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Adult Palliative Day-Care Services:

An investigation of the factors influencing access to services using the case of a cancer network in the  
United Kingdom

Volume One

**By**

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A thesis submitted in fulfilment of the requirement for the  
degree of

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Finally as a Christian I would like to give the highest praise to God for His wisdom, providence and guidance throughout this entire research process.

### **Declaration**

I declare that this thesis is my own work, and that it has not been submitted to another university. Material which arose out of the work for the thesis and that has been previously published, has been included in the text. Results of phase one of the work pertaining to fear of the term hospice and its impact on access have been published in the form of an abstract for a poster presented at the 7<sup>th</sup> Palliative Congress, Glasgow, Scotland, 29<sup>th</sup> April - 1<sup>st</sup> May 2008. In addition, the concept of the psychological trajectories discussed in chapter eight was published in 2010, the form of a rapid response in the British Medical Journal. The references for these publications are given below.

### **References**

GREAVES, N.S., DALE, J., and ONG. P., 2008. The term “Hospice” and its potential impact on access to adult palliative day-care: mis-messages, meta- messages and marketing. *Palliative Medicine* 2008; 22; p. 582.

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Signed: Natalie Greaves Date: June 12 2012

## List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
APDC	Adult Palliative Day-Care
BMJ	British Medical Journal
C	Cancer
CEO	Chief Executive Officer
CHF	Chronic heart failure
CNCD	Chronic Non Communicable Disease
CI	Chief Investigator
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COPD	Chronic Obstructive Pulmonary Disease
COREC	Central Office of Research Ethics Committee
DIPEX	Department of Primary Health Care, University of Oxford

DH	Department of Health
DM	Diabetes Mellitus
DN	District Nurse
EMBASE	Excerpta Medica Database
ESRD	End-Stage Renal Disease
EU	European Union
GP	General Practitioner
GSF	Gold Standards Framework
HAART	Highly Active Anti Retroviral Therapy
HC	Hospital Consultant
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
IELTS	International English Language Testing System
ID	Identity Card
IHD	Ischemic Heart Disease
IMD	Index of Multiple Deprivation
IT	Information Technology

Mac N	Macmillan Nurse
MDT	Multi Disciplinary Team
MEDLINE	Medical Literature Analysis and Retrieval System Online (U.S. National Library of Medicine's life science database)
MND	Motor Neuron Disease
MPhil	Master of Philosophy
MS	Multiple sclerosis
MSc	Master of Science
NC	Non-cancer
NCPC	National Council for Palliative Care (Formerly the National Council for Hospice and Specialist Palliative Care Services- NCHSPC)
NGO	Non Governmental Organisation
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NOF	New Opportunities Fund
NRES	National Research Ethics Service

ONS	Office for National Statistics
OSOP	One Sheet of Paper
Palliative Care	Palliative Care
P.C.N.G	Palliative Care Network Group
PCT	Primary Care Trust
PsycInfo	Psychological Information Database
PDC	Palliative Day-care
PhD	Doctor of Philosophy
PIS	Participant Information Sheet
PPC	Preferred Priorities for Care
QSR	Qualitative solutions and research
R&D	Research and Development
RSCD	Regional Study for Care of the Dying
ScHARR	(Sheffield University) School of Health and Related Research
SDE	Self-Declared Ethnicity
SHO	Senior House Officer

SPCS	Specialist Palliative Care Services
SPSS	Statistical Package for the Social Sciences now “SPSS”
UK	United Kingdom
USA	United States of America
WB	White British
WHO	World Health Organization
WMS	Warwick Medical School

## **Abstract**

**Background:** Literature indicates underutilization of Palliative Care Services in the UK, with possible inequalities of access. These trends in underutilization are seen in Adult-Palliative Day-Care (APDC), a Specialist Palliative Care Service delivered in the outpatient setting. However, gaps in knowledge remain regarding if underutilization in APDC is real, and the identity and nature of the factors which determine access.

**Aim:** The overall research question was “What are the factors which act to determine access to APDC?”. Five sub-questions for exploration in the context of access were formulated relating to the: perceived health care needs of users; the benefits of using APDC, and understandings of the role of APDC as a palliative care service.

**Methods:** The study site was a cancer network in the Midlands of England which covered rural and urban areas. It contained 5 APDC units, 3 Primary Care Trusts, and 3 Acute Care Trusts. Fifty semi-structured in-depth interviews were conducted with: 19 providers of APDC; 13 health professional referrers; 11 palliative care patients who had used the service; and 7 of their carers. The reasons for non-attendance for 149 patients who were referred to day-care but did not attend were also analysed.

Thematic analysis with constant comparison and content analysis were used to analyse transcripts and document data respectively.

**Results:** Eighteen determinants of access were identified arising out of the characteristics of the: potential service user (2), the health service or organization (9), and from interactions between potential service users, the family, the wider society, and the health service (7). The study found that utilization measures in APDC may not be accurately representing service use, as APDC units maybe functioning at their maximum capacity while current calculation methods report underutilization.

**Conclusion:** New insights into accessing APDC are presented which and may have applications for future policy and research.

## **Preface**

### **Introduction**

Within human societies there has been the need to provide care for the sick, particularly those whose illness was thought of as being likely to result in death. Opinions and evidence regarding (a) what constitutes care; (b) who should be the primary care giver(s); and (c) where care is best provided?; vary and continue to undergo change. Increasingly around the world, care of the dying or those with life-threatening illnesses is seen as needing to encompass all of the elements of the World Health Organization's definition of health<sup>2</sup> (WHO), including physical, mental and social well-being. Despite the debate and continued evolution of thought about how best to provide care for the dying (and those with life-threatening illnesses), it is being advocated that this form of care be integrated into health systems, and that it should form one of the basic components of health care to which citizens of countries might expect to have access.

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<sup>2</sup> The WHO definition of health states that "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on April 7 1948.

<http://www.who.int/about/definition/en/print.html/> (Accessed May 19 2010)

## **Personal story**

It is from this perspective, of their needing to be a form of care which addresses the needs of those persons who are dying or ill and facing the possibility of death, that my interest in palliative care started. The work presented in this thesis was part of a cancer network project which was conducted between 2005 and 2010, the data collection period being between July 2006 and 2008. This work on access to day-care is part of a personal journey to understand the organization and delivery of palliative care, and to gain the skills that would allow me to develop such services in my home country of Barbados.

My interest in palliative care began in 2003 while a House Officer in the Paediatrics Department at the Queen Elizabeth Hospital in Barbados. During this 3 month period, I had what has come to be the life-changing opportunity of being involved in the clinical management of children who had been diagnosed with malignancies (mainly haematological). In many cases, these children, along with their parents, were trying their best to cope (sometimes struggling) with the realities of life-threatening illness and, in some cases, imminent death. Despite the best clinical care by our team, I was aware that in some cases, there was a missing element, and that we were somehow not being able to fully address the needs of our patients and their relatives.

While managing one young boy, in particular, who was terminally ill (who I now in retrospect see as having multiple specialist palliative care needs), I was introduced to the concept of palliative care by a UK trained cancer charity volunteer who was visiting the patient. As a result of this very brief conversation my eyes were opened up to the wonderful possibility that death need not be a fearful,

painful or dreaded event. From this point, I had the strong conviction that I should do my best to improve the approach to, and the clinical management of those who face the possibility of or imminent death in Barbados.

As a result, my career path changed direction from the planned Senior House Officer (SHO) in Surgery (Orthopaedics) to SHO in Radiotherapy (despite its name, this department is mainly responsible for providing radiotherapy, medical oncology and end-of-life care for adult patients with solid tumours in Barbados) so as to gain as much knowledge and experience in oncology, palliation and end-of-life care. Over the next almost year and a half, I educated myself on clinical issues in end-of-life and palliative care and, under the supportive guidance of Department Consultant, Dr R K Shenoy and Registrar, Dr Michael Inniss, I was given the opportunity to develop my oncology clinical skills, and have my ideas about research taken seriously.

As there is no physical palliative care training in the Caribbean, I knew that to further my understanding of the area, I would have to leave the region at some point. With the help my husband, I researched and considered entry routes to and the content of various palliative care programmes. Studying in the United Kingdom was one of the main options as I was natively fluent in English and already fully registered with the country's General Medical Council. In addition to language and medical registration, one of the main considerations with respect to my career path was finding a programme that would allow me to understand how palliative care services were organized, managed and delivered, while still having the possibility of improving knowledge of clinical palliative care. My initial thoughts were that studying in the UK would fit both of these criteria. Barbados is a Commonwealth country and has some similarities to the UK. In particular, similarities exist with

respect to the structure of the health care systems and the expectations of the population (and politicians) with respect to how health care should be provided, particularly that health care should be provided free at the point of delivery. Therefore, in terms of likely relevance and transferability of palliative care organization that could be studied, the UK seemed to be an appropriate model for examination. My plans, therefore, were to pursue an academic Master programme, followed by clinical training in a specialist palliative care programme (first having completed the Royal College of Physicians exams necessary for entry).

It was with this career pathway in mind that I applied for a Master of Science by research at the Warwick Medical School (WMS) in 2005, at the then Centre for Primary Health Care studies. The attraction of the University of Warwick was in the description of the research project to be undertaken for the Masters degree. At the time of my application the project as advertised entailed analyzing, and mapping the models of Adult Palliative Day-care (APDC) provided within the local cancer network. Therefore, I saw that undertaking this course of study at Warwick could provide me with the opportunity to research and understand how palliative care services are organized in the UK context. In addition, I saw the project as a means of being able to investigate first-hand, the benefits of what has been termed the social and medical models of palliative care, and the potential challenges associated with delivering these.

On applying for and being interviewed for the MSc (my first visit to the UK, May 2005) I was subsequently offered a full time PhD Studentship, with arrangements to work up to 8 clinical hours at an APDC unit with the network. One of the challenges to accepting the offer to study at WMS was the availability of only partial funding for my tuition through this scholarship (the scholarship being

originally intended for a UK or European Union (EU) student only). Not being willing to give up the scholarship, with the recommendation of my department consultant in Barbados, Dr Shenoy, I applied for the very competitive Barbados National Development Scholarship in the area of Medicine. In July of 2005, I was awarded the scholarship which came with the caveat that I had to return to Barbados on completion of studies to contribute to the development of palliative care on the island (a challenging task but one I was happy to accept).

The aim of the PhD studentship as outlined by the project funders was that the research would focus on mapping the routes of referral to APDC. It was suggested that exploring these routes might reveal the causes of the low rates of utilization of APDC services being reported within the network. However, on performing early literature searches it became evident that it was possible that more insight into utilization rates could be gained if the focus of the work was broadened from mapping referral routes to the larger more intricate process of accessing palliative care. Therefore the broad line of enquiry became focussed on identifying and understanding the factors which act or interact to determine access to APDC.

Understanding the factors which determine access to services is important as it can assist policy makers and service designers in identifying core characteristics of their service which, whether previously acknowledged or not, exert an influence on access. Such information would be useful in informing any service change, development, and funding and or marketing processes. From a medical, sociological, and ethical view point understanding the determinants of access to APDC is important as it may assist in identifying the presence and cause of any inequalities or inequities in service provision to user groups which have lower than expected access levels or utilization rates.

### **Macrostructure of the thesis**

This thesis has eight chapters presented in three parts. Part one (Chapters One, Two and Three) presents the background and theoretical information that underpin the work. It discusses evidence on access to palliative care which led to the derivation of the research question. This part of the thesis also provides a description of the study site. Part two of the thesis (Chapters Four and Five) contains the research design and findings. The last section (Part three) discusses the results and the limitations of the study. It also presents the clinical implications, policy, and research impacts of the research findings, and new contributions to knowledge.

### **Specific organizational features of the thesis**

Each chapter with the exception of Chapter Five starts with an introduction and concludes with a chapter summary. In some cases the chapter summary is in the form of a text box figure which covers the key points discussed in the chapter.

Appendices are presented in volume II and are numbered sequentially one through to seventeen.

**PART ONE:**

**Background and Theoretical Underpinnings**

BECAUSE THAT YOU ARE GOING

Because that you are going  
And never coming back  
And I However, absolute,  
May over look your Track-

Because that death is final,  
However, first it be,  
This instant be suspended  
Above Mortality...

EMILY DICKINSON

## **Chapter One: Background**

Chapter One sets out to outline the scope of the research question and explain the rationale for researching access to APDC services in the UK. In so doing the chapter comments on:

- the definitions of terms commonly used in palliative care research and policy;
- the current models of palliative care provision in the UK;
- the current understanding of issues thought to be affecting access and utilization of APDC;
- and the gaps in knowledge regarding the basis for current access and utilization trends in APDC.

## **Chapter Two: Access and need: The basis for frameworks investigating inequalities of access to APDC**

An understanding of access to APDC may be facilitated by considering the research and theories on access to health care in general. Therefore, Chapter Two presents a discussion on these. As shown in this chapter, access is a complex term, which in the context of health care is closely associated with issues of needs and demand. As such (in Chapter Two), current research and theories of access, need and demand for health care are combined to form new frameworks for identifying and understanding determinants of access to APDC. The chapter concludes with a presentation of the research question answered by this study.

## **Chapter Three: Choice of the research site**

Chapter Three describes the relevant demographic, geographic, and health system characteristics of the cancer network that was the setting of the study. In particular, it provides descriptions of the five

APDC services at which the research was conducted. In so doing, it is a key chapter, providing context to assist the reader in the interpretation of the results presented in Chapter Five.

## **CHAPTER ONE:**

### **Background**

#### **1.0 Introduction**

This chapter aims to present the rationale for researching access to Adult Palliative Day-Care (APDC) services in the United Kingdom (UK). The chapter begins by setting forth the argument that both the event of death and the action of caring for the dying have been important spiritual and moral issues in human societies. It advocates that the presence of aging populations in economically developed societies, coupled with changes in the global mortality and morbidity profile, means that good quality care of the dying is becoming ever more important and is increasingly viewed as a public health and human rights issue. As a result, research which could be used to inform the provision of palliative care at the macro<sup>3</sup> level is timely and important.

Furthering the aim of providing the theoretical underpinnings of this work, section 1.6 (page 55) describes the results of the literature review which informs this work on access to APDC. It discusses the utilization patterns which have been generally observed in the palliative care sector within the UK. In particular, the chapter reviews research conducted in the UK that has suggested that palliative care services, including specialist palliative care services,<sup>4</sup> have been underutilized by certain potential user groups e.g. persons with non-cancer diagnosis and ethnic minorities. Within palliative care and

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<sup>3</sup> Here macro is taken to mean the level of the health system as described by Fulop et al., 2001, p. 12.

<sup>4</sup> It should be noted that in the studies cited that the term Specialist Palliative Care Services (SPCS) included inpatient hospices, APDC services as well as hospice at home services.

Department of Health (DH) policy literature, these patterns of underutilization have been seen as being potential indicators of there being inequalities of access to palliative care services; therefore the literature on utilization and inequalities of access to palliative care services is also examined.

Within palliative care policy, research, and health care, there is a complex vocabulary to describe processes, institutions, services, training, care activities, and professionals. Some terms, though commonly used, are recognised to have changed in meaning over time. Such terms include “palliative care” itself. Variations in meaning (and in some instances variations in philosophy), may potentially impact palliative care provision by altering the target clientele of services; therefore the definitions of key terms such as palliative care are discussed in the context of how their changing meanings could impact on access.

The chapter concludes by summarising the current gaps in knowledge regarding inequalities of access to APDC as indicated by the literature review. These gaps in knowledge are presented in section 1.8 (page 66-68), and have been used to derive the overall research question of this thesis which is presented at the end of Chapter Two and referenced at the beginning of Chapter Four.

## **Part One: Death in human society**

### **1.1 The Significance of death in human society**

Death has been described as one of the common denominators of human experience and follows as a natural consequence of being born (Byock 2002, p. 108-110, Higginson 1997, p. 184). It is perhaps the

acknowledgement of this shared fate that explains why the care of the dying has occupied such a consistent and sometimes prominent place in human societies.

Historical references of ancient societies, such as those of the Romans, Greeks, and Hebrews, as well as accounts of pre-modern Christian societies, all indicate that the care of the dying and the event of death were of significance (Cowley et al 1992, p. 1474-1477<sup>5</sup>, Werber 1996-1997, p. 17-18). Within these societies (albeit to varying degrees) similar practices can be found regarding the care of the dying and include attempting to manage and in some cases alleviating the physical symptoms of the dying (Donnelly 1999, p. 59-60).

In today's western Anglo-Saxon society<sup>6</sup>, it appears that the religious significance of the care of the dying has been reduced (Lewis 2007, p. 11, 14). However, it can be argued that the overall importance of caring for the dying, and the events surrounding the point of death have not lessened. As shown by Epstein (2007, p. 24-30), issues such as the moral, legal, and economic justifications of euthanasia are continually debated within the medical and legal disciplines. In addition, within the medical discipline there is also continued debate regarding the balance between the physician's (perceived or real)

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<sup>5</sup> Cowley et al's work is a historical examination of the ethics surrounding the care of the dying from ancient civilisation to the post modern era. It uses the opinions and philosophies of prominent societal figures as a means of gaining information (Cowley et al. 1992, p. 1474). Their comments on the limitations of their work are worthy of note, particularly with respect to the use of their work as a reference in this thesis. On referring to the care of the dying in ancient civilisations they state "... it is difficult if not impossible to accurately characterize the moral attitudes of a civilisation that spanned the greater part of a millennium..." (Cowley et al. 1992, p. 1474).

<sup>6</sup> The term western Anglo Saxon is based on the work of Lewis (2007, p. 11,14) which comments on the decline of religion in the following countries- Australia, Canada, Great Britain, and the United States of America. It is recognised that the degree of decline may be different in individual countries.

responsibilities to: (a) prolong life; (b) not hasten death; (c) alleviate pain; d) respect patients' right to self determination and autonomy (Cowley 1996, p. 1480-1481). Further, as shown in the seminal work of Kubler-Ross (1969, p. 166-167, 189-192, 268), the contemplation of imminent death remains capable of evoking strong emotions in the individual who is dying, their relatives, friends, and the health professionals who care for the dying person.

At a macro level the significance of death and dying in today's society is perhaps also evidenced by the increased level of priority placed on the provision of such care in health policy (Sepulveda et al. 2002, p. 91, Bosnjak et al. 2006, p. 9, Clark 2007b, p. 430). During the twentieth century, a major focus of governments, health systems, and international health institutions, was the reduction of the number of deaths, as well as premature deaths within their given populations<sup>7</sup>. In the twenty-first century however, caring for persons who are at the end of their life, as well as those facing the challenges associated with chronic life-threatening illness is increasingly being advocated as an integral part of health care, alongside curative and preventative aspects of clinical care and public health (The Lancet 2010, p. 1960).

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<sup>7</sup> This focus was and continues to be reflected in global and national level initiatives which seek to reduce mortality rates from specific causes, and within specific population age groups. Recent global initiatives have focussed on reducing mortality rates:

- among children (WHO, Millennium development goals <http://www.who.int/mdg/goals/en/index.html> (Accessed Dec 7 2009);
- of specific diseases, e.g. HIV (WHO. II. UNAIDS. III. UNICEF 2008, p. 26, 28), Malaria (WHO 2008, p. 3-6) and Chronic Non Communicable Diseases (PAHO 2008).

One of the national level initiatives which has sought to reduce mortality rates in the UK is the prevention of accidental deaths in infants and children (DH 2002, p. viii, 3, 9-16).

Within the European context, as stated by Clark and Centeno (2006, p. 198), policy guidelines devised for member states of the Council of Europe recognize palliative care

*“as an essential and basic service for the whole population”*

and that

*“Good quality palliative care should be equally accessible to everyone, independent of ethnicity, age, religion, geographical location, type of disease, life expectancy, and socio-economic status”.*

In the UK, an increased macro level policy focus on palliative care is perhaps evidenced by the increase in government investment and the continued interest in the viable funding of this form of care (Seymour *et al.* 2002, p. 6, Palliative care Funding Review, Interim report 2010, p. 3). With specific reference to England, initiatives such as the Gold Standards Framework for palliative care (GSF)<sup>8</sup>, is a recipient of government funding (Graham and Clark 2007, p. 65).

Some of the factors which may have potentially contributed to the increasing prominence of palliative and end-of-life care provision in macro level health policy are discussed further in section 1.2 and 1.3 (pages 37-40).

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<sup>8</sup> GSF-“ is an approach designed to strengthen the organization and quality of primary palliative care” It includes emphasis on the systematic identification of palliative patients, patient empowerment and a coordinated multidisciplinary approach to care( Dale et al. 2009, p. 174, 175).

## **Part Two: Factors contributing to the increasing prominence of palliative care in macro level health policy**

### **1.2 Increased research, advocacy, and organization in palliative care to achieve the goal of a good death**

Over the past 40 years within the health care and medical disciplines, there has been a growing global interest and consensus about the importance of providing care for the dying and those facing the challenges associated with life-threatening illnesses (Clark 2007, p. 430, 437). Advocacy for the alleviation of pain<sup>9</sup> has been one of the most successful instruments for generating specific interest in the clinical management of, and the organization of care for the dying (Sepulveda *et al.* 2002, p. 91; WHO 2004a, p. 7, Seymour *et al.* 2005, p. 6-10, Clark 2007b, p. 430). The discourses in the late nineteen seventies and early nineteen eighties that served to inform the formation of the WHO Analgesic Ladder (Clark 2007b, p. 433; Clark 2007a, p. 102) were followed by a series of events which moved care of the dying from “The Margins to the centre”, as termed by Clark (2007, p. 430).

These events included:

1. an increase in academic and research activity revolving around the clinical care of patients who are dying or who face the challenges associated with life-threatening illnesses (Doyle 2007, p. 84);
2. an increase in the number of professional and academic associations focused on improving care for the aforementioned patients (Clark and Centeno 2006, p. 197, Doyle 2007, p. 79); and
3. the recognition of palliative medicine as a medical specialty (Clark 2007b, p. 430, Gelfman and Morrison 2008, p. 36), with the subsequent expansion in medical education, medical

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<sup>9</sup> The work here refers to both physical and non-physical forms of pain.

literature, and academic journals relating to the specialty (Lewis 2007, p. 128, Doyle 2007, p. 80).

The changing patterns of illness around the world, and the aging population of many countries have also been significant factors in increasing the importance of care of the dying and those with advanced illness at the national health policy level (The Lancet 2010, p. 1960). These are discussed below.

### **1.3 Changing patterns of illness and its effect on the care of the dying**

In the past century, great strides have been made by modern medicine to significantly reduce death from infectious diseases (Graham and Clark 2007, p. 64). There is, however, in the twenty-first century another epidemic facing the world's population; that of non communicable diseases such as cancer, diabetes mellitus (DM), hypertension, and other cardio vascular diseases such as ischemic heart disease (IHD) and chronic heart failure (CHF) (Clark *et al.* 2004, p. 266, Graham and Clark 2007, p. 64).

The World Health Organization estimates that by the year 2030, 70% of all deaths in the world will be caused by non communicable diseases (World Health Statistics 2007, p. 12). As it relates to the United Kingdom, it is estimated that in the same year (2030) 85.4% of all deaths would have occurred because of non-communicable diseases, with cancer and cardiovascular diseases accounting for 22.6% and 38.6% of death respectively. (WHO Global information base <http://www.who.int/infobase/report.aspx?iso=GBR&rid=119&goButton=Go> Accessed November 11 2008).

