC makes a unique contribution to people who are terminally ill through its offer of social support. In the past it has been suggested that PDC is the Cinderella service of palliative care (Gibson 1993), a view that is dispelled by this research in its assertion that PDC has something vital to offer to some people with progressive and life threatening conditions. This assertion would need to be substantiated by further evaluation of PDC with social support as its focus, a proposal also made by Goodwin et al (2003) based on the findings of their study of PDC.

Second the findings suggest that those working in PDC need expertise in psychosocial care. A recommendation has been made in the past that social care is delivered by those with expert knowledge, namely social workers (National Council for Hospice and Specialist Palliative Care Services 2000), but this does not appear to be reflected in the skill mix of staff working in PDC. Previous research is equivocal about the level of involvement by this professional group in PDC (for example that conducted by Bray 2001 and Copp et al. 1998) and there appeared to be little or no input by social workers into DC1 and 2. Although care in these settings appeared highly skilled in general, there was also description of aspects of community life which were potentially damaging to its members as a consequence of limited expertise on the part of staff members and volunteers.

These included the burden of reciprocal relationships, the lack of professional distance between staff members, volunteers and patients, and the emphasis on meeting subjective patient needs, regardless of formal objectives or operational policies. This might have been reduced if professionals with psychosocial expertise had been involved in service provision on a regular basis.

In my view these findings could help to differentiate the care provided by PDC to that offered by other palliative care services, particularly those offering community based care. Even so, questions remain about whether PDC serves as an alternative for these services, whether it should work in tandem with them to achieve the best quality of life for the patient, or whether aspects of the service are duplicates of others. In the light of the scarcity of resources available to palliative care services, this issue requires further exploration as a basis for recommendations about how PDC should be positioned in the future. Within these considerations, attention is required to the advantages and disadvantages of a model of PDC which serves as a central source of help including that which could, by definition, fall outside the arena of palliative care. This requires a realistic review of the aspirations for seamless care between different agencies, within the context of a rapidly changing illness that often gives rise to a variety of needs.

9.2.2. The users' perspective – a highly positive viewpoint

The highly positive nature of PDC according to its users is notable. The joint constructions of DC1 and DC2 are based on strong claims about the service on the part of patients and their carers that far outweighed any concerns regarding PDC. In relative terms, the number of concerns regarding the service were few, and those that I identified in relation to the services studied were commonly rejected from the respective joint constructions on the grounds that they were not consistent with the experience of those using the services. Furthermore patients described a process within which they negated the negative aspects of the service in the light of its positive contribution to their lives. Even when I witnessed incidents which I felt were unhelpful for users, these were reconstructed by the user and others around them as a positive element of attending the service.

On reflection, two questions are raised by this situation. The first is concerned with the possible reasons for the high value placed on PDC by users, to the point that unsatisfactory aspects of the service were ignored. The second relates to the degree to which my own concerns had validity, given that users did not seem to identify with them.

In relation to the first question I can only speculate, drawing on the data collected during the course of the current study. I wonder whether the value that they placed on PDC related to the quality of the rest of their lives, whereby attending DC1 or DC2 was experienced as a highlight compared with the difficulties that they experienced the rest of the time. Often patients described an existence outside PDC that was lonely, degrading and uncertain. It may have been related to their previous experiences of health and social care, in which they had felt disregarded – a situation which many patients felt had been reversed at the point that they were referred to PDC. Commonly patients had been told that there was nothing further that could be done for them by other health professionals, and care had been withdrawn as a consequence. This left them bereft of previous support and fearful about the availability of care in the future. Another explanation may be that patients and carers felt compelled to speak favourably about the service, for fear of upsetting the staff members and volunteers, on whom they were dependent for care and support. This would explain the scenario encountered during the focus group held in DC2 in which patients who had described concerns at interview were reluctant to discuss them openly with others involved in the service in a group setting. Alternatively they might have felt a need in themselves to construct a setting that was caring and inclusive, as a means of surviving the loneliness of dying. This would explain the times when they offered a positive connotation for behaviour on the part of staff members or volunteers which I found unacceptable.

In relation to the second question, I wonder whether my distance from death (at least as far as I am aware), compared to that of the patients attending the service

does effectively deny my views any validity regarding their experience of the service. Whilst I sought to adopt an empathic stance in relation to their situation, there is no way that I can really know how it feels to live with a progressive and life threatening condition or how this affects one's view of the world. Thus, whilst I might view aspects of the service as negative or unhelpful, this may be perceived differently by patients in the light of their experience of their illness and its meaning for them. However, if the reason for the positive descriptions of DC1 and DC2 lies in an unspoken pressure for patients and others involved in the service to speak only favourably about PDC, then the views of an outsider who does not have to yield to such pressure are even more important in evaluating this service.

These issues require further exploration and consideration. Attention is required to the question of whether these issues are unique to the current study and its participants or whether they arise in other studies when users can determine what and how data is presented. In the meantime the value of such research is considered further in Section 9.3 in terms of the strengths and weaknesses of this methodology.

9.2.3. PDC – a complex service from an outsider's perspective

When my own experiences, values and beliefs are imposed on the data collected for this research I see a service that is complex. It arises as a consequence of the many needs of the different members of the community, their relationships, the separation of the community from the outside world and members' requirement of an alternative reality. This complexity is hardly addressed in the literature and was rarely acknowledged during the course of this research, even by those who were familiar with the service. This in my view serves as an important omission, as this complexity is at the heart of both the benefits of the service and its potential harm to those involved in it. This juxtaposition means that elements of community life that are usually perceived as helpful and valuable by those involved in the service can also be highly destructive to community members if their complex nature is unrecognised. The relationships that I observed in DC1 and 2 were a good

illustration of this. They were intimate, reciprocal and informal in nature and offered benefits to patients that included renewed self-value, a sense of equality and the experience of being part of a family. However they could also lead to confusion in the members about whose needs were paramount in this setting and sometimes served to disempower patients from asserting their rights as users of the service. They could also subject surviving members to a series of distressing losses when patients died in quick succession.

A complexity of PDC that I noted related to the balance required within the service to facilitate a group experience whilst also serving individual members and their needs. When this balance was lost and the group experience was all-important, a more detrimental side of community life became evident. Within it, patients' individuality was denied and their autonomy was undermined. This aspect of PDC was often unrecognised by those involved in DC1 and 2, as it was counter to their rhetoric regarding the care that they were providing and because it was derived from aspects of the service that were well intentioned. This concealment potentially makes this aspect of PDC even more harmful on the grounds that no efforts are made within the service to monitor the balance, neither are there mechanisms in place to safeguard against the potential loss of individuality within the group.

Another complexity of the service lay in the relationship that I observed between care and control in this setting. It seemed that control of death was effected by the care offered by the staff and volunteers, manifested to a great degree by their contribution to the alternative reality of the community. At times it seemed that the need in staff members and volunteers to limit the impact of death overrode their commitment to hearing the individual needs of patients, particularly that which could not be met within the alternative reality. In this instance their needs and their right to have them met were denied. The relationship between care and control has been considered in detail by Hockey (1990) as she describes the process of managing death in her book "Experiences of Death". She suggests that in the face

of physical deterioration and decay leading to death self-control and the control of others are complex and challenging issues. They must be balanced "lest they be transformed into uncontrolled, unmanageable caring or careless, callous control" (ibid. p.196). However, I am aware that autonomy within hospice settings is a complex issue in itself. The control given to terminally ill patients in hospice settings was considered by Mesler (1995) as part of an ethnographic study concerned with how those working in hospice settings define and accomplish their work. He concluded that despite efforts on the part of hospice staff to enable patients to be autonomous in their care, their attempts were often constrained by issues related to treatment, the care setting, disease status and staff boundaries. I noted many of these constraints in DC1 and 2. Many of the patients that I met believed that their condition demanded that they were cared for, that they required the input of experts and that the professionals located within the hospice knew more about their condition than they did. For these reasons they were happy to hand management of their illness over to the staff, making themselves even more vulnerable to an inappropriate balance of control within the caring relationship of the community.

Another element of the complexity of PDC is linked to the self-perpetuating nature of the service. This arises as a consequence of its principal concern to meet the needs of its users. Whilst this focus gives rise to a highly attentive and responsive service for patients who feel cared for and valued as a result, it may limit opportunities for a broader perspective. The concern by staff members and volunteers to attend to the needs of those currently using the service mean that they may ignore the needs of others currently outside the service, particularly those with alternative wants for care. It may also serve to deny any attention on their part to the requirements of other external stakeholders such as policy makers and purchasers. The mutually endorsing relationships established between staff members and volunteers and the patients can be sufficiently engaging to a point that any objective reflection of them is rare. In my opinion this inward perspective makes the service and those within it vulnerable. It means that PDC may be

unaware and therefore unprepared for changes in the health and social care arena that could jeopardise its future. It may also result in an accusation that PDC only cares for a small proportion of those who might benefit from attending the service because those involved in service provision are simply unaware that others exist or choose to exclude those who present with alternative needs. The lack of reflection may also account for the emotional pain exhibited by some staff arising from their relationships in this setting. I felt concerned for their wellbeing and that of their patients in the long-term given the level of personal involvement by some staff members and their lack of insight in this regard.

This complexity is difficult to address, not least because criticism of the service felt difficult for me to deliver and seemed particularly hard to accept on the part of those involved in the service. This may be linked to the strong moral component of community life that Kennard and Roberts (1983) describe, commonly related to the nature of relationships within the community. This component, according to them is double-edged. Whilst it serves to generate enthusiasm and commitment in those working in these settings and is galvanising in nature, it can also result in idealisation, within which criticism is neither heard nor accepted. This was supported by my experience of the focus group in which previous comment about the service, which could have been perceived as negative, was withdrawn by participants when they were in the company of others.

The degree to which any conclusions can be drawn from my views of PDC is uncertain as they are highly subjective in nature. Moreover I was unable to find others within the service that were willing to discuss these insights with me as a means of ascertaining the degree to which they were shared. Staff members, volunteers and patients alike were resistant to consider them on the grounds that they were negative in nature, a stance that I found disturbing. It seemed that there was no freedom afforded to anyone in the community to raise concerns about the service, in case the negativity served to destroy the valued aspects of community life such as the positive regard within which its members held each other. As a

consequence these particular observations are, to a large degree, unsupported by those inside the service, and so the following implications are proposed on a tentative basis only.

First, I would suggest that this degree of complexity in organisational life calls for skilled leadership. If this is lacking, then patients' wellbeing is potentially at risk. The literature describes a situation in which the leaders of PDC services are employed at a range of grades, including some who have no formal qualifications at all (Bray 2001). This suggests that the difficult nature of the Day Care Leader's job is sometimes unrecognised. In the past there have been calls for minimum standards relating to the staffing of PDC services (Faulkner et al 1993), but this has not been addressed to date.

Second, if staff members and volunteers do not receive regular supervision and support related to their work in this setting, their contribution to the relationships of the community may be experienced as destructive by the very people they seek to help. Supervision would provide an opportunity for them to reflect on their contribution to the community, and its impact on them and would help to ensure that any needs they have arising from working in PDC are addressed, whilst also protecting patients from inappropriate demands on their part. Supervision needs to be offered by individuals who are sympathetic to the work and life of the community and the role of staff members and volunteers therein. This supervision is common in other forms of community life such as therapeutic communities (Kennard & Roberts 1983) for the very reasons identified above.

Third, PDC is at risk if it does not seek to become more outward looking and reflective in its operation. Its self-perpetuating nature is, in part, a consequence of its isolation. This suggests that integration of PDC with other palliative care services is essential to ensure a service that is responsive to the context in which it is operating. This point reinforces the recommendation made by Myers as to the development required of PDC to ensure that it is able to respond to challenges in

the future (2001). It will also assist it to become aware of potential users of the service with different needs. However it would be naïve to see this merge as straightforward. The boundary established between PDC and the external world has an important function of separating the insiders and outsiders, and integration may serve to threaten this. However, as DC2 demonstrates, the PDC community can work effectively as an integral part of a bigger hospice service.

Finally, this complexity needs further exploration in future research in order to ascertain, with more certainty, its origins and contributing factors. I am left with unanswered questions about the unspoken rules of the communities of DC1 and 2, the shared language that I observed in both settings and ways in which members behaviour was fashioned according to the values of the community. These elements of community life require further examination by researchers in the future.

9.2.4. PDC – a service little understood by outsiders

As I reflect on the research, it seems that the understanding of PDC by its different stakeholders varies according to whether they are insiders or outsiders of the community. Those on the inside are familiar with patients' stories, they understand the difficulties of living with a progressive and life threatening condition and comprehend how PDC works to amend this experience. Moreover, a significant proportion of those working in the setting share many of the same needs as the patients that they care for. In contrast those on the outside often have little understanding of the context of patients' lives or their problems and are ignorant of the nature of PDC and its provision. These differences in comprehension are, in part, a consequence of various aspects of community life. For example they arise as a result of the boundary established around the community that keeps outsiders away and the lack of interest by those within it to work with external stakeholders at the cost of providing care to their members. The organic nature of the service that evolves in response to the needs of those using it regardless of formal

objectives that are communicated to the external world also contributes to the different levels of understanding.

The lack of understanding of PDC on the part of external stakeholders has important implications for the service. First it could serve to deny funding for the service if those with responsibility for allocating monies are unaware of its vital role in the lives of those using the service. Second, managers may disregard vital elements of PDC in any plans for development of the service, particularly when aspects such as social support are assigned little value in their view. Third, there is little opportunity for those referring patients to the service to make informed decisions about who is likely to benefit from PDC if they do not know what happens within the service. Finally there are calls for new evidence about the effectiveness of PDC (National Institute for Clinical Excellence 2004a). If the outcome measures chosen to provide this evidence are not commensurate with the nature of provision and its outcomes, then the findings will be unfavourable even though the current study reveals a service that is highly valued by its users.

9.2.5. The PDC community – an overarching model of care

As described in the previous chapter, the case studies of DC1 and 2 build on the limited work that has been reported in the literature regarding patients' experience of the PDC. They reinforce the value of the social support provided in PDC which has been described by others (Goodwin et al. 2002; Hopkinson 1997; Lawton 2000), particularly that derived from relationships established in this setting. They also reiterate the value of the alternative reality described by Lawton (2000). They link these valued aspects of PDC to the experience of patients of living with a progressive and life-threatening condition. As such the findings reflect the consequences of advancing, terminal illness that are described in the literature, particularly the loneliness of dying and the degradation of self.

From the perspective of those using the service, there is little evidence of differentiation of services according to the different models of PDC that they

purport to provide. It would seem that the tems "social" and "medical" models of care, which were proposed in the past by Eve et al (1994) as a means of differentiating services have no currency in the context of patient experience. The more recent proposal of a "creative" model of PDC (Higginson et al 2000) would also seem to be irrelevant in this context. This may be explained on the grounds that professionals rather than patients have assigned these labels to the service in the past.

The proposition offered in this research, whereby PDC serves a community, has currency in at least two services – DC1 and 2 even though these services purported to provide different models of care and their care provision was dissimilar in many respects. This would suggest that the proposal of PDC as a community could serve as an overarching explanation or model of PDC, within which variations in care provision are possible. According to this research belonging to the community offers a variety of benefits to its members. Many of them have been claimed in the past on behalf of PDC, although there has been limited explanation as to their origin. The proposition amends this situation, highlighting the place of relationships within the community, its alternative reality, its milieu and activities as the basis for the improved quality of life ascribed to PDC in the literature (Spencer & Daniels 1998).

The degree to which this proposition would be true in other services is uncertain. In addition a question remains as to whether services based on a rehabilitative model of care as described in the literature (Hopkins & Tookman 2000) would also provide a community for those using it. Further research is required to consider these issues further.

9.3. Strengths and weaknesses of the research

These are considered in relation to the focus of the research, its methodology and outputs.

The focus of the research on user views of PDC is, I believe, a strength of the research. It is timely, given governmental interest in users' perspectives and their importance in service development and evaluation. It is also necessary in the light of the relative paucity of research regarding user experience of PDC. The work has been valuable to those working in DC1 and 2 as they seek to make their services more patient-centred, not only through its findings but also as a consequence of being involved in the process of learning these views. The research has served to substantiate existing findings concerned with user experiences and views of PDC services and build on them in its proposition. This identifies aspects of PDC that are particularly important according to users, which could form the basis of outcomes for evaluation of the service in the future. These characteristics also serve to differentiate it from other palliative care services such as outpatient clinics or home-care teams.

The use of case study has been valuable in meeting the aims of the research. It provided a detailed description of two PDC services and enabled patient views of PDC to be linked to the structure and process of care in this setting. This enabled the identification of those aspects of PDC perceived as particularly beneficial by its users. In many instances this insight built on existing research particularly that which was phenomenological in approach (for example Hopkinson & Hallet 2001), by adding detail regarding the way the service operated to knowledge of patient experience. This detail was key to considering the question of how patient experience related to models of PDC. In the past the literature has considered models of PDC according to who worked within the service (Eve & Smith 1994), its activities (Higginson et al 2000), and discourse within the setting (Langley-Evans 1999). Attention was required to these various facets of the service to consider the issue of models of care further. A case study strategy enabled this, given its ability to consider the phenomenon of interest in a multi-faceted way by drawing on a variety of data. This research strategy also served to place DC1 and 2 in context, highlighting how they related to other hospice services and the wider

external environment in which they operated. The choice of which studies were included in the research drew on previous research which identified medical and social models of care (Eve & Smith 1994). This choice represents a potential weakness as it does not allow the findings to be extended to other purported models, including that concerned with rehabilitation (Hopkins & Tookman 2000). Another potential weakness of the research lies in the boundaries identified for each case. Whilst I included patients who had been discharged or who had left the service, all those that I interviewed had left within a year of the interview. Suggestion has been made by other stakeholders within the service that the issue of discharge from PDC, according to users would have generated different data had I interviewed people who had left the service after a longer period, during which time they had adjusted to life without PDC.

The chosen methodology of constructivist inquiry has been successful in offering patients a central role in shaping the research and its findings. The organising foci of claims, concerns and issues within the interviews enabled participants to identify those aspects of the service which they most valued, which then became central to the joint construction of each service and the proposition regarding PDC. This was key to learning about the service from their perspective. It served to redress some of the shortcomings of previous research into PDC such as that described by Goodwin et al (2003), who highlight the limitations of studying the service on the basis of professional views of PDC rather than those belonging to patients. Learning how patients constructed the service led to an understanding of the various contexts of their lives including that of living with a progressive and life threatening condition and how these were affected by attendance in PDC. This link has not always been explicit in previous research regarding the service, and as such serves as an important contribution to understanding about PDC from the perspective of its users. Furthermore it helps to identify circumstances faced by patients which exacerbate their need for the support available in PDC. In addition the hermeneutic dialectic process of constructivist inquiry allowed patients an active role in the collection of data and its analysis. In planning the research I

hoped that this input would take the form of a partnership between the researcher and the research participants. The degree to which this was achieved is debatable. According to the Oxford Dictionary a partner is defined as "One who has a share or part with another; a partaker, a sharer". In many respects users and others involved in DC1 and 2 were partners in this respect – they had a share, a part in the research and its findings and have undoubtedly influenced its outcomes, this being particularly evident in the changes to the construction of DC2 following the focus group in that setting. However I am uncertain that my relationship with other participants could be considered an equal one. I believe that this was because of our different roles in the service, our dissimilar perspectives on life and death and our diverse experiences of healthcare provision in the past. I was never more aware of this than when I was talking about the possibilities for the research and its findings in the future. Regardless, the working relationship that we established to identify a joint construction of the service seemed to be an empowering and engaging process for patients, and on occasions took the research in a direction that I had not expected. There was no evidence that it was burdensome for those participating and I am unaware of any distress caused by their involvement. Patients would often remain involved in the research longer than expected, suggesting that engagement in the process was valuable for them. On balance it is an approach that I would seek to replicate in the future, but with an increased awareness of the complexities of establishing a relationship of equality.

Despite such favourable aspects of constructivist inquiry, there are also some potential drawbacks associated with the methodology in my view. Most notable is the requirement that my views regarding the service could only be included in the joint construction if users of the service concurred with my offering. This meant that if my experiences or judgements of the service were at odds with those using the service, they were disregarded in terms of the joint construction. Whilst the main aim of the study was to describe PDC from a user perspective, I believe that an outsider's view of the service could be valuable, particularly if patients find it difficult to describe negative aspects of a service (see section 9.2.2 for further

discussion in this regard). I have sought to get around this problem by describing my views that were excluded from the joint constructions of DC1 and DC2 in this and Chapter 10. However, they have not been allowed to shape the joint constructions described in Chapters 5 and 6. Given this, it may benefit future research projects that utilise constructive inquiry to seek out joint constructions held by other stakeholder groups in addition to that belonging to the user, as proposed by Guba and Lincoln (1989) in their description of Fourth Generation Evaluation. The differences in the constructions could then be negotiated in an open way, bringing the outsider view alongside that held by users.

The focus group conducted at the end of the study of DC2 was designed as a form of member checking – with the aim of ensuring that the multiple realities that formed the basis of the joint construction were those that the patients provided during the course of the research. This served as an important means of ensuring the validity or credibility of the research (Guba & Lincoln 1989). However, the amended views of participants in a group context compared with those learnt during interviews made this process complex, and raised questions about how to use the data that the group generated and indeed whether this form of data collection was effective. I made the decision to use the data, based on a personal belief that all data has value when it is viewed in context. Furthermore there were outcomes from the group such as clarification of the claims most important to patients that were generated through group discussion that would have been hard to discover in interview alone, particularly given the limited time that I had in each setting to repeat the hermeneutic dialectic circle. For this reason I believe that the focus group in DC2 was useful in building its joint construction, although it had some limitations. By implication, failure to conduct a focus group in DC1 served as a weakness of the research, not least because it represented a difference in methodology between the two studies.

The research gave rise to a proposition regarding PDC which suggests a common experience of PDC by users across different services. This serves as a new way of viewing PDC and would seem to be a working hypothesis based on the response of

people involved in the service who have considered the findings of this research (PDC Leaders, verbal communication, Day Care Leaders Conference 2002; Hospice Nurse Managers, verbal communication, Hospice Nurse Managers Conference 2004). However this proposition remains tentative and requires further testing in other settings to assess its validity in other PDC settings. A potential weakness of the research lies in its efforts to identify a proposition from research based on a methodology of constructivist inquiry. In pure terms, a methodology which stresses the uniqueness of the individual's viewpoint does not lend itself to generalisation of its findings although Guba and Lincoln (1989) do suggest that constructions may be shared. This has been overcome to some degree by efforts within the thesis to provide sufficient detail about DC1 and 2 to enable the reader to assess the degree to which they are similar to other settings, and therefore whether the findings of the research are transferable.

The research questions regarding the similarities and differences between patient views and those of other stakeholders have only been addressed briefly in relation to the two services studied. This is a potential weakness of the research in the light of its original aims of the current study, but reflects a change in the emphasis of the research as it got underway, in the light of the complexity of PDC according to its users. If the research were to be replicated the hermeneutic dialectic circle could be repeated to include other stakeholder groups, as undertaken within Fourth Generation Evaluation (Guba and Lincoln 1989). This would make the picture of PDC more complete and provide new opportunities for negotiation between stakeholder groups as they work towards a joint construction (ibid). In so doing, it would enable exploration of differences between the views of the different groups. In DC1, for example, it would have been useful to consider how the lack of attention to carer needs was perceived by patients. It has been speculated that they enjoy the experience of an exclusive activity which serves to build their self esteem but this has not been discussed with patients attending the service.

9.4. My contribution to the research

Throughout the research I have been mindful of the interaction between the research and me. Much of the time it has been deliberate on my part; I have called on my experience of being part of the life of PDC to build upon and interpret the data offered from other sources. At other times the interaction has been subtler and I have suddenly become aware of viewing the data in a certain way based on previous values and experiences. The purpose of the following section is to make these values and experiences explicit in order that the reader can determine their impact on the research and its findings, a strategy endorsed in the literature, particularly that concerned with qualitative research (Creswell 1998; Glesne 1999; Peshkin 1988). In so doing, I have concentrated on the key tasks of the research – that of describing PDC from the users' perspective, comparing it with that of other stakeholders, developing a proposition from the data and translating it for potential readers.

In considering the first task – that of articulating the views of users regarding PDC – a question must be posed as to how faithful I was to them. This ambition for the research was certainly challenged by aspects of my self, in particular, my fear of the depth of pain and vulnerability described by some of the patients with whom I spoke. This surprised me when it first happened. I had worked in palliative care for some years and had been exposed to the stories of patients that were dying many times before. However as a researcher I had none of the protection afforded to me as a health care professional. I could offer very little to these patients in terms of advice or support and was unable to busy myself in the tasks of assessment, referral and hands-on care that I would have done as a nurse interacting with the patient. In addition the vivid descriptions by patients of the loneliness and fear that they experienced reawakened similar feelings in me, reminding me of a time some 20 years previously when I had received a tentative diagnosis of malignant disease. This identification with patients' stories sometimes resulted in reluctance on my part to remain part of conversations that focused on these feelings. It also posed a question in my own mind concerned with how I would feel about PDC if I

were a patient in this setting which served to deflect my attention from learning the views of those currently using the service. I hope that in becoming aware of these aspects of self, their impact on the research was lessened. They may even have been helpful, as this identification gave me added impetus to tell their story, and to convey the desperation that some felt about their predicament. However it may have contributed to my experience of "going native", described in Section 4.9, which potentially served to undermine the value of the contributions of other stakeholders to the detail of the joint construction. As such, it was vital that this subjectivity was acknowledged and monitored.

The subjective experience of undertaking this research affected a secondary task of the research – that of comparing users' views of PDC with those of other stakeholders. When I started the research I saw myself as a health professional interested to learn more about patient views of PDC. As the research progressed I became aware of a shift in loyalties associated with a preoccupation to tell the patients' story in the research. I no longer felt the same need to place their experience of PDC in the context of the experience of other professionals. Instead I simply wanted to ensure that their viewpoint became known. I believe that this is reflected in the emphasis of this thesis, within which there is limited portrayal and discussion regarding the perspectives of PDC held by other stakeholders. This shift in loyalties was one that I could not reverse even when I became aware of it. I found it increasingly hard to comprehend the views of some professionals that I spoke to and was aware of wanting to negate their perspective when it appeared to undermine that of the user. I recall, for example, finding it particularly difficult to explore the issue of discharge of patients from PDC with professionals who appeared unaware and dismissive of the distress that I had noted in those patients who had been discharged from the service against their will. I would find myself in a position where I wanted to make them understand the patients' view on it, rather than listening to their experience and views of the process. As I became aware of it, I sought to amend my approach in order to hear their perspective,

acknowledging my commitment to the patients' perspective openly within the interview and afterwards in its analysis.

The third task – that of drawing the data together and interpreting it – has been the element of the research which I feel has benefited most from my subjective stance in relation to the research. In a considered way I would regularly reflect on my experience of being part of PDC as a means of understanding the data offered by patients. On occasions this was particularly illuminating. For example my experience of being cared for in DC2 as a consequence of being pregnant gave me first hand experience of the sort of care that patients received in this setting. In addition I learnt much from reflecting on my experiences of joining and leaving the services that I studied. I would however seek to temper the place of this experience in my interpretation of the data in the knowledge that my situation was not the same as the patients. In the development of the joint construction this was achieved by posing my views to patients for their critique and comment; in the formation of the proposition, I sought data that either confirmed or refuted the emerging interpretation, thereby embedding my experiences in those of the patients and their families. Reflecting on my experience of writing this thesis has also been helpful in drawing together my findings. For example I found it particularly difficult to write about my views of the service which were negative in nature. I believe that this reflected the problems experienced by others of articulating concerns about the service, something that I had noted during the research.

The final task – that of translating the findings of the research for others – is based to a large degree on my previous experience of working as a nurse and manager in palliative care. My reflections on the research and their implications, described earlier in this chapter, draw heavily on this experience. In some instances the implications that I highlight reflect gaps in my knowledge in the past such as that concerned with who is most likely to benefit from attending PDC. In other instances, the recommendations that I make seek to amend views that I have held

in the past that I now believe to be incorrect. For example, as a manager I was committed to evaluating services according to their efficiency and quality of care based on measurable and objective outcomes. I want to challenge this perspective now, in the belief that PDC is a valuable service even if it does not meet those criteria, hence the recommendation for subjective evaluation as well as that which is objective in nature.

9.5. The contribution of the research to me, the researcher

The process of undertaking this research has been a personally enriching one, offering substantial development of my professional and personal self.

At a professional level, the experience of the research has offered me new philosophical insights, particularly those related to the complex nature of healthcare delivery and receipt. The concept of multiple realities has been made real through my exploration of different constructions held by individuals involved in the same service. Their multi faceted nature and derivation serve as areas of new learning – vital, I believe, in understanding why people experience the same service so differently. The research has also given me increased respect for PDC, in the light of the high value ascribed to the service by those using it. My beliefs about the service in the past have been greatly challenged by the views of patients and carers who contributed to this research, leaving me with a constructive concern about healthcare evaluation in general based on outcomes identified by professionals alone. I am aware from my experience of this research that even when a desire exists to learn the user perspective this can be hard to achieve, given the different contexts that users and professionals inhabit. Even so, I feel excited about possible work in the future concerned with development and evaluation of services, within which patient experience has a central place. I believe that this will be challenging but am confident that it will be rewarding too. The experience of undertaking this research has been an empowering one in the main, and one that I wish to build upon in the remainder of my career.

At a personal level the process of undertaking the research has been an inspiring one. It afforded me opportunity to engage with people who have a progressive and life threatening condition or those caring for them. I was able to listen to their stories, explore their perspective and reflect on what they told me, then relating it to various experiences in my past, both professional and personal. I feel privileged to have had this opportunity and have grown through it. At times it was not easy. I remember moments of embarrassment as I reflected on actions that I had taken in the past in ignorance of patients' experience of illness and service provision. Sometimes I felt deeply sad as I became aware of the predicament facing individuals that I met. On occasions it made my own mortality feel frighteningly real. However my resounding sense at the end of the research is of a process that has been hugely positive and rewarding. I hope that this was reciprocated, to some degree at least, for other participants.

9.6. Summary of the chapter

This chapter has described my reflections on the process of undertaking the research and its findings. It highlights the key implications of the research, which arise from my opinions in relation to it. It considers the strengths and weaknesses of the research in my view. Finally it describes my relationship with the research and how we have had an impact on each other. These reflections are the basis of the final chapter which summarises the key findings of the research and makes recommendations, based on the findings of the research.

CHAPTER 10
SUMMARY AND CONCLUSION

10.1. Introduction to the chapter

This chapter concludes the thesis by providing a summary of the research and its findings. It describes the unique contribution that the research makes to existing knowledge. It also identifies the implications of the research findings and key recommendations that arise from them given the context within which PDC operates. Finally it makes suggestions regarding further research required to build on that described in this thesis.

10.2. Overview of the research

This research sought to learn about PDC from the perspective of those who used the service. It encouraged active engagement on the part of patients, family members and carers and others involved in PDC in the process of ascertaining these views. The research comprised two case studies of PDC services that gave rise to descriptions of them, primarily from the perspective of patients and their families. These offered insights into the nature of PDC and its value according to its users. They also enabled exploration of the concept of models of PDC. These descriptions were then compared with the views of other stakeholders of PDC and the literature to ascertain the degree to which they resonated with each other.

Data collected for these studies were then analysed further to produce a proposition regarding PDC which serves as an overarching explanation of the service from the patient's perspective.

10.3. Summary of the findings

The current study revealed similarities in the constructions of the two services studied, despite purported differences in relation to their model of care. The similarities were concerned with the provision of highly valued social support for users of the service. This support was particularly beneficial for people whose

social being was at risk. They were commonly people who were socially isolated, whose lives were dominated by their condition or those who were biding time until they died. Attending the service offered them opportunity to maintain or rebuild their social self as a consequence of the relationships that they established in this setting, the care and support on offer, its milieu, and its activities. These benefits were increased when the care on offer in PDC acknowledged the multi faceted nature of their needs, including those physical and practical in nature, when it was individualised and when it considered the future needs of people with progressive and life threatening conditions and their families as well as their present requirements. In so doing, the care drew on the skills of a broad multi disciplinary team, utilised other components of palliative care provision and undertook regular assessment and review of the patient's condition.