It is important to note that, as with patients with a diagnosis of cancer, it is recognised that patients

with other chronic non communicable diseases are likely to experience significant periods of morbidity during the course of their illnesses (O'Brien *et al.* 1998, p. 286, Jabalinski 2008, p. 206, Bausewein *et al.* 2010, p. 1110-1115). During these periods, it is likely that the traditional, well established principles used in the care of the dying and those facing the challenges associated with a diagnosis of advanced cancer would be appropriate (Jabalinski 2008, p. 206). Given the increasing incidence and mortality rates of non communicable diseases discussed above, it is likely that over the next 20 years the number of persons requiring this care will increase.

The number of persons requiring care when dying, or when facing the challenges associated with life-threatening illness, is also likely to increase because of continued medical advancements which are contributing to increasingly older populations around the world (Rajagopal 2007, p. 301). The natural history of HIV/AIDS for example, has been affected by medical advancements, particularly the availability of highly active anti retroviral therapies (HAART) (Karim *et al.* 2009, p. 1195, 1207). However, as noted by Harding *et al* (2005, p. 251, 255):

“Prolongation of the chronic disease phase can be associated with cumulative drug toxicities and symptomatic sequelae”

as well as

“new HIV-related co-morbidities” that make the need for palliative care likely.”

The net result of the factors discussed above, namely: advances in medical technology, the increasing incidence of Chronic Non-Communicable Diseases (CNCDS), and the aging population of the world, is that more persons are likely to be needing care when facing the challenges associated with life limiting illness, and will require such care for increasing periods of time. Within this context, it becomes an

important aspect of health care research to understand how palliative care services can be best organized to meet the current and projected needs of the population.

#### **1.4 Right to health care**

As stated by Hunt (2009, p. 336, 337) obtaining “the highest attainable standard of health” may be seen as a legally binding human right in many modern countries; including the UK. As signatory to the International Covenant on Economic Social and Cultural Rights (particularly Article 12-The right to health) the government of the UK, is seen as having some responsibility to ensure equitable access to health care, including the provision of palliative care (Joint NGO Report to the United Nations Committee on Economic Social and Cultural Rights April 2002, p. 24,

<http://www.justice.org.uk/images/pdfs/ICESCR%20report.pdf> Accessed December 22 2010). In

keeping with this responsibility, the DH has placed importance on providing care which is responsive to the needs of patients or carers of patients facing the challenges associated with death, dying, and life-threatening illnesses. This is evidenced by recent statements of the Secretary of State for Health<sup>10</sup> in outlining the objectives of social care system reform. Using the term personalisation he states

“We must give people control of their own care, so they can choose services that best meet their needs... In a compassionate society, patients – both adults and children – should be able to receive palliative care in the manner they wish, in the setting they choose.”

The changing demographics and disease profiles discussed above, accompanied by the responsibility to facilitate and be responsive to the needs and rights of the health care consumer, make it important to research issues relating to organization and delivery of palliative care as a whole. This thesis is

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<sup>10</sup> Secretary of State for Health's speech to the 5th International Carers Conference - 'The principles of social care reform' 9 July 2010. [http://www.dh.gov.uk/en/MediaCentre/Speeches/DH\\_117331](http://www.dh.gov.uk/en/MediaCentre/Speeches/DH_117331) (Accessed December 14 2010).

concerned with the organization and delivery of APDC in the UK; particularly as it relates to accessing services.

The case in support of the relevance of understanding access to APDC was informed by literature which suggests that there is potential underutilization and inequalities of access to these services in the UK. The literature review process used to inform this work is detailed below.

### **1.5 Literature review process**

The work on this study started in September 2005. Between September 2005 and week four of October 2005, a literature review was conducted with the aim of furthering my understanding of palliative day-care service; including its development and access to services issues. During this six week period literature was searched in the following electronic databases: Cochrane Database of Systematic Reviews (CDSR), ACP Journal Club, Database of Abstracts and Reviews on Effectiveness (DARE), Ovid MEDLINE(R) and Journals@Ovid . The search strategy was iterative. Initially three very broad terms were used to find data relating to palliative care organization:

- palliative hospice, palliative care services, palliative care organization\* AND/ types, organization, social- Journals@Ovid, CDSR, ACP Journal club, DARE, Ovid Medline [mp=title,original title, abstract,tx,ct,sh,keyword,nm.hw]
- Hospice services AND definition- Journals@Ovid, CDSR, ACP Journal club, DARE, Ovid Medline [mp=title,original title, abstract,tx,ct,sh,keyword,nm.hw]
- Palliative day-care- Journals@Ovid, CDSR, Ovid MEDLINE(R)

These were not restricted by time, and did not exclude historical reviews or personal views in editorials. The search strategy was then altered to collect data from the MEDLINE database relating to access and palliative care. The following terms were used: hospice care,\*day-care, palliative care, access\*, \*access to health care or Health service Accessibility (this was a Mesh heading applied to Medline only). The search strategy limited in MEDLINE was limited by time 1996-2005, and studies reporting on patients under 18 years old were excluded as this work was concerned with adult palliative care services. The reference list of articles that were found to be relevant were also reviewed (retrieval of full text articles was enhanced by the use of the Scopus database). The study was not limited by language. Results of the broad search strategy are shown overleaf in Figure 1.0 .

**Figure 1.0 Broad Strategy**

Search terms	Date	Number of electronic results	Results after application of exclusion criteria	Number relevant
palliative hospice/ palliative care services/ palliative care organization* AND/ types/organization/social-Journals@Ovid, CDSR, ACP Journal club, DARE, Ovid Medline [mp=title,original title, abstract,tx,ct,sh,keyword,nm.hw]	2005/09/05	11	1	1
Hospice services AND definition-Journals@Ovid, CDSR, ACP Journal club, DARE, Ovid Medline [mp=title,original title, abstract,tx,ct,sh,keyword,nm.hw]		2	0	0
Hospice movement-Journals@Ovid		10	0	0
Palliative day-care-Journals@Ovid, CDSR, Ovid MEDLINE(R)	2005/09/07	22	10	10
hospice care/*day-care/AND palliative care AND access to health care or Health service Accessibility-MEDLINE (Limited to English) [mp=title, original title, abstract, substance word, subject heading](1996-to October Week 4)	2005/10/04	712	36	9

The MEDLINE strategy was continued until December 2006 so that new results could be used to inform the study as it progressed.

In addition to those early broad strategies, the Scopus database (August 2006-present), and the Wellcome Trust History of Medicine (Feb 2008- March 2010) were accessed, and relevant search strategies conducted as findings emerged.

In 2010 while preparing this thesis a final narrative review<sup>11</sup> was conducted specifically in an attempt to verify that all relevant data on APDC had been reviewed during the process of the study. In addition to original databases, EMBASE, PsycInfo and CINHAL were included to further reflect the multidisciplinary nature of APDC and the likely location of any published literature.

Grey literature was also searched. This involved the use of databases which contain theses and dissertations namely: Index to theses of Great Britain and Ireland; DART-Europe Portal; ProQuest Dissertations and Theses; EThOS (British Library Electronic Thesis Online Service); and WRAP- Warwick Research Archive Project.

Academic journals associated with palliative care conferences and associations were also hand searched; along with the publication lists of policy and university departments known to be involved in palliative care research and development initiatives e.g. International Observatory on End-of-life Care of the University of Lancaster and The King's Fund.

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<sup>11</sup> From the broad initial literature review, it was evident that the sources of data needed to generate knowledge might be varied. For example descriptions of what services do could be obtained from empirical research, as well as reports from national organizations such as the National Council for Palliative Care (NCPC). On the other hand data addressing the effectiveness and benefits of APDC might be supplied by quantitative and qualitative empirical studies. Therefore, a narrative synthesis review was used as it allows for use of various forms of data.

The aim, research question and search strategy for the narrative review and grey literature search were similar; however, the sources of data searched were different. The overall strategies for the narrative review and the Grey Literature search are provided in Figure 1.1 and 1.2.

**Figure 1.1 The process for the narrative review**

<p><b>Aim of review</b></p> <p>To contribute to the generation of knowledge on APDC organization, and delivery in the UK. In particular identifying and synthesizing data pertaining to: service models; and the effectiveness of APDC as a health care intervention.</p> <p><b>Main review questions</b></p> <p>What is Adult Palliative Day-Care (APDC) in the UK context?</p> <p><b>Sub-questions</b></p> <ol style="list-style-type: none"><li>1. What are the service delivery models of APDC in the UK?</li><li>2. What is the clinical effectiveness of adult palliative day-care services in the UK as compared to other palliative care services?</li></ol> <p><b>Framework of search: Population:</b> adult population in the UK, <b>Intervention:</b> APDC, <b>Time frame of the review:</b> January 2005- March 2010. Results not restricted to English</p> <p><b>Exclusion criteria-:</b> studies reporting on services with a target clientele under 18 years old, studies reporting on single patients, and studies outside of the population</p> <p>Reference list from the articles found to be relevant using the search strategy were searched. The reference list of articles which met the search strategy criteria other than being conducted in the UK were also searched to identify any UK studies not found in the bibliographic databases.</p> <p><b>Databases for sub-question 1:</b> EMBASE, CINAHL, PsycInfo, MEDLINE (1950- ), Cochrane Library</p> <p><b>Search strategy for sub-question 1:</b> (palliative day-care or hospice day-care or terminal day-care or supportive day-care or end-of- life day-care) AND (service structure or care model or infrastructure or service capacity or clinical intervention* or activit* or service model* or organi*e or organi*ation or (organi*ation and administra*) key word heading</p> <p><b>Framework of the scoping search for sub-question 2: Population-</b> adult population in the UK, <b>Intervention-</b> APDC, <b>Broad Comparator-</b> All other forms of palliative care services in the UK, <b>Broad outcome:</b> Changes in (improvement or decline) or maintenance of quality of life.</p> <p><b>Databases:</b> Cochrane Library, MEDLINE (1950- ) - PsycInfo, CINHALL <b>Search strategy:</b> palliative day-care or hospice day-care or supportive day-care or end-of- life day-care AND benefit*OR effect* OR quali*</p>
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**Figure 1.2 Strategy for Grey Literature search (Search strategies one and two)<sup>12</sup>**

**Question:**

Search one-What do APDC services do? What are the service delivery models of APDC in the UK?

Search two-What is the clinical effectiveness of adult palliative day-care services in the UK as compared to other palliative care services?

**Framework of the scoping search:**

**Population:** Adult population in the UK

**Intervention:** APDC

**Time frame:** 2000- March 2010

**Search Strategy one:**

**Aim:** To retrieve documents with relevant key words reporting on or purporting to address the organization and delivery of palliative day-care (or relevant synonyms), especially as it relates to models of care/ care delivery.

**Key words:** (palliative day-care or hospice day-care or terminal day-care or supportive day-care or end-of- life day-care) AND (service structure or care model or infrastructure or service capacity or clinical intervention\* or activit\* or service model\* or organi\*e or organi\*ation or (organi\*ation and administra\*).

**Search strategy two:**

**Aim:** To retrieve articles which claim to address the effectiveness or benefit of palliative day-care, especially as it relates to other palliative care services.

**Key words:** **Search two** palliative day-care or hospice day-care or supportive day-care or end-of-life day-care AND benefit\*OR effect\* OR quali\* **Broad Comparator**-All other forms of palliative care services in the UK, **Broad outcome:** Changes in (improvement or decline) or maintenance of quality of life. **Time frame of review** January 2000- March 2010.

**Exclusion criteria:** Studies reporting on services with a target clientele less than 18 years old; and those outside of the population, intervention, and timeframe limits of the scoping search.

**Reference list from the articles found to be relevant using the search strategy were searched.**

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<sup>12</sup> This search resulted in 4 theses (two PhD, one MSc. and 1 Doctor of Clinical Psychology) along with 7 conference abstracts being identified.

**Figure 1.2 Strategy for Grey Literature search one and two (continued)**

**Databases:**

Index to theses of Great Britain and Ireland; DART-Europe Portal; ProQuest Dissertations and Theses; EThOS (British Library Electronic Thesis Online Service); and WRAP- Warwick Research Archive Project.

**Hand searching**

*Academic Grey Literature*

Hand searching journals associated with major UK and International Palliative care conferences

Conferences/Associations and their associated journals

1. **European Association of Palliative Care- European Journal of Palliative Care (1994-present) and Palliative Medicine**
2. **Palliative care congress -Palliative medicine**
3. International Palliative Care Congress-Journal of Palliative Care

*Policy Grey Literature*

Searching the archives or publication list of research/policy units especially those whose units producing palliative care work namely:

1. The King's Fund;
2. National Council for Palliative care;
3. Help the Hospices;
4. and the International Observatory on End-of-life Care.

### *Results of the narrative review*

The narrative review identified five articles addressing question one, and one article addressing both question one and two. Of the five articles retrieved which addressed question one, three had been previously identified using the broad review strategy in September-October 2005. The fifth article identified was on the same topic and by the same author as another article that had been previously identified. The results of the search strategies as well as summaries of the content of the five articles that had been identified by search strategies one and two of the narrative review are given in Tables 1.1, 1.1a, 1.2, 1.2a ,and 1.2b.

**Table 1.1 Results of scoping search one**

<b>Database</b>	<b>Electronic search results based on key heading words</b>	<b>Results after application of exclusion criteria</b>	<b>Number of relevant studies reviewed</b>
<b>Cochrane</b>	1	1	1
<b>Medline</b>	0	-	-
<b>EMBASE</b>	0	-	-
<b>CINHAL</b>	1	Limit to 0- conducted in the UK	0
<b>PsycInfo</b>	3	2 (Limit by time 2005-2010) Limit to 1, conducted in the UK	1

Alterations were made to search strategy in Medline and EMBASE, as the search criteria was too restrictive given the biomedical and pharmacological focus of these databases. A further scoping search strategy was used, this also had limited results. Given the limited results, very broad search terms of (palliative day-care or hospice day-care or terminal day-care or supportive day-care or end-of-

life day-care) were used in **all fields**. There were **no documents retrieved in EMBASE**. The results for Medline are given below in Table 1.1a.

**Table 1.1a Results of a modified scoping search strategy for MEDLINE database**

Database	Electronic search results based on key heading words	Results after application of exclusion criteria	Number of relevant studies reviewed
Medline	32	Limit to 20 by all adult (19 plus years)" and limit to 8 last 5 years  Limit to 4, conducted in the UK	Relevance on abstract review 4 (The 4 studies retrieved using this method had all been previously identified in the initial broad review)

**Table 1.2 Results of scoping search two**

Database	Electronic search results based on key heading words	Results after application of exclusion criteria	Number of relevant studies reviewed
Cochrane Library	3	1 (Limited by last 3 years)	1*
Medline	11	1 (Limited to 3 by all adult (19 plus years)" and last 5 years. Then limited to 1 study conducted in the UK Context "	1*

\*Same article both databases

**Table 1.2a Summaries of articles retrieved in the narrative review**

Study reference	Type of study	Study Aim	Methods	Results
<p>DAVIES, E., and HIGGINSON, I.J., 2005. Systematic review of specialist palliative day-care for adults with cancer. <i>Supportive Care in Cancer</i>, <b>13</b>(8), pp. 607-627.</p>	<p>Systematic Literature Review</p>	<p>To evaluate data available on process and structure in APDC and their impact on outcomes for adults with cancer; including symptom control and quality of life.</p>	<p>A database literature search up to 2003 in EMBASE, MEDLINE, British Nursing Index, PsycInfo, CINHAL and Cancer Lit. Qualitative and quantitative studies were included.</p>	<p>15 relevant papers identified-12 observational studies. No studies were identified on referral to day-care. Only one study reported the views of relatives and carers.</p> <p><i>Funding</i>- Funding of APDC found to be mixed. 64% units in the UK funded by independent sector.</p> <p><i>Service Models</i>- Units had mixed models of attachment-1/3 were attached to inpatient unit, 1/3 to inpatient units with home care, and 1/3 were freestanding or attached to home care. Places: Units were open 3-5 day a week; provided 1.77 places per 10,000 population. The majority of units were nurse lead with varied allied health staff. No guidelines or evidence based standards for care were identified. Models of care were described as –social, medical or combinations of social and medical.</p> <p><i>Referrals</i>- Psychosocial care was the most common reason for referral. Most referrals were found to be from home care teams or inpatient services. Referred patients were commonly over age 60, and the predominant diagnosis was cancer. There was limited evidence on ethnicity or employment status; however, the available data suggested a white, retired profile.</p> <p><i>Effectiveness of APDC</i>- No evidence to support improvement of health related quality of life. Evidence of consistent appreciation by patients for social contact which day-care unit provide. There was evidence of carer satisfaction with respect to the respite offered by APDC; however, the authors note that “attempts to recruit relatives [in studies largely was] unsuccessful”.</p>

Study reference	Type of study	Study Aim	Methods	Summary of Results
<p>KERNOHAN, W.G., HASSON, F., HUTCHINSON, P. and COCHRANE, B., 2006. Patient satisfaction with hospice day-care. <i>Supportive Care in Cancer</i>, <b>14</b>(5), pp. 462-468.</p>	<p>Semi structure survey</p>	<p>To evaluate the “extent to which day services meet the needs of patients and the philosophy of hospice care in Northern Ireland”</p>	<p>Semi structured (26 item) survey carried out in one day- care centre over 3 weeks. Review of medical records for the same period. The study was described as exploratory-as part of a service quality enhancement process. The survey items assessed: “referral; benefits from attending day-care; satisfaction with services; awareness of multi-professional team; and areas of improvement”.</p>	<p>58% (26/50) of respondents were less than 70 years old. 31% of respondents attended day-care for less than 3 months.</p> <p>Primary reason for referral identified as emotional and spiritual care, followed by respite, and need to meet others.</p> <p>The principle benefit identified was meeting other people who are “in a similar circumstance”.</p> <p>Valued activities included elements of a warm welcome on arrival and having a quiet place “to chat”.</p> <p>16/26 respondents were satisfied with the day-care structure with respect to length of visit (10 am- 2 pm).</p> <p>The number of attendees to day-care per day (12 persons) was viewed by patients as appropriate-with the finding that they were too “few younger patients”.</p> <p>Awareness of who the members of the MDT were important for patients; however, varying levels of awareness were identified being interpreted as a need for education on the function of MDT members.</p>

Study reference	Type of study	Study Aim	Methods	Summary of Results
<p>DOUGLAS, H.-R., NORMAND, C.E., HIGGINSON, I.J. and GOODWIN, D.M., 2005. A new approach to eliciting patients' preferences for palliative day-care: The choice experiment method. <i>Journal of Pain and Symptom Management</i>, <b>29</b>(5), pp. 435-445.</p>	<p>Choice method</p>	<p>To identify information on what an acceptable service would be to a person using day-care.</p>	<p>Choice method conducted in 4 APDC units in the south of England on patients who attended APDC for at least one month. Probit analysis with goodness of fit statistics. The attributes tested were: hairdressing and bathing; routine access to a doctor; type of access (by appointment only or all day access); and opening hours (10 am-3 pm or 1 pm- 6-pm).</p>	<p>81 patients recruited-response rate of 66% 46% male, 54% female. Mean age 61 years.</p> <p>All attributes except bathing and hair dressing had a significant impact on choice to use service.</p> <p>Most important attribute was access to specialist therapies, followed by access (staying all day) and routine access to a doctor.</p> <p>Staying all day at APDC was found to be preferred to appointment only. 10 am-3 pm was preferred to 1 pm-6 pm.</p> <p>Patients under 65 seemed to show stronger preferences for specialist therapies than older patients.</p>

Study reference	Type of study	Study Aim	Methods	Summary of Results
<p>WILSON, K., SEDDON, L., THAIN, CW., ROSE., KE. Referrals to a voluntary sector cancer day-care centre: a descriptive study. <i>European Journal of Cancer Care</i>, <b>14</b>(4),pp. 342-352.</p>	<p>Case record Review</p>	<p>To evaluate referrals to a "cancer care day-care centre" in order to describe user demographics, referral source/ reasons and subsequent care given.</p>	<p>Consecutive referrals 18 years or over from Oct 2002-Sep 2003 subjected to case review. Data accessed from: the clinical database of list of patients; day-care centre referral form; patient case notes; and any referral document. The text was subject to content analysis and SPSS 11.0 for descriptive statistics.</p>	<p><i>Demographics</i>- 220 referrals analysed [ 70.9% persons with cancer, 20.4% carers of persons with cancer, 8. 7% bereaved persons]. Carers using the service were mainly female- 76.6% Majority of patients attending lived in the same suburban post code as the day-care unit, 23.8% in the adjoining inner city postcode, 27.3% in an affluent suburban and semirural district, and 8.8% lived more distant-within a 20 mile radius of the day-care centre. Data on ethnicity was not collected.</p> <p><i>Referrals</i>- 16% of persons with cancer only attended once. There was no documentation in the report of the number of patients who were referred to day-care but who were unable to attend. Patients were mainly referred by a health professional (63.2%) as compared to 9.7% of carers. Most referrals were from nurses via telephone call. 77.9 % of patients were described as having a challenging diagnosis requiring palliative versus supportive care. 79.4% of patients were receiving cancer related or other treatments at the time of diagnosis.</p> <p><i>Sources of support prior to referral included</i>-specialist clinical nurse, community palliative care nurses, and district nurses. Reasons for referral- referral for specific services e.g. breathlessness clinic. There were few referrals for counselling and complementary therapy etc.</p> <p><i>Care given</i>- referrals for non specific support were translated into treatment with complementary therapies, "counselling and nurse led support". Complementary therapy services had a waiting list of 9 weeks.</p>

Study reference	Type of study	Study Aim	Methods	Summary of Results
PAYNE, M., 2006. Social objectives in cancer care: The example of palliative day-care. <i>European Journal of Cancer Care</i> , <b>15</b> (5), pp. 440-447.	Literature review	To review literature on social objectives in palliative care as a means of identifying how social and health care interact and to comment on the importance of attention to social as well as health care outcomes	Search of all electronic databases provided to the NHS by Dialog Datastar. Hand searching of St Christopher's Hospice library, its index on palliative day-care and the King's fund library.	<p>“Social objectives are major aspects of day-care provision as intended by providers; however, these objectives are not defined in ways that facilitate evaluation. Four types of social objectives were identified namely:</p> <ol style="list-style-type: none"> <li>1. emotional and spiritual care;</li> <li>2. general social care;</li> <li>3. services for families and carers;</li> <li>4. and creative arts</li> </ol> <p>Day-care was found to meet “various non palliative care needs and to have a role in managing care relationships” in the wider network of services”.</p>

## **1.6 Summary of the findings of the literature review**

### **1.6.1 Defining Adult Palliative Day-Care**

Adult Palliative day-care (APDC), also termed day-hospice care<sup>13</sup>, is a health care service which aims to maintain or improve the quality of life of patients and carers who face the challenges associated with having a diagnosis of “pre-terminal”<sup>14</sup> cancer or debilitating chronic diseases (Wilkes et al. 1978 p. 1053, Spencer and Daniels 1998, p. 220, Myers and Hearn 2001, p. 5).

### **1.6.2 The first APDC unit**

The first purpose built APDC unit was opened at St. Luke’s Hospice in Sheffield (UK) in 1975 (Davies and Higginson 2005, p. 607, Hospice and palliative care facts and figures 2005). Descriptions of APDC show that from its inception it has sought and continues to address the: physical; spiritual; social; and emotional needs of its clients (Wilkes et al. 1978, p. 1054-1055, Spencer and Daniels 1998, p. 220, Myers and Hearn 2001, p. 3, 6). The service is described as providing a holistic form of care through a multidisciplinary team approach that is in keeping with the ethos of the modern hospice movement (Lewis 2007, p. 125). However, APDC does differ from other domiciliary or community palliative care services<sup>15</sup> in that it is designed to be delivered in an outpatient setting other than the patient’s home or usual place of residence (Higginson 1997, p. 189).