Based on the commonality of experience by users in DC1 and 2 of this service, a proposition was developed which serves to explain the value of PDC for its users. It suggests that PDC provides a community to which those with a progressive and life-threatening condition can belong, regardless of the model of care ascribed by professionals to the service. The community of PDC is created when people who share a similar situation come together, and meet in the company of others who understand their predicament. Being part of the community enables people to retain membership of the social world, feel that they are living with their condition rather than dying from it, retain or rebuild a positive sense of self and feel some control of their lives. This community becomes a lifeline for many of the patients who join it and represents new family or friends for them. It is suggested that the concept of PDC as a community could serve to describe an overarching model of PDC, which encompasses variations in provision such as the availability of symptom control and rehabilitation for example. In so doing, it acknowledges the prime value of PDC as a provider of social care for people with progressive and life threatening conditions.

This construction of PDC according to patients resonated with the views of those stakeholders who were closely involved in the service. It was at odds with those who worked at some distance from PDC, resulting in differing values being ascribed to the service and its component parts than that identified by patients and their carers.

10.4. The contribution of these findings to existing knowledge

10.4.1. Knowledge of PDC

This research serves to confirm many of the findings reported in the past derived from studies which have sought to learn about PDC from the perspective of its users. It corroborates the importance of the social support offered by PDC for its patients identified by others (Goodwin et al 2002; Hopkinson 1997; Lawton 2000). It also reinforces the findings of Lawton (2000) which link the value of this social support on the part of people with progressive and life threatening conditions to their experience of a disintegrating and lost self. It confirms the value of an holistic approach to meeting people's needs, identified as a characteristic of this service in the past (Birch et al 1997) as a means of attending the multi faceted nature of these needs as identified by Edwards et al (1997) and others. It also reinforces the need for an alternative reality described by Lawton (2000) for people who cannot cope with the implications of their condition.

In addition the current study builds on the findings of others. Its exploration of the wider context of patients' lives provides indicators as to the circumstances in which attendance of PDC is particularly valuable. It highlights the importance of this service for people who are increasingly isolated at a social or emotional level, or those whose sense of identity is being lost as a consequence of their illness.

In addition the research makes a unique contribution to knowledge through its proposition that PDC serves as a community. It highlights those aspects of community life which are essential for people with progressive and life-

threatening conditions and how the community operates to the benefit of its members. The proposition provides new information about the structural elements of PDC and the processes of care that give rise to the social support provided in this setting that patients value so highly. In particular it highlights the importance of the relationships established within the service and its alternative reality, enhanced by the activities on offer, the milieu of the service. It also offers explanation for aspects of PDC that have previously been difficult to understand including the problem of discharge of patients from this service and the barrier between PDC and the external world experienced by some professionals (as identified by Hospice Nurse Managers, verbal communication, Hospice Nurse Managers Conference 2004). In so doing, it would seem to be both valid and relevant, resonating with the experience of those involved in the service and facilitating new understanding of its complexity for those involved in planning, managing and providing this care.

10.4.2. Knowledge regarding the research process

This research confirms the value of case study in learning the nature and detail of healthcare services and supports the use of multi methods to learn the complexity of a service. It suggests that patients using palliative care services can actively contribute to research regarding healthcare provision even when their health status is deteriorating and their position in relation to healthcare provision is a vulnerable one. They do not appear to be damaged by the process and would seem to benefit from it, deriving pleasure and purpose from making a difference to people who will use the service in the future. I received feedback from patients confirming the pleasure they experienced from taking part in the current study, including a card thanking me for the opportunity to contribute. However the current study does suggest that user views that would be gained in a private interview may be amended in a group context, the reasons for which require further exploration. It also raised an ethical issue arising from the dissemination of findings regarding the value of services (particularly when they are negative in nature) to those involved

in providing the service, particularly when service users are still attending. This is previously unreported in the literature and needs further exploration.

Many of the principles of user involvement described in the literature appeared valuable in assisting the current study to achieve its aims. Patient and carer involvement in identifying the focus of the interviews, achieved through the hermeneutic dialectic process, took the research in directions that I had not anticipated. Similarly users' contribution to the analysis and interpretation of the emerging construction offered it a depth and breadth that I could not have developed alone. The commitment to learning about the wider context of users' lives beyond that of PDC was valuable in exploring the value that they placed on the service and helped to identify personal characteristics of those most likely to benefit from PDC. When this contextual information was brought together with knowledge of PDC and details of its operation, a new awareness of the complexity of processes such as discharge become evident. The use of qualitative methods of data collection was useful in exploring the detail of such complexity.

10.5. Implications and recommendations

10.5.1. Policy related implications and recommendations

The findings of this research suggests that PDC has a major part to play in the care of people with progressive and life threatening conditions, such as cancer, through its provision of social support. This support is essential to enable a proportion of people with progressive and life threatening conditions to cope with their illness, particularly individuals whose social self is at risk of disintegrating (as described by Charmaz 1983). Key to the provision of this support is the opportunity for people with progressive and life threatening conditions to meet with others that have the same condition. This support is not available from other services, palliative care or otherwise. Its provision benefits from close working links established between PDC and other palliative care services, including inpatient services, as a basis for holistic care for the patient and their families/carers. Its

value is enhanced when care is individualised and focused on meeting the outcomes required by the user.

These findings are important in the context of current policy relating to end of life care and that pertaining to day care in general.

Current policy concerned with end of life stresses a need to improve the quality of care for people with incurable conditions (Department of Health 2004;National Institute for Clinical Excellence 2004a). Calls for improved provision have been made on behalf of existing users of supportive and palliative care, in particular that which addresses user dissatisfaction arising from poor communication and inadequate support (National Institute of Clinical Excellence 2004). Similar calls have also been made on behalf of those who have been previously denied palliative care as a consequence of their geographical location, social difference or diagnosis (House of Commons Health Committee 2004). In addition there is an identified need to provide end of life care for new user groups, emerging as a consequence of recent societal changes that give rise to longer life expectancy, multiple and chronic conditions in old age and lone habitation (M.Richards, Personal Communication, Help the Hospices Conference 2004; WHO 2004) . The improvement that is sought has a holistic focus, consistent with recommendations for effective palliative care in the past(National Council for Hospice and Specialist Palliative Care Services 1997b). As such it addresses social need, along with physical, psychological and spiritual issues (National Institute for Clinical Excellence 2004). It also acknowledges the importance of enabling people nearing the end of their life to be cared for in their place of choice – which is often at home (Seymour 2004;The National Council for Palliative Care 2005b) Recent guidance regarding supportive and palliative care for people with cancer and other progressive and life threatening conditions provides recommendations that will guide service development plans for the future (National Institute for Clinical Excellence 2004a). As described earlier this influential document is ambiguous about the place, style and value of PDC for people facing such conditions as a

consequence of the lack of evidence available regarding the effectiveness of this service (ibid.).

In a wider context of day care for other groups of people, such as older people including those with dementia, adults with learning difficulties, people with mental health problems and people without a stable home life, calls have been made by policy makers and others for changes that will serve to transform current provision. At the heart of these changes is a demand that day care services work towards social inclusion on the part of their users (Clark 2001). In so doing, day care services are required to provide a range of services and activities that place users firmly within the wider community, rather than encouraging dependence on the community of day care (Spencer 2004). According to Clark (2001) this means the fostering of roles, activities and identities outside the care context, with the aim of promoting eventual independence from the formal service. This shift is facilitated by care that focuses on the diverse needs of users in new, responsive and flexible ways (ibid.) and represents a move away from a "one size fits all" approach in mental health provision to bespoke, individualised care which focuses on providing new kinds of help, including rehabilitation (McCulloch & Howland 2004 p.2). It is hoped that this shift will redress the situation of the past, where the lack of attention to individual needs and circumstances in day care gave rise to a situation in which users and their families were stuck in a situation that offered little hope (ibid.). This care must be culturally and ethnically sensitive, flexible in terms of time and place and integrated with other services (ibid.). As such it should serve as a point of access to other services (ibid.) and constantly looking to improve, based on a process of audit and research (Al Mahdy 2004;McCulloch & Howland 2004).

In this context, the findings potentially contribute to policy development and debate in a number of ways.

First they indicate that PDC could help to improve the quality of care for people at

the end of life, given the evidence provided by the study regarding the value assigned to PDC by people with progressive and life threatening conditions. As such they serve to strengthen the place of PDC in the improvement of supportive and palliative care for people at the end of life. They offer new clarity about what PDC offers to people with progressive and life threatening conditions and indicate that the social support it offers is unique within the arena of palliative care. In so doing, the findings suggest that PDC should have a role in plans to improve end of life care for people with cancer and other progressive and life threatening conditions, and indicate that the service is an integral part of specialist palliative care provision.

Second, they provide pointers as to the conditions required for effective provision of day care for people with a progressive and life threatening condition. For example they highlight the importance of enabling people with progressive and life threatening conditions to attend with others who have the same affliction. They also indicate the increased value of PDC when it is a connected element of comprehensive palliative care provision. In so doing they challenge suggestions that the care people receive in PDC could be offered in other non-specialist day-care settings or as satellite units. In addition they serve to support the recommendation that day services, palliative care or otherwise, are integrated with other services in the future, and act as a gateway to other services.

Third, they indicate what sort of model of care is required according to users. The current study begins to redress the gaps in guidance with regard to effective models of PDC by proposing a new and overarching model of care that is valued by users, regardless of labels assigned to different styles of PDC by professionals in the past. Having said this, the current study does not measure the relative effectiveness of the different styles encountered in DC1 and 2. Neither does it consider the model of care required to accommodate the new groups of people identified as needing palliative care, in particular those with conditions other than cancer.

Key recommendations for PDC, within this policy context are as follows.

First, collection of further evidence regarding the effectiveness of PDC as a provider of social support for people with progressive and life threatening conditions is required as a basis for confirming its place and contribution to the improvement of end of life care. The findings of the current study and the research of others (for example Goodwin et al 2002 and 2003) need further substantiation and development. This will offer purchasers, planners and providers new confidence of the value of PDC and provide information about the models of care that are most effective in meeting the needs of those facing the end of life.

Second it is recommended that those involved in providing PDC highlight the social support available in this setting as a core offering of the service. This will enable them to focus the help they extend to their patients, it will facilitate appropriate referrals and they will begin to generate evidence of the effectiveness of their provision if audit programmes reflect this focus. Clarification regarding the core offering of PDC may also assist those with responsibility for planning and purchasing end of life care to identify the relative importance of PDC in relation to other services. Even so, there are potential lessons to be learnt from changes in non-palliative day care provision. In particular, PDC should consider a response to the call for a broader range of day services, which spread beyond the boundaries of institutional care settings and offer new kinds of help, delivered in flexible ways in response to individual needs and requirements on the part of users.

Third, it is recommended that plans for the development of PDC acknowledge the importance of enabling people with progressive and life threatening conditions to meet others in the same situation. The support offered to users of PDC by "sympathetic others" within PDC is unlikely to be replicated in settings which do not specialise in caring for this specific group of people, not least because people will have a variety of underlying conditions and face many different circumstances and problems. However, further work is required to consider whether the shifts in

non-palliative day care towards social integration should be replicated in any way in PDC settings, and whether care in this setting should work towards promoting ordinary life for those with terminal conditions that may progressive slowly over a period of many months or years.

Fourth, a recommendation is made for the maintenance of close working links between PDC and other palliative care services. This research has highlighted the value that users place on being able to transfer quickly and easily between PDC and other palliative care services in the event that they experience new problems or need more care. It also identifies benefits for users when staff members in PDC can call on the skills of colleagues to address complex problems that their patients present with. In the event that PDC services become separate at geographical or organisational levels, these relationships become vulnerable and patients are likely to lose the sense of security that they have afforded in the past. The challenge for PDC, if it is to consider new styles of provision, as recommended for non-palliative day care, is the maintenance of such links as it moves from a service led philosophy of care to one that is needs led. This shift could effectively change traditional working relationships with other palliative care services.

10.5.2. Practice related implications and recommendations

At a practice level, the findings of this research imply that PDC requires skilled leadership. This is necessary to ensure that individuals' needs are met within the group created in this setting. The findings also suggest that staff members and volunteers working in this setting need skilled supervision of their input to the service to ensure that community life is beneficial for all involved. Care provision in this setting is enhanced when staff members have broad skills which encompass symptom control and practical nursing care as well as social support. It is further improved when those involved in PDC work closely with colleagues in primary care and other palliative care services, utilising their various skills to meet patients' individual and myriad needs.

A recommendation arising from these findings is that investment is made to PDC in terms of skills, support and supervision. Traditionally PDC has been seen as a relatively cheap and straightforward service to provide. This research does not support this viewpoint in the light of its identification of PDC as a complex service requiring skilled leadership, insightful providers of care and ongoing support of those working in this setting. Where these were lacking, users identified unfavourable aspects of the service such as a lack of individualised care. They also accounted for, in my view, some of the damage that staff members described in relation to working in this setting and organisational shortcomings such as an inward looking service that I noted as an outsider. The research also suggests that where the staff have well developed specialist skills (such as those related to symptom control) the experience of attending the service is enhanced. For this reason it is recommended that staff members working in this setting have specialist skills, that they receive ongoing training to maintain their knowledge base and have access to advice in the event that they are presented with particularly complex problems.

The research identified disparity between some professionals' views of PDC and those attending the service, for example those related to discharge from the service. In this regard various stakeholders were mystified and somewhat frustrated by the difficulties they experienced implementing this course of action, unaware of the meaning and implications of discharge for patients who felt that they were being forced to leave the one setting in which they felt accepted, safe and normal. This gives rise to a recommendation that issues such as these are considered in the light of their meaning for patients. This would enable professionals to adapt their approach accordingly and engage with users in a way that acknowledges users' perspectives on their actions.

10.5.3. Research related implications and recommendations

This research confirms the importance of seeking user views as a means of ensuring patient-centred services. Its findings indicate that the views of patients

are not always reflected in those of professionals involved in the service particularly whose involvement is peripheral. For this reason service plans which are based solely on professional views could be at odds with the preferences of those they seek to serve. The process undertaken in this research amends this potential inaccuracy in relation to PDC, and appears to be one that could be replicated in other palliative care settings.

The findings of the current study reinforce the suggestion in the literature that evaluation of PDC should embrace the provision of social support in this setting through relevant quality of life measures or similar (Goodwin et al 2003). Furthermore the research offers details of the nature of this social support - related to being part of a community and its relationships therein, to which any measures must be sensitive.

The experience of disseminating the findings of this research at a local level suggests that sensitivity is required in this process to ensure that staff members and volunteers remain confident and empowered in the work that they are doing. Detailed explanation of the process of the research, interpretation of the findings and support for staff members and volunteers should be offered as they consider the findings in relation to their practice.

A key recommendation arising from the research in this regard is that user views are sought as a basis for learning about healthcare services. This research suggests that professional views cannot be used as a proxy for patient views, although there was resonance between the views of those working directly with patients and their carers in this research and those described by the patients and carers. The research also suggests that gaining user views is possible, even when the users are perceived as fragile and vulnerable.

10.6. Further research required

The findings of this research would benefit from further investigation.

In the first instance, an additional case study using the same approach as applied to DC1 and 2 is required to study a PDC service purporting to provide a short term rehabilitation model of care. This would answer the question posed by many PDC Leaders as to whether these services represent a new genre of PDC that is quite different to that provided in the past, or whether patient experience is similar despite differences in the way that these services are delivered and their aims.

In addition, the proposition that PDC serves as a community needs to be tested as to its applicability in other PDC settings. In this event the proposition would serve as a working hypothesis against which patient experience of other services are considered. The proposition offered in this setting is relatively unsophisticated at present and would benefit from development, particularly that which considers in more details aspects of community life, such as its culture and language. Many aspects of community life that the data served to identify have only been described briefly in this research, and represent areas for further exploration and explanation as a means of building depth into the proposition. In my view, it would be particularly beneficial if this was undertaken as an ethnographic study, that is one in which "there is an ongoing attempt to place specific encounters, events and understanding into a fuller, more meaningful context.....,[and which] combines research design, fieldwork and various methods of inquiry to produce historically, politically and personally situated accounts, descriptions, interpretations and representations of human lives." (Tedlock 2000 p. 455).

Third, there is a need to explore further the differences between DC1 and DC2 as well as the similarities presented in the proposition. For example, the holistic nature of the care in DC2 and its focus on the future needs of users as well as those presently experienced are aspects of care delivery that would benefit from further examination. The differences noted in the two cases could provide important pointers as to what constitutes high quality care in this setting, particularly in terms of meeting user needs and requirements.

Finally the relative value of PDC compared to other palliative care services needs exploration. Whilst the research clearly identifies that PDC is valued by those using the service, it does not explore whether it is more or less valuable than other services, except by implication. Given the context that PDC is operating in, within which resources are limited and finite, purchasers and planners need to know the degree to which PDC duplicates, supplements or supplants other services as a basis for deciding whether to invest in it further or redirect resources currently allocated to it.

10.7. Final thoughts

Some time after study of DC1 was finished, I received an unexpected phonecall informing me that many of the individuals I had known in DC1 had been involved in a major road traffic accident one Tuesday. It transpired that patients, staff members and volunteers had been involved in a head-on collision with a lorry whilst enjoying a trip out from DC1 in the minibus. The collision resulted in the instant death of two patients and serious injuries in most of the others.

According to the PDC Leader and others, the consequences of this tragic accident are still apparent one year on. For many months after the incident, Day Care on a Tuesday either didn't happen or was a small and highly subdued affair – "the group had disintegrated" (PDC Leader, personal communication, 2004). No further trips were offered and the minibus was not replaced. Some patients never returned to the service, and legal issues related to the loss of life from the accident continue. A number of people who were injured had residual physical and emotional problems, some requiring treatment in relation to them up to 12 months after the accident. In addition there was a sense of injustice felt by staff members and volunteers who had had to watch patients recover from the accident only to die from advanced disease some weeks or months later. Apparently, only a total change in the group of people attending PDC on a Tuesday has enabled the service to recover, and in so doing, regain some of the "life" that it enjoyed in the past.

The ramifications of the accident can be understood in the context of the findings of this research. The community of PDC, its offerings and some of its members were effectively destroyed at the point of collision. Its boundary that had previously safeguarded those within the service from the dangers of the external world were smashed in the accident, allowing death and suffering, so feared by this group of patients, to become an unavoidable reality that they must face. Its alternative reality and the associated security, safety and fun that patients had experienced in the past was replaced, in an instant, by a new experience of pain, loss and fear arising from injury in self or others that could not be ignored. The previous commitment by individuals within the group to look beyond their own suffering and to be cheerful and optimistic as a means of buoying oneself and other members could not be sustained by anyone involved in Tuesday Day Care, given the overwhelming impact and consequences of the accident. According to the Day Care Leader this event was catastrophic, from which nothing good has come.

There is little that I would wish to add to this story, except to note that the loss identified by the Day Care Leader and others associated with the disintegration of the community highlights, in my view, its very presence and its value for those within the service. I feel indebted to have been part of the community that existed in DC1 and I feel sad as I reflect on its many losses as a consequence of the accident. For this reason, I dedicate this work to those that died in it and also to its survivors, grateful once more for what they have taught me.

APPENDIX 1
CRITIQUE OF RESEARCH INCLUDED IN CHAPTER 2

Overview of the criteria on which critique of the literature is based:

➢ Clarity regarding the aims of the research
➢ Appropriateness of chosen methodology and the nature of the research question
➢ Match between sampling strategy and the aims of the research
➢ Match between the methods of data collection and the research aims/questions
➢ Attention to the ethics of the research process
➢ Evidence of systematic data collection and record keeping
➢ Rigour of the analytic process
➢ Adequate description of the context of the research
➢ Consideration of relationships within the research process and their impact on the research and its findings
➢ Clarity regarding the findings and their interpretation, with distinction between the two
➢ Identification of the limitations of the research and questions that require further investigation
➢ The degree to which the findings are generalisable/transferable
➢ Relevance to academic audiences, practitioners, managers and strategists in healthcare
➢ Connection of research and its findings with the existing body of knowledge and theory
➢ Opportunity for peer review and consideration by other researchers

(Based on guidelines developed by the CASP collaboration for qualitative methodologies Critical Appraisal Skills Programme (2000), a series of papers within the BMJ by T. Greenhalgh in 1997 regarding critical appraisal of published papers, guidelines produced by the Medical Sociology Group in 1996 and the book "The Pocket Guide to Critical Appraisal" by I.Crombie, published in 1996).

Critique of research papers included in Chapter 2

Authors and date of publication	Type of study	Strengths and weaknesses of methodology	Contribution to the current study
Bray 2001	An investigative study of activity within PDC using postal questionnaires An MSc Dissertation	**Strengths** Use of closed and open questions within questionnaire Satisfactory response rate (78%) Details of findings arising from quantitative component of research **Weaknesses** Little evidence of reflexivity Lack of detail regarding analysis of qualitative data Tentative links between findings and implications Not published No peer review	Identifies the variety of activities on offer Identifies who working in PDC Considers level of support available to volunteers working in this setting
Cartwright 1991	Studies of adult deaths in 1969 and 1987 using interviews with carers/family members	**Strengths:** Large sample size Same methodology replicated in both studies Weaknesses Use of carer opinion as a proxy for patients	Provides numerical data regarding age, circumstances and place of death, care settings and support. Comparison provides interesting data re trends and societal changes
Copp et al 1998	Telephone survey of 131 PDC units within the UK.	**Strengths:** Undertaken by external researcher Size of sample Use of open-ended questions within survey Detail regarding methodology and results Clear separation between findings and their interpretation Explicit relationship to existing knowledge **Weaknesses:** Only sought professional views of PDC	Describe nature of PDC provision from a professional perspective, management and organisational issues. Also nature of common problems and care issues. Consider issue of models of care and their link to funding sources. Identify opportunities for further research around models of care including their impact on patient outcomes

Authors and date of publication	Type of study	Strengths and weaknesses of methodology	Contribution to the current study
Douglas et al 2000	Exploratory research, using observation of 5 PDC services to learn about the structure and processes of PDC and to identify ways in which service outcomes could be evaluated and measured Designed to inform a large multi centre trial in PDC	**Strengths:** Clear description of the role of the observer, focus of the field notes and checking process No information about process of analysis **Weaknesses:** Choice of services studied based on previous relationships established between services and the research centre Limited opportunities to ascertain patient views from observation alone Model of care identified by professionals Discussion is hard to relate to the results Generalisability from study of 5 services will be limited	Details about the structure and processes of care Discussion regarding similarities and differences between services regarding their structure and process of care
Edwards et al 1997	Study of characteristics of 38 people using PDC, and the level of medical input required to meet their needs over an 8 month period	**Strengths:** Detailed description of data collected that describes characteristics of users of PDC **Weaknesses:** Lack of clarity regarding aims of research or its methodology Lack of clarity regarding process for collecting data and its analysis Data collected by those involved in providing the service	Demonstrate a role for doctors within PDC Highlights multifaceted nature of needs of people using PDC

Authors and date of publication	Type of study	Strengths and weaknesses of methodology	Contribution to the current study
Exley 1998	Qualitative sociological research that explores the experience of living with cancer and a terminal prognosis from the dying individual's perspective. Based on a study group of 19 patients who were interviewed on at least one occasion. A PhD thesis	**Strengths:** Detailed description of methodology, data collected, its analysis and interpretation Explicit links with the literature Inclusion of raw data to illustrate findings Evidence of reflexive process to collecting and analysing data	Details regarding the experience of dying from the perspective of the dying person
Faulkner 1993	Commissioned by Help the Hospices as an evaluation of PDC. Comprised observational study of 12 units based on an evaluative proforma plus data collected via previsit questionnaire completed by staff.	**Strengths:** Considered a variety of day care services **Weaknesses:** Very limited period of observation in each setting. Observation undertaken by different people in each setting. Previsit questionnaire was restrictive in style Criteria for evaluation of good practice based on evaluators beliefs rather than research evidence Lack of patient input to process Lack of information about processes of analysing and presenting data No links between findings and literature	Highlighted multi faceted nature of PDC and similarities and differences between services Suggests reasons for the differences observed Makes recommendations for the development of services to reduce limitations of PDC

Authors and date of publication	Type of study	Strengths and weaknesses of methodology	Contribution to the current study
Goodwin et al 2003	A prospective comparative study of 120 patients referred to PDC to assess the effectiveness of PDC in improving pain, symptom control and quality of life. Comparative group comprised 53 patients who received other palliative care services but not PDC. Patients assessed at 3 interviews using measures of health-related quality of life. Patient groups also compared using preset criteria such as age, sex, marital status etc	**Strengths** Part of a large multi centre trial evaluating PDC Explicit link with the literature Use of a comparative group (but full number of patients required in this group not accrued – representing a weakness in the research) **Weaknesses** No measure of Quality of Life of patients prior to their starting PDC Incomplete baseline information for PDC patients against which to consider changes identified during attendance in PDC Use of QOL measures that were not sensitive to the outcomes related to PDC identified by patients Five services based in the London region. Not representative of rural PDC services	Highlights the limitations of existing quality of life measures to measure the effectiveness of PDC. Highlights the opportunities offered of studying PDC using case studies to learn more about the structure and process of care
Goodwin et al 2002	A study of patients' experience of five PDC services as part of a larger study considering the effectiveness of PDC. Descriptive data collected during interview was analysed and reported in a separate paper	**Strengths:** Inclusion of raw data providing detail of patients' responses Implications for practice, policy and research notes **Weaknesses:** Limited information regarding process of conducting interviews, analysis and interpretation of data collected Analysis based on labels ascribed to services by professionals No link between findings and literature regarding patient experience of the service	Themes generated substantiate the findings of the current study, in particular those concerned with meeting others who share the experience of having a progressive and life threatening condition

Authors and date of publication	Type of study	Strengths and weaknesses of methodology	Contribution to the current study
Goodwin et al 2000	Workshop at the Palliative Care Congress regarding methodological issues in evaluating PDC	**Strengths:** Details regarding the methodology and its limitations according to the researchers **Weaknesses** Limited findings available	Conclusion that patients and families appreciate different components of the service and verbal communication about the shortcomings of a questionnaire methodology to examine a complex service was helpful in devising the methodology of the current study
Hargreaves & Watts 1998	Semi-structured questionnaire to assess the acceptability of intravenous treatments in this setting according to patients and volunteers	**Strengths:** Anonymous questionnaire Acceptable response rate (74%) **Weaknesses:** No description of the process of devising the questionnaire or its detail No description of its analysis Limited description of results No discussion regarding negative findings	Illustrates changes in the nature of care within PDC and provides some information about patients' responses to them
Higginson et al 2000	A survey of the 43 PDC services in the North and South Thames Regions using a questionnaire that considered management, staffing and organisational policies. Also the numbers, types and reasons for referral and the services and care provided	**Strengths:** Explicit link between research aims and its findings with the literature Detail regarding the methodology Good response rate (93%) Detail of results **Weaknesses** No involvement/ representation of users Limited data regarding actual activity compared with that planned	Overview of current provision in terms of size of service, characteristics of patients, services provided, staff and volunteers involved Valuable data against which data collected in DC1 and 2 could be considered to identify the degree to which they shared characteristics

Authors and date of publication	Type of study	Strengths and weaknesses of methodology	Contribution to the current study
Hopkinson 1997/ Hopkinson & Hallett 2001	A phenomenological study of 12 patients attending PDC to ascertain what was important about their PDC experiences An MSc Dissertation later written up as a research paper	**Strengths:** Clear exposition of methodology Explicit links with literature Evidence of reflexive approach to research in dissertation Clear results **Weaknesses:** Implications of research findings are tentative No link between these experiences and the model of PDC to which they relate	Suggests that users value PDC Highlights the importance of the PDC atmosphere, the opportunity for choice and the reduced sense of isolation arising from attendance in PDC. Also identifies two ways of coping on the part of people with a progressive and life threatening condition Substantiates many of the findings of the current study
Kennett 2000	Phenomenological study of 10 patients and 11 facilitators involved in an arts project based in a PDC unit. Data collected using semi-structured interviews	**Strengths:** Links with the literature regarding PDC and theories regarding motivation Description of context of the research Clear description of methodology and participants Use of raw data to substantiate findings **Weaknesses:** Research undertaken by leader of the PDC service under study Belief by researcher that she knew how patients viewed the subject being described	Provides detail regarding value of creative activities within PDC according to patients

Authors and date of publication	Type of study	Strengths and weaknesses of methodology	Contribution to the current study
Langley-Evans 1999	Ethnographic study of 3 PDC units over a period of 10 months comprising observation, audio-recordings of spontaneous discussion, collection of documents and semi-structured interviews. Data analysis informed by discourse theorists. Presented as	**Strengths:** Detailed description of aims, methodology, results, their analysis, and their implications **Weaknesses:** Not published No peer review outside of university	Identification of four discursive environments that exist within PDC – based on how patients, volunteers and professionals construe day care, and how they function with the structural constraints of different organisational contexts.
Langley Evans and Payne 1997	Ethnographic investigation into a PDC unit to explore communication processes amongst patients with terminal conditions in an "open awareness" context. Based on participant observation over a 7- week period.	**Strengths:** Explicit link with the literature and theory therein Detail regarding the context of the research Detail regarding the approach to the research, its methodology and analysis of the data collected Inclusion of raw data to substantiate findings and their implications Detailed discussion regarding findings **Weaknesses:** ? length of time spent in unit	Importance of limiting talk on death and illness in this context as a means of maintaining a positive outlook and distancing oneself from his/her own death. Contribution of nurses and volunteers to this process

Authors and date of publication	Type of study	Strengths and weaknesses of methodology	Contribution to the current study
Lawton 1998/ Lawton 2000	Anthropological study of PDC over a period of 5 months comprising observation and interviews with 40 patients and 12 family members. Formed one part of a two part study of a hospice	**Strengths** Clear description of methodology and process of analysis in thesis. Interesting perspective combining a patient and managerial perspective of the service **Weaknesses:** Relatively short period of data collection and analysis Possibility that the PDC service studied cared for particularly sick patients given admission policy of hospice – therefore not representative of other PDC populations Complexity associated with the role of the research as part of a formal evaluation of the service, crucial in determining its future Lack of detail in the book about the methodology, process of analysis, interpretation, involvement of patients in this process. Relative lack of data to support findings described in the book NB Critique of book by Clive Seale – highlighting sensitivity of researcher to issues concerned with death and dying	Findings substantiated and informed the current study e.g.: Description of the alternative reality of PDC Identification of the substitute role of PDC for family and friends Loss of social self in many of the people using PDC

Authors and date of publication	Type of study	Strengths and weaknesses of methodology	Contribution to the current study
Martlew 1996	Action research to evaluate on site physiotherapy in a PDC unit. Open ended interviews undertaken with 10 patients	**Strengths:** Details of the process of recruiting patients Attention to the ethics of the research Details of the interview process Presentation of raw data to substantiate findings **Weaknesses:** No details about questions posed in interview Confused approach to the research and its analysis – reference to action research/grounded theory/evaluation Mention of quality of life measures but not validated – arising from the research itself Research conducted by the physiotherapist Presentation of findings as graphs	Findings highlight the value of inter-relationships within PDC, social and emotional support available in this setting
Sharma et al 1993	Examination of the medical role in PDC using a patient questionnaire and a record kept by the doctors regarding their input to the service	**Strengths:** Attention to patient expectations and attitudes Places research in the context of existing knowledge regarding PDC **Weaknesses:** Lack of detail regarding questionnaire Selective presentation of results of questionnaire Lack of critical review of the design of the research e.g. single setting only Possible bias in the report of the findings	Part of the debate regarding the role and value of medical staff within PDC Highlights the paucity of research regarding user views of PDC and its benefits

Authors and date of publication	Type of study	Strengths and weaknesses of methodology	Contribution to the current study
Slater 2001	A literature review to identify outcomes for PDC – part of a BSc undertaken at the Institute of Cancer Research	**Strengths:** Clear description of process and papers identified Well presented results Informed by insights gained from working in this setting	Review of literature regarding PDC Interesting discussion regarding outcomes for the service
Spencer and Daniels 1998	Literature review of that pertaining to PDC	**Strengths:** Overview of literature pertaining to PDC **Weaknesses:** No information about terms of reference for literature review No information about criteria used to determine inclusion/exclusion of literature	Valuable overview of pertinent literature including that only available by handsearch
Wilkes et al 1978	Description of first 26 months of DC unit. Draws on audit data and that collected via postal questionnaire from patients and bereaved relatives	**Strengths:** Description of service supported by detailed audit data **Weaknesses:** Findings are unlikely to be representative of PDC 25 years later Less than 50% response to questionnaire Lack of detail regarding questionnaire	First research paper focusing on PDC. Makes early assertions regarding the value of PDC – e.g. cost effective and easy to implement Recommends integration of PDC with a hospice inpatient unit

APPENDIX 2
INFORMATION SHEETS AND CONSENT FORMS
PRODUCED FOR PARTICIPANTS

PATIENT INFORMATION LEAFLET
Introduction to the research

PROJECT TITLE: A Study of Hospice Day Care at XXX
                       Hospice

NAME OF RESEARCHER: Heather Richardson

INTRODUCTION

Hello, and thank you for taking the time to read this. The aim of this leaflet is to introduce myself, to provide some details of my research project, and to invite you to take part in it. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take the time to read the following information and discuss it with family, friends or the staff here in Day Care. Ask us if there is anything that is not clear or if you would like further information. Take time to decide whether or not you wish to take part.