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<sup>13</sup> The term ‘day hospital’ was originally used to describe the service by Wilkes *et al.* 1978.

<sup>14</sup> The term ‘terminal’ was not defined by Wilkes et al., but review of contemporary literature reveals a common definition of the last weeks and or months before death. Therefore, the term pre-terminal could refer to (at a maximum), all points of the disease’s trajectory outside of this period or (at a minimum) the time period immediately before this phase.

<sup>15</sup> For example inpatient and hospice at home services.

From analysing the original model at St Luke's, it can be seen that access to APDC was not limited to a specific diagnosis category e.g. cancer. However, prognosis and disease trajectory were factors that likely played a part in determining access, as indicated by the words "pre-terminal" and "the chronic sick" by Wilkes et al in describing the target clientele (Wilkes et al. 1978, p. 1054). In addition, from the descriptions of the early service model, it can be seen that patients spent five hours at the "day hospital" (Wilkes et al. 1978, p. 1054). This indicates that for potential users to benefit from this early form of APDC they would have needed to be well enough to travel to and remain comfortable at APDC for this five hour period (Wilkes et al. 1978, p. 1054). This model of APDC as an outpatient service with visits averaging more than an hour was still found to be present in the UK more than 20 years later (Goodwin et al. 2003, p. 203).

Over the past 35 years APDC has grown rapidly<sup>16</sup> (Coop et al. 1998, p. 162, Higginson et al. 2000, p. 278, Goodwin et.al. 2003, p. 202-203), with there being an estimated 279 day-care centres in the UK (<http://www.helpthehospices.org.uk/about-hospice-care/facts-figures/> Accessed October 6 2010).

Much of the growth in APDC has been attributed to the actions of voluntary charitable organizations which may have seen the establishment of facilities to care for persons who may be dying as inherently good or morally worthy causes<sup>17</sup> (Hern and Myers 2001, p. 5). However, it has been noted that APDC units (and other palliative care services) have been established without performing scientifically based needs assessment. This has resulted in the unplanned proliferation of APDC and palliative care

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<sup>16</sup> The rapid growth seen in the number of palliative day-care units in the UK during the 1980s and 1990s as described by Higginson was not an isolated phenomenon but was rather indicative of a the growth that was being experienced in palliative care services as a whole (Lewis 2007, p. 121), both in the UK and internationally (Lewis 2007, p. 121).

<sup>17</sup> As noted by Randall and Downie 2006, these views regarding the goodness of palliative care services possibly originate from the Christian value system of charity which still influences the British society (Randall and Downie 2006, p. 6).

services as a whole<sup>18</sup> (Hern and Myers 2001, p. 5, Lewis 2007, p. 121). The result is that services may be located in communities that were able to set them up rather than those of greatest need (Davies and Higginson 2005, p. 623).

This pattern of establishing APDC units based on the interest and resources of communities as opposed to epidemiologic needs assessment has implications on access and utilization. It is possible that in such cases, access and use of APDC would be influenced by the distances which users may have to travel. Also, it is likely that access and utilization rates may reflect the fact that services are in an area of low consumer epidemiologic demand as compared to volume of service provided.

The patterns of utilization and access seen in APDC are discussed in the next section.

### **1.7 Adult Palliative Day-Care: Utilization trends, and access<sup>19</sup>**

Review of the minimum data set<sup>20</sup> on activity of specialist palliative care services from the National Council for Palliative Care shows, that for the years 2002-2005, the percentage use of available places in day units was approximately 62% (National Council For Palliative Care, National Survey of Patient Activity Data for Specialist Palliative Care Services 2002-2005) suggesting that the service is being underutilized by the target clientele). In addition, the minimum data set activity also shows lower than

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<sup>18</sup> This comment relates primarily to voluntary sector palliative services such as inpatient hospice care, (Higginson 1997, pp. 189-190, 229-230); and home care teams which “offer advice and support to health workers in the community...” (Higginson 1997, p. 190).

<sup>19</sup> The following section presents a review of the literature relating to the inequalities of access to specialist palliative care services; particularly adult palliative day-care services.

<sup>20</sup> This minimum data set reports activity of all hospices and specialist palliative care services located in England, Northern Ireland and Wales that are listed in the directory of Hospice and palliative care of the National Council. Services in Scotland no longer fall under the remit of the council but of the Scottish Partnership for Palliative Care.

expected levels of use of the service by patients with a non-cancer diagnosis, senior citizens over the age of 85 and persons from ethnic minority groups. The utilization trends of palliative day-care services presented above have also been noted in other forms of specialist palliative care delivery in the UK (Eve and Higginson 2000, p. 397, 401,402).

### **1.7.1 Underutilization and access by patients with a non-cancer diagnosis**

Over the past decade and a half there has been an increasing body of evidence which suggests that there is some underutilization and inequality of access to palliative care services <sup>21</sup> (Addington-Hall et al. 1998, p. 419)<sup>22</sup>. Particularly well documented, is under-access and underutilization of services by patients with a non- cancer diagnosis. It has been noted that during the course of their illness<sup>23</sup>, this category of patient will have similar symptoms<sup>24</sup> to cancer patients who receive and benefit from palliative care (Addington-Hall et al. 1998, p. 420; Kite et al. 1999, p. 481, 482, 484; Horne and Payne 2004, pp. 292, 294, 295; Murtagh et.al 2007, p. 94-96, Addington-Hall and Gibbs 2000, p. 361 (editorial); Fakhory and McCarthy 1998, pp. 422-426). In fact they are even likely to experience these

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<sup>21</sup> The results which emerged from of the Regional Study for Care of the Dying (RSCD) were significant in highlighting the perceived unmet need of non-cancer patients with respect to palliative care as expressed by care givers (Addington-Hall et al. 1998, p. 419). The study found that in the period surrounding death, the symptoms experienced by non-cancer patients who did not use palliative care services were similar to those of cancer patients who had received palliative care (Addington-Hall et al. 1998, pp. 419-420). The results were also significant for indicating that non-cancer patients were also more likely to be older and to live alone or in nursing or residential care in the last year of life (which causes one to consider whether such patients would more likely benefit from palliative care services which may reduce social isolation such as APDC). While the results were not intended to be “definitive” as stated by Addington-Hall et al. (1998, p. 422), they have added significantly to the evidence base which inform policy on widening access to palliative care services in the UK.

<sup>22</sup> The work of Seymour et al. (2002, p. 5-11) suggest that inequalities may exist from the stage of service planning.

<sup>23</sup> Particularly during periods of decreased functioning.

<sup>24</sup> Symptoms which may experienced by patients with both cancer and progressive non-cancer illnesses include- Pain, difficulty with breathing e.g. dyspnoea, nausea and vomiting, depression and sleep disturbances ( Higginson 1998, p. 196 (as per Cartwright and Seale), Watson et al. 2005, p. 574-575).

symptoms for longer periods of time (Addington- Hall et al. 1998, p. 422; O'Brien et al. 1998, p. 286). However, it has been shown that they have levels of service use and access which appear to be disproportionate to expected epidemiologic need. However, more recently there has been an effort to address this situation, with specific mention of the need to broaden access to this client group (along with the aged and ethnic minority groups) being part of national palliative and end-of-life care policy End-of-life care strategy Equality Impact Assessment Template: Progress Report [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_118937.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_118937.pdf) (Accessed June 14 2012). Underutilization and access by the aged and ethnic minority groups is discussed further below.

### **1.7.2 Underutilization and access by the Aged (> 85 years old) and those ethnic minority groups**

The work of Eve and Higginson 2000 (p. 397-401) and Koffman and Higginson 2005 (p. 43-60) has served to highlight that, even among patients with a diagnosis of cancer, there exist inequalities of access. From the 1990s, it has been noted that in the UK context, persons who are above the age of 85 years have decreased access to palliative care services (Addington-Hall et al. p. 1998, 1014-1015; Eve and Higginson 2000, p. 397, 400, 402). This trend of decreased use by older persons has even been described as being “discrimination” (Seymour et al. 2001, p. 269). It should be noted that trends of lower than expected use has also been found to extend to ethnic minority groups (Eve and Higginson 2000, p. 401).

### **1.7.3 Ethnicity Cultural and Social Acceptability**

The likelihood of a person accessing a health service has been shown to be influenced by its cultural and social acceptability (Szczepura 2005, p. 141-147). To this end, as it relates to APDC, there is the possibility that the environment of APDC may not be cultural or socially acceptable to ethnic minorities. Yasmin Gunaratnam in her interviews with members of ethnic minority groups, revealed patient concerns about day-care, ranging from fears regarding inter-racial relations, to the suitability of the food provided (Gunaratnam 2001, p. 23-42). Douglas et al in a study of palliative day-care units in London noted concerns by health professionals who felt that patients from ethnic minority group may not access services because it was seen as a white middle class environment (Douglas et al. 2000, p. 336-334). It is therefore possible, that such issues of social and cultural acceptability may affect access by ethnic minority groups, but the full mechanism and extent to which this occurs is unknown.

In addition to ethnic and cultural acceptability, practitioner knowledge has also been identified as a factor possibly affecting access to services. This is discussed briefly below.

### **1.7.4 Informational Constraints**

The amount of information a patient has about a service and its perceived usefulness can determine whether it is accessed. In palliative day-care, most persons are referred into the system by another party with a minority being self referred (Higginson et al, 2000, p. 277-286, Spencer and Daniels 1998, p. 221). This highlights the point that access to palliative day-care for most patients is going to be affected by the opinions of another person who determines when and if the services offered by day-care are suitable for them (Douglas et al, 2000, p. 336-344).

In the UK, the package of care offered by individual palliative day-care units varies (Copp et al. 1998, p. 164, Spencer and Daniels 1998, p. 221, Higginson et al. 2000 p. 279, Douglas et al. 2000, p. 339-340), with some services placing emphasis on what has come to be described as medical or social components of care (Coop *et al.* 1998, p. 164, Higginson et al. 2000, p. 279). Most units provide a service which involves nursing care, psychological or spiritual counselling, as well as physiotherapy as core components (Copp *et al.* 1998, p. 164). Increasingly, complementary and diversional therapies are also being provided (Copp et al. 1998, p. 164, Hearn and Myers 2001, p. 6).

If referring persons do not have current and factual information regarding the range and quality of services offered, then it is possible that their ability to make informed decision about the suitability of palliative day-care referral may be affected. Douglas in a pilot study of palliative day-care centres in London noted observations to this effect: she states, “rates of referral to day-care seemed to depend on local health care staff knowing about the hospice and on clinicians and patients “belief in its value” (Douglas et al. 2000, p. 336-344).

It is possible that deficiencies in practitioner knowledge about APDC may be a reflection of general ambiguities regarding the scope of palliative care as a whole (Douglas et al. 2000, p. 336-344). It may be argued that since 1990, and in particular since 2002, the definitions of palliative care as put forth by the WHO have served to expand and possibly complicate the scope of palliative care as they: a) have included family members as clients<sup>25</sup>; b) are not disease specific; and c) state that palliative care is

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relevant early in the course of an illness (WHO 2002 definition)<sup>26</sup> (Watson et al. 2005, p. 82, Randall and Downie 2006).

It is possible that such expansions in definition are needed, in that, by not stating a preferred patient client group they indirectly advocate care for patients who may experience inequalities of access, based

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#### The WHO Definition of Palliative care 1990

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families.

- Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment
- Palliative care:
  - affirms life and regards dying as a normal process
  - neither hastens nor postpones death
  - provides relief from pain and other distressing symptoms
  - integrates the psychological and spiritual aspects of patient care
  - offers a support system to help patients live as actively as possible until death
  - offers a support system to help the family cope during the patient's illness and in their own bereavement.

Radiotherapy, chemotherapy and surgery have a place in palliative care, provided that the symptomatic benefits of treatment clearly outweigh the disadvantages. Investigative procedures are kept to a minimum.

#### <sup>26</sup> The WHO Definition of Palliative care 2002

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;

Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

on diagnosis, or age (pages 58-59). However, while definitional changes may seek to broaden access they do not necessarily translate into actual service changes, as providers may not have the willingness and or resources to expand their services. It is therefore possible that an environment which fosters variation in service models has been created by changes in the scope of palliative care and variations in its application. This may be particularly relevant to situations where funding is not uniform or is mainly through the voluntary sector (such as in APDC (Davies et al. (2005, p. 607-627))). It is therefore reasonable to query the extent to which funding variations and excessive variations in service models contribute to any lack of understanding by referrers, on how they should use palliative care services.

This possible link between: a) changes to the scope of palliative care; b) its effect on variations in service models; and c) the referral of patients to services, may be an important part of understanding utilization and access to APDC, given the wide variation in service models that has been documented in these services (Davies et al. (2005, p. 607-627)).

As a whole much remains to be understood regarding the underutilization trends seen in APDC. It is true that there is previous work which has sought to understand why there are low utilization rates of specialist palliative care services among some potential user groups (Virnig et al. 2004, p. 731, Hill 2005 p. 216, Wood et al. 2004, p. 545-547, Sanders et al. 2004, pp. 197-198, Seymour 2001, p. 269-270 (editorial)).<sup>27</sup> However, the majority of the research conducted has tended to treat palliative care services as a whole (McGrath 2007, p. 105-113), including grouping of specialist palliative care

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<sup>27</sup> The work of Hill was conducted in the American health system. While the financial structure of the American health care system as well as the eligibility criteria for hospice care differs from that in the UK (Virnig et al. 2004, p. 731, Cassaret and Abraham 2001, p. 2057), other issues such as cultural differences and its impact on the acceptability of care by minorities may be applicable to both the American and British settings.

services Ahmed et al. 2004, pp. 526, 528-531), and where there has been an examination of a particular specialist palliative service, this has tended to be of inpatient hospice care.

Although palliative day-care may be classified as a specialist palliative care service (Hearn and Myers, 2001, p. 2, Davies and Higginson, 2005, p. 607), it is recognized to have an organizational structure that is very different from other forms of specialist palliative care provision. For example, day-care services appear to be more reliant on non health professional volunteers to supplement staffing (Douglas et al. 2000, p. 337). Also, there seems to be greater heterogeneity in the therapeutic packages offered by individual units as compared to those offered by inpatient hospices, hospice at home teams, and specialist community palliative care nurses such as Macmillan nurses (Douglas et al. 2000, p. 339).

Given the differences between the organization and delivery of palliative day-care and other forms of palliative care, it is important that day-care specific studies be conducted to understand the processes which are influencing utilization and by extension, access to these services.

Ahmed et al. (2004 p. 525-542 ), in their systematic review of the literature on barriers to accessing specialist palliative care, found 40 studies internationally, with only 17 being UK based. Of these 17 studies, only two were specific to day-care. These two studies sought to comment on service structure, user group profiles, and referral patterns. One of these studies used a solely quantitative survey instrument which was completed by health professionals only. The second study used a mainly quantitative survey supplemented by semi-structured telephone interviews. Therefore, of those studies which have sought to illuminate issues of access to APDC, the focus at times has been on quantifying

referral patterns and user characteristics rather than understanding reasons, experiences and perceptions which underscore access and referral patterns (Copp et al. 1998, p. 161-170, Higginson et al. 2000, p. 277-286). As a result, such studies have not illuminated the complex real life issues and processes which may be affecting access.

Other studies which have investigated access to specialist palliative care services have focussed on the role of geography, and geographic distribution of services, as a means of identifying disenfranchised geographic populations (Wood et al. 2004, p. 543-544). The work of Wood et al. on “equity of access to adult inpatient hospice care in the north west of England” presented novel ways for calculating equity of access to palliative care service (Wood et al. 2004, p. 543-549). However, as they note, their study design is limited in its applicability to day-care because of the greater variability in the transport options of the more ambulant day-care patient versus the patient who travels to an inpatient setting for assessment and likely admission (Wood et al. 2004, p. 548). Though limited in its direct applicability to palliative day-care the work of Wood et al. is useful as it proposes a methodology for quantifying demand for palliative care services that take into account issues of access. However, as a solution to understanding access and use of palliative care service, it presumes or at least suggests that if problems of geography are resolved, and palliative care services are present in the prescribed population to unit ratios, that the services will be used. This may not necessarily be the case.

## **1.8 Summary of literature review**

It can be summarised that the literature has shown that in the UK there is evidence of underutilization of palliative care. This underutilization may be a potential reflection of inequalities of access. This trend has been seen in APDC though most of the research exploring access has been on other aspects of specialist palliative care provision. The literature suggests that use of day-care may be affected by: the cultural acceptability of the service (in the case of ethnic minority groups); the level of practitioner knowledge and belief in usefulness of the service; the role of geography with specific reference to distance to be travelled. However, lower than expected utilization rates do not directly translate into confirmation of there being inequalities in utilization or inequalities in access. However in noting the trends of low utilization by particular user groups, the question arises on why these low utilization rates are occurring. It is therefore reasonable to ask whether:

- the underutilization or under-access to APDC is real or perceived;
- there is a need for palliative day-care;
- there is a need for palliative day-care by apparently marginalised groups;
- underutilization by potentially marginalised groups is a marker of consumer choice for an ineffective service model?

In addition, given the lack of specific research in APDC, further questions remain about the extent to which unique features of APDC affect:

- use and access;
- the application of non APDC research to the day-care setting;
- the approach used to measure use and access in APDC in the first instance.

From reviewing the literature and articulating the gaps, I saw that these gaps could be placed in categories, namely gaps in knowledge related to:

- need;
- issues of the suitability of current measures of access and utilization of day-care;
- the unique features of day-care and how these impact on need;
- the measurement of access;
- and the application of non APDC research to the day-care setting.

At this point two significant directions in the research occurred. Firstly a deeper knowledge of theories of need and access was needed to guide the formulation of an actual research question that could address some if not all of the gaps in knowledge. Secondly, I recognised that the gaps in knowledge contained many exploratory issues which would likely involve developing theory based on participant experiences (e.g. exploring client and health professional decision-making pathways). This seemed to indicate the possible need for a qualitative methodology.

Chapter Two addresses the theories of need and access used to guide the answering of the research question. It also presents a conceptual framework for approaching understanding access to APDC. The question of the type of methodology used in this study is addressed in Chapter Four after the descriptions of the study site in Chapter Three.

## 1.9 Chapter Summary

From this chapter it can be seen that in the context of the UK and other developed and developing countries there is a current and growing need for palliative care services both by the cancer and non-cancer patients. In the UK (and other developed countries) however, palliative services continue to be used predominantly by persons with a diagnosis of cancer. In addition, there is also evidence which suggests that utilization of palliative services is lower than expected for patients from ethnic minority groups and those over 85 years of age. In the UK, during the 1990's and the last few years of the 21st century, there has been an increasing emphasis on investigating and addressing inequalities to palliative care services. This is within the general context of cancer care reform and addressing general inequalities of access to health in the wider NHS and DH policy agenda (Tackling health inequalities: 2004-06 data and policy update for the 2010 National Target DH 2007, p.

4). Although classified as a Specialist Palliative Care Service (SPCS) there has not been a particular focus on understanding access to APDC services specifically. A specific focus on APDC is necessary as the service models of APDC differ from those of other SPCS services; therefore research on access in these areas may not be directly transferable.

## 1.10 Key Points

### Chapter One: Key Points

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- Provision of care for dying and those with life-threatening illness is an important aspect of modern health care provision.
- Because of the combined effects of the phenomenon of aging populations and changes in disease patterns, the number of persons requiring such care is likely to increase. Therefore, it is important to understand and improve how relevant health care services, such as palliative care, are organised and delivered.
- There are many definitions of palliative care in use, both in the UK and internationally. As used in this thesis, palliative care is an umbrella term for a form of care which has its origins, and philosophies grounded in the modern hospice movements.
- Over the past 20 years, there have been an increasing body of research suggestive of there being inequalities in access to palliative care services in the UK; including adult palliative day-care
- Apparently marginalised groups include patients with non-cancer diagnosis, and those from ethnic minority groups.
- This study seeks to add to the body of knowledge on inequalities of access to adult palliative day-care in the UK, by investigating how access to palliative day-care occurs. In particular identifying and understanding what determines access to day-care.
- It is hoped that the results of this research will be used to inform the future design and delivery of adult palliative day-care. Thereby enhancing the ability of these services to address the needs of all members of their potential client groups.

## **CHAPTER TWO:**

### **Access and need for health care: The basis for frameworks investigating inequalities of access to APDC**

#### **2.0 Introduction**

##### *Chapter Aim*

In Chapter One there was discussion about palliative care provision increasingly being seen as an important component of health care systems around the world, including in the United Kingdom (UK). In that chapter, it was noted however, that inequalities were supposedly being observed in the utilization of palliative care services, including Adult Palliative Day-Care (APDC) services in the UK. Chapter One goes on in section 1.8 (pages 66-67) to demonstrate that the reasons for these observed inequalities are not fully understood. Therefore, in this chapter (Chapter Two), a framework for understanding and investigating what might determine access to APDC is proposed. The framework is informed by theories of (1) access, (2) need, and (3) factors which may affect the supply of health care. Chapter Two also provides further refinement of the research question.

##### *Chapter Outline*

Firstly, in section 2.1-2.2 (pages 72-77), the chapter seeks to define the phrase ‘access to health care’ by reviewing existing theories on how access to health care can be understood. This results in the proposal of a new definition of access. This definition has the benefit of allowing potential factors which may affect access to health care to be considered (i.e. factors affecting a person’s ability to enter

into), while allowing the phrase (access to health care) to remain measurable (i.e. allowing measuring of the act of entering into).

In the proposed definition of access, the concept of need is a core component. Therefore, in formulating a framework for understanding access, it was important to explore the concept of need and to define need for health care.

Though core to defining the term “access”, the presence of need is not likely to be the sole determinant of whether access to health care occurs. In this thesis, higher level groupings are used as a means of providing a condensed and organised way of viewing the factors likely to affect access. The proposed higher-level groupings have been termed characteristics. They are individual, social, family, societal, and health system/service.

Sections 2.6 and 2.7 (pages 85 and 87) describes how the characteristics mentioned along with need, may be used to formulate static and dynamic frameworks for investigating, and understanding access to APDC.

In keeping with the chapter structure for the thesis, Chapter Two concludes with a chapter summary in the form of Key Points (section 2.10, page 90).

## 2.1 The Importance of the issue of equitable access to health care in England

Access to health care is an important issue for patients, health care providers and policy makers (Gulliford et al 2002, p. 186, Wellstood et al 2006, p. 122), with improving access to health care being an important public health approach to addressing inequalities in health (World Bank 2009).

In England, the correction of inequalities of health is one of the priority areas of the Department of Health (DH), with there being specific national targets for the reduction of inequalities<sup>28</sup> (Tackling health inequalities: 2004-06 data and policy update for the 2010 National Target, DH 2007, p .3).

Importantly, featuring in the DH's strategy for reducing health inequalities is "addressing **fair access** to the NHS for everyone<sup>29</sup>" (Tackling health inequalities: 2004-06 data and policy update for the 2010 National Target DH 2007, p. 4). The NHS's commitment to this goal of equitable access and reduced health inequalities is exemplified by the fact that these issues have been and remain priority areas within the organization's operating framework (NHS Operating framework in England 2011-2011, 2009, p. 14). In addition, the DH's commitment to tackling inequalities and providing accessible services continues into the future, as stated in the vision document *NHS 2010–2015: from good to great*, (2009, p. 7):

"Now our challenge is to accelerate this quality improvement, creating services that are not just good, but universally great, increasingly designed around the needs of the individual and accessible to all. In doing so, we will continue to ensure that NHS values are at the heart of what we do and we remain committed to tackling inequalities and promoting equality."