WHO AM I?

I am a researcher from Southampton University carrying out a study of Hospice Day Care services. I am also a qualified nurse with experience of hospice care.

WHAT IS THE PURPOSE OF THE RESEARCH?

Hospice staff are keen to know about the preferences and priorities of patients and their families, so that they can plan services that will meet patient needs in the future.

This research is designed to help provide this information. As part of the research I am keen to understand what happens in Day Care and how the service is experienced by those involved in it. I hope to look at the service "through the eyes" of patients, volunteers and staff, and so I am particularly interested to hear about your views, perceptions and experiences of Hospice Day Care.

WHAT WILL THE RESEARCH INVOLVE?

I am planning to spend between five and six months in Day Care.

Part of this time will be spent taking part in activities and talking to staff, patients and anyone else involved in the service. At other times I will just sit quietly and watch what is going on.

In addition I am hoping to interview some patients, family members, staff and volunteers, but you will be approached separately about this and will be offered additional information about what it involves prior to the interviews taking place.

I will also be collecting and reading documents related to Day Care, such as policies, procedures and leaflets in order to understand better how the service works. This includes the inspection of patient notes in order to understand more about the care provided.

If you chose to take part in the research I will be talking to you and watching you, along with the other patients, staff and volunteers, as you participate in Day Care. You can chose at any time <u>not</u> to talk to me without giving a reason.

HOW DO YOU BECOME INVOLVED?

You will be invited to take part in the study, along with all the other patients attending Day Care, but it is up to you to decide whether or not you wish to participate. Your decision will not affect your care and treatment in Day Care in any way.

If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part you are free to withdraw from the research at any time and without giving a reason. This decision will not make any difference to the care you receive.

WHAT IMPLICATIONS ARE THERE FOR YOU IN BECOMING INVOLVED?

If you decide to take part, I will inform, with your agreement, your GP and the Doctor looking after you in the hospice, so that they are aware of your involvement in this study.

The study will be written up as part of a thesis to be submitted to the University for examination. Aspects of the study may also be included in publications and presentations to other professionals working in similar settings. Please be assured that any information I collect during the research period will be treated as confidential and all results and findings will be anonymised, so that individuals cannot be recognised in any reports, publications or presentations.

WHERE CAN YOU GET FURTHER INFORMATION?

If you would like additional information speak to the staff in Day Care, your hospice consultant or contact me directly. My phone number is 023 8059 8202

Thank you for taking the time to read this and for considering taking a part in the research.

Heather Richardson
School of Nursing and Midwifery
University of Southampton
Highfield
Southampton SO17 1BJ

PATIENT INFORMATION LEAFLET

The interview process

PROJECT TITLE: A Study of Hospice Day Care
                             at XXX Hospice

NAME OF RESEARCHER: Heather Richardson

INTRODUCTION

Hello again! By now, most of you will be familiar with this research study and my presence in Day Care. As you know I have been spending time in Day Care over the last few weeks in order to try and understand what happens here, and how the service works.
As part of the research, I am now interested to learn more about the views of those coming to Day Care, and I would like to talk to patients in more detail about their experience of the service. This will help me to understand what you find particularly helpful (and unhelpful) about the service.

WHAT WILL THE INTERVIEWS INVOLVE?

These interviews will be quite informal and will take place in private. I will ask you a number of general questions regarding your feelings, experience and views of Day Care. Our discussions will be tape recorded, and will normally take between 30 minutes to an hour. However, if you grow tired or do not wish to continue with the interview, you are free to end it any point.

WHAT WILL HAPPEN TO THE INFORMATION COLLECTED DURING THE INTERVIEW?

Everything you say to me during the interview will be treated as confidential. Following the interview the recording of our discussion will be typed up and any names or references to individuals removed from the transciption so that you cannot be recognised from it. You will then receive a summary of the transciption to check and amend if you wish. The tape-recording of the interview will be kept in a locked filing cabinet and erased once the study is complete. No reference will be made in the final report to you as an individual, or what you said during the interview.

WHAT HAPPENS NOW?

Unfortunately I will not be able to interview everyone coming to Day Care, because the time available to me for this aspect of the research is limited. Instead, I will be approaching just a few patients, who I hope will provide me with a variety of views and perspectives about the service.

WHAT DO YOU NEED TO DO?

Taking part in an interview is voluntary, and your decision about whether to take part or not will not affect your care and treatment in Day Care in any way. If you decide to take part, you are free to withdraw from the research at any point and without giving a reason. If you prefer not to be approached about taking part in an interview, it would be helpful if you would tell a member of staff, so that I know not bother you.

If you are unsure about the details of the research or my background I have attached a copy of the initial information sheet called "Introduction to the Research, which gives details of its aims and implications.

WHERE CAN YOU GET FURTHER INFORMATION?

If you would like additional information, talk to a member of staff in Day Care, your hospice doctor or contact me directly. My phone number is 023 8059 8202.

Thank you for taking the time to read this and for your interest.

Heather Richardson
School of Nursing and Midwifery
University of Southampton
Highfield
Southampton SO17 1BJ

**LETTER TO GENERAL PRACTITIONER / HOME CARE NURSE / HOSPICE
CONSULTANT (as appropriate)
REGARDING RESEARCH AND THE INVOLVEMENT OF A PATIENT UNDER
THEIR CARE**

Dear

Re: [Name and address of patient]

I am writing to introduce myself and to inform you that [Name of patient] has been recruited into a research study based at XXX Hospice.

I am a research student at the University of Southampton undertaking a study of palliative day care for people with advanced disease as part of an M.Phil. / Ph.D. I am also a qualified nurse and have worked in palliative care in the past.

The research I am proposing comprises in-depth studies of two palliative day care services including the service based at XXX Hospice. The research project seeks to explore the views, experiences and perceptions of Day Care by those involved or participating in the service. In undertaking the research I will be observing the activities and interactions in Day Care, interviewing patients and their relatives and examining key documents associated with the service such as operational policies and patient records.

Whilst we hope that the research will not be harmful in any way to participants, we are mindful of the possible distress that patients may experience as a result of discussing their illness, and the reasons why they attend day care. We also acknowledge the fact that relatives may also become upset in discussing the patient's illness and its impact on them. As a consequence the research has been carefully designed to minimise any distress to patients or others taking part in the study with attention to issues of consent, how the interviews are conducted, and the availability of support for the patient should he/she become
distressed as a result of the research. All participants will be made fully aware that they can withdraw from the research or stop the interview at any point without giving a reason and without any consequences for the care and treatment of the patient in Day Care.

If you would like further information about the research please get in touch with me and I would be delighted to come and see you or send you the information you require. You can contact me by phoning 023 8059 7979 during the day. Alternatively email me on H.Richardson@soton.ac.uk .

Thank you for taking the time to read this.

Yours sincerely

Heather Richardson RGN, RMN, MA
Post Graduate Research Student

INFORMATION LEAFLET FOR CARERS

PROJECT TITLE: **A Study of Hospice Day Care**
at XXX Hospice

NAME OF RESEARCHER: Heather Richardson

INTRODUCTION

Hello. The aim of this leaflet is to introduce myself, to provide some details of my research project and to invite you to take part in it. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take the time to read the following information and discuss it with family, friends or the staff in Day Care at XXX Hospice. If there is anything that is not clear or if you would like further information please ask one of us for help. Take time to decide whether or not you wish to take part.

WHO AM I?

I am a researcher from Southampton University carrying out a study of Hospice Day Care. I am also a qualified nurse with experience of hospice care.

WHAT IS THE PURPOSE OF THE RESEARCH?

I am interested to learn about what happens in Day Care and to know more about how it is viewed by those involved in it. As part of this work, I am keen to explore the experiences and perceptions of patients using the service. I am also interested to hear the views of family members or other carers at home about Day Care, and what it is like when a relative or friend uses this service.

I hope that this work will help to improve patient care by providing information about the preferences and priorities of patients and their families or carers at home. Hospice staff are keen to know more about this in order to help them plan services that will meet patient needs.

WHAT WILL THE RESEARCH INVOLVE?

I would like to talk to family members or other carers at home on an individual basis about their experience of caring for a sick relative, and the role that Day Care plays in this. This is important in helping me to understand the benefits and limitations of Day Care in response to the needs of individuals using the service, and their families and other carers.

WHAT WILL THE INTERVIEWS INVOLVE?

These interviews will be quite informal and will take place in private. I am happy to come and visit you at home if you wish. I will ask you a number of general questions about your experience of being a carer at home and what difference, if any, Day Care makes to this experience. The discussion we have will be tape recorded, and is likely to take between 30 minutes and an hour. However, if you grow tired or do not wish to continue with the interview, you are free to end it any point.

WHAT WILL HAPPEN TO THE INFORMATION COLLECTED DURING THE INTERVIEW?

Everything you say to me during the interview will be treated as highly confidential. Following the interview the recording of our discussion will be typed up and any names or references to individuals removed from the transciption so that you cannot be recognised from it. You will then receive a summary of the transciption for you to check for accuracy. The tape-recording of the interview will be kept in a locked filing cabinet and erased once the study is complete. No reference will be made to you as an individual, or what you said during the interview, in the final report.

WHAT DO YOU NEED TO DO?

Taking part in an interview is voluntary, and your decision whether to participate or not will not affect the care and treatment your relative or friend receives in Day Care in any way. If you decide to take part, you are free to withdraw from the research at any point and without giving a reason.

WHAT HAPPENS NOW?

A letter is attached to this leaflet, in which I ask you whether you would be willing to be interviewed. If you are agreeable at this point, complete the form and send it back. I will then contact you to make a date and time to meet. Prior to the interview I will ask you to sign a form consenting to be interviewed. If you change your mind between sending back the form and the interview, you simply need to let me know that when I contact you.

WHERE CAN YOU GET FURTHER INFORMATION?

If you would like additional information, talk to a member of staff in Day Care or contact me directly. My phone number is 023 8059 8202.

Thank you for taking the time to read this and for your interest.

Heather Richardson
University of Southampton.

LETTER TO CARER INVITING HIM/HER TO PARTICIPATE IN RESEARCH

Dear [Name of carer]

I hope you don't mind me writing to you. I have recently been talking to [name of patient] who comes to Day Care at XXX Hospice and he/she thought that you be willing to help me with some research I am currently undertaking in Day Care.

I am a researcher from the University of Southampton, currently based at the Hospice. I have recently started a research study concerned with Hospice Day Care, and I am interested to talk to relatives (or other carers at home) of patients who come to Day Care.

I have attached a leaflet to this letter that will give you more information about the research and how you could participate in it.

If, having read the leaflet, you would be willing to be interviewed, please fill in the form attached and send it back to me in the envelope enclosed. There is no need to put a stamp on the envelope. If you chose not to participate, then please be assured that this decision will not, in any way, affect the care [name of patient] receives at XXX Hospice.

If you wish, you do not need to tell [name of patient] that you be taking part in this research. I am happy to visit you at home or at another venue of your choice, when your [name of patient] is at Day Care, so that we can talk privately and alone. If you would like someone else from your family to join you for the interview that would be fine. Please be assured that your participation and everything you say will be treated as confidential.

Thank you very much for taking the time to read this letter and the leaflet.

Yours sincerely

Heather Richardson
Researcher

To: Heather Richardson, Researcher, c/o XXX Hospice

I, ...
(name),

of ....(address)

am agreeable to you contacting me on   ....(telephone no.)

or writing to me to invite me to be interviewed as part of your research project.

I understand that my participation is voluntary and that it is subject to me giving formal consent to be interviewed. I am free to withdraw from the study at any time, without giving any reason and without the care of my relative attending Day Care, or my legal rights, being affected.

Signed .... Date..........................

Attach leaflet for carers

**LETTER TO
STAFF MEMBER, VOLUNTEER AND OTHER STAKEHOLDERS**
(excluding patients and their relatives/carers)
INVITING HIM/HER TO PARTICIPATE IN RESEARCH

Dear

Re: Study of Palliative Day Care

As you may be aware there is currently a research project in progress at XXX Hospice concerned with studying palliative day care.

I am writing to introduce you to the research in case you are unfamiliar with it, and to introduce myself. I am responsible for undertaking the research and will be spending between five and six months in Day Care studying the service and the care it provides. I have attached a leaflet with this letter that provides more information about the research and its aims for your interest.

I am also writing to ask whether you would be willing to participate in the research by taking part in an interview to discuss your understanding, views and experiences of Day Care. The interviews are confidential and your anonymity is assured. The time and place of the interview can be arranged to suit you. Of course this participation is voluntary and if you do not wish to be interviewed, this wish will be respected.

I would propose to contact you in the next week or so to make an appointment, unless I hear from you that you do not wish to be interviewed. You can simply leave a message on my ansaphone on 023 80 598202 or email me on <u>H.Richardson@soton.ac.uk</u>.

In the meantime my thanks to you for reading the letter and the leaflet.

Yours sincerely

Heather Richardson RGN, RMN, MA
Post Graduate Student
University of Southampton

Attach: Leaflet for volunteers, staff and other stakeholders

APPENDIX 3
COPY OF A SET OF OBSERVATION NOTES

I arrived early and sat in the main day room area waiting for the rest of the multi disciplinary team to arrive for the morning multi-disciplinary meeting. It is held in the Day-care sitting room, a large square room with chairs all around the walls. At about 8.45 am others began to join me – about 10 or 11 in total including two doctors, the care manager, an occupational therapist, two ward staff (representing the two nursing teams on the ward),and the day care leader. I am unsure who the others were.

[The day care leader] started, feeding back about a couple of patients who attended day care the previous day. One of the doctors talked about one of the patients that [the Day-care Leader] had mentioned, discussing her symptoms and plans for future management. Then the ward sister started to hand over the ward patients. A number were known to day care including some being discharged from the ward back to day care.

Then about 9.45 we both went into the staff room in day care to hand over the patients. I noticed that in describing one of the new patients starting today that [the day care leader] did not mention the negative comments made about him and his wife in the earlier meeting. In general the meeting felt unhurried, informal and inclusive, and there was a strong sense of teamwork, as staff discussed individual patient requirements and how these would be met. [The Day-care Helper] asked about names on a calendar, which identify patients who have a birthday and said that she needed to cancel one on the grounds that the patient was a Jehovah's Witness and therefore doesn't celebrate. She duly went off to do this. Notable within this meeting was the continual references to symptom control and basic nursing care required for many of the patients – including checking blood sugars, blood pressure, giving blood and checking when a warfarin level had last been checked.

Then at about 10.15am we all went out into the main day care area and I walked towards the main sitting room. I hesitated to go in on the grounds that it was absolutely full, so much so that there were no free chairs at all, and some patients were still in their wheel chairs. As a result I headed into the art area and started to talk to [the day care helper] about her role in day care and the activities arranged for patients. In broad terms she describes a service that is flexible and pretty easy going – some patients doing a lot of art, or sewing, others doing none at all. She is responsible for organising concerts and trips out. I was struck how individual many of the activities seemed to be as she got out books labelled with individual patient names and bags of sewing labelled similarly. She described a number of key volunteers responsible for running art on various days during the week.

I sat down and a couple of patients soon joined us. Initially I sat opposite the two men, introducing myself. It is striking how everybody seems to have read the piece

of paper and is aware of the research and my arrival in day care. When [one of the patients] goes out for some treatment I move over and chat to the other patient who is doing a painting with acrylics. He says that previously he was a photographer but that he is unable to do this anymore, and so he is painting some of his photographs instead. He seems absorbed, and quite single minded about his work although he comments that art is great when the table is full because of the banter. When [the patient] returns I move back to the other side of the table and chat to him instead. He says that he has been coming on and off for four years, and comments that whilst the service is great, the downside of it is that you lose many of the people around you. Interestingly this was a comment made by another lady I sat next to later in the morning who had been coming for over two years. [the patient] says that he won't start painting today as he is awaiting a chiropody appointment and so he does the cross word instead. He is doing an oil painting which has been put out on an easel in front on him.

[another patient] is sitting next to me and I talk to her. She has been coming only a couple of months and laughs at the art work she is doing. However, she appears pleased and absorbed in it also as she colours in a picture using a template for guidance. She explains that she prefers to do the art than sewing, having done the latter for years previously.

Towards the end of the morning I moved into the main day care room and introduced myself to a couple of people. The first gentleman I spoke to talked about the rest that day care offered to his wife. One of the women I talked about spoke about how day care enables her to get out, given the increasing limitations her arthritis imposes on her. Interestingly she says that her cancer is no longer her main problem, her tumour having decreased in size since she has started. She also commented on how when she looks around her at day care she realises how well off she is.

[the day care helper] served out lunch with help from one of the volunteers. A number of patients commented on the high quality of the lunch. Lunch was a three course meal, at which volunteers sat with the patient. In the main the meal was unhurried and many of the patients chatted with each other over their table.

Soon after lunch I went into an outpatient clinic run by [the hospice consultant] with assistance from [one of the staff nurses]. He saw four patients this afternoon between 1.30 and 3.30pm, offering 30 minutes to each patient. Two of the three patients seemed pleased with their progress and Iain seemed keen to encourage them to be positive. The care offered in the outpatient clinic was comprehensive and holistic – a medical examination, attention to medication, blood tests, and discussion regarding life at home. A question remains for me though about how the outpatient clinic fits into day care apart from using its staff. It is a different group of patients in the main.

I left early, about 3.15pm and got a lift back to the boat with one of the volunteers and a couple of patients. We dropped [one patient] off first in Sainsburys, so that he could do some shopping prior to going home (which is close by) and then a patient who had attended day care for the first time today. When I asked him how it had been he said that he hadn't done anything, but the lunch was nice. Anything was better, he said, than his recent experience of spending 7 weeks in the local hospital, where he had had chemotherapy. The volunteer driver later commented to me that he didn't seem to have enjoyed it very much.

REFLECTIONS ON THE DAY:

1. Attention to patients' symptoms and nursing needs within day care
2. The confidence of the staff to address these needs independently and as part of the wider hospice team
3. The emphasis given by staff in their work with patients to enabling them to live positively, confidently and independently at home. Much of [the consultant's] approach in the outpatient clinic seemed focused on this e.g. telling patients how much better they looked, suggesting a longer break between clinic appointments with the responsibility lying with the patient to contact the hospice if they need help earlier
4. The apparent attention to the patient as an individual in day care with little time or effort made to pull the patients together as a group. Looking around the main room, many of the patients sit quite alone, doing the cross word or reading the paper. Some chat to each other, but there isn't the same sense as [Day-care 1] of everybody being a member of one group.
5. How integrated the day care unit is with the rest of the hospice. I don't know numbers but if day care has between 80 and 100 patients, then this must represent a high proportion of the hospice population as a whole. Staff in day care are interested in the progress of inpatients. Similarly inpatient staff and other hospice staff seem interested to know about day care patients.

OUTSTANDING QUESTIONS

1. How many out patients does day care have?
2. How many patients attend day care and what proportion is this of the total number of patients under the care of the hospice at any one time?
3. Do patients value the same things that they did in [Day-care 1] particularly those related to new relationships and being in the same boat etc. or do they come for something quite different? If they do, is this because they have different needs or are these similar, but they are simply responding to a different model of service provision?

APPENDIX 4
THE INTERVIEW GUIDE

INTRODUCTION TO THE INTERVIEW GUIDE

This guide outlines the opening and closing statements to be included in any interview and identifies the questions that will be used to shape the interviews with patients.

The style of the interviews is such that additional questions are likely to be required to explore comments and views expressed by those being interviewed in more detail. For example, if a patient identifies a particular activity as helpful or enjoyable the researcher may ask the patient to tell her more about what happens in that session and what is particularly helpful or enjoyable about the process of taking part. In addition the researcher is keen to explore the beliefs and values underpinning the comments made by respondents. This will be achieved by asking follow up questions such as "Why do you think that is?" of "Why is that important to you?".

Additional questions may be asked based on what the researcher observes or reads in documents. The researcher may ask the patient to describe or explain an aspect of the service she requires further information or verification about. For example she may ask patients to comment about the degree to which the service experienced reflects the explicit aims of day care outlined in the operational policy.

In addition the researcher will seek the views of patients regarding comments and observations made by other stakeholders about the service. These comments will be presented in general terms for example: "Other people have told me that the service…..would that be true for you too?" or "One of the recurring themes in my interviews with other people is…. Would you recognise that in your experience of this service?"

OPENING STATEMENTS

Thank you very much for your time today and for agreeing to take part in this research. The aim of this research is to help me to understand day care from the perspective of those attending or involved in the service and so your views are very important to me. As a result of this interview and interviews with others I hope to build a detailed picture of day care in my mind so that I can describe what happens in day care, how the service is experienced and how you rate it. This information will be made available to staff in the hospice as a basis for future development and included in my research report, but I will not identify any individuals in any report or presentation I make. This means that your involvement in the research is anonymous

During the interview I would like to ask you about your experience of day care, what you do when you are here and the ways in which it is helpful to you. I would also like to hear your views about how the service could be improved. If you do not mind I will tape record the interview so that I can listen to it and examine the transcription at a later date.

Before we begin, can I just remind you of a few things:

- You are free to halt the interview at any time. You do not need to give a reason why.
- Stopping the interview will in no way affect the care you receive in Day Care in the future
- You are free not to answer any questions you do not wish to. Again you do not need to give a reason why
- All information you give me will be kept confidential

Before we start the interview are there any queries you have about the interview or any questions you would like to ask me.

INTERVIEW SCHEDULE

Introduction and background
- Can I start by asking you when you started to come to Day Care and why?
- If you can I would like you to think back to the first day you came to Day Care. What did you expect Day Care to be like?
- What did you find when you arrived?
- I would be interested to know what you do on a normal day in day care? Take today for instance. What have you done?
- What do you enjoy most about coming to Day Care?
- What do you enjoy least?

Looking back on your experience of coming to Day Care:
- How helpful have you found Day Care?
- What are the most helpful aspects of Day Care?
- What are the least helpful?
- What do you do now that you didn't do before coming to Day Care?
- Are there aspects of the service that confuse you, or you are unclear about?
- Can you recall any issues about which you have disagreed or sought clarification regarding, in relation to the service?
- Is there anything about the service that you have discussed with others, and found that your views are at odds with theirs?

We have been talking about your personal experiences of the service. Now I would like to ask you about your opinions of the service
- What would you say the strengths of the service are?
- What are its weaknesses?
- How in your view could the service be improved?
- If you had the power to change things about day care what would you make different?
- Is there anything else you think would be helpful for me to know about Day Care or that you would like to tell me about Day Care?

CLOSING STATEMENTS

What you have told me has been very interesting and very informative and I am very grateful to you for your time and help.

Would you be interested to see a copy of this interview. If so, I will bring you a copy within a week. If you would like to talk to me about it, that would be fine and if you would like to change anything that I have recorded in it, that it fine too.

I am aware that talking about some of the things we have covered today can be upsetting. Before we finish can I check how you feel after the interview and whether you feel you would like some support or someone to talk to on leaving the interview?

Can I also remind you that if you find yourself upset or requiring further support later on today or in the next few days after the interview one of the day care staff will be happy to talk to you.

Thank you very much for your time

APPENDIX 5
A COPY OF A TRANSCRIBED INTERVIEW

INTERVIEW WITH MP2.1

NB. Preliminary conversation not transcribed. Concerned with identifying tape recorder, requesting consent, reiterating confidentiality and commitment to stopping interview at any point that the interviewee wished.

HR:
Tell me how long you have been coming and what led you to a point of attending this service

MP2.1:
I started about a year ago actually, just over a year ago and it all began when I was talking to my motor neurone visitor [name of visitor] and she was asking me how I was getting on with my water colour painting because I had started to do watercolours instead of oils simply because it was less messy and with one hand it was difficult and she said "well don't worry, we can always get somebody to help you". There were two possibilities. One was a possibility of a roving visitor that was interested in water colour and the other one was to come here because of the crafts section. So I said immediately that I would come. I knew the hospice from previous experience when my wife was here and very well cared for. So that was what started me, that's what got me interested and I said Yes straight away. But I was rather surprised that they would take me on so soon because I knew my prognosis was two to four years and they said "It doesn't matter". They like to know you as thoroughly as possible which is a great thing and instead of being left until you are more or less incapable and in extremis and then taking you in for two or three weeks they were prepared to do it. And that is what started me, about a year. I think it was in either late June or early July last year.

HR:
It sounds as if you were familiar with the hospice if your wife had been here. Was day care what you expected?

MP2.1:
Well it was more than I expected because I didn't know there was such a thing as a craft section for all those people who were interested and I was quite happy to come because quite frankly I felt that being near to a source of instant access for medical problems, you could just say something to a person and they would immediately engage, they knew, they understood what your problems were and you could get it

sorted out quickly and so from that point of view I was keen
to come and when I found that they were active in the arts
line, at that time being able to use one hand pretty well
but not fully, I really leapt in and thoroughly enjoyed
myself. I still do now but I can't do much but I can enjoy
talking to the other people and the staff are very
anticipatory of what people's needs are. They are watching
all the time, I've noticed that since I've been here. No one
can get by with feeling tough or rough. They are watching
all the time.

HR:
Was it the art that attracted you then, or was it an added
bonus?

MP2.1:
It's the bonus. I was very pleased when they said "You can
go." People will keep an eye on you. That was the first
thing.

HR:
So it was the medical and nursing side that was most
important?

MP2.1:
Yes, and it was the art side that actually initiated it,
because as I said [name of motor neurone disease association
visitor] said "Well you don't need to worry about your art.
If you go there you will get a lot of help. They get the
equipment for you and provide the interest" so I was really
raring to go. I really felt that this was a great asset in a
situation where you know your time is limited but you don't
want to sit around and dwell upon it. You would rather be
doing something as far as you can.

HR:
At the time of starting here, did you have specific needs or
problems that you hoped would be addressed in day care?

MP2.1:
Not medically no. I felt alright then. I felt that I, well I
knew from my experiences with the consultant from the
mainland, [name of consultant] that my future was more or
less mapped. It wasn't defined that it was going to be at
such and such a time, but I knew that it was mapped and I
didn't feel that I needed any more special attention, only
the single tablets that I take, that are the only
known...they may not be a cure but they are a kind of, I
can't think of the word, but it was alleged that they
delayed the onset, nobody knew for sure. Each person reacted
differently apparently. Some couldn't take them. Poor (name
of another patient)in there that can't speak. She can't take

them because as soon as she started to take the tablets she was sick apparently, so I have been very fortunate in that respect, that the tablets have not upset me.

HR:
You sound as though you have a very pragmatic approach to your illness and its consequences

MP2.1:
I've not, my attitude is that you reach a time in life when you know that you have done what you are supposed to do and there is no way of squirming out of it, you have had illnesses and you have accidents and I have only had a couple of minor operations and you know that some time or other you have to pass on, and I just accepted it. A lot of people said to me "I can't understand how you come to accept it" but honestly there is nothing else you can do, you just try and make the best of it from day to day and certainly coming here provides, it's a highlight. It breaks the week up otherwise the days go on and you don't know whether it is Christmas, Easter, Saturday or Monday.

HR:
It sounds as though it offers a routine in the week

MP2.1:
That's right.

HR:
One thing I am interested to know more about it your interest in art. Have you always been an artist?

MP2.1:
Well in a certain way yes. I was, my occupation was in naval architecture which is a long word for ship design and that started because my careers master who was the geography teacher said "This young man is very good at art. He should be a draughtsman", so yes I had dabbled in art as a past time. As a kid I used to do charactures and relatives and friends who were interested, it sort or aroused my interest but then I went to the formal kind of art because draughtsmanship is very formal, but I never lost the sense of art in the design of ships, infact I have got a number of anecdotes which relate to my differences of opinion on the grounds of art in the case of ship design, because my elders were very staid in their attitude to the aesthetics of ships – aesthetics were a waste of money and I was of the contrary opinion so I kept, so I have had this artistic bent, you could call it, but I wouldn't say I was a clever artist but I can work at it.

HR:

Have you painted all your life?

MP2.1:
Well for quite a long time when we moved to the mainland and
the kiddies were growing up through secondary school I
didn't do a lot, but I picked it up again in 1976

HR:
So being able to maintain it later on, has been important in
continuing this interest and area of enjoyment?

MP2.1:
That's right

HR:
What are the most important things that day care gives you
one year on?

MP2.1:
Well first of all it is the sense of safety, that's the
biggest thing for me. I feel when I come here that if there
is any problem I only have to mumble about it and they take
it up for you. Not that I have had a lot really to require
that. But I did have one little incident when I felt that I
had a minor blackout and I was glad that happened here. If
it happened at home... I don't move about much at home, I
tend to be very sedentary simply because if I start
wondering around the estate, even though it is only around
150 feet by 40 feet. I am concerned that I might drop down
or trip or something so I tend to be mostly in the house but
up here I can wander around and as I said I was glad that if
it had to happen, it happened here. So it is a sense of
security and people keeping an eye on you because when you
live alone, although I don't feel lonely there is that
little risk aspect to it.

HR:
Given that assurance you have that people will pick up and
address any problem you have in day care, where would you
see the focus of the care you receive in general. Is it your
GP, hospital consultant or here for example?

MP2.1:
Day Care. Because there is a wonderful staff here and they
are very very concerned about how you are going on and old
(name of hospice consultant), I always say old but I should
say young [name of hospice consultant] wanders backwards and
forwards and he will always stop and say "Good morning" or
"How are you?", or "Can I help?". So yes most of my medical
care, the only time that I have to go to the GP I had to,
well I decided that when I don't need my brain and spinal
cord anymore they are going to have a look at it and that

was the only time that I have only had to talk to a doctor
and even then my daughter took me down and she simply signed
the form, and that was that. She [the doctor] doesn't really
know much about what is going on other than the fact that
she gets the results of a blood test every three months, so
she just kind of just passes me on to the care of the day
care unit. So it is not just coming here and having a bit of
a laugh and a meal. It is simply the fact that you know you
are being watched all the time and cared for.

HR:
And are your prescriptions provided by the hospice or your
MND consultant?

MP2.1:
Prescribing no. My doctor [GP] does the everyday drugs.
Infact I get two months prescriptions at the time and she
does that. Infact all I have to do now, is that I have a
little prescription sheet from the doctor that I think has
got an ongoing repeat, which is a bit much. And we have to
do it through the pharmacy of Boots. So I think that Boots
and the Clinic enter into some sort of arrangement where it
can be repeat prescribed under the instruction of the
doctor, but it is very easy and she will know when I have a
repeat prescription. Infact she will know when I don't have
a repeat prescription and that's really about it

HR:
I remember you saying that the friendships you make here are
really important

MP2.1:
They are

HR:
And I notice that quote from George Elliott...[offered by
MP2.1 to day care in the form of a picture]

MP2.1:
That was from my wife actually. She picked up a little card
during the latter parts, the latter months of her illness
she picked up a card, I think she may have found it on a
coach trip somewhere and she used to go off, there was one
coach trip that was called the Across, they used to go to
Lourdes but apart from that they go on odd coach trips under
the same auspices of the Red Cross and she picked up this
little card and quotation and she always had it standing on
the sideboard and it sort of got engrained. I kept looking
at it and thinking and I thought it was a very apt
description of the kind of relationships that we very
quickly make. Some of the people I found that, there are a
couple of, three new ones [patients] that I have met since I

have been coming and several of those have taMP2.1 a bit of
time to open up and they sort of look around, they look at
you from the corners of their eyes but gradually they open
up and there is one lady, one dear lady called (name of
patient) and she started water colour painting, I think for
the first time in her life and she is so thrilled with it,
she sits there and she dabbles away at this and she has got
quite talkative now. So that is what happens when you come
here. Gradually you can't help but get involved in the
closer friendships and chat, and sometimes you feel a bit
browned off and say "I've got a bad back" or "this hurts me"
or whatever and you talk to each other, sometimes they have
a bit of a weep. Then one of the ladies comes around and
looks after them and sometimes I feel a bit down and they
come and put a hand on your shoulder, but it is a very,
what's the word, emotional, close relationship. And we have
plenty of fun

HR:
That's obvious

MP2.1:
Plenty of fun

HR:
Would you say that you make friends with the volunteers and
staff as much as with other patients?