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<sup>28</sup>In the United Kingdom in 2007 "The Health Inequalities National Target [was] to: Reduce health inequalities by 10% by 2010 as measured by infant mortality and life expectancy at birth." (Tackling inequalities of health DH 2007, p. 3).

<sup>29</sup> Bold print supplied

As was discussed in Chapter One, research conducted in England demonstrated that with respect to palliative care provision, it could be argued that inequalities in access to care exist. The work of Addington-Hall et al (1998, p. 1011-1016), Gunaratnam (2001, p. 23-42) and Eve and Higginson (2000, p. 397-401, 402), demonstrate that, in the presence of equal or greater need, patients who have a non-cancer diagnosis, were from ethnic minority groups, or who were age 85 years or older, have lower than expected levels of service utilization (utilization used as a proxy for access). Given these findings (apparent inequalities), at a policy level (within England/UK) there has been the outline of goals to reduce inequalities of access to palliative care.

In the NHS Cancer Plan (NHS Cancer Plan: A plan for investment, a plan for reform) published in 2000, Chapter Seven outlines planned improvements to care. Noticeably, the following statements regarding addressing inequalities of access are found:

1. “7.23 - All patients should have access to the specialist palliative care advice and services that they need to improve care”.
2. “7.25- by 2004 the NHS will invest an extra £50 million to end inequalities in access to specialist palliative care and to enable the NHS to make a realistic contribution to the cost hospices incur in providing agreed levels of service”.
3. “7.27- There is evidence that black and ethnic minority communities and socially deprived groups have reduced access to palliative care services. Patients from these groups are unlikely to take up services, which are culturally unsuitable or are delivered in an insensitive way. A total of £23.25 million has been allocated by the New Opportunities Fund (NOF) for the Living with Cancer initiative. This is exclusively

aimed at providing palliative care, home care support, support for carers and information about cancer and cancer services to black and minority ethnic communities and socially deprived groups”.

Within the context of this focus of this thesis on APDC, it should be noted that in 2003, the DH confirmed the provision of £50m<sup>30</sup> “from the central budget” for the years 2004-2006. One of the major intended uses of these funds was the tackling of “inequalities in access to specialist palliative care”. With the document stating that, “specialist palliative care includes... day-care...” (DH, 2003 p. 3, Planning and funding specialist palliative care provision 2003/04 – 2005/06).

Interestingly, despite this emphasis on equity of access and the need to improve access (including monetary investment), the term access itself remains difficult to define (Goddard and Smith 2001, p. 1150-1152). Review of the literature reveals two broad constructs which may be used to inform a definition of access, specifically as it relates to access to health care.

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<sup>30</sup> As noted by the DH in 2003 progress towards fulfilling £50m investment in specialist palliative care services was slow. This resulted in the “creation of a new £50m per annum central budget for specialist palliative care” for the period 2003-2006 (DH, **2003 p. 3** PLANNING AND FUNDING SPECIALIST PALLIATIVE CARE PROVISION 2003/04-2005/06).

## **2.2 Constructs informing a definition of access to health care**

In the first construct, access to health care refers to a person's entry into a health care system (Penchansky and Thomas 1981, p. 127-130) or as stated by Gulliford et al., "the initiation into the process of utilization" (Gulliford et al. 2002, p. 186) where utilization refers to the act of using a service. The second construct which was advocated by theorists such as Aday and Anderson, is not concerned with the outcome of "entry into" care but rather, focuses on the factors which characterise or affect this entry (Aday and Anderson 1974, p. 209, 211-214; Penchansky and Thomas 1981, p. 127-130; Gulliford et al. 2001 p. 187-188).

By focussing on what characterises entry as opposed to identifying when entry has actually occurred, the second construct allows one to consider the concept of potential access, including drivers and hindrances of such access. A limitation of defining access in terms of "what characterises entry" is that it does not assist in identifying issues relating to when access actually occurs. Therefore, one of the main criticisms of this construct is that it makes access to health care more difficult to measure (Aday and Anderson 1974, p. 210; Penchansky and Thomas 1981, p. 127).

Hence, one of the main challenges of defining access to health care lies in developing a definition which (a) considers the characteristics needed for access to occur, while (b) allowing access to be measurable. There are two definitions of access which, when combined, meet requirements (a) and (b). These definitions were proposed by Penchansky and Thomas in 1981 and Aday and Anderson in 1974, and are discussed below.

Penchansky and Thomas (1981, p. 128) describe access to health care as occurring when there is a “degree of fit” between the patient and the health care provider. It should be noted that what exactly constitutes an acceptable degree of fit, who should determine it, and when it can be said to have occurred, all remain potential sources of contention. Despite the apparent lack of commentary on the intricacies of the “degree of fit” theory, Penchansky and Thomas’s definition remains important because it recognises that access can be inhibited by the characteristics of either the consumer or the provider, i.e. by either individual or system barriers (Shengelia et al 2005, p. 98-99).

Aday and Anderson’s framework for understanding access to health care is important as it establishes that *need* should be a characteristic of the consumer of health care. They state “perhaps it is most meaningful to consider access in the context of whether those who **need** care receive it” (Aday and Anderson 1974, p. 218). This statement provides a theoretical link between the concepts of need and access to health care. In addition, it highlights the ethical importance of access to health care, and perhaps explains the close association which this term sometimes has with issues such as equity, and inequality, as well as the emotions of entitlement it is capable of evoking.

For this study a definition of access to health care is proposed, which is a combination of those previously put forward by Aday and Anderson, and Penchansky and Thomas. This new definition is deemed necessary so that various aspects of the concept of access to health care may be considered simultaneously. In so doing, factors which may affect or determine if access occurs can be considered alongside those which comment on how access occurs, and how many persons are able to achieve access. In addition this new definition is seen as being advantageous because, it allows access to be viewed as a process or pathway with multiple dimensions. These dimensions are seen as being: (1) the

stage of potential access which occurs when the degree of acceptable similarity between what a client needs and what a health care service provides are being assessed and negotiated; (2) an entry point, which occurs when an acceptable similarity is seen as having been reached and first use of service occurs; (3) continued use of service (in phase 3 utilization may be a measure of access). The proposed definition is found in Box 2.1 and will be operating in a conceptual framework, which considers that access is the outcome of a complex process in which need for health care is a core element.

*Access to health care is the entry into a health care system by a patient who **needs** the service, and occurs when there is a sufficient degree of fit between the user's need and the health care services provided.*

**Box 2.1 Definition of access to health care**

**2.3 Social determinants of health and access to health care**

Understanding the factors which determine the use of a health care service by potential clients is an important aspect of health services policy, management and research (Shaikh 2008, p. 53-54). In an optimal health service-to-user relationship, it may be expected that the health service would precisely meet the health care needs of the user. In reality, however, there are economical, political, social and other factors which act to define the precise way in which the needs of individuals are expressed and recognised as well as how a health service can respond to the needs of a given population (Wright 2005). Determining what legitimately constitutes a “need” is debatable, as the definition varies depending on the philosophical perspective of the person defining the need (Wright et al. 1998a, p. 310-313; James 1999, p. 167-169; Asadi-Lari et al 2003) and the time at which the assessment was done (Wright and Kyle 2006).

## 2.4 Defining need

Higginson et al., in their review of needs assessment in palliative care, found that the two most common definitions of need which “underpinned most approaches” were those put forward by Maslow and Bradshaw (Higginson et al. 2007, p. 502).

Maslow’s hierarchy of needs and Bradshaw’s “taxonomy of social need” (Bradshaw 1972, p. 71-82) are similar in that they imply that needs (a) exist and are experienced by the individual, and (b) when experienced have the potential to trigger an action (Bradshaw 1972, p. 73). In addition, Bradshaw’s concepts of felt need and normative need allow for differentiation between who is experiencing the need, and who may actually be “defining it” (Bradshaw 1972, p. 72-73, Asadi-Lari et al. 2003). This he expresses as two concepts: *felt need* and *normative need*. Felt need is a subjective feeling experienced by the primary individual, whereas normative need is defined not by the individual experiencing the need but rather by the “expert or professional”. Therefore, in the case of normative need, an individual is usually identified as having a need if they “fall short of a previously defined ‘desirable standard’ ” (Bradshaw 1972, p. 72-73). Viewed in another light, normative need may sometimes occur when the primary need as experienced by the individual is assessed and interpreted by a secondary party who is viewed as an authority or expert within a system (Liss 1993, p. 37; Higginson 2007, p. 502).

Though Bradshaw’s taxonomy of need was originally formulated to demystify “the concept of social need” (Bradshaw 1972, p. 71), the framework he proposes has far reaching implications. The distinctions which the framework offers between the various ways of defining need, such as felt need (discussed above), become particularly relevant when considering need for health care.

In addition to felt need, Bradshaw's framework also includes the concept of expressed need. Bradshaw defined expressed need as "felt need turned into action". He saw this expressed need as being synonymous with demand (Bradshaw 1972, p. 73). Importantly, when demand is viewed as being demand for health care, then it becomes possible to consider that a measure of need for health care may be obtained by analysing levels of service use (Higginson 2007, p. 502).

However, in this instance it is important to note that use is only an approximate measure of demand as it only reflects the situation where an individual feels a need and then decides to act on this need in the presence of a health care service that is available to meet this need. In addition, there must be no intervening factors preventing the individual expressing need /demand from using the service, i.e. there must be control over normative assessments of need so that these do not act as potential final barriers to use.

By combining the above concepts, it becomes possible to define need as "*A dynamic and subjective experience on the individual level, which may be subject to the interpretation of another individual; and which may then trigger an action*". When viewed as such, need appears to be very generic, with there being little difference between it and a want. In fact, in his definition of felt need, Bradshaw does state that "need is equated with want" (Bradshaw 1972, p. 73). Liss argues that it is not clear what Bradshaw meant in this statement (Liss 1993, p. 36). Though Bradshaw's statement may appear unclear and may be viewed as being a broad generalisation, it is particularly relevant to today's health service environment which is becoming increasingly consumer driven (Jubb 2002, p. 343). This

consumer orientation and quest to make “health care more responsive to users” (Elliot and Popay 2000, p. 461), may result in what an individual wants being seen as a need, regardless of arguments of cost and or issues of effectiveness.

When the proposed definition of need which is given above is analysed, it can be seen that it encompasses Bradshaw’s taxonomy as it includes the components of (1) a subjective feeling or want being experienced by an individual; (2) the potential for the interpretation of this subjective feelings by a second party and (3) an action being taken by the individual experiencing the subjective feeling, when this feeling is perceived. Of note, however, what is missing from this proposed definition is an explanation for why an action may be triggered when this subjective experience is perceived. In other words, what could potentially explain the transformation of perception into a health seeking behaviour?

One potential explanation for this transformation is that the individual is motivated by the desire to reach some acceptable social norm (Franks 2000, p. 93-104). In considering the potential motivators for action, the definition of need must undergo a further change to reflect why an action may, and or should be triggered. As a result, it is then possible to define need as *“desire to compensate for some disequilibrium”*, which when perceived by an individual may trigger an action. Though felt individually, it may be subject to interpretation by another individual who may or may not influence the action triggered. Of importance, need is not static and is subject to re-evaluation by the primary and secondary individual. Of further significance, when need is thus defined and then considered in relation to health and health care, the view that it may originate from a desire to correct a state of disequilibrium or to reach an acceptable social norm, positions the concept of need for health care within a health inequality and ethical framework (Aday and Anderson 1981, p. 5, International

Covenant on Economic Social and Cultural Rights [Article 12-The right to health]

<http://www2.ohchr.org/english/law/cescr.htm> (Accessed December 27 2010).

#### **2.4.1. Need for health care and the capacity to benefit**

The definitions of health care need which hinge on an individual's right to correct some felt disequilibrium, and or to achieve a desired social norm, are not without opposition. When defining need for health and health care, it may be argued that such ethically positioned definitions are not particularly pragmatic as the reality is that health systems, and by extension health care interventions, operate in an environment of limited resources (Wright and Williams 1998, pp. 1310-1313). Therefore, given these financial limitations in health care systems, it may be logically argued that what a person can be said to need in relation to health care must be bounded by two parameters. Firstly, by the availability of an effective intervention which can correct the state of disequilibrium or bring about the attainment of an acceptable social norm, and secondly, when exposed to this effective intervention the individual must have the capacity to obtain benefit from it.

The implication of the first parameter is that the existence of need seems inextricably linked with the presence of an effective intervention, with it potentially being argued that there may be no need if no effective intervention exists. This view is not commonly held given the symptom-solution oriented approach of modern medicine. However, parameter two, which concerns the individual's capacity to benefit still informs current understandings of need for health care as described later.

By introducing the capacity to benefit clause, the approach used by some health economists in defining need becomes very useful as it poses a challenge to make some kind of assessment as to what forms of intervention are actually required to bring about benefit. In so doing, the concepts of health needs and health care needs are distinguished, as they can be seen as being met by different interventions (Wright and Williams 1998, p. 1310-1313). Health needs are those “*that can benefit from health care or from wider social and environmental changes*” (Wright and Williams 1998, p. 1310-1313), whereas health care needs “*are those that can benefit from health care (health education, disease prevention, diagnosis treatment)*” (Wright and Williams 1998, p. 1310-1313; Stevens and Gillam 1998, p. 1448-1452).

Another advantage of incorporating the term capacity to benefit into definitions of need for health and health care is that the term “benefit” is broad. By using such non-specific terminology, the economist-based definitions may be used in complex health areas like palliative care, where outcomes are sometimes seen as less traditional (biomedical) and or objectifiable (Higginson et al. 2007, p. 502).

Indeed, from the above discussion it can be seen that formulating a precise definition of need, health need, and health care need is challenging. Culyer (1995, p. 727-729) when discussing the concepts of need and health care need, notes that though the terms are difficult to define, ironically they remain indispensable as “*having a need remains a necessary condition for receiving anything at all*”. This is also echoed in the work of Elliot and Popay who state that,

“Within the UK health authorities responsible for purchasing care were increasingly required to allocate resources on evidence of effectiveness and on the needs of communities (“health needs assessments”) (Elliot and Popay 2000, p. 462).

In spite of these definitional challenges, it is necessary to set the boundaries in which the research presented in this work will occur. Hence, definitions of need are presented in Box 2.2.

*Need: A “desire to compensate for some dis-equilibrium”, which when perceived by an individual may trigger an action. Though felt individually it may be subject to interpretation by another individual who may or may not influence the action triggered. Of importance, need is not static and is subject to re-evaluation by the primary and secondary individual.*

*Health needs: Those needs that can benefit from health care or from wider social and environmental changes” (Wright and Williams 1998, p. 1310-1313).*

*Health care needs: Those needs “that can benefit from health care (health education, disease prevention, diagnosis treatment)” (Wright and Williams 1998, p. 1310-1313, (Stevens and Gillam 1998, p. 1448-1452).*

#### **Box 2.2 Definitions of need, health need and health care need**

#### **2.4.2 Summary of the concept of “need” and its potential importance in health and health care**

It can be seen that the concepts of need, need for health, and need for health care, though difficult to define, underpin much of the debate about health services today. In addition to being central to the process of the individual legitimately (seeking health and health care) receiving “anything at all”, the ability to demonstrate the presence of need also has population level applications for the purchasing and provision of services (Elliot and Popay 2000, p. 401). These applications include the lobbying for

resources, informing policy decisions on resource allocation, and informing health services research (Higginson 2007, p. 500,504). Of interest to this work, need may be seen as having a theoretical link to access to APDC, potentially providing a baseline for identifying and understanding gaps between need and service provision.

## **2.5 The Potential link between need and understanding access and inequities of access to APDC**

Throughout much of its history in the UK, APDC has focused on providing care for patients with cancer (Murtagh 2004, 277-286). As was discussed in Chapter One, there has been recognition of the fact that persons with non-cancer diagnoses do have physical, psychological, social, spiritual and other needs and would benefit from the services provided by palliative day-care units but their use of the service appears to be low (Sepulveda et al. 2002, p. 91-96, Harding et al. 2005, 251-258, Watson et al. 2005, p. 553). It is reasonable, therefore, to raise the following questions:

1. how great is the mismatch between what these palliative patients need and what services are being provided (Murtagh 2004, p. 39-44)?
2. is this mismatch contributing to reduced access or apparent inequities of access?

As was also shown in Chapter One access to palliative care and other health services is affected by factors other than need. These include factors such as, the gate-keeping role of health professionals (Backus et al. 2005, S:17), and aspects of an individual's life which may make them susceptible to social exclusion (Koffman and Higginson 2005, p. 47-53). These factors have been considered in the design of a two-part conceptual framework for understanding the determinants of access to APDC, as discussed in the next section.

## **2.6 Conceptual frameworks for investigating access inequalities in Adult Palliative Day-Care: An interaction between individual, family, societal, and health system factors, as influenced by need, demand and supply.**

By way of introduction, part one of the framework was designed as a partially static model and serves to emphasise **the types of** factors that may potentially affect access. Part two of the framework is more dynamic, illustrating **how** potential factors may hypothetically act to affect the process of obtaining access to APDC.

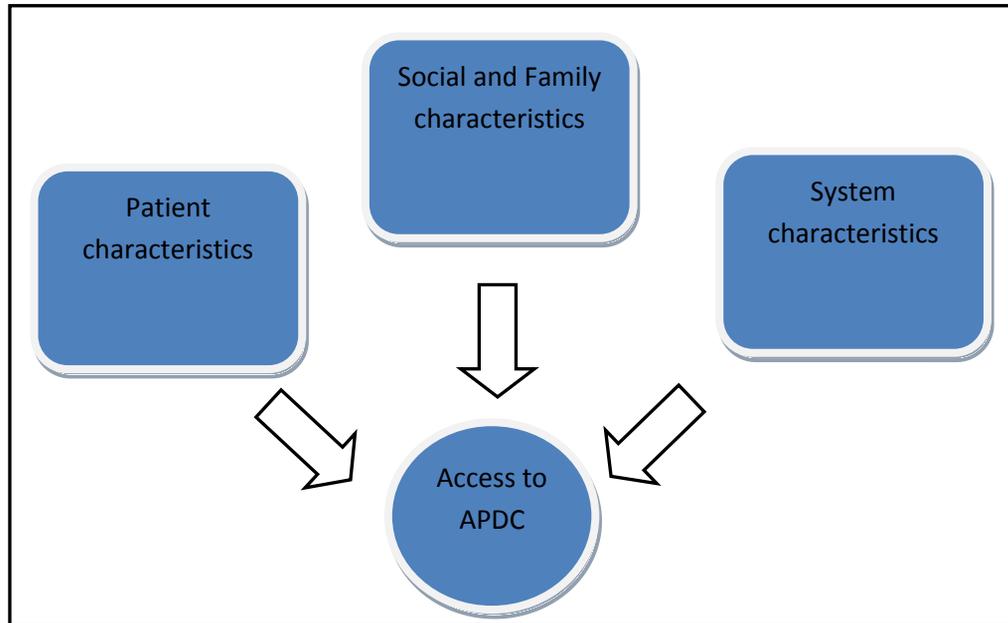
### **Part One - A static model for understanding the factors which may act to determine access to APDC**

This part of the conceptual framework considers that access to health care occurs as a result of the degree of fit between the patient characteristics and the health care system (system characteristics). In the context of this work, health care system characteristics include organizational characteristics, such as written policies and physical infrastructure. The term ‘health care system characteristics’ has also been extended to include the behaviours of individuals. In this research, these individuals are defined as those health professionals and volunteers who are involved in the provision of or referral to adult palliative day-care.

In addition to a patient’s individual characteristics and the characteristics of the health care system, the patient’s social environment and their family dynamic have also been recognised as influencing decisions to access and use palliative care services (Virnig et al. 2002, p. 77). In view of this, a complete framework of the types of factors which may potentially affect access to APDC should also

reflect this possible influence. Hence the static framework proposed for understanding the determinants of access is as shown in Figure 2.1 (page 87).

**Figure 2.1 A static framework showing the types of hypothetical characteristics which may interact, to determine access to APDC**



### **2.7 A Dynamic model for understanding the process of accessing APDC**

In addition to its static elements within the conceptual framework, the patient and system characteristics are hypothesised as operating or exerting their effects in a dynamic relationship between need, supply and demand factors. Figure 2.2 on page 88b illustrates this relationship in a diagrammatic representation of the links between health care need and access to health care, in the presence of an effective health care intervention. The first three levels of this dynamic conceptual work, have been adapted from the 2007 work of Gursoy et al. p. 423-432, which focussed on defining need in health care.

For this pathway to be applicable to the study of access to APDC two underlying assumptions have been made:

- firstly, APDC addresses health care needs;
- and Secondly, adult palliative day-care is an effective health care intervention.

**Figure 2.2: A Dynamic, Conceptual Model Depicting the Hypothetical link between Health Care Need and Access to Health Care when an effective Health Care Intervention is Available (see page 88 b).**

## **2.8 The research goals**

This chapter has presented definitions and theories for consideration in informing the investigation of access to health care and inequities of access to health care. It proposes that access is affected by determinants which may be related to patient, system, family characteristics, and that the degree of fit between the system and other parameters may act to determine whether access occurs. Secondly, being informed by theories of need it proposes that it is conceptually possible to see access not simply as use/availability or a ‘point of entry into’ but a staged journey, where need and assessment of need are important in determining the direction and progress along the pathway. In light of these additional theories, and conceptual frameworks, the final overall research question and sub-questions are listed below in Box 2.3.

**Overall research question**

*What are the factors which act to determine access to APDC?*

**Research sub-questions to be explored in answering the overall research question**

1. *What do patients and carers who are potential users of APDC services perceive or view as their health care needs, and what are the perceived/experienced benefits of using APDC, especially as it relates to addressing these needs?*
2. *How do patients, carers, health professionals' and volunteers' perceive APDC and what is their understanding of the role of and benefit of APDC in palliative and end-of-life care?*
3. *What are the Health professionals' and volunteers' perceptions and understandings of what constitutes a person in need of the APDC or an appropriate referral to the APDC service?*
4. *What do patients and carers experience and perceive as being the **non-self factors** which influence their decisions to access APDC (both barriers and facilitators)?*
5. *What are the specific organizational features of APDC services and their referral pathways which may be affecting access?*

**Box 2.3: Final goals of the research**

**2.9 Conclusion**

Achieving equity of access to health care is an important goal for many health care systems. There is, however, the lack of a consensus definition of the term with the debate including issues of whether the term access defines factors which determine an event, or whether access refers to an event which occurs at a singular point in time. Despite the debate, because of the central role which access has come to occupy, it is a concept that should be operationalized and measurable if it is to be of practical significance to researchers, health care providers, and policy makers. Therefore, in this chapter a

definition and two conceptual frameworks for approaching access to health care have been outlined based on a review of existing theories. The proposed definition allows access to be seen as a process with inputs, an access point and a measurable output or result.

The development of an approach to defining access to health care as set forth in this chapter, was an important “theoretical starting point” in conceptualising how access to APDC may occur, and thus for framing the design of this research investigating the determinants of access to this service.

## **2.10 Summary in the form of the Key points**

### **Chapter Two: Main Points**

- Access to health care has been constructed as a process which may hypothetically be influenced by a number of characteristics, including need, demand and supply.
- Though terms such as access, access to health care, health care needs, and health needs are important in health services research, no consensus definition of the terms exists for the purpose of this research.
- Identifying and understanding need, supply, and demand factors as well as the interaction between what have been termed, patient, social, family and system characteristics, is proposed as a hypothetical way of framing the investigation of what determines access to day-care.

## **CHAPTER THREE:**

### **Study Site: A cancer network in the UK**

#### **3.0 Introduction**

Previous sections of the thesis have set out the context for the research in terms of the evidence base, policy, and debates about palliative care and access. This chapter aims to further contextualise the research by giving a description of the cancer network chosen as the site of the study.

Firstly, the chapter describes the interest the network would have had in researching access to Adult Palliative Day-Care (APDC), and the impact that this had on the decision to choose it as the location of the study. The chapter then describes relevant aspects of the geographic, socio-demographic and health services profile of the network, at the time this research was conducted.

The chapter concludes with a summary of the main characteristics of the network which influenced the research design, and in turn the interpretation and application of the research findings which are presented in Chapters Six and Seven respectively.

#### **3.1 Overview of the study site**

The cancer network chosen as the study site was located in the Midlands region of England and at the time of conducting this research, was one of thirty four (34) cancer networks in England. Like other

cancer networks, it was tasked with facilitating the implementation of the recommendations of the NHS Cancer Plan, ultimately aiming to improve care for patients with cancer by defining pathways to care and undertaking service planning and monitoring<sup>31</sup>.

In its (2005) Structure and Accountability framework, the network stated that its vision was:

“To provide the highest quality, safe, equitable and locally accessible services, in line with the NHS Cancer Plan and NICE guidelines, to the people of [specific names of locations in the network]”.

It should be noted that although titled as an NHS Cancer Plan, the priorities within the plan were not limited to oncology treatment services, but also extended to prevention, and of relevance to this work, the improvement of palliative and supportive care<sup>32</sup>. At the time of commencing this research, the organizational structure of the cancer network chosen as the study site included a Palliative Care Network Group (P.C.N.G); the responsibilities of which include facilitating “joint care pathway mapping” and “developing network-wide policies, referral criteria, clinical guidelines and directories” (The network’s structure and accountability framework 2005). As part of their work the P.C.N.G allocated funding for palliative care focused health services research.

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<sup>31</sup> The content of this sentence references the cancer network’s website. The Uniform Resource Locator is not provided as this would result in the identification of the network.

<sup>32</sup> (This interest in the development of palliative care services is also contained in the NHS Cancer reform strategy 2008, p. 28, 80. [http://www.cancer.nhs.uk/documents/cancer\\_reform\\_strategy/cancer\\_reform\\_strategy.pdf](http://www.cancer.nhs.uk/documents/cancer_reform_strategy/cancer_reform_strategy.pdf) (Accessed January 2 2010).

As discussed in Chapter One, research that improves the understanding of access to APDC in the UK is of relevance as the service has been observed as having lower than expected utilization trends. Review of the minimum dataset<sup>33</sup> on activity of specialist palliative care services from the National Council for Palliative Care show that for the years 2002-2005, the percentage use of available places in APDC units nationally was approximately 62%<sup>34</sup> (National Council for Palliative Care, National Survey of Patient Activity Data for Specialist Palliative Care Services 2002-2005). For the same time period, the percentage use of available APDC places in the cancer network chosen as the study site was below the national average at 58% (National Council for Palliative Care, National Survey of Patient Activity Data for Specialist Palliative Care Services 2004-2005. Feedback to individual units).

In addition to the percentage use of available spaces being lower than the national average, the user profile within the cancer network also indicated under-representation of certain user groups e.g. patients with non-cancer diagnosis<sup>35</sup> (National Council for Palliative Care, National Survey of Patient Activity Data for Specialist Palliative Care Services 2004-2005. Feedback to individual units Hospice). This pattern reflected that seen nationally (Addington-Hall et al. 1998, p. 1014, Kite et al 1999 pp. 478, 481). As was mentioned in Chapter One, in addition to patients with non-cancer diagnosis (see Table

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<sup>33</sup> This minimum data set reports activity of all hospices and specialist palliative care services located in England, Northern Ireland and Wales, that are listed in the directory of Hospice and palliative care of the National Council. Services in Scotland no longer fall under the remit of the council but of the Scottish Partnership for Palliative Care.

<sup>34</sup> Of note, the above data reports also query whether the usage levels reported nationally could actually be lower (National Council for Palliative Care. National Survey of Patient Activity Data for Specialist Palliative Care Services 2004-2005).

<sup>35</sup> Evidence indicates that patients with non-cancer diagnosis have similar symptoms as cancer patients, (though the duration of their symptoms may be longer O'Brien 1998) and derive benefit from palliative care intervention (see chapter one).

3.1<sup>36</sup> in the footnote of page 94), under-represented groups also include those from ethnic minority groups and elderly patients over 85 years of age (Dunlop 2001, O'Brien et al 1998, Eve and Higginson 2000, p. 397-401, Koffman and Higginson 2005, p. 43-60).

Given the network's APDC utilization trends<sup>37</sup>, its interest in researching access to palliative care services, and the availability of research funding, the network was viewed as a possible study site. In addition to the above, other factors also made this particular cancer network an appropriate study site; these included the type of APDC units it contained and the geographic profile of the area. These are described below.

### 3.1.1 Location

As stated previously, the network is situated in the Midlands region in the centre of England. The geographic area covered by the network was relatively diverse containing one city (Area 1), a

<sup>36</sup> Table 3.1 Percentage of new patients attending palliative day-care (PDC) by diagnosis in the UK, 2002-2006

Year	2002-2003	2003-2004	2004-2005	2005-2006
Non cancer Diagnosis	6.2	8.0	7.9	9.3
Cancer diagnosis	93.8	92.0	92.1	90.7

<sup>37</sup> The utilization rate of APDC at the time of undertaking the study was lower than the national level. However, the categories of patients found to be underutilizing the service were the same as those seen nationally, i.e. patients with non-cancer diagnosis, patients from ethnic minority groups and patients over the age of 85 years.

significant rural<sup>38</sup> county (Areas 2, 3 and 4), an other urban area<sup>39</sup>, and a significant rural<sup>40</sup> Local Authority<sup>41</sup> (Area 5).

*Transport systems and connectedness to the remainder of the country*

Although containing significant rural or other urban areas, the network is well connected to the remainder of the country through rail, motorways and an international airport. Within the network there is also a rail network, which links major towns, however, most public intra network transport is via bus service.

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<sup>38</sup> A “significant rural” is a term used to describe higher level geographies such as counties that have <74% / >=26% of their population living in urban or rural areas respectively. ‘Rural and Urban statistics in England: Guidance notes’ <http://www.statistics.gov.uk/geography/downloads/rural-stats-guidance.pdf>. (Accessed December 15 2009).

<sup>39</sup> Other urban refers to local authorities with less than 26% of their population living in rural settlements and larger market towns. <http://www.defra.gov.uk/evidence/statistics/rural/documents/rural-defn/laclassifications-techguide0409.pdf>. (Accessed December 15 2009).

<sup>40</sup> Significant rural refers to local authorities with more than 26% but less than 50% of their population in rural settlements and larger market towns. <http://www.defra.gov.uk/evidence/statistics/rural/documents/rural-defn/laclassifications-techguide0409.pdf>. (Accessed December 15 2009).

<sup>41</sup> “Local Authority - these are the most local forms of government in any part of the UK. Local Authorities include non-metropolitan districts, metropolitan districts, unitary authorities and London boroughs in England; unitary authorities in Wales; council areas in Scotland; and district council areas in Northern Ireland.” West Midlands Public Health Observatory; Public Health and Statistics exchange. <http://phase.esriuk.com/Default.aspx>. (Accessed April 14 2008).

### 3.1.2 Description of the population of the study site

*Population: total population and spread across the network*

According to the England and Wales National Census of 2001, approximately one million people live in the area which is served by the network. Within the network, over three hundred thousand persons live in Area 1; over five hundred thousand in Areas 2, 3 and 4 combined; and over one hundred thousand in Area 5 (ONS census 2001, see Table 3.1, page 100).

**Table 3.1b Populations of the PCT areas (pre 2006)<sup>42</sup> within the cancer network (These are historically the areas served by the APDC units within the network).**

Area	Population
1	300,848
2	237,415
3	180,992
4	87,453
5	162,361

Data source: ONS 2001 census

#### *Sex and Age Distribution*

“The sex distribution of the population is similar across the [geographic areas of the network] and similar to England and Wales, with the male to female ratio approximately being 50:50” (Awad 2006, p. 12).

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<sup>42</sup> In 2006 an NHS restructuring process was completed which changed the composition of some PCTs, also see section 3.1.3.

With respect to age, according to the ONS census 2001, the population structure of England and Wales was such, that an estimated 21% of the population or 10,953,010 persons were over the age of 60 (ONS Census 2001, AWAD 2006). Similarly, in the study site, approximately two hundred thousand persons (200,000) or approximately 20% of the population were over the age of 60 years.

Numerically, most of these persons live in the city (Area 1) (ONS 2001, Awad 2006, p. 12). However, within the network, Areas 2 and 1 have the largest proportion of their population being over the age of 60 years<sup>43</sup> (ONS Census 2001, Awad 2006 p. 12-13) at 23%, notably above the national average, also see Table 3.2 below.

**Table 3.2 Percentage of persons over 60**

<b>Location</b>	<b>Percentage of people over 60</b>
Area 1	20 (19.877)
Area 2	23 (22.594)
Area 3	20 (19.958)
Area 4	21
Area 5	19

Data source: ONS Neighbourhood statistics (Primary Care Organizations)

<sup>43</sup> Table 3.2–Percentage of the population over the age of 60 years - (Data source: ONS Neighbourhood statistics (Primary Care Organizations)).

### *Ethnicity*

As stated earlier in this chapter, an estimated one million people live in the cancer network (ONS census 2001). Fourteen percent of the population in the cancer network was of an ethnic minority group, with approximately 6% of persons being of white minority ethnicity and approximately 8% (actual percentage 7.89%) of persons being non-white ethnic minorities.

The percentage non-white ethnicity of the cancer network as a whole is in keeping with the averages seen nationally. However, the proportion of non-white ethnic minority groups within the cancer network is lower than that seen in the region in which it is located, which has a percentage non-white ethnic minority percentage of 11.26% (higher than the national average) (Awad 2006, p. 13).

Therefore, the areas of the cancer network are likely to have fewer ethnic minority patients in their palliative care populations than surrounding geographic areas in the Midlands.

Within the cancer network itself, there is a further variation in ethnic composition. In Area 1 the percentage ethnic population of 21% is more than one and a half times the national average in England (ONS). Also in this area, 16% of the population is from non-white ethnic minority groups, of whom, more than 70% are of Asian or Asian British Ethnicity. The remaining areas of the network, i.e. Areas 2 to 5 have percentage non-white ethnic minority population which are lower than the national average, as shown in the data informing a palliative care needs assessment of the network by Awad (2006, p. 13), also see Table 3.4 (page 102) for further statistics on the precise composition of some ethnic categories using national statistics- ONS Neighbourhood statistics (Primary Care Organizations).

**Table 3.3 Resident populations by ethnicity across the areas in the cancer network**

	All White	All Non- White	Mixed	Asian/ Asian British	Black/ Black British	Chinese/ Other
<b>Area 1</b>	83.98%	16.02%	1.72%	11.27%	1.80%	0.73%
<b>Area 2</b>	95.63%	4.37%	0.81%	2.67%	0.31%	0.59%
<b>Area 3</b>	96.29%	3.71%	0.58%	2.68%	0.25%	0.20%
<b>Area 4</b>	93.97%	6.03%	1.15%	3.46%	0.97%	0.28%
<b>Area 5</b>	96.38%	3.62%	1.03%	1.69%	0.58%	0.32%
<b>Network</b>	92.11%	7.89%	1.12%	5.25%	0.86%	0.66%
<b>Region</b>	88.74%	11.26%	1.39%	7.32%	1.98%	0.31%
<b>E and W</b>	91.31%	8.69%	1.27%	4.37%	2.19%	0.44%
Source: 2003 Compendium of Clinical and Health Indicators/ Clinical and Health Outcomes Knowledge Base (nww.nchod.nhs.uk) Primary source of data: National Statistics						

**Table 3.4 Percentage resident populations by ethnicity across the areas in the cancer network using ONS Neighbourhood statistics (Primary Care Organizations)**

	White British	White Non British (White Irish+ White Other)	Mixed	Asian/ Asian British	Black/ Black British	Chinese Other	Other Ethnic Group
<b>Area 1</b>	78.32	5.65	1.72	11.27	1.80	0.73	0.51
<b>Area 2</b>	91.84	3.39	0.81	2.67	0.31	0.30	0.28
<b>Area 3</b>	94.77	1.52	0.58	2.68	0.25	0.12	0.08
<b>Area 4</b>	91.16	2.81	1.15	3.46	0.97	0.28	0.17
<b>Area 5</b>	94.28	2.10	1.03	1.69	0.58	0.19	0.13

## *Deprivation*

Within England one of the tools used to guide policy on addressing variations on levels of deprivation between communities has been the indices of deprivation; at the time of undertaking this work the most recent model was the Indices of Multiple Deprivation 2004 (IMD2004). (Indices of Deprivation 2004, p.1 <http://www.communities.gov.uk/documents/communities/pdf/131209.pdf> accessed January 3 2010). The IMD 2004 is a “composite of different dimensions or domains of deprivation” (Indices of Deprivation 2004, p. 10). These domains (seven in total) include; income, employment, and health deprivation, as well as crime (Indices of Deprivation 2004, p. 14, Awad 2006, p. 21). IMD 2004 measures may be presented at different levels including that of the PCT (Indices of Deprivation 2004, p. 10).

As shown by Awad (2006, p. 26), in the context of the national ranking of average scores IMD scores for PCT's there is notable variation in the network with the highest ranking being 44 and the lowest 222<sup>44</sup>. Within the cancer network studied i.e. one PCT area relative to another the following pattern by “increasing order of deprivation” occurs- Area 2 < Area 4 < Area 5 < Area 3 < Area 1 (Awad 2006, p. 26). In summary Area 1 (city), is the most deprived area, and the significantly rural Area 2 being least deprived. Table 3.5 from AWAD 2006 shows the PCT scores and ranks of the areas of the network within the overall IMD 2004.

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<sup>44</sup> All PCTs are ranked from 1 to 306 with 1 being the least deprived and 306 the most deprived.

**Table 3.5 PCT [/ Area] scores and ranks within the overall IMD 2004**

Area	Rank of Average Score (Out of 306)	IMD 2004 Score
1	229	28.158
2	47	10.798
3	155	19.541
4	98	14.815
5	81	13.582

### **3.1.3 Health care in the network**

As in other parts of the UK, persons within the network have recourse to health care through the country's National Health Service (NHS). Individuals are also able to purchase private health services if they so choose. At the time of conducting this work, restructuring of the organization of services was occurring in the NHS, with the number of Strategic Health Authorities and Primary Care Trusts being reduced. In the study site three PCTs were merged, and of October 1, 2006, the network contained three (3) Primary Care Trusts<sup>45</sup>. In addition to Primary care there were also four (4) Acute Trusts.

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<sup>45</sup> Primary Care Trusts are not responsible for the direct delivery of services, but rather commission services from health care providers for the populations they serve. Health care providers from which services can be commissioned include general practitioners, and some end-of- life care providers such as APDC units.

### *Palliative care*<sup>46</sup>

Within the network palliative care services included hospice at home services, inpatient hospice care, dedicated palliative care beds at a local hospital, and four (4) adult palliative day-care units operating at five sites consistent with the previously mentioned PCT areas (Personal observations and discussions October 2005-Feb 2007, Awad 2006 p. 31-32).

With specific respect to APDC services, there are 5 APDC units across the network. (No units in Area 1, two units in Area 2, and one unit in Areas 3, 4 and 5 respectively). At the time of conducting the research all of these were nurse lead with varying levels of medical practitioner input. All of the units historically operated for approximately five hours per day (note however that the number of days per week varied in the network see section 3.1.4), usually 10 am- 3 pm. On these days units intended to accommodate 15 patients per day. One unit had in the year prior to commencing phase one of the study, implemented a drop in service on one day a week.

The social aspects of care provided by the APDC units across the networks were found to be similar; including meals, activities such as games, or craft (some craft activities were part of diversional therapy). In addition patients could have assistance with their personal hygiene needs e.g. hair

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<sup>46</sup> The information presented in this section is informed by observations made and discussions held with management level providers at all of the APDC units during the period of study design and negotiating access to the study site. The information collected during this period was found to be compatible and complementary to that which emerged from the care model node (please see chapter 4 and Appendix 10.a, page 319). It is also similar to that described by Awad 2006 in a needs assessment of the network.

care/dressing (found at all APDC units) and bathing (this was identified as a structured part of the daily activities of one APDC unit).

In addition to the social elements of care mentioned above, APDC units also offered clinical and complementary services such as chiropody, physiotherapy and aromatherapy.

All but one of the APDC units in the network were implementing or actively seeking to implement a discharge policy where the needs of patients would be assessed after having been in APDC for 12 weeks, with a view to assessing if further service use was necessary.

As noted in the beginning of this chapter section 3.1 (pages 91-94), the APDC units in the cancer network studied were noted to have an average occupancy rate that was slightly lower than the national average with the profiles of users of the service mirroring those seen nationally, e.g. low use of services by patients with non-cancer diagnosis as well as ethnic minorities. These utilization patterns for the network are discussed below in the context of assessing need and volume of service provision of palliative care services.

The approaches used to assess need for palliative care in the United Kingdom include epidemiological approaches used by Higginson (1997, p. 191-201) and Tebbit (2004, p. 7-10)<sup>47</sup>. Key factors for

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<sup>47</sup> The methods of both Higginson and Tebbit were influenced by the earlier work of Cartwright (1991) and Seale (1991).

determining likely palliative care need in both methods are: a) the annual incidence of death from cancer and other causes in the given population; and b) estimations of the prevalence of symptoms commonly experienced by patients with “cancer and progressive non-malignant disease”<sup>48</sup> (Higginson 1997, p. 191-201, Tebbit 2004, p. 5).

The epidemiological approach has been combined with other “approaches” for assessing need (e.g. demographic and socio-economic approaches) to form a more comprehensive needs assessment method for palliative care services at local levels (Tebbit 2004, p. 5-17), and is part of a manual for assessing population level needs for cancer networks in the UK. Although the manual (Tebbit 2004, p. 5-32), and the work of Higginson (1997, p. 191-201) provide means for calculating volume of service provision and staffing numbers for inpatient hospice and hospice at home services, the methods with respect to APDC are less prescriptive. Tebbit (2004, p. 24) citing national guidelines states that

*“NICE Guidance does not recommend day-care as an essential service.... However, given that [APDC units] are available very widely... some advice no matter how tentative, may be useful”.*

Using the “advice” given by Tebbit (2004, p. 24) (which is based on the Sheffield University School of Health and Related Research (ScHARR) model) and national averages of the number of day-care

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<sup>48</sup> As discussed in chapter one there is increasing evidence suggestive of the fact that persons with advanced progressive non-cancer diagnosis have similar symptoms and would benefit from palliative care (Addington-Hall et al. 1998, p. 417-427, Kite et al. 1999, p. 477-484, Horne and Payne 2004, p. 291-296, Murtagh et al. 2007, p. 82-99, O’Brien et al. 1998, p. 286-289). Also, the work of Higginson (1997), informed by empirical research conducted in the UK during the Regional Study for Care of the Dying by Addington-Hall et al. (Addington-Hall et al. 1998, p. 417-427), suggests that some 2/3 of persons who die from non-malignant diseases would have experienced periods of “palliative care need”. It further suggests that these persons would have benefited from receiving palliative care in the last year of life (Addington-Hall 1998, p. 417-427) (Notable exceptions being those persons who would have experienced sudden death). In light of the above, epidemiological approaches for assessing need in palliative care include the number of persons with both noncancerous and cancer diagnoses who are likely to need palliative care.

places available, it is possible to estimate the number of APDC places that could be provided within a cancer network. In the cancer network selected as the study site it was possible to extract the number of cancer deaths and the number of non-cancer deaths with likely palliative care needs in the network from Awad 2006<sup>49</sup>, (see Table 3.6 below), however, the work did not comment on the volume of APDC that would be needed given the likely level of palliative need.

**Table 3.6 The annual number of deaths from cancer and non-cancer causes<sup>50</sup> (2001-2002)<sup>51</sup>**

<b>Area</b>	<b>Cancer deaths</b>	<b>Non-cancer deaths with likely palliative care needs</b>
1	1524	2929
2	1119	2472
3	865	1821
4	702	1611
5	455	911

<sup>49</sup> The number of non-cancer deaths with palliative care needs is calculated using methods as proposed by Higginson 1997, p. 191-201- based on the work of Cartwright and Sale, and is calculated as “2/3 of total deaths less cancer deaths” for the area (Tebbit 2004, p. 9).

<sup>50</sup> It is recognised that not all of the above persons will have the same level of need and that it is likely that percentages of patients with problems may give a more accurate measure of patients needing particular interventions/ symptomatic care during the last year of life. Therefore, tables showing these results for the network are direct references from Awad 2006 p. 18-20).

<sup>51</sup> A potential limitation of this data is that it does not use 3 year rolling averages therefore the “highs and lows” of incidence may not be corrected (Tebbit 2004, p. 7).

Using the advice given by Tebbit as mentioned above an estimation of the number of places per population is given below.

**Table 3.7 The number of places per population is given (This calculation is designed to include 6% of places for non-cancer patients)<sup>52</sup>.**

Area	Population	Number of APDC places per year given ONS census population	Number of APDC places per week
1	300,848	3911	75
2	237,415	3086	59
3	180,992	2353	45
4	87,453	1137	22
5	162,361	2111	41

At the time of undertaking the study, there were zero day-care places being offered in Area 1, as the APDC unit located there was recently closed in November 2005<sup>53</sup> (Munday 2007, p. 25). In Areas 2- 5 all units aimed to provide 15 spaces per day, one unit in Area 2 and the unit in Area 5 was opened 4 days a week, the remaining units were operated 5 days a week (Monday-Friday).

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<sup>52</sup> These calculations use the assumption of 13,000 APDC places a year per million population.

These results show that in the network, at the time of conducting the study, the area of likely greatest need for APDC had no available spaces. The remaining areas of the network (based on service descriptions from Management level providers and calculating at a 52 week year) indicate that APDC units had more spaces than indicated by the populations they serve. This is a possible explanation for the lower than national average percentage occupancy referenced in section 3.1. This may also be evidence in support of previous arguments set forth in Chapter One which indicated that palliative care services may not be established on the basis of needs assessments, and may not be in locations of greatest need. It should be noted though, that the unit in Area 1 had a capacity of 50 spaces per week before it closed, and that on closure provision was made for patients from this area to travel to neighbouring PCTs to receive care.

The above data raises the possibility that with respect to this network, there is the prospect that the lower rates of usage may be due to there being more spaces than are needed in this network. It should be noted that within the network the percentage use of services by ethnic minorities and patients with non-cancer diagnosis is low (0.6% and 4.4% respectively compared to national means of 3.6% and 8.5% respectively) and this may not necessarily be explained by the existence of spare capacity.

### 3.2 Chapter Summary in the form of Key Points

#### Chapter Three: Key Point

- The site chosen for this study was located in the Midlands of England. Although the choice of location was influenced by the availability of funding, the network chosen was suitable as it could allow for sampling to achieve maximum variation across parameters such as geography, and ethnicity.
- The network contained a mixed geographic area, including areas classified as city, urban, and significantly rural.
- With respect to ethnicity though grossly in keeping with national averages, the network contained sections served by APDC units that had ethnic minority populations that were higher and lower than national averages.
- In addition to geography and ethnicity, there was also notable variation across the network by level of deprivation.
- With respect to service provision the APDC units all had services which provided some elements of social and medical care.
- The APDC units in the network were noted to have lower than average % use of day-care places, perhaps a reflection of over capacity thus exemplifying the unplanned development of palliative care services noted in the literature (see chapter one).
- Services in the network also reported lower levels of service use by ethnic minorities and patients with a non-cancer diagnosis, a pattern that has also been reported in the literature.
- Given the characteristics described above the network was seen as a possible study which might reflect some aspects of the realities of other APDC units in other parts of the country.