MP2.1:
Oh yes. The volunteers very soon learn your name and they
know your needs. For example when I get home if I am not
released from my buttons I shall have to go to bed with my
shirt on, but you only have to tell them once. I said to
one "Would you mind doing this?" and then the next time they
come, and it is not always the same ones [drivers], quite
often different ones arrive where they have changeovers,
holidays or illnesses or whatever, but they are very quick
to help and you do get to know them yes. And they talk to
me, I found one person that I was talking to and her in-law
relative, she said "Oh my niece is married to (name). He was
a lecturer at [a local]Institute of HE". I said "(name), I
used to sit and have coffee with him". You know, you get to
know people and it is amazing the connections that you can
pick up. They are very talkative and they do it be because
they are dedicated. I often think to myself, just after my
wife died, I started to try and do things to get myself
together and I often think "If only I had been introduced to
this kind of volunteering I might have done that instead"
but instead of which I sort of took over the watching eye
over my elderly neighbour who died last Christmas at 92
nearly, so that my used to be my little contribution,
keeping an eye on her. But certainly these car drivers, they

drive all over the [area]and handling people who are in
wheelchairs - that just amazes me.

HR:
One thing that I have noticed is that there would seem to be
quite two separate communities in day care, particularly the
days you come. There is one group that sits around the art
table and then another group that sits in the sitting room.
How accurate is that observation?

MP2.1:
Its not personal. It's a question of how much you want to be
involved or how much you can. A lot of people who come into
the other.., well I call it the sitting room, they are
either on chemotherapy or some other drips so they just have
to sit and they can't do much else. But some of them I think
are, the ones I have talked to are capable but perhaps it is
not their kettle of fish or their metier, I suppose you
would call it but some of them have tried but have said
"well I don't think that is for me". But is is there for
them, they know...

HR:
When you say "that's not for me" are they referring to the
art?

MP2.1:
The art. They always say "Oh I couldn't possibly do that"
and sometimes..there was a lady called (name of patient)
that came in about a fortnight or three weeks ago and she
sat down and really got involved and I thought "Good, we've
got another artist" because one had just left us you see.
But it wasn't quite what she was up to doing. She felt she
wasn't doing justice to it, so she has declined, but it is
there. Those people in the other room are mostly people who
have got problems that mean that they can't move about quite
so freely and can't engage in it, and that is why they do
the word puzzles as you have seen I am sure. It keeps their
mind occupied and not only that, I don't know whether you
have seen any of the periodical visits that we get when
musicians turn up and just recently we had visit from I
think it must have been someone connected with the social
services, two or three folk that were into demonstrating
something called a sound beam, to make music by interrupting
a sound beam. It is like a microphone in reverse. It emits
inaudible sounds and if you put your hand infront of it you
can adjust the position and make notes on the equipment. And
they were demonstrating at one of the MND meetings, it was
the annual general meeting and they came in and demonstrated
this and (name of hospice CEO) was there and after they had
finished the demonstration they invited comments and I had a
word with them and I asked them if they could get several

people involved in doing the same thing at once. My idea was
to get a few people in there that could sit infront of it
and perhaps all play like a cacophony but nevertheless feel
that they were participating. So they said "we'll get them
to come over" and (name of hospice CEO) was as good as his
word and they came over and started to get us interested and
one or two ladies were very reticent and shy and they had a
bash at it and it was amazing. I wish the people who had
been demonstrating, it was a new chappie and not the one
that had demonstrated at the meeting and he didn't seem to
have the charisma of the other chappie who was jumping up
and jumping about and I thought if only he had come and got
more people interested. But I think they enjoyed it when he
came so it's a question of trying to find things that those
people can do, rather than just sitting still.

HR:
Are there any aspects of the service which concern you or
which you think could be improved or changed.

MP2.1:
No. I've heard one or two people suggest that the craft area
could be increased and from what I have heard I believe they
are working on it. They are always trying to work to improve
the facilities.

HR:
Do you mean that they could be increased in size?

MP2.1:
Yes I think so. Perhaps it might be possible to have it in
one area, in a bigger area where all those that those who
tend to sit and do word puzzles could see what is going on
perhaps. But they would like I know, (name of day care
worker) would like to be able to do that but in a very small
room she makes an amazing contribution to motivating people
and some of them, when we are really busy and we have got
about six or seven people at the table some have to sit at
the end and of course that is a passage way and a little bit
nippy in the winter because unless you keep all doors and
certain windows shut you get a draught through there. We
don't mind the people coming and going but to do that, to
create the access it does create a little bit of a draught.
They know, (name of day care worker) knows it and she tries
to arrange it to the best of her ability.

HR:
Are there any aspects of the service which distress or upset
you?

MP2.1:

Not me personally. I mean if somebody is taken seriously
ill, one of the ladies was taken away on a stretcher about a
fortnight back, that doesn't distress me. It is only my own
philosophy which is that once you have experienced time here
you realise that if you are in trouble you are going to be
looked after. You are not going to suffer any pain, this is
the main thing and my only concern really, is pain and the
route by which you pass along. That's the only thing that
has ever really concerned me and I feel that here you have
got so much assurance that you won't suffer. I know my wife
didn't suffer. She was well looked after and another old
colleague of mine and one time neighbour and his wife also
passed away here most comfortably and peacefully and I don't
feel any fears really and to see anybody else in trouble I
feel the same thing for them as it were.

HR:
Are there any aspects of the service which mystify or
confuse you?

MP2.1:
Well I don't want to appear over zealous or enthusiastic but
I can't think of anything that mystifies me. I really can't.

HR:
Do you think that your views, particularly the value you
place on the security, friends and fun you have here are
shared by other patients, or do you think that individual
patients get something quite different from day care?

MP2.1:
Well I am sure they must do, but all I would say is that
some of the people who pass through, I don't know where they
have gone but they have come here for extended treatment and
have moved on. I don't mean passed on, they have moved on.
But I think that most of the people that are here in the
terminal stages are of the same mind and they feel
comfortable. One little lady, I haven't seen her for some
time but she now comes here three days a week, sadly three
days that I don't come. I come Tuesday and Thursday and she
comes Monday, Wednesday and Friday and I know that she..I
had a talk to her, she used to sit next to me and started
doing silk painting when she had seen me dabbling and
producing funny effects on the silk painting and she said
she would like to have a go. And she was quite good at it.
And she used to come and sit next to me because I am a bit
talkative. If they want to talk I can generally offer a few
anecdotes that will interest them and she used to say to me
"Oh I wish I could come Thursday but I can't because I go to
the church on a Thursday to help with meals for the old
people". She had done it for years. And I said to her "You
should be allowing people to look after you". Well she can't

do it now in any case, but she used to say "I'm so glad I
come up here, I'm so glad that people introduced me to this
and my relatives say to me 'don't you find it frightening?'
and it is amazing - even my own daughter, the first time
that I was coming up here she went silent for a few minutes,
I think she thought this was the end because she knew that
her mother came here only for three weeks and I say 'No, it
isn't like that' and eventually I managed to get Amanda to
come here just to see what was going on and she couldn't
believe it. She doesn't worry now. I just give her a call
when I get back and tell I am home and she is quite happy
and as you pointed out when I stopped doing silk painting I
managed to get her interested and that was really exciting
for me. It was another achievement. I felt that I was still
carrying one and she really enjoys it. She has been the
beach this week with her daughter and her daughter gets into
the water and literally lives there for two hours at a time,
in the sea, that is, and my daughter then sketches, what
for? - for silk painting. So I really am pleased. She was
quite a good little artist, a little bit thwarted in her
younger years by, I think, total ignorance of teachers who
seemed to think that the best way to teach a person art was
to get them to draw something and then tell them that it
was rubbish to see if they could spill their spirit. Well
she hasn't lost her spirit, so I am really chuffed to think
that she is carrying on now.

HR:
I loved the picture I saw she had done of tulips

MP2.1:
Well one of the nurses, the cheerful, cheeky one, the dark
haired lady, she's got three of her paintings in her,
whether it's a new house I wouldn't be sure, but she was
looking for paintings for the wall and she took three of
them. But my daughter is so self effacing that I keep
telling her to try and bolster her ego, I keep telling her
how much people appreciate it, and I think I am winning. I
think she is going to carry it on.

HR:
Given the fun and the laughs you describe there is something
I am unsure about. Do people still talk about their illness
or do people try and forget their illness when they are
here.

MP2.1:
Well they don't positively try and suppress it because
sometimes, as I said, a person will break down a bit and say
'I can't cope today' but mostly it is because I think it is
the same kind of philosophy. There is no point in all being
miserable together. The purpose of being here is to try and

give you some sort of comfort in the latter stages of your
life no matter how long it should be. [name of another
patient] has been having problems for about six years I
think he told me.

HR:
So it isn't taboo to talk about your illness

MP2.1:
Not at all no. Infact I think we talk about it more than our
relatives do, from what I gather. Relatives try and cushion
you a bit I think but here we can talk about it, if we have
got a problem and even (name of another patient), you know,
she has to write down on a tablet and even she will write
down things like I remember when she was having difficulty
eating and they gave her a peg, a feeding tube into her
stomach and she wrote one day "I can't eat a crumb". We just
looked at each other. I commiserated and she wanted to know
what my problems were and the next thing we were away again
in our art so they do talk about it and I think rightly so.
You can't bottle it up completely and people who have got a
problem I think accept those sort of comments a lot better
than relatives who really, their main concern is "can we
stop you from dying?".

HR:
And it doesn't stop the fun and pleasure of being here?

MP2.1:
No, somebody will make a joke, and [name of day care worker]
is pretty good at that I can tell you. You need the right
staff, I would say this. All the staff are, I don't think
there is one, that hasn't got a spark of humour. That is
essential. They have got to get to know the patients because
some people might be a bit more delicate put it that way,
you don't want to offend people but if a new person, when we
had the two new ladies came in, we are very careful, we are
always cracking jokes or making comments or double speak as
it were but until you get to know the people and know what
they are prepared to accept you have to be careful. But
little cheeky jokes, this is what keeps us all going. If
[name of another patient] was told she, like me, if I was
told that I couldn't come any more I would be devastated
because it's a kind of extra community that has been created
and to have that happen when you know you are in the later
stages of your life is just amazing. You think that you have
got to the stage where you have had your life and all your
different experiences, social connections and so on are
coming to an end, to have this, to come to a place such as
this and as good as this is simply amazing.

HR:

Two last questions. The first is could you recommend someone
else for me to talk to who might have had a different
experience to you of day care and might have different views

MP2.1:
I only know fairly well those few that have done the art
stuff and others that I know in what I call the sitting room
have difficulty in speaking. I mean there is a chap called
(name of patient) in there who has got tongue problems. He
has got a writer. But if only he could talk. He was a
printer in his working days and he often does a bit of
printing even now. And he is a gardener. If only he could
talk fluently I think he would be worth listening to. Other
ladies I don't really know in the sitting room. I mean [name
of another patient] has got a lot to tell us. He has been
here a while so it might be a good idea to talk to him. He
has got so much to say. He has done so many jobs. I mean I
have done two. I designed ships and then I went off and
taught other people to do it. But (name of another patient)
has done so many things, he is a musician, he has made
musical instruments, so many things he has done

HR:
Is there anything you would like to ask me?

MP2.1:
No I don't think so. Only one thing, when you take this
back, how is it going to be used. Where will it be published
and will it be disseminated amongst hospices.

HR:
I hope so. There is a lot of interest in day care units to
appreciate more fully to what it is about the service that
patients value. Part of the motivation in this is ensuring
that units provide the right things for people given their
different needs.

MP2.1:
I just hope that it is used. I hear different stories and
different styles of responses recounted from hospices on the
mainland from what I have been told and I don't know whether
there is something special here. I have only experienced
this one, but certainly I would recommend that anyone who
needed the care to come. I would try and encourage them. And
it is the setting of course which makes a difference. The
environment here makes a difference.

HR:
Finally I just wanted to check that I hadn't distressed you
in any way during the interview

MP2.1:

Good heavens no. I can't say that everybody would be the
same. Some people may be, one or two in the sitting room
might perhaps prefer to talk about it, but there are some
lovely people in there, the majority are ladies, and I have
talked to a few of them and they seem quite happy here

HR:
Well I hope that anyone I approached would feel happy to say
no if they preferred not to be interviewed

MP2.1:
Well we had the original communication saying that you would
like to talk to us and then one through the post so we have
got plenty of opportunities to say no.

HR:
Thank you very much indeed for your time. One final thing,
would you like a copy of your interview once I have typed it
up.

MP2.1;
Yes, it would be interesting. I can reflect upon what I have
said.

END OF INTERVIEW

APPENDIX 6
DESCRIPTION OF DOCUMENTS COLLECTED AND ANALYSED IN DC1 & DC2

DC 1:

Reference no.	Description of document	Date of document and/or comments
D 1.1	Day Care Newsletter	Autumn/Winter 2000
D 1.2	Agenda for meeting of Wednesday Day-Care group	January 2001
D 1.3	Minutes of Day Care Update, incorporating admission and discharge policies	August 1996
	LEAFLETS	
D 1.4	Getting to know us – Day Care Centre Leaflet	No date. Produced 2001
D 1.5	Web site description of service	August 2002
D 1.6	Leaflet – Introduction to Day Care	No date. In use at start of study
D 1.7	Leaflet – Reiki for Day Care Patients	No date. In use at start of study
D 1.8	Leaflet – Day Care . Thursday. Creative Arts	No date. Used during 2000
D 1.9	Postcard and flyer – Hidden depths. An exhibition of artwork undertaken in Day Care	January 2001
	BUSINESS CASES AND ANNUAL REPORTS	
D 1.10	Business case for services to be funded by the Friends of the Hospice	July 1998
D 1.11	Business case for 5 day dedicated day care unit	Not dated. Probably produced in 1997
D 1.12	Business case for Activity Organiser in Day Care	Not dated. Probably produced in 1998
D 1.13	Day Care Annual Report	1997
D 1.14	Day Care Annual Report	1996
	POLICIES AND PROCEDURES	
D 1.15	Admission procedure. Draft 4	2001
D 1.16	Organisational structure: Lines of Managerial Responsibility	1997
D 1.17	Organisational structure: Lines of Clinical Responsibility	1997
D 1.18	Aims and objectives of the Grand Round	No date. Produced 2001
D 1.19	Operational Policy for Day Care	May 1997
D 1.20	Admission policy for Day Care and referral form	May 1996
D 1.21	Discharge policy for Day Care	May 1996
D 1.22	Palliative Care Referral Guidelines	Not dated
D 1.23	Hospice Discharge Guidelines	1994
D 1.24	Drivers guidelines	1993
D 1.25	Hospice philosophy statement	Not dated
	REVIEWS	

D 1.26	Annual review of art group initiative	Not dated. Probably produced in 2000
D 1.27	Day Care Review	March 1996
D 1.28	Day Care Service Review	November 1992
	JOB DESCRIPTIONS	
D 1.29	Job description of Day Care Leader	1999
D 1.30	Job description of Nursing Auxiliary	No date. Probably 2000
D 1.31	Job description of Activity Organiser	Feb 1999
D 1.32	Job description of a Day Care Assistant	
	REPORTS AND EVALUATIONS	
D 1.33	Report on Creative Arts Programme	October 2000
D 1.34	**CORRESPONDANCE**	
D 1.35	Cards from staff on leaving service	April 2001
D 136	Letter from Activities Organiser to patients	December 2000
D 1.37	Request for entries into magazine	Not dated
D 1.38	Christmas calendar of events	December 2000
D 1.39	Memo to patients re Day Care closures over Christmas	November 2000
D 1.40	Letters from staff and patients to a local newspaper regarding an article about the creative art group	Feb 2001
D 1.41	Progress report on implementation of local Palliative Care Joint Investment Framework	June 2001
D 1.42	Joint Investment Plan for Palliative Care Services	Not dated. Probably written in 1999
D 1.43	Review of palliative care services for the local health authority	June 1998