**PART TWO:**

**METHODOLOGY AND FINDINGS**

## CHAPTER FOUR

### Methodology and Methods

#### 4.0 Introduction

Thus far Chapters One and Three have shown that APDC services<sup>54</sup> have patterns of use suggestive of underutilization and possible inequalities of access by certain potential user groups (sections 1.7, pages 57-60). However, there remain gaps in understanding regarding if these observations are in-fact a reality and why they might be occurring (section 1.8, pages 66-67 and section 3.1.3 pages 101-107).

From a theoretical perspective many of the gaps in knowledge in the literature seemed to revolve around the concepts of need, its assessment and how these might affect access (section 1.8, page 66). In addition there was a gap in knowledge relating to the understanding of how unique organizational features of day-care may be impacting on the achievement of access. These gaps in knowledge lead to the development of the research question and sub-questions which are presented below (these were first presented in section 2.8, page 88-89).

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<sup>54</sup> In the cancer network chosen as the study site as well as in the UK as a whole.

***Overall research question***

*What are the factors which act to determine access to APDC?*

***Research sub-questions to be explored in answering the overall research question (guided by gaps in knowledge from the review of literature)***

- 1. What do patients and carers, who are potential users of APDC services, perceive or view as their health care needs, and what are the perceived/ experienced benefits of using APDC, especially as it relates to addressing these needs?*
- 2. How do patients, carers, health professionals, and volunteers perceive APDC and what is their understanding of the role of, and benefit of, APDC in palliative and end-of-life care?*
- 3. What are the Health professionals' and volunteers' perceptions and understandings of what constitutes a person in need of the APDC or an appropriate referral to the APDC service?*
- 4. What do patients and carers experience and perceive as being the **non-self factors** which influence their decisions to access APDC (both barriers and facilitators)?*
- 5. What are the specific organizational features of APDC services and their referral pathways which may be affecting access?*

In order to address the above research question and sub-questions any study conducted would need to:

- a) gather and analyse the personal perceptions and experiences of palliative care patients and their carers as a means of understanding their health care seeking behaviours;
- b) gain insight into the policies and decision making processes of institutions as well as health professionals, volunteers or other non-client persons who could theoretically affect access;
- c) explore the interactions between the above individuals and the policies and structures governing APDC.

This chapter outlines the choices of methodology, methods, and the actual process used in answering the research question and sub-questions. It is organised into two (2) parts. Part one discusses the rationale behind the choice of methodology and the specific research methods; part two describes what was actually done in terms of sampling, recruitment, data collection and analysis. It also gives an account of the ethical issues which impacted the work.

The chapter ends with a summary box which highlights key points regarding the conduct of the study.

## **Part One: The rationale behind the choice of methodology**

The rationale behind the methodology will be presented in the context of what was likely to be appropriate to addressing the research question and sub-questions. Therefore, philosophical paradigms as well as the suitability of quantitative, qualitative and mixed methodological approaches are discussed.

### **4.1. Philosophical Paradigms: their changing influence on choice of methodology**

Denzin and Lincoln (2003, p. 245) define a philosophical paradigm as the core “*set of beliefs*” that define a researcher’s “*worldview*”. They state that this core set of beliefs:

*“...encompasses the concepts of ethics, epistemology, ontology and methodology”; where  
“epistemology asks, how do I know the world?... Ontology asks about the nature of reality ...  
[and] methodology focuses on the best means for gaining knowledge about the world”.*

They add that these core set of beliefs, act to “*guide*” the research process (Denzin and Lincoln 2003, p. 245).

Previously, many researchers viewed the core set of beliefs held within a given paradigm as being so distinct, that they rendered paradigms separate from each and unmixable (Bryman 1984, p. 75-80).

More recently, however, there has been a gradual shift away from this view of unmixability to a growing acceptance of a “blurred” boundary between traditionally distinct paradigms (Lincoln and Guba 2003, p. 253-254; Clark 1998, p. 1243). The result has been an increase in the conduct of research which now combines previously traditionally opposed “world views”, such as positivism and phenomenology (Sale et al. 2002, p. 44).

In addition to the combining of paradigms, the blurring of boundaries between philosophical paradigms has assisted in the creation of a general research environment which has seen the emergence of **new** “more moderate paradigms” (Fulop 2001, p. 7). There has also been the rise of what has been termed, the pragmatic approach to research (Bryman 2006, p. 116).

Previously, the goals of the researcher may have been to locate their work in the *perfect* paradigm and to arrive at “*absolute truth*” (Lincoln and Guba 2003, p. 272). However, the current research environment has moved towards a more moderate view. The notion that there is no perfect paradigm, and by extension, no perfect methodology in which researchers are to locate their work, is now becoming more widely accepted (Lincoln and Guba 2003, p. 272). Instead, choices of methodology and methods are now increasingly based on “pragmatic” logic, where researchers consider a combination of factors when deciding their approach. These factors include the nature of the research question, the social context in which the research is to be conducted, the implications for funding, and the target applications of the research outputs (Bryman 2006, p. 116). Elliot and Popay (2000, p. 463) suggest that:

“ when developing research applications, the contexts within which findings are to be implemented and the need to persuade others of the relevance of research has to be taken into account”.

Bryman’s comments on the increasingly “pragmatic attitude” to the design of research was based on his work with social scientists. However, as stated by Pope and Mays (2006, p. 3), the pragmatic design of research may be relevant to the conduct of

“health services research... [given that] research here [i.e. in health services] tends to be geared towards specific practical problems or issues, and this rather than theoretical leanings may determine the methods employed”.

These modern views on the “mixability” of research paradigms and the use of *pragmatic* approaches to health services research influenced me while I was designing this study.

#### **4.1.1 Adopting a pragmatic approach**

This study as indicated in the acknowledgements and in Chapter Three was partly funded by a cancer network. It occurred at a time when there was a clear need for research to inform the process of broadening access to palliative care services; both on the national and local levels. Therefore, if the results of this study were to remain relevant to researchers and policy makers, they needed to be produced in a timely manner. Also, because of the gaps in the literature, any research specifically focussed on access to palliative day-care would be largely exploratory in nature. Given these features a pragmatic approach was taken. This led to the research process being guided by an interpretive philosophical paradigm which used mixed methodologies (Lincoln and Guba 2003, p. 267).

Specific discussions on interpretivism are presented in section 4.1.2 (page 116) as explicit disclosures are recognised to assist readers in understanding research context, findings, and the scope of the possible applications of results (Grix 2004, p. 57-59, Bowling 2002, p. 119) (thereby actually increasing the usefulness of results). The discussion on interpretivism is followed by sections on the actual methodology and methods.

#### **4.1.2 The Philosophical Paradigms shaping this research on access to APDC**

This work was informed by an interpretivist philosophy, which holds the view that the actions of humans are “inherently meaningful” (Schwandt 2003, p. 296). The term meaningful as used by Schwandt is used to distinguish the social actions of human beings, from the actions of “physical objects” (Schwandt 2003, p. 296). The underlying theory is that the social actions of humans are never without purpose. Further, an interpretivist philosophy emphasises that in order to understand the meaning of human action, one must be aware and obtain an understanding of both the context of the action, and the intentions of the actor. To illustrate this point, Schwandt uses the example of the human action of the raising of an arm. He explains that in order to understand what these actions mean, one must know the context and intention:

“physical movement of raising ones hand may be interpreted as voting, hailing a taxi or asking for permission to speak, depending on the context and intentions of the actor” (Schwandt 2003, p. 296).

As described by Schwandt, there are various processes which may be used to obtain an understanding of context and intent, but some commonalities do exist (Schwandt 2003, p. 298). Firstly, all processes highlight that understanding context and intention involves accessing and interpreting the subjective experience or “self understandings” of the research participants. Secondly the subjective experiences being researched are recognised as valid forms of knowledge. And thirdly, subjective experiences can be collected, analysed, and interpreted in an “objective manner” (Schwandt 2003, p. 296-300).

When the principles of an interpretivist philosophical paradigm are applied to this work on understanding the determinants of access to APDC, then specific human actions and interactions are seen as having a purpose. More precisely, a purpose, and resultant effect of either possibly hindering or facilitating access to APDC. For instance, using the conceptual frameworks given in Chapter Two (sections 2.6 and 2.7, pages 85-88b) it was hypothesised that the potential actions of users and health care professionals could influence whether access was obtained. The hypothetical actions considered included the gate-keeping role of health professionals and the concerns and expectations of users with respect to the ability of APDC to respond to their **needs** (i.e. the degree of fit between the system and user; Box 2.1, page 77). By applying an interpretive philosophical paradigm the hypothetical actions mentioned above and their influence on access can be best understood by investigating the **context** in which the actions occurred and by obtaining **insights into the intention or thought processes of the person/s involved**.

In addition to an emphasis on understanding social context, thoughts and the intent behind actions, an interpretivist paradigm was used as it also emphasises that it is possible for the outside researcher to gain a true “inside understanding” of research participants’ actions, and what their “definitions of situations” mean (Schwandt 2003, p. 296-297). This philosophy differentiates interpretivism from other philosophical paradigms associated with researching human actions, such as social constructionism. Like social constructionism, interpretivist philosophies do acknowledge that what can be understood is shaped by social and historical perspectives (Schwandt 2003, p. 298, 305-307). However, interpretivist philosophies maintain that a true understanding of human actions can be

obtained and that this truth can be obtained in an objective<sup>55</sup> manner (Schwandt 2003, p. 297). It is argued that objectivity in this paradigm is demonstrable “if the researchers employ methods” that improve their awareness and ability to assess their impact on the research process. Effective methods include reflexivity (Schwandt 2003, p. 297-298) which was used in this work. The reflexive account of this study is presented and discussed in Chapter Seven (page 244).

The methodology associated with adopting an interpretivist philosophical paradigm and those eventually chosen for use in this work are discussed in section 4.1.3 (page 118).

#### **4.1.3 Methodologies associated with an interpretive philosophical paradigm and those used in this work**

As stated on page 118, the term methodology refers to “the best means for gaining knowledge about the world” (Denzin and Lincoln 2003, p. 245). In today’s research environment, two of the more dominant methodological categories are qualitative and quantitative (Clark 1998, p. 1243-1246, Green and Thorogood 2005, p. 5). Quantitative methodology refers to ways of gaining knowledge through quantifying the characteristics of a phenomenon under study, as a means of developing causal links or explanations (Silverman 2007, p. 37-39). Qualitative methodology, on the other hand, describes gaining knowledge by understanding the meaning of human action through the interpretation or construction of those difficult to quantify, or unquantifiable phenomenon of the social world (Clark 1997, p. 159-160).

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<sup>55</sup> The ability to conduct research which could be later viewed as being objective and credible was an important aspect of preserving the usefulness of this work given the likely policy maker readership of its results (page 27). This need was therefore met by an interpretive philosophical paradigm.

As it relates to the association of paradigms with a particular methodology, traditionally, a qualitative methodology more so than a quantitative methodology has been associated with an interpretive philosophical paradigm (Schwandt 2003, p. 294). Despite the traditional stance, this study used both quantitative and qualitative methodologies. However, the quantitative methodology served a *minor* role; supporting the arguments in favour of the suitability of the cancer network as an appropriate site for this study on access. Specifically these methods were used to analyze the demographic data and calculate the percentage use of day-care spaces within the cancer network. A qualitative methodology was used to guide the process of collecting and analysing data on the experiences and perceptions of participants.

Admittedly the contribution of quantitative methodologies was limited. However, I recognise that this study may be classified as using a mixed methodological and mixed method approach. Therefore, the potential benefits of mixed methodologies are briefly discussed below<sup>56</sup>.

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<sup>56</sup> Section 4.2 (page 12) presents the benefits of mixed methodologies, however, I am aware that there are limitations to be considered. Bryman in his study with social researchers notes that mixed methods work is not without challenges. Here he suggests that the quality of a mixed methods study may be reduced when the researcher:

1. has not considered the appropriateness of the approach to the research question (Bryman 2006a, p. 124-125);
2. does not have the necessary training or skills required to competently use the various methods involved (Bryman 2006, p. 121).

During this work, consideration was given to which methods would be best suited to answering questions raised during the different stages of the research process. In addition, the issue of the competent use of mixed methodologies was considered during the conceptual stages of this work, and reflected on during the entire research process. As a result, where necessary I acquired new skills and strengthened existing ones (see Appendix 1 on page 285 for information regarding the process for acquiring new research skills and strengthening existing ones). Finally in employing a mixed methodological approach, care was taken to use each methodology (qualitative/quantitative) in accordance with the rules commonly accepted to govern its use.

#### 4.2 Mixed Methodology and their potential benefits in research

Mixed methodological research refers to the practice where more than one methodology is used in the answering of a research question (Dobratz 2006, 260). As was previously discussed in sections 4.1 (pages 113-115), there has been an increasing acceptance of pragmatic approaches to research design, including the use of more than one methodology in a given study. These may be used *as long as* they are viewed as being beneficial to answering the research question (Bowling 2002, pp. 130-131).

In the literature mixed methodological research is represented as having the benefit of allowing researchers to develop a holistic or “better overall view” of the event being studied (Green and Thorogood 2004, p. 207-208, Sale 2002, p. 51); particularly when the subject of the research is a complex social action (Green and Thorogood 2004, p. 207-208). Expanding on this theme of obtaining a holistic view, O’Cathain et al. (2007, p. 8) note that *health services researchers* in the United Kingdom seemed to be using mixed methodologies for the purposes of “complementarity, expansion and development”, and to achieve the goal of obtaining a “comprehensive understanding”.

In addition to the above purposes, mixed methodological research is also represented as being a potential way for verifying and validating results by facilitating triangulation of methods (Moran-Elis et al. 2006, p. 47). However, it is debatable whether triangulation of methodologies and their associated methods can actually verify and validate research results (Moran-Elis et al. 2006, p. 48-49)<sup>57</sup>.

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<sup>57</sup> It has been argued that when the epistemology and ontology of research methodologies are different, the methodologies cannot be truly said to be examining the same phenomenon (Sale 2002, p. 50, Brannen 2005, p. 176). Thus, because of these fundamental differences, methodologies cannot verify or validate each other. The views of

In this work, a mixed methodological approach was used in a way that is similar to what O’Cathain et al. (2007, p. 8) termed “development”, in that a quantitative methodology was used to support the study design with respect to the choice of study design. The remainder of the study design e.g. sampling, data collection, analysis and reporting methods were based on a qualitative methodology. This decision was pragmatically based on the assessment that these methods were the most appropriate to answering the research question and sub-questions (given in section 4.0, pages 110-111). The reasons in favour of a dominant qualitative methodology (and methods) are below in section 4.3 (page 122).

### **4.3. The reasons for the predominant use of qualitative methodologies in this study**

#### **4.3.1 Reason one: The exploratory nature of the research subject and the need to generate descriptive data on social context and human perceptions and experiences**

Given the gaps in knowledge regarding access to APDC, the research question, and sub-questions could be seen as being exploratory in nature. Therefore, addressing these questions would involve the generation of data which would need to **describe the human experiences, perceptions and social context which influence whether access occurs**. Further as stated on page 27 results were likely to be used by policy makers. Therefore, providing local contextual information would be important (Murphy 2001, p. 44) especially in light of the variability in service models which exist in APDC services in the UK (Myers and Hearn 2001, p. 4, Copp et al. 1998, p. 164, Higginson et al. 2000, p. 279-280).

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researchers such as Sale et.al (2002, p. 48-50) which argue against the use of mixed methodology research for the purpose of validation seem definitive. However, they are perhaps best interpreted as words of caution to researchers employing mixed methods. This is echoed by Silverman (2000, p. 99) who states that care should be taken when using mixed methodological research for the purpose of validation of results by triangulation of methods.

Qualitative methods assist with the meeting of the above needs. In particular qualitative interviewing and observational<sup>58</sup> methods have the ability to obtain: “rich” descriptions of “everyday” social contexts, and health care processes (Miles and Huberman 1994, pp. 1, 10; Green and Britten 1998, p. 1230; Bowling 2002, p. 35). Qualitative methods are also recognised as being “potential” sources of local service organization and delivery information (Pope et al. 2002, p. 150).

It is acknowledged that experiences can be gathered by the use of other interviewing methods, including structured quantitative survey methods (Britten 2006, p. 13). However, these methods have not been as effective in providing deeper insights into persons’ health related behaviours (Bowling 2006, p. 35).

As it relates to theory development, qualitative methods are more likely to assist in developing theory in studies which are focussed on phenomenon (like access to APDC) that are poorly understood or defined (Britten et al. 1995, p. 105). In fact, as stated by Murphy in cases when a phenomenon is not well understood, using quantitative methods may be difficult, and may even present a potential waste of resources (Murphy 2001, p. 44).

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<sup>58</sup> Observations is one of the most commonly used methods of qualitative research, for obtaining an understanding of what persons do as opposed to what they say they do. Therefore this method was considered in this study as a primary data collection tool, however, it was not used. Various factors including the ethics around maintaining patient and carer privacy; and the effect of the researcher on the observed phenomenon informed the decision not to use observation methods. These are presented in detail in Appendix 3, page 289.

#### **4.3.2 Reason two: The sensitive nature of the research topic and the involvement of vulnerable participant groups.**

The discussion of issues surrounding death and dying is recognised as being a sensitive research subject (Burr 1996, pp. 173, 177). Palliative patients are also classified as a vulnerable patient group by research ethics committees (Watson et al. 2005, p. 32) as they might be experiencing physical, emotional, social, and or spiritual distress, in addition to the possibility of imminent death.

While designing this work, it was considered that in obtaining deep descriptive data, participants may need to reflect on, and or give accounts of, situations which might potentially cause emotional distress (to both the researcher and the participant). Qualitative methods such as semi-structured in-depth interviews are recognised as being useful when dealing with sensitive topics (Bowling 2002, p. 379, Bloom and Crabtree 2006, p. 315) and were used as the primary data collection method in this work. The interview schedule consisted of open ended questions. Framing questions in an open ended way has been shown to be a very effective means of collecting the type of data needed in this study, as this sentence structure provides participants with the opportunity to expand and express themselves.

The semi-structured in-depth form of interview also offers flexibility which assists in rapport building (Dickson–Swift et al. 2006) (rapport building facilitates the development of trust between the participant and the researcher. Such trust can facilitate the collection of sensitive data (Britten et al. 1995, p. 105)).

Semi-structured in-depth interviews are also flexible in that they allow for the alteration of the order or phrasing of questions, in addition to the use of prompts and probes in response to a participant's comfort level (Bowling 2002, p. 385). Having this flexibility was important, as it was likely that some patient participants would have functional deficiencies related to their age or health condition. Therefore, being able to clarify, expand, simplify, and redirect questions in response to participants' cues was important. It is unlikely that such flexibility would have been offered by quantitative methods (Britten 1995, p. 251), given the "rigidity" often associated with these (Ziebland and MacPherson 2006). Thus using qualitative methods provided participants with the opportunity to share the insights and experiences which they alone have, without having to conform to preset or limited modes of expression (Ziebland and MacPherson 2006).

#### **4.3.3 Reason three: The need for flexibility in the overall research design**

In addition to the benefits in flexibility offered by semi-structured in-depth interviews, a qualitative methodology also provides flexibility in the overall approach to the various aspects of research design e.g. sampling, data collection, and analysis (Miles and Huberman 1994, p. 10, Bryman 1984, p. 78, Green and Thorogood 2004, pp. 20-21). Such flexibility was important given the exploratory and sensitive nature of this work, and was an important means of ensuring that detailed data were collected from the most appropriate sources.

#### **4.4 Summary regarding the philosophical paradigms and methodologies which have shaped this work**

In summary, in designing this research, philosophical paradigms and methodologies were considered.

Given the research question and sub-questions, an **interpretivist stance** was viewed as being most relevant. A **pragmatic** approach was employed to guide the work resulting in a mixed methods design.

**Qualitative methodology was the dominant methodology** as its “theoretical and ideological parameters” (Clark 1997, p. 160) as well as its associated methods, were seen as being more appropriate for the answering of the research question.

Table 4.1 provides a summary of the reasons for using a qualitative methodology that were previously presented in this section.

**Table 4.1 A summary of the nature of the research and the reasons for the predominant use of qualitative methodologies in this Study**

<b>Nature of research area/nature of research question and sub-questions</b>	<b>Suitability of qualitative methodology</b>	<b>Impact on research design</b>
<p>The research:</p> <ul style="list-style-type: none"> <li>• was <b>exploratory</b>;</li> <li>• needed to generate <b>descriptive data that could develop theory-including descriptions of local context</b> and service organization and delivery;</li> <li>• needed to obtain the personal <b>perceptions, experiences and social interactions</b> of different persons regarding a health care process;</li> <li>• needed a <b>flexible</b> methodology given the sensitivity of the research topic, vulnerability of some research participants and the exploratory nature of the work.</li> </ul>	<p>A Qualitative methodology is more suited to investigating topics that are largely exploratory in nature. They are also more suited to investigating perceptions and experiences of human beings.</p> <p>The overall approach to using qualitative research methods is more flexible than quantitative ones. Such flexibility is important when research is exploratory and the absolute research pathway/ variables to be investigated are not clear from the outset.</p>	<p>A cyclical qualitative approach was used in the research process. This resulted in :</p> <ul style="list-style-type: none"> <li>• the interview schedule being iterative thereby permitting emerging themes to be investigated by incorporating them into the interviews schedules of subsequent participants;</li> <li>• the sampling frame being altered based on emerging data</li> </ul> <p>Semi-structured in-depth interviews were used. This kind of interviewing method:</p> <ul style="list-style-type: none"> <li>• has the ability to generate descriptive data (Miles and Huberman 1994, pp. 1, 10; Green and Britten 1998, p. 1230; Bowling 2002, p. 35, Pope et al. 2002, p. 150 ) including in unexplored areas Britten et al. 1995, p. 105);</li> <li>• is valuable when researching sensitive issues including health and illness (Ziebland and MacPherson 2006, p. 406-407);</li> <li>• can facilitate the safe collection of data.</li> </ul>

## **Part two: What was done: an account of the actual research process**

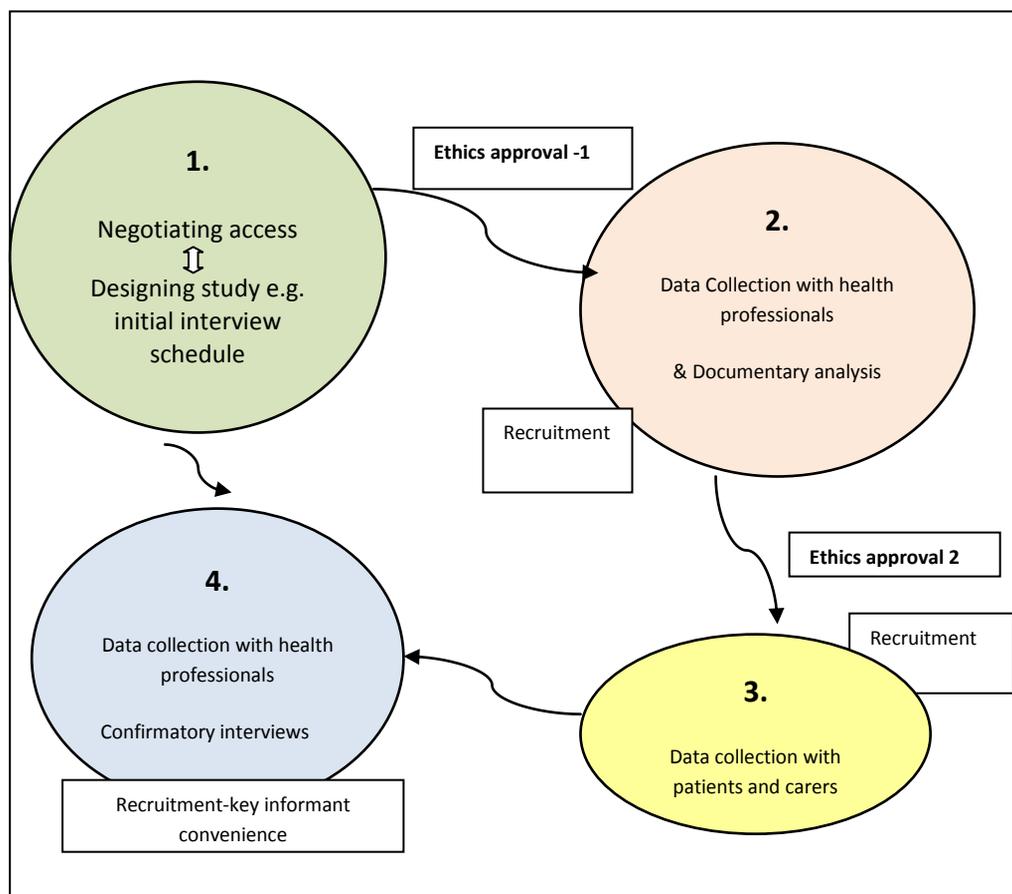
As was stated earlier, this study was exploratory in nature. It was also focussed on a sensitive research topic that involved vulnerable participants. Because of these factors a flexible and cyclical approach was taken to the overall conduct of the research. This allowed the process of analysis to begin very early in the research cycle. There was also constant reflection to ensure that the research design was suitable to the research aims given the emerging data.

The research cycle used was influenced by data analysis models advocated by Miles and Huberman (1994, p. 12) especially their concept that in qualitative research more than one process can occur at once. This resulted in some components of the work occurring simultaneously, with processes such as study design, data collection and sampling all influencing each other. In addition, throughout the entire research process there was an overarching environment of reflection and analysis<sup>59</sup>. Figure 4.1 (page 128) gives a summary of what was done, while the remainder of the chapter (sections 4.5-4.13) provides an account of what was done.

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<sup>59</sup> The interactive model of data analysis by Miles and Huberman (1994, p. 12) including the components of data collection, data reduction, data display, and conclusion drawing were used to analyse results this is discussed in section.

**Figure 4.1 A summary of the research process which occurred in the context of continuous analysis and reflection**



#### **4.5 The research process: Study design- Negotiating Access**

As described in Chapter One (page 61), the models of adult palliative day-care operating across the United Kingdom are quite varied with there being social, medical and mixed models of care (Coop et al. 1998, p. 164; Higginson et al. 2000, p. 279). Very early in the research process the day-hospices within the funding network were visited and through observation and discussions with APDC staff it became evident that the variability in models of care seen nationally was also reflected in the network.

These findings supported the arguments in favour of using the funding site, and all of its units as the actual location of the study (section 3.1.3 page 101-107).

This section on negotiating access describes the interactions between myself and the APDC units prior to the collection of any interview data. It shows the impact of these early observations and discusses the overall study design e.g. the recruitment methods used for patients and the use of documentary data.

#### **4.5.1 Preliminary field work**

In September of 2005 while still conducting literature reviews I attended an executive meeting and was introduced to members of the board of management of the various day-care units. I was briefly introduced as a researcher from the university who would be assisting the network with research on understanding day-care. Some months later when my research was more informed by the literature, I contacted each day-care unit in the network and arranged a site visit and meeting with their APDC manager. I intended to use this meeting to inform the APDC managers of the likely direction of the study, and to learn about their care models. On my visit to the sites I had discussions with the manager on the specifics of the services they offered, their staffing levels and typical client profiles. In addition I also had a guided tour of the (APDC) units including treatment and administrative areas<sup>60</sup>. This tour gave me the opportunity to see how space was utilised at the respective units, and to do an early

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<sup>60</sup> In addition to the general tour, one full day (10 am-3 pm) of pre-research participant observation was spent at one of the APDC units. This was facilitated by one of the academic supervisors of the research. This day included attending morning case conference, interacting with and having discussions with patients, staff and volunteers, including having lunch.

assessment regarding the availability of a quiet confidential area that could possibly be used during any data collection.

From these first visits I realised that the APDC units in the network did vary in their care-models and that they were suitable sites for conducting the research. After this I started to formulate my detailed research protocol (study population, sampling and data collection methods). I visited each unit on two more occasions to discuss the study design with the managers and to obtain their feedback and suggestions. This process of engaging with the managers and having them participate in the study design was beneficial. Firstly, these meetings gave me the opportunity to further position myself as an objective researcher from the university and to establish and build a trusting relationship with the managers. This was an important means of allaying any fears regarding the APDC units being audited<sup>61</sup>. Secondly, by participating in the study design the managers were able to have a sense of ownership of the research process. Of note, the managers also identified naturally occurring data on access which all the units possessed, and gave advice on possible methods for effectively recruiting palliative patients. In fact, as will be discussed later, initial contact with participants was facilitated through the palliative day-care unit. This level of support from the respective day-care units was invaluable.

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<sup>61</sup> This research was conducted at a time when there was restructuring of the Primary Care Trust systems of the NHS. Though most of the units received their funding from private charitable contributions, there was much debate in the wider palliative care arena, as well as within the network, about the advent of a payment by result system which might affect any NHS contributions made to individual services.

Finally, from these early visits it became evident that in order to understand the access processes to APDC, it would be necessary to interview a wider range of individuals from within the day units than had been suggested by the literature. Therefore, the study sample was expanded to include persons who may affect access by virtue of their sanctioning or interpretation of referral acceptance criteria e.g. board members and volunteers.

The final study design was approved by the individual units and the local research ethics committee.

The ethical review process and details of the study design including interview schedules is given below in section 4.6.

## **4.6 The research process: Ethical review and interviewing methods**

### **4.6.1 Peer review and ethical approval**

The study protocols for this study were reviewed and approved by researchers from the University of Warwick (May 2006) and by two independent research ethics committees<sup>62</sup>. The first was in June 2006 (COREC)<sup>63</sup> and the second in March 2008 (NRES). In addition honorary contracts and permission to conduct research were also obtained from the Research and Development (R&D) “departments” of the APDC units and the various Primary Care and NHS Trusts involved in the network.

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<sup>62</sup> Undergoing an independent peer review process and obtaining ethical approval is in keeping with recommendations for safe conduct of research with human participants made in the Helsinki declaration (World Medical Association Declaration of Helsinki 2008, p. 3 <http://www.wma.net/en/30publications/10policies/b3/17c.pdf> (Accessed December 21 2010) , and is especially important when conducting research with patient participants who are from a vulnerable participant group.

<sup>63</sup> The geographic area in which the study occurred was in one health domain within England. Therefore, approval from two local ethics committees was sufficient to grant permission for the conduct of research throughout the network.

At the ethics review in 2006 I presented a research protocol which proposed to collect data from all categories of participants simultaneously. One group of participants was palliative patients. On review the proposal, the independent local research ethics committee expressed the view that the palliative patient participant group should be protected as far as possible, and interviews with them should only be conducted if absolutely necessary. Their recommendation was that the interviews with health professionals be conducted before interviews with patients and carers. This was a valuable suggestion and was taken up although it had the net effect of extending the length of the project. However, the data which emerged from interviews conducted with health professionals reaffirmed and very strongly demonstrated the value of obtaining the views and experiences of palliative care patients. This led to granting of permission to recruit these patients in 2008. The effects of this phased approach to the research design is considered in the limitations (Chapter Eight, page 256).

#### **4.6.2 Interviews**

As stated by Wilkie in her work which discusses the ethical issues in palliative care “sometimes a patient might have coped by not concentrating on certain topics” (Wilkie 1997, p. 322). Although there was the need to unearth rich data, I always sought to prevent participant distress and to operate within the guidelines stated in the declaration of Helsinki, namely “concern for the interest of the subject must always prevail over the interests of science and society.” (Wilkie 1999, p. 321). Therefore, achieving balance between participant safety and unearthing appropriate data guided my specific choice of interviewing method. It is thought that the more unstructured and interactive an interview, the more likely it is that a deeper level of discussion will be achieved (Clark 1997, p. 161). However, I felt that there was a need to protect participants with respect to the way in which they accessed their memories. In addition, I also wanted to ask each participant about specific topics e.g. access, and need, while still

giving them freedom to express themselves. To this end, I used a semi-structured in-depth interview format as this would allow for a measure of consistency between interviews while giving participants the freedom to express themselves.

#### **4.6.3 Design of the interview schedules**

The interview schedules used with health professionals and volunteers were designed with the advice from an experienced qualitative researcher AL, who was at the time independent of the project. The advice given led to the reordering of a few of the interview questions and the inclusion of two open ended ice-breaker questions at the start of the interview. Ice breaker type questions serve to increase participants' comfort level, and facilitate the development of rapport (Bloom and Crabtree 2006, p. 316).

The schedule was first piloted in August 2006 on two health professionals involved in the provision of care at two separate palliative day-care units within the network. The pilot interviews were then transcribed verbatim and reviewed by a second qualitative researcher (HB), who was also independent of the project. HB's review of the transcript commented on several issues, including: the appropriateness of the interview schedule to the research question, and my interviewing technique. In addition, HB identified early emerging themes for exploration in further interviews<sup>64</sup>.

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<sup>64</sup> These themes were subsequently incorporated into the interview schedule, in keeping with the iterative process which was being used to ensure participant comfort and maximum data collection (McAvoy and Kaner 1996, pp. 732-734; Pope et al. 2002, pp. 148-152).

#### **4.6.4 The interview**

Interviews with non- patient, non-carer participants explored the experiences and perceptions of participants concerning:

Their definition of need for adult palliative day-care service:

- what constitutes an appropriate referral to APDC;
- the presence and application of referral criteria for admittance to the service;
- patterns of referrals to day-care;
- current referral routes within the cancer network;
- their current sources of information about palliative day-care services in the network;
- the affect of referral on patients and their relatives and or carers;
- and how could the referral process to palliative day-care services be improved ( i.e. if they perceived or viewed improvement to be necessary)?

At the end of each interview with health professionals and volunteers, participants were asked their ethnicity. The collection of demographic data may sometimes be seen as a threatening question to some research participants (Boynton et al. 2004c, p. 1434), as such, this question was asked last. In addition to increase participant comfort as advocated by Boynton et al. (2004c, p. 1434), a clear explanation was given as to why this demographic information was important to the study. Also participants were reminded that their answer to this question was entirely voluntary.

Interviews with patients and carers explored:

- how patients and their carers first came to know about day-care; and what were their first impressions;
- who or what were their sources of information;
- what were the major factors which influenced their decision-making process regarding acceptance or refusal to attend APDC;
- what were their perceived and experienced benefits of using APDC?

It should be noted that participants would have been aware of the aims of the research and the broad topics to be covered. These would have been included in the participant information sheets (PIS) that were included in the packages used in recruitment. In addition the PIS sheets would have informed persons that participation was voluntary and without influence on their employment or care. Also there was no financial or other incentive used to encourage participation and persons were free to withdraw at any time without giving a reason (Appendix 4, page 292). The actual sampling and recruitment process is introduced in the next section.

#### **4.7 The research process: Sampling**

##### *Overall approach to study population*

After reviewing the literature and going through the process of negotiating access (section 4.5 pages 128-131) it became evident that understanding access to APDC would require the involvement of four categories of participants: patients; carers; providers of and referrers to APDC services. As stated

previously the study question and sub-questions were seen as best being answered by a qualitative methodology and methods. Therefore, sampling was driven by the need to achieve maximum variation in perspectives and experiences (Ziebland and McPherson 2006, p. 406) and not statistical representation as seen in quantitative work (Britten 2006, p. 19). The characteristics of the specific participant groups chosen are outlined in the next sub section.

### Details of Participants Chosen

#### *Patients*

Identifying and understanding what determines access to APDC services was at the core of the research, therefore there was a need to obtain direct patient accounts of their perceptions and experiences while deciding to use the service. Sampling was designed to involve patients who were able to use APDC as well as those who were offered a place but did not take up the service. Sampling was also designed to include patients representing the “typical” palliative care clientele (White British ethnicity, over the age of 65, with a diagnosis of cancer) and those from apparently marginalised groups, e.g. persons of ethnic minority origin, and those with non-cancer diagnosis. The specific subgroups of patients and the eligibility criteria are summarised in Figure 4.4 on page 139 along with summaries of the eligibility criterion for the other three categories of participants presented below.

### *Health professionals: Referrers to APDC*

Previous palliative care research suggested that the community-based care of patients in their last year of life is mostly provided by the GP and the District nurses (Shipman et al. 2002), and that these persons along with specialist palliative care nurses play major roles in referring to palliative day-care (Spencer and Daniels 1998, p. 219-229). Also, as shown by the work of Spencer and Daniel 1998, p. 219-229, Higginson et al. 2000, p. 277-286, Low et al. 2005, p. 65-70, hospital based consultants in Palliative Medicine and oncology are also likely to act as referrers to palliative day-care. In this study the list of hospital consultants was expanded to include those who are primarily responsible for the care of non-cancer patients e.g. nephrologist, cardiologist, infectious disease specialist and neurologist. This was in light of literature which suggests underutilization and decreased access by patients with a non-cancer diagnosis despite theoretical benefit (page 58).

### *Health professionals: Providers of APDC services*

The study design took into consideration the multidisciplinary approach and varied service models of APDC units (section 1.6.2, page 55, and section 1.7 specifically on page 61). In so doing, provider participants who make clinical decisions were included; both allopathic and allied health professionals. However, non-clinical and managerial staff were also included in the sampling frame as it was found that this group was involved in formulating, approving, and guiding the implementation of clinical care and referral acceptance policies. Members of this group included the Chief Executive Officer (CEO), Clinical Managers and Board of Trustee members. It is important to note that for the purposes of preserving anonymity, professional categories were used to classify individuals, as opposed to specific job titles. In many instances participants were the sole occupier of a particular post at a given APDC unit; therefore using a job title, plus any specific geographic information could lead to the

identification of an individual. As such a system of using three professional categories that contained more than one job title was developed:

1. “Management”- this term describes management level staff and includes the following job titles; Chief Executive Officer, Clinical Nurse Manager, Board Members.
2. “Nursing and Allied Health professionals”- this term includes clinical nursing staff, physiotherapist, chaplains, complementary therapist, behavioural and diversional therapist.
3. “Volunteers” - this term described APDC unit based volunteers and includes: drivers; games co-ordinators; as well as volunteers who perform a companion type role.

Palliative day-care units tend to have volunteer staff members by Hoad 1991, p. 239-246, therefore, this study was designed to also include volunteers, specifically those who had prolonged contact with patients. This was done as they represented the perspective of the on-the-ground work force that was responsible for the interpretation of service policies and guidelines.

### *Carers*

Carers were included as a participant group by virtue of the affect that they might have on a patient’s decision and ability to access care as a result of their familial, social or emotional bond. The study design sought to include carers of patients who both accepted and did not accept referral to the service.

The eligibility criteria of all participant groups is summarised in Figure 4.4 on page 139, while recruitment is presented in section 4.8 (page 140).

**Figure 4.4 Categories of participants and their eligibility criteria**

Type of Participant	Patients (those who were referred and attended, and those who were referred but did not attend)	Carers	Health Professionals involved in referral to APDC	Health Professionals in provision of APDC	Volunteers
Sub categories	<p>Patients with: Non-Cancer diagnosis</p> <p>Patients under the age of 65</p> <p>Ethnic minorities</p> <p>Self-declared ethnicity of British White</p> <p>Age over 65</p>	<p>Carers of patients who were referred to APDC and attended on at least one occasion</p> <p>Carers of patients who were referred to APDC but did not attend</p>	<p>General Practitioners</p> <p>District Nurses</p> <p>MacMillan Nurses</p> <p>Nurses</p>	<p>Hospice Nurses</p> <p>Allied Health professionals</p> <p>Hospice Managers (Chief executive Officer, Clinical Hospice Manager, Board Member)</p>	<p>Volunteers who interacted with patients and carers on a regular basis e.g. carers assistants, drivers</p>
Eligibility criteria	<p><b>Inclusion</b> Age=<math>\geq</math> 18 years</p> <p><b>Exclusion</b> Karnofsky<sup>65</sup> Performance score <math>\leq</math> 40</p> <p>Significant<sup>66</sup> psychological or psychiatric illnesses</p> <p>Refusal to give informed consent</p>	<p><b>Exclusion</b> Refusal to give informed consent</p>	<p><b>Inclusion</b> A minimum of 3 months work experience in the study site<sup>67</sup></p> <p><b>Exclusion</b> Refusal to give informed consent</p>	<p><b>Inclusion</b> A minimum of 3 months work experience in the study site</p> <p><b>Exclusion</b> Refusal to give informed consent</p>	<p><b>Inclusion</b> A minimum of 1 year work experience in the study site</p> <p><b>Exclusion</b> Refusal to give informed consent</p>

<sup>65</sup> I was aware that patients' emotional and physical state may be such that participation in the research may be a source of undue stress. So, in keeping with the Helsinki declaration and the responsibility of the researcher to keep the safety of the research participant paramount, a minimum physical performance status score was set to guide the selection of eligible patient participants. The Karnofsky performance scale was the objective measure used for physical status. A patient with a Karnofsky scale score of 40 or below is usually not well enough to take care of their daily need. Persons with such scores and below (where death is imminent or the patient moribund) were not eligible for recruitment into the study.

<sup>66</sup> Persons who were identified by the clinician based at the palliative day-care units as having significant psychological or psychiatric illnesses, were also not eligible for participation in the study. This was particularly the case for those patients and carers with unstable anxiety and depressive disorders, which were or were not related to the illness for which they sought care at the palliative day-care unit. It was thought that participation and reflection on the issues which would need to be explored during the research, could potentially negatively impact on, and complicate other aspects of these persons' clinical management

<sup>67</sup> This minimum period of three months was applied in an attempt to minimise bias which may occur if a person is not familiar with the network and the procedures of its various units.

#### **4.8 The research process: a summary of recruitment**

Although the Clinical managers were involved in the study design, each day-care unit was still formally recruited into the study. After ethical approval had been obtained recruitment packages were sent to the Chief Executive Officer and clinical manager and written consent<sup>68</sup> obtained for the conduct of the research at each APDC site (Appendix 7 page 315). Permission was also sought for the day-care managers or designee to act as non-paid local research facilitators at the units.

The recruitment process designed and used for all participants is given in the sections 4.8.1-4.9 (page 140-152).

##### **4.8.1 Health care professionals and volunteers involved with the provision of palliative care**

After permission to conduct the study was obtained a poster was displayed at the APDC units informing staff and volunteers that the site had been enrolled in a study. The poster was displayed for two weeks before recruitment began. This was done to give staff and volunteers who would not want to participate sufficient time to declare this.

Subsequently each local research facilitators compiled alphabetised staff<sup>69</sup>, list categorising persons by role e.g. Hospice nurse, allied health professional or front-line care volunteers. Three alternate names

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<sup>68</sup> Participation in this research project was entirely voluntary and APDC units and individual participants were free to withdraw at any time. At the time of individual interviews, the consent form was reviewed, and consent reconfirmed (Addington-Hall 2002, p. 222). This was seen as an important part of ensuring that the study was conducted safely and transparently (Sheldon and Sargeant 2007, p. 172).

<sup>69</sup> This staff list excluded persons who asked not to participate on seeing the study poster as well as those who did not meet the eligibility criteria.

from each alphabetised list (nursing staff, allied health and volunteer list) were then selected for recruitment. Although three participants were selected only one person was actively recruited at any given time.

Participant recruitment letters were printed on APDC unit letter headed paper. However, all stationery and postal cost for the project were covered by the research budget and actual mailing was done by me. Invitation letters were mailed with a prepaid interest card. If this card was returned with a positive response and contact details-potential participants were then sent a PIS and a consent form, which was to be returned at the time of the interview. Letters were followed up with a telephone call, if participants had not responded within two weeks.

In total, 24 potential provider participants were contacted and 19 participants consented to participate: nine management staff, seven nursing or allied health professionals, three volunteers. Three of the persons declining to participate were from two day-care units which shared human resources. At the time of the study these units were undergoing major organizational change, therefore it was noted by the research facilitator from these two sites that recruitment was problematic due to work constraints.

#### **4.8.2 Patients referred to APDC but who did not attend: documentary analysis**

During the process of negotiating access it was found that each APDC unit had patient “files” which could be used as potentially unobtrusive ways of gathering information about persons who were

referred to day-care and did not attend (see the section 4.5, pages 128-131 on negotiating access). In the case of three of the APDC units, when a patient was referred a “file” was created for them. In the other two units, the patient’s referral form was stored as the sum total of their “file”, until a referral was accepted. In the APDC units the usual process was that on receiving a referral the patient was contacted (usually via phone), and arrangements made for the patient to have an introductory meeting and visit to the unit. If a patient did not attend this meeting, a call was made by an APDC nurse to ascertain the possible reason(s) for non-attendance, and to enquire as to the health of the patient. Arrangements for a new meeting date were also made if relevant. If a referred patient was found at this time to be unable or unwilling to attend APDC the reason for this non-attendance was recorded on the “file” by the nurse making contact.

In this study I wanted to collect the reason for non-attendance as documented for all patients who were referred to APDC but did not attend during the calendar period prior to the start of the study. I also wanted to collect their age, diagnosis category and self-declared ethnicity. Given the data protection rules in the UK, I was able to gather this information with the assistance of the clinical managers who did the actual handling of the patient files for the extraction of this data. The information extracted was recorded on documentary analysis sheets (Appendix 5, page 297) without reinterpretation and then collected by me. At the time of collection, I discussed with the data extractor whether there were any unforeseen problems or issues which arose during collection. I also verified that the reasons documented were as per recorded in the relevant patient file.

A total of 149 reasons were collected from four of the five hospices. At the time of conducting the study, major organizational changes were occurring at one of the hospice sites and the research

facilitator at this hospice, was unable to collect data for this site. It should be noted that 149 reasons for non-attendance are the documented reasons for non-attendance after referral for 149 patients.

In addition to documentary data the study was designed to recruit patients for interviews using qualitative interviewing methods. As with documentary data the recruitment of patients was facilitated by the clinical management of the APDC units. This is described below.

#### **4.8.3 Further information on the recruitment of patients (including those who accepted their places and those who did not)**

Patients were recruited from all the APDC units within the network. As in the recruitment of health professionals, study posters were displayed in the APDC units informing patients about the study, giving them with the opportunity to ask for further information or declare that they did not desire to participate. The APDC clinical managers or designee compiled alphabetical list of all their patients who had attended day-care on at least one occasion. The list made note of patient's age, diagnosis category (cancer or non-cancer), self-declared ethnicity and the presence of a carer. Patients who were assessed by the clinical staff as being in psychological distress or being too physically ill were removed from the list and not subject to recruitment. Starting from the top of the remaining list the first patient to fit the characteristics of a sub-group was selected for participation. Sub-groups were applied to the list. In addition to the first patient selected, a second and a third choice patient was also selected for recruitment (The same method was used for selecting other patients for participation if the first three selected patients declined to participate). Although more than one person was identified for recruitment only one person per category was approached at any given time to avoid over-recruiting. Invitation

letters were then mailed to the selected patient's home. The letters were printed on hospice letter headed paper, but all other stationary and mailing costs were covered by the research budget and actual mailing was done by me. A prepaid interest card which patients could return to me for requesting more information on the study was also mailed with the invitation letter.