DC 2:

Reference no.	Description of document	Date of document and/or comments
	PATIENT INFORMATION	
D 2.1	Informal details of discharges from the Day Unit	Ongoing during period of study
D 2.2	Details of patients attending on a weekly basis	Ongoing during period of study
	LEAFLETS AND INFORMATION ABOUT SERVICE	
D 2.3	Day Unit Leaflet	Not dated, but probably produced in mid 1990s
D 2.4	An introduction to Day Care for patients	Not dated but in use at the time of study
D 2.5	Leaflet regarding Family Support Service	Not dated but in use at the time of study
D 2.6	Presentation by Day Care Leader for volunteers regarding service	Not dated but used between 1994-1999

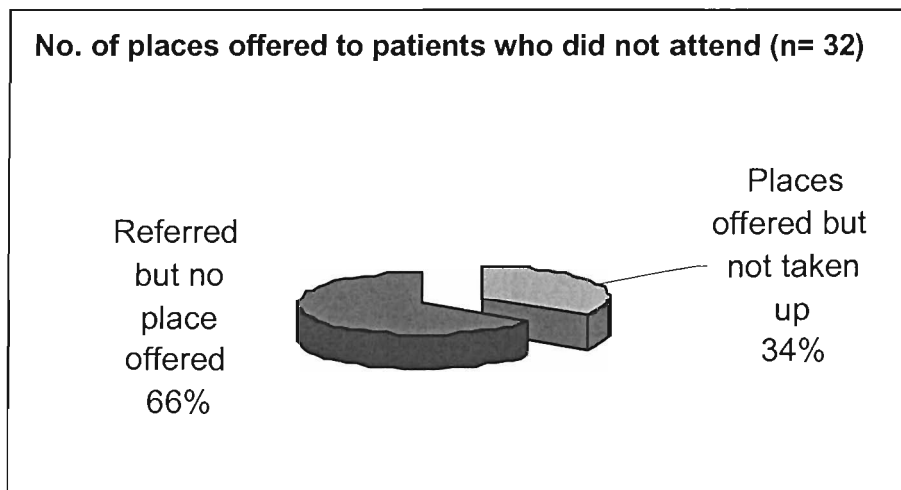|	PUBLICATIONS	
D 2.7	Tilting at Windmills – collection of poetry by a patient	1995
D 2.8	National Association of Hospice and Palliative Care Leaders Newsletter. Contains article on Day Care Unit	Spring 2002
D 2.9	Letter from patient published in local paper regarding Day Unit	No date on copy
	POLICIES AND PROCEDURES	
D 2.10	Philosophy of Day Care	Not dated. Provided by previous Day Care Leader
D 2.11	Objectives for Day Care	Not dated. Provided by previous Day Care Leader
D2.12	Admissions policy for Day Care	Not dated. Provided by previous Day Care Leader
D 2.13	Admissions policy for Day Care, Referrals and Criteria for Acceptance	Updated 14-01-1996. Provided by previous Day Care Leader
	REVIEWS	
D 2.14	Annual review of progress by Day Care Leader	1993-1999
D 2.15	[Area] wide Audit of Palliative Care	April 2000
	JOB DESCRIPTIONS	
D 2.16	Job description of Day Care Leader	October 2001
D 2.17	Job description of Staff Nurse (E grade)	Sept 1999
D 2.18	Job description of Staff Nurse (D grade)	October 2001
D 2.19	Job description of Nursing Auxiliary	October 2001
D 2.20	Job description of Day Unit Helper	Updated July 2001
	REPORTS AND EVALUATIONS	
D.2.21	Hospice guide to management and funding, including philosophy of service	2000
D.2.22	Hospice Information Pack	August 2000
D 2.23	Description of population served	2000
D 2.24	Hospice Annual Report	2000-2001
D 2.25	Macmillan Nursing Service Annual Report	2000
	CORRESPONDANCE	
D 2.26	Leaving cards from patients, staff and volunteers	November 2001
D 2.27	Copies of cards to Day Care from relatives on the death of a patient	Sept- Nov 2001
D 2.28	Copies of cards from patients to Day Care during periods of absence (arising from sickness, treatment etc)	July- Nov 2001
	OTHER VISUAL DATA	
D 2.29	Photograph of picture presented to staff in Day Care	

APPENDIX 7
GRAPHS GENERATED REGARDING PATIENTS
ATTENDING DC1

Site of cancer of patients attending the service (n=55)

Length of attendance of patients (n=55)

Length of attendance of patients attending for one year or less (n=39)

Gender of patients using Day Care

male
31%

female
69%

Age of patients using Day Care (n=55)

age (yrs)

Referrers to Day Care (n=55

Hospice
Inpatient Unit
4%

Hospice
Consultant
22%

Hospice
Specialist
Registrar
13%

Hospice
Community
Nursing Team
61%

Reasons for referral to Day Care (n=55 patients)

Pattern of attendance over period of Study (n=24 weeks)

12%   0%

88%

- ☐ Average no. of patients attending Day Care one day a week
- ■ Average no. of patients attending Day Care two days a week
- ☐ Average no. of patients attending Day Care three days a week

Number of patients referred to the service during the study

32   26

- ☐ No. of patients who attended the service
- ■ No. of patients who never attended

Reasons for non attendance (n = 32)

- Deteriorating condition 9%
- Admitted to inpatient unit 3%
- Feeling too unwell 9%
- unknown 26%
- On holiday 6%
- Sudden death 16%
- Pt refused DC 22%
- Receiving other treatment 9%

No. of places offered to patients who did not attend (n= 32)

- Referred but no place offered 66%
- Places offered but not taken up 34%

APPENDIX 8
GRAPHS GENERATED REGARDING PATIENTS
ATTENDING DC2

Length of attendance of patients during the period of the study (n=109)

| □ <1 |
| ■ 1-2 years |
| □ 2-3 years |
| □ 3-4 years |
| ■ 4-5 years |
| □ 5-6 years |
| ■ 7-8 years |
| □ 8-9 years |
| ■ 14-15 years |

Period of attendance of patients attending for to 12 months (n=83)

No of patients

No of months of attendance

□ Ongoing ■ Completed episodes

Age of patients attending Day Care during the period of the study (no=109)

No. of patients

Age

Most common diagnoses of patients (% of total)

- □ Bronchus and Lung
- ■ Breast
- □ Prostate
- □ Colo-rectal
- ■ Lymphoma
- □ Motor Neurone Disease
- ■ Oesophagus

4 4 4 20
6
8 17
10

Pattern of attendance of patients during the study (n=109)

4% 3% 6% 1%
28%
58%

- □ 1 day/wk
- ■ 2 days/wk
- □ 3days/wk
- □ fortnightly
- ■ monthly
- □ other

Domestic arrangements of patients (n=109)

1% 2% 3% 3%
1%
35% 55%

- □ Lives with family
- ■ Lives alone
- □ Lives with friend
- □ Nursing Home
- ■ Residential/ Rest Home
- □ Lives with partner
- ■ Unknown

Referrers of patients using the Day Unit during the period of the study (n=109)

Gender of people using the service (n=109)

Reasons for discharge from the service (n=53)

APPENDIX 9
DESCRIPTION OF ANALYSIS
ACCORDING TO METHOD OF DATA COLLECTION

Method of data collection	Process of analysis
Observation of the services studied	Notes scanned for common themes and aspects of the service requiring clarification
Examination of documents and visual information pertaining to each service	Documents, notices, letters and memos scrutinised and notes made on their content, highlighting issues of interest or confusion
Examination of patient records in each setting	Re-organisation of data into graphs and examination of them
Interviews with patients using PDC and other stakeholders	➢ Note additions and changes to the construction of the service offered by the interviewee immediately following interview ➢ Transcribe interview and analyse transcription using constant comparison method to develop "themes" for discussion with other participants ➢ Refer to reflexive diary to identify contribution of self to interview, its analysis and interpretation
Focus group	➢ Record process of the group immediately following it ➢ Transcribe group discussion ➢ Analyse transcription using constant comparison method ➢ Build on substantive codes derived from interview data and merge to create categories

APPENDIX 10
SYMBOLS USED IN THE TRANSCRIPTION OF INTERVIEWS

Symbols used in the transcribing process

Symbol	Meaning
XXXX	Content undiscernable
( )	Names changed/removed to ensure anonymity of participants
[ ]	Words added to retain meaning

Symbols used in the presentation of the data within the joint constructions

Symbol	Meaning
....	Section of data left out for ease of reading
( )	Names changed to ensure anonymity of participants/participating services
[ ]	Words added to assist comprehension of meaning by readers

APPENDIX 11
ANALYSING DC1 – CLAIMS MADE ABOUT THE SERVICE

Initial codes	Substantive codes	Categories	Contribution to Chapter 5
Volunteer transport Regular place available Time away from family	Getting out of the house	A day out from home	Section 5.3.7. – A day out from home
Getting out Different "set of walls" New relationships	Change of scene		
Time off for carer Reduced sense of burden	Respite care		
Structure within the week Meeting new people Having fun Links with the past	Something to look forward to	An enjoyable way to pass time	Section 5.3.5. - An important pastime Section 5.3.8. - A pleasant place to be
Availability of lunch Alcohol before and with lunch Entertainment The right balance Interesting day	Pleasurable time filler		
Friendly staff and volunteers Chance to meet other people Physical signs of affection	Company		
Happy atmosphere Help and support available Undemanding environment Relaxed environment Protection from outsiders	Pleasant and safe milieu		
New friends Friendships	New relationships	A group to belong to	Section 5.3.1. - A place to relate Section 5.3.2. - A place of give and take Section 5.3.3. - A source of friendship and companionship Section 5.3.8. - A pleasant place to be
Feeling safe Patient welfare of prime importance	Protection from outsiders		
Reciprocal relationships	A family		
Friendly environment Easy milieu Time to chat Meet the same people each week	Convivial atmosphere		
Parity in relationships Warm welcome Easy entry	Somewhere to belong		

No sense of being different to others Same diagnosis "All going the same way" Meeting people with the same problem	"All in the same boat"		
Presentations and talks	New knowledge	Feeling stimulated	Section 5.3.5. – An important pastime
Activities Trips out	New interests		
Creative art sessions	New skills		
New art techniques	Feeling challenged		
Diversion from illness Finding new talents Something else to think about "gives you a lift"	New optimism	An uplifting experience	Section 5.3.5. – An important pastime Section 5.3.6. - A place of support and care Section 5.3.8. - A pleasant place to be
Renewed purpose Feeling valued Confidence to go out again Able to make a contribution Treated as normal	New confidence		
Positive environment Lack of emphasis on disability Lack of discussion regarding illness	Positive milieu		
Treats Feeling cared for Attention of volunteers	Feeling special		
No pressure to talk about problems	Feeling in control		
Link between the ward and home Opportunity to try Day Care Time off the ward	First step home	A half way house	Section 5.3.8. – A pleasant place to be

APPENDIX 12
ANALYSING DC2 – CLAIMS MADE ABOUT THE SERVICE

Initial codes	Substantive codes	Categories	Contribution to Chapter 6
Medical support Knowledgeable nurses Occupational therapist Physiotherapist Immediate help Easy access to help Anticipation of new problems Creative solutions to problems Attentive staff and volunteers Ongoing monitoring of condition	Easy and immediate access to help	A place of safety	Section 6.3.2. – A source of care Section 6.3.3. – Assurance regarding the future
Feeling cared for Feeling supported Viewed as an individual Needs anticipated Staff "know you" No favourites amongst patients Offer of "added extras" Balance of care (help vs independence) "Nothing too much trouble"	Feeling cared for	A sense of importance	
Time off from illness "Takes your mind off things" Diversion from problems New focus for attention Light hearted atmosphere	Diversion from illness	A place of hope	Section 6.3.4. - A place of recreation Section 6.3.5. – A place of fun and hope
Jokes Humour of staff Having a laugh	Fun and Laughter		
Choice and variety of activities Availability of help and support New skills New opportunities to learn art High quality finished articles Raising money for hospice	Opportunity to do art and crafts		
Optimistic environment Improvements in condition New opportunities New goals Optimistic staff Reduced problems Learning how others cope Seeing others in worse situations Energising activities	Finding hope		

Opportunity to meet new people New contacts Friendly staff Friendly volunteers Meeting other patients Sociable environment Time to chat	Company	A family of friends	Section 6.3.1. – A family of friends
Sense of belonging Being part of a community Joining a group Sense of camaraderie Regular attendance Being with kindred spirits Reciprocal relationships	New group to belong to		
Care for staff by patients Reciprocal relationships Familiar relationships Easy relationships Equal relationships Informal relationships	Being part of a family		
Treated as normal Illness ignored Focus on abilities Being with others with similar problems	Feeling normal	Renewed sense of normality	
Regular "date" Transport provided Time away from family Trips from Day Care Change in scene Respite care for carers Flexible arrangements for attendance	Getting out of the house	A pleasant day out from home	Section 6.3.6. – A day out from home Section 6.3.7. – A pleasant place to be Section 6.3.8. – A source of support for carers and families
Regular attendance Same day each week Punctuating time	Structure within the Week		
Feeling accepted Lack of stigma Feeling safe	A haven		
Friendly environment Undemanding setting Informal environment Relaxed surroundings Familiar relationships Easy routine Non-institutionalised approach to care Open style of communication	Pleasant milieu		
Hot meal Drink before lunch Beverages Attentive service Choice of menu	Availability of food and drink		

APPENDIX 13
DATA CONTRIBUTING TO THE PROPOSITION
THAT PDC SERVES AS A COMMUNITY

Substantive codes of data related to Day Care 1 contributing to the proposition	Substantive codes of data related to Day Care 2 contributing to the proposition	Summary of the proposition that PDC serves as a community for people with progressive and life threatening conditions
Somewhere to belong Group to belong to	New group to belong to	PDC serves as a new community for people with progressive and life threatening conditions
Protection from outsiders	A haven	The community is bounded restricting membership of the community, thereby ensuring the safety of members
Being with others who have the same complaint "All going in the same direction"	"All in the same boat"	Criteria for membership of this community is based on an experience of having a diagnosis of a progressive and life threatening condition
Feeling comfortable Making friends	Feeling at home Feeling comfortable	If the criteria for membership is met, then access to the group is easy
Warm welcome Easy relationships	Valued physical affection Feeling at home	Members are welcomed warmly
Structure within the week Something to look forward to	Structure within the Week	A place is available to them within this community on a regular basis
Getting out of the house Change of scene Respite care Company New relationships A family Convivial atmosphere Positive milieu Feeling special Feeling in control Help and support Parity in relationships Being creative Opportunity to care for others	Feeling cared for Fun and Laughter Opportunity to do art and crafts Company Being part of a family Opportunity to get out of the house Availability of food and drink Being with kindred spirits Care for each other Reciprocal relationships New friends	The community offers: - Companionship and friendship with others who appreciate what they are going through - a day out from home on a regular basis (similar to a club) - relationships that are similar to those that they have enjoyed in the past (reciprocal, equal) - relationships that enable the person to feel cared for and supported - recreation and fun - an alternative family - creative activities in a supportive context
Pleasant and safe milieu Relaxed environment	Pleasant milieu Consistent environment	The community exists in an environment that is familiar, homely, comfortable and undemanding
Being with others "in the same boat" Pleasurable time filler New knowledge New interests New skills New optimism New confidence Feeling well	Easy and immediate access to help Diversion from illness Finding hope Feeling normal Valued relationships Lack of stigma Being amongst	As a consequence of being part of this community, its members enjoy - camaraderie with others in a similar situation - feeling cared for - diversion/ time off from their illness - reintegration into a group - renewed self worth

Feeling cared for	friends Being seen as an individual Finding new life Sense of belonging	- new hope - encouragement and optimism for their own future arising from seeing others in worse situations - new purpose arising from their relationships and role in Day Care, and creative activities - Feeling safe - Sense of normality

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