On return of a positive interest card, patients were mailed a package with a participant information sheet, an interest card, a consent form, and a prepaid envelope (for returning their interest form and or their consent form). Therefore, recruitment of patients was multistep. Although this prolonged the recruitment process, it ensured that patients were well informed and that their freedom of choice regarding participation was confirmed at every step.

*Carers of patients who were referred to APDC an accepted*

The recruitment of carers was linked to that of patients in the sense that if a patient had an identified (non-professional) carer this patient was selected for recruitment into the study. The recruitment letters were also printed on hospice headed paper. However, the recruitment packages for patients and carers were mailed separately, and carers could participate whether or not the person for whom they cared accepted the offer (this was stated in the PIS). However, this scenario did not occur.

Twenty-eight patients were invited to participate in this study; two did not have identified non-professional carers. Of the 28 patients, 12 participants indicated a willingness to participate by return of the consent form. Four other patients indicated *verbally* to their local hospice facilitator that they wanted to participate, but were not able to do so. Three of these patients had changes in their clinical

conditions that prevented participation, while one patient had a decline in their relationship with hospice staff.

Of the 12 patients who returned consent forms 11 were actually interviewed (one participant was later unable to participate because of recent bereavement). All of the 11 patients interviewed had identified carer; seven carers agreeing to participate. Patients and carer participants were given the choice of having their interview via telephone or at the hospice on the days when they were in attendance. This was done in an attempt to especially respect the choice of palliative patients concerning how they spend their time. In total five interviews were conducted face-to-face, with the remaining 13 being conducted by telephone. Only one patient and carer requested to have their interview together.

*Patients who were referred but did not accept*

Attempts were made to recruit patients who were referred to day-care but did not attend. The recruitment process for this category of patients was such that once a patient indicated that they would not be attending APDC, in that conversation, the APDC unit facilitator would inform the patient about the study to gauge their willingness to have more information sent. If a patient consented to having more information a recruitment package was then mailed by the APDC facilitator. From this point the process for recruitment was then identical to that used with other patients (pages 143-144). I was not able to recruit any patients from this category of participant. One APDC unit thought that the approved recruitment method was potentially too intrusive and did not attempt to recruit any patients. Another unit had one client who was interested in participating and who was sent a recruitment package, however, an interest card accepting or declining interest was not received by me within a week. On follow-up by the APDC facilitator the patient was found to have deteriorated to the point of being

moribund. During the study period the three remaining units had no contact with patients who were referred to day-care but did not want to attend.

#### **4.8.4 Referrers to APDC**

##### *Nurses*

Macmillan and District Nurses were selected purposively. Lead Macmillan<sup>70</sup> and District nurses were contacted by phone and email, and asked to assist with the identifying key participants. The Lead nurses were provided with an executive summary of the research study protocol and PIS. The names and work sites of key informant nurses with experience referring to APDC units in the study site were then given to me.

I then sent the potential key participants a recruitment package containing a PIS, and an interest card, on which they were asked to confirm their interest and provide their preferred contact information. On the return of an interest card I then contacted each nurse by telephone to address any queries, and to schedule an appointment for their interviews. Written consent was confirmed at the interview.

Seven nurses were recruited (4 District nurses and 3 Macmillan nurses) and all were interviewed in the process of reaching saturation.

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<sup>70</sup> Macmillan nurses were recruited with the assistance of the Macmillan development manager and Macmillan community networks development coordinator for Macmillan support in the region.

## General Practitioners and Hospital consultants

### *General Practitioners: Pragmatic sampling: A combined random and key informant strategy*

The names of General Practitioners in the various PCTs in the study site were obtained electronically from NHS GP listings. One list was compiled for each PCT. These were then alphabetized by surname<sup>71</sup>, of lead practitioners. Where only the title of the surgery was stated, this title was treated as a surname in the process of alphabetization of the list for sampling. Where practices had branch surgeries these were treated independently. Each name on the compiled list was then assigned a number starting with the number one for the first name, and increasing by one with each subsequent name<sup>72</sup>.

The list of General Practitioners was then sampled randomly using a manual process using RAND random digits.

Previous research has suggested that the response rate of General Practitioners recruited for postal surveys in the UK is approximately 32% (McAvoy and Kaner 1996 p. 732-734). Although this work was not a postal survey this finding was noted and 4 practices per PCT were randomly selected for

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<sup>71</sup> Followed by initials as necessary

<sup>72</sup> It is important to note that during the process of conducting the research there was reorganization of the Primary Care Trusts in England which affected the number of and catchment areas of the PCTs in the study site. Three of the PCTs with 15, 51, and 38 practices were reconfigured to form one PCT with a total number of practices of 102. In addition the border of one PCT was expanded to include 54 practices which were outside of the cancer network, and also quite distant from the areas served by the APDC units. Therefore, the names of these geographically distant practices were removed from the sampling frame of this PCT.

The total number of practices in each areas sampled was as follows: PCT1-t=80, PCT 2 t=27 and PCT 3 t=102.

contact regarding participation. Twelve practices were randomly selected from PCT 3 as this was an amalgamation of 3 former PCTs served by 3 different APDC units within the study site.

Originally recruitment of General Practitioners was based on random sampling only as described above, however, early in the recruitment process this was seen as having some limitations, as none of the first seven GP contacted returned an interest card in the allotted time (one week). On making follow-up calls to these practices it became evident that the response rate might be improved if: the letters were specifically directed to key informant practitioners (i.e. the practitioner most responsible and or involved in the provision of palliative care); and if the GPs had the option of having telephone interviews. As a result changes were made to the study design (approved as a minor amendment by the local research ethics committees) with calls being placed to practice managers to identify the key informants who the study invitation and information should be addressed. After these changes a second round of recruitment was conducted which included re-contacting the seven practices from which there was no previous written response.

In keeping with a flexible study design and the need to ensure that data saturation was achieved, two additional interviews were conducted with General Practitioners, during the closing stages of phase two. These practitioners were purposively sampled, because of their geographic location of their practice within the network, and in the case of one GP, their involvement in other aspects of palliative care provision in the network.

### *Hospital consultants*

Hospital Consultants whose case load was likely to include palliative care patients were identified using the consultant profiles of the NHS Trusts within the network. The eligibility criterion of working in the network for more than three months was then applied. Eight consultants were identified. The names of these consultants were then submitted to the Research and Development Departments of the Trusts. Following this the consultants were mailed invitation letters and interest cards and asked to indicate their interest within two weeks. One consultant responded within two weeks. The other consultants were given follow-up calls, and a second round of recruitment letters was sent.

In total, eight hospital consultants were recruited. Four indicated a willingness to participate but only 2 (1 consultant and 1 consultant proxy) were able to participate.

In summary, 32 health professionals involved in referring to palliative care were approached, and 16 consented to be interviewed; however, three persons (one GP and two hospital consultants) later declined to be interviewed citing time and work pressures. As a result, the 13 interviewees consisted of four district nurses, two “hospital consultants”, four GPs, and three Macmillan nurses. All of the persons declining to participate were from the General Practitioner and hospital consultant categories. The only reasons for non-participation cited related, to time limitations as a result of work pressures<sup>73</sup>.

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<sup>73</sup> As this trend was detected and reflected upon, the study design was altered, with General practitioners and hospital consultants being offered the possibility of having telephone interviews of a shorter duration. Of the 32 interviews conducted with health professionals or volunteers, 28 were face-to-face and 4 were via telephone.

#### **4.9 Recruitment summary**

I conducted interviews with 50 participants: 32 with health professionals and volunteers (19 providers, 13 referrers); 11 patients; and 7 carers. Twenty-eight of the health professional interviews were face-to-face and four via telephone. Three patients and one carer had face-to-face interviews while 8 patients and 6 carers had telephone interviews. All health professional interviews were held individually, however, one patient and his carer had a joint interview. Only one interview was conducted per participant. On average, the face-to-face interviews were 50 minutes long<sup>74</sup>. Telephone interviews with health professionals were approximately 35 minutes long. Those with patients and carers were approximately 20 minutes long.

Table 4.2 (page 151) gives a summary of the overall number of participants recruited by category and also gives the number of the types of interviews conducted. Tables 4.3a (page 151) and 4.3b (page 152) give further demographic information for patient and carers participants. A list of all 50 participants is given in Appendix 16, however, because some participants were the only person with specific characteristics in a particular post their, gender and ethnicity<sup>75</sup> has been excluded to avoid identification and each participant has been given a number. In addition the number system used in Chapter Three to represent areas in the study site is replaced by a letter system. Please note that only the age of patient participants was gathered in this study.

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<sup>74</sup> The longest interview being 97 minutes (day-care manager) and the shortest being 37 minutes (hospice volunteer).

<sup>75</sup> With respect to the 19 provider participants, 18 persons declared their ethnicity. All of the 18 persons who declared their ethnicity were British White. The lone objection was on the basis of the participant's view that ethnic and racial classification as used in health services and the wider society was unhelpful, particularly given that persons may not classify themselves according to or fit into predefined categories.

**Table 4.2 Number of participants recruited by category, geographic area, and type of interview**

Participant Category	Number of recruited participants	Areas in the study site represented/served	Number of Telephone interviews	Number of Face-to-face interviews
Management level provider of APDC	09	ALL	0	09
Hospice Nurse or Allied Health Professional	07	ALL	0	07
Front line Volunteers	03	2,3,4	0	03
General Practitioners	04	1,3,4,5	4	0
Nurses	07	ALL		
Hospital Consultants	02	1,4,5	0	2
Patients	11	ALL	8	3
Carers	07	1,2,4,5	6	1

**Table 4.3a Patient-participants and their important sampling characteristics**

Participant Number	Primary Diagnosis category	Self-declared Ethnicity	Age	Sex
1	Cancer	White British	84-88	F
2	Cancer	White British	84-88	M
4	Cancer	White British	39-43	F
6	Cancer	White British	89-93	F
9	Cancer	White British	54-58	F
15	Cancer- Non Hodgkin's lymphoma	White British	79-83	F
11	Non-cancer illness	White British	89-93	M
13	Cancer	White British	74-78	M
19	Cancer	White British	59-63	F
16	Non-cancer	White British	69-73	M
14	Cancer	White British	84-88	F

**Table 4.3b Characteristics of care giver participants**

<b>Participant Number</b>	<b>The relationship of the care giver to patient</b>	<b>Primary Diagnosis of patient</b>	<b>Self-declared Ethnicity</b>	<b>Sex</b>
3	spouse	cancer	White British	F
5	friend	cancer	White British	F
7	child	cancer	White British	M
8	child	cancer	White British	F
12	child	Non-cancer illness	White British	M
29	spouse	Cancer	White British	M
17	spouse	Non-cancer	White British	F

#### **4.10 Recording interviews**

All interviews were audio taped with the exception of three face-to-face interviews, which were conducted within a 48 hour period when there was an equipment malfunction and no possibility of rescheduling. Instead of cancelling these interviews I decided to proceed, making notes during and immediately after the interviews. On the day following the interviews I contacted the participants and reviewed the transcript with them, very few corrections were made and the participants approved the transcripts as accurate accounts of their interviews.

The fact that these participants reviewed transcripts was not far removed from the study design as all participants were offered the opportunity to review their transcripts for accuracy<sup>76</sup>. In the case of

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<sup>76</sup> Reviewing transcripts was also seen as a means of collecting any additional data which patients might have remembered after the interview.

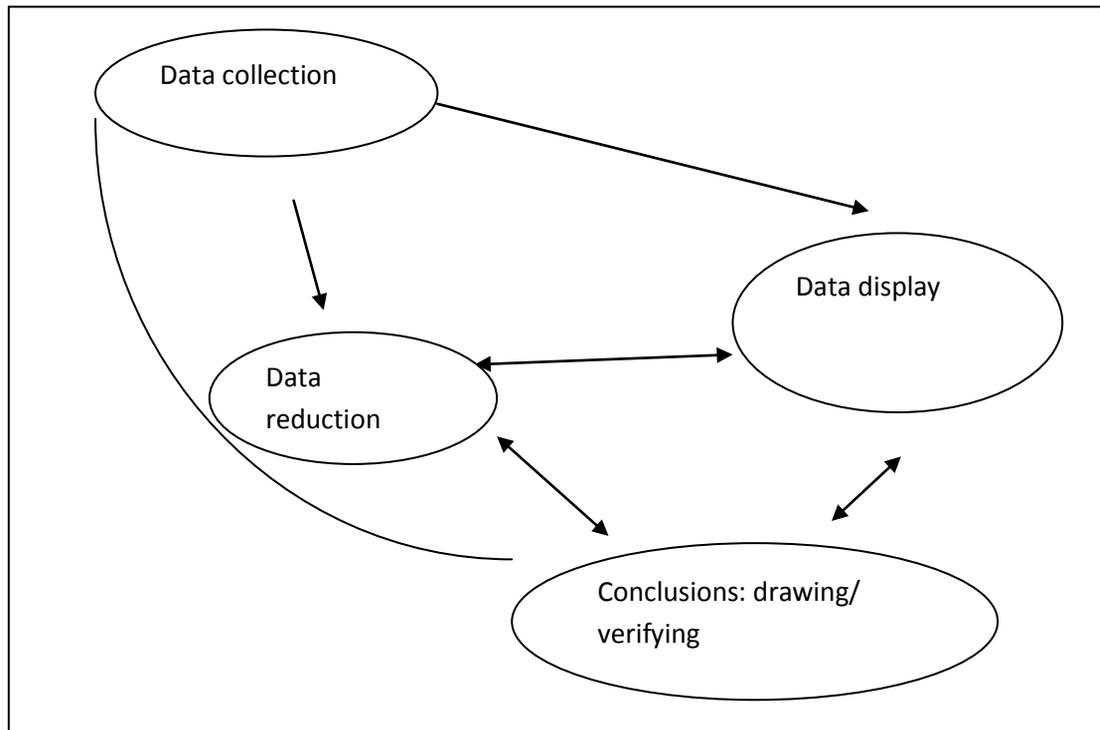
patients it was intended that transcripts would be made available in 4 weeks given the possibility of deterioration in physical condition. For all other participants transcripts were offered for review in 6-8 weeks. In addition, to the three unique cases described above two participants asked to review copies of their transcripts; one clinical manager and one patient. On review these two participants made no changes to their transcripts and provided no additional information.

During the week following the interview, patient and carer participants were mailed personalised thank you letters (Appendix 8, page 317).

#### **4.11 Data Analysis: interviews**

A qualitative researcher (AL) who had given input into the design of the interview schedule became an advisory member of the research team, with specific emphasis on supporting data analysis. The framework used for analysis was heavily based on the dynamic analysis cycle advocated by Miles and Huberman (1994, p. 12) (see previous comments on page 127 and Figure 4.5 on page 154).

**Figure 4.5 Components of Data analysis (including the data collection period): An Interactive model minimally modified from (Miles and Huberman (1994, p. 12)**



As this was the framework used, the names of some of the components in this analysis model are used as the subheadings in the rest of this section which describes how data analysis actually occurred.

#### **4.12 Data Collection- Analysis: immediately after interviews**

After each interview I documented experiences that appeared to be important. For example in the first few interviews there was frequent use of the term “appropriate referral”. However, when asked to expand or clarify on the meaning of the term, I found that there was no standard meaning. Therefore, by documenting this experience the anticipated themes of the need to explore concepts of appropriate

referral and the disconnect in meanings between participant groups were identified and affirmed early in the data collection process.

In addition to noting my experiences I also listened to each tape soon after finishing the interview i.e. before it was transcribed. Listening to the tapes early was important, as it gave me the opportunity to reflect on the interview while it was still in recent memory. In the case of interviews with health professionals and volunteers I listened to audio tapes on the day of the interview but in some cases on the day after the interview. The tapes were then given to the transcriber, resulting in a period when I was separated from the audio data. Interviews with patients were taped electronically, and were delivered to the transcriber via a secure upload system. In these cases there was no period of separation from the audio data.

#### **4.12.1 Transcription**

The audiotapes with the exception of two interviews which had decreased quality, were transcribed verbatim with indications for pauses, laughter, and raised voiced noted. Since the goal of analysis was to indentify emerging themes, verbatim transcription was seen as being an important aspect of preserving the spoken word and avoiding error (Dickson –Swift 2007 et al., p. 330).

After receiving the transcripts, I read them while listening to the audio of the interview. At this time I checked the transcripts for accuracy and also made notes of significant expressions or interactions

which occurred during the interview. Note was also made of sections of text which were seen as relevant to the research question e.g. emerging themes and links.

For the first 15 interviews I recorded my thoughts formally on a contact summary sheet (Appendix 9 on page 318). On this sheet I recorded significant impressions and any themes which emerged from the interaction that I wanted to follow-up. I had intended to use these sheets in research group meeting as a means of updating team members on emerging themes. After, the first 15 interviews, I abandoned the summary sheets as an analysis tool as, I later felt that sharing the summary sheets might potentially bias the other members of the research team who were independently commenting on the data analysis process.

In addition, I found that the memos made directly onto the transcripts served as good records of emerging themes and could form part early of the data reduction process which was primarily done through coding, using the NVivo 2 (and NVivo 8) data management software.

#### **4.13 Data Reduction: Coding scheme**

An initial coding scheme was created based on the literature reviewed regarding access to APDC, the concept of need, and the hypothetical factors which may affect the process of obtaining access to health care. The initial coding scheme is shown in Appendix 10a on page 319. It contained 10 broadly descriptive nodes e.g. patient characteristic and day-care characteristics. These 10 themes were then subdivided into child nodes which were used to identify more specific portions of text related to a particular theme e.g. the patient characteristic theme was subdivided to code for text relating to age, ethnicity and diagnosis etc.

As data collection and analysis progressed, themes for investigation and possible associations between factors emerged. As a result the coding scheme was expanded (Appendix 10b, page 323) and included inferential and interpretive codes (Appendix 11, page 324). Transcripts were revisited to ensure that all relevant text was included.

#### **4.13.1 Data Reduction: The actual coding process**

The first two transcripts were coded using the highlight and comments function of Microsoft Word; (Appendix 12 on page 325) shows an excerpt from one transcript which was coded this way). This was found to be time consuming and did not offer an efficient way of generating nodal summary reports as compared to software such as NVivo. This lack of efficiency was discussed with AL and a definitive decision was made to adopt a qualitative data management tool. NVivo 2 was chosen as the data management software as it had comparable performance to other qualitative computer analysis software. Also, it was the software package that I was familiar with which was also available on licence from the University of Warwick. Therefore I used NVivo throughout the research. I started with NVivo 2 and later upgrading the entire project to NVivo 8.

#### 4.13.2 Working in NVivo

Transcripts were uploaded into NVivo in rich text format. These were then coded using the previously described coding scheme.

As data were coded a summary report was made which included all text that was coded under a particular theme<sup>77</sup>. The nodal report was then analysed to identify anticipated and emerging themes. These were then summarised on one sheet of paper (OSOP). The OSOP Method is advocated by Ziebland et al. (Qualitative data analysis course- DIPEX, Department of Primary Health Care, University of Oxford 2007, September 13-14). This method involves reviewing nodal reports, with the aim of identifying emerging themes, causal links, relationships, and theories which are representative of the entire data set and documenting these on one sheet of paper (OSOP). The idea being that, by using only one sheet of paper the researcher is challenged to focus their thoughts and in the case of this research, develop relationship maps. Appendix 13 on page 326 shows one of the OSOPed nodal reports.

Two major nodal reports were independently reviewed by AL and I. We discussed our findings and identified issues affecting access which could be explored in the context of existing literature. All other major nodes were OSOPed by me. However, the emerging themes and their supporting data were discussed with AL and other members of the research team.

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<sup>77</sup> Appendix 13 on page 326 gives an example of a nodal report.

The OSOPing process described in section 4.13.2 was a significant step in condensing and analysing the transcribed data from interviews. However, a display model was needed, which would allow for the identification of patterns between achieving access and factors such as the characteristics of APDC units and or participants. As such, a results table matrix was developed using Microsoft Word 2007.

#### **4.14 Data display and drawing and verifying conclusions**

The decision to design a table matrix which could display and analyse data was informed by:

1. Miles and Huberman's views that:
  - a. Data displays are useful in facilitating the analysis of qualitative data, as they allow the researchers to see and "absorb" large amounts of data quickly (Miles and Huberman 1994, p. 92)
  - b. qualitative researchers should seek to design purpose built display models suited to the peculiarities of their own project (Miles and Huberman 1994, p. 93)
2. the need to be as iterative as possible during the data analysis process; with emerging themes feeding directly into the process of understanding of how determinants of access might be linked.

The stepwise process for making the matrix is summarised below.

- Step 1 - Emergent and anticipated themes from the OSOP process were listed, then through a process of discussion and grouping of associated themes by NG (Natalie Greaves), patterns of overarching determinants were identified.

Step 2 - The overarching factors found to be affecting access and their associated subthemes were then placed in a colour-coded table. Two colours were used to distinguish between factors which act as barriers and or those which act as facilitators of access.

Step 3 - The colour-coded tables were then extended to include columns which documented and allowed comparison of the themes identified and the characteristics of participants and units.

The table matrix used is provided in Appendix 15 (page 328) while results and discussed are presented in Chapter Seven.

#### 4.15 Chapter Summary in the form of Key Points

##### Chapter Four: Key Point

- The aim of this research was to identify and understand factors which determine access to APDC services.
- The investigation was particularly focused on identifying and understanding determinants of access through the experiences, views and perceptions of participants.
- The study was informed by an interpretivist philosophical paradigm. A mixed methodological approach was used.
- Qualitative was the dominant methodology informing data collection methods.
- Semi-structured in-depth individual interviews, and the examination of naturally occurring documents were the data collection methods used.
- Sampling was performed to achieve maximum variation of persons likely to affect access across the study site. The categories of participants included, patients, carers, and health professionals.
- Recruitment of participants and data collection was performed over a 2 year period (post NRES ethical approval) using a 2 phased approach.
- Phase one [which included interviews with health professionals, volunteers and documentary analysis] informed phase two, which included interviews with patients and carers.
- There was a small research team, resulting in the chief investigator being the designer of the study, the sole interviewer and person primarily responsible for data analysis.
- An iterative approach informed by Miles and Huberman guided the data collection and analysis process; with thematic and content analysis methods being used to identify emergent and anticipated themes.
- Data analysis was supported by the use of NVivo 2 and 8 software as well as manual OSOPing and data display models.
- Identified determinants of access are presented in chapters 6 and 7.

## **CHAPTER FIVE:**

### **Results**

#### **5.0 Introduction**

This study was aimed at identifying and understanding the factors which act to determine access to APDC. It was driven by gaps in knowledge related to concepts of need, the assessment of need and how unique organizational features of APDC may impact on the achievement of access (section 4.0, page 110-111).

The study was conducted in a cancer network in England which contained five APDC units which showed underutilization trends similar to those seen nationally (section 3.1.3, page 101-107). It was approached from an interpretivist philosophical view point, and sought to answer the research question primarily through interpreting the subjective experiences, perceptions and social interactions of patients, carers, and those involved in the referral to and provision of APDC (section 4.4, page 125-126, section 4.7, page 135-139). The study design was pragmatic using quantitative and qualitative methodologies. The dominant methodology was qualitative. Documentary analysis and semi-structured-in-depth interviews were the data collection methods used.

The reasons for non-attendance for a 149 patients were collected using documentary analysis while 50 interviews were conducted. Thirty-two interviews were face-to-face while 18 were by telephone.

Data were analysed for anticipated and emerging themes using thematic analysis with constant comparison. Data analysis was aided by NVivo software with condensation of coded themes using the OSOP method (section 4.13.2, pages 158-159).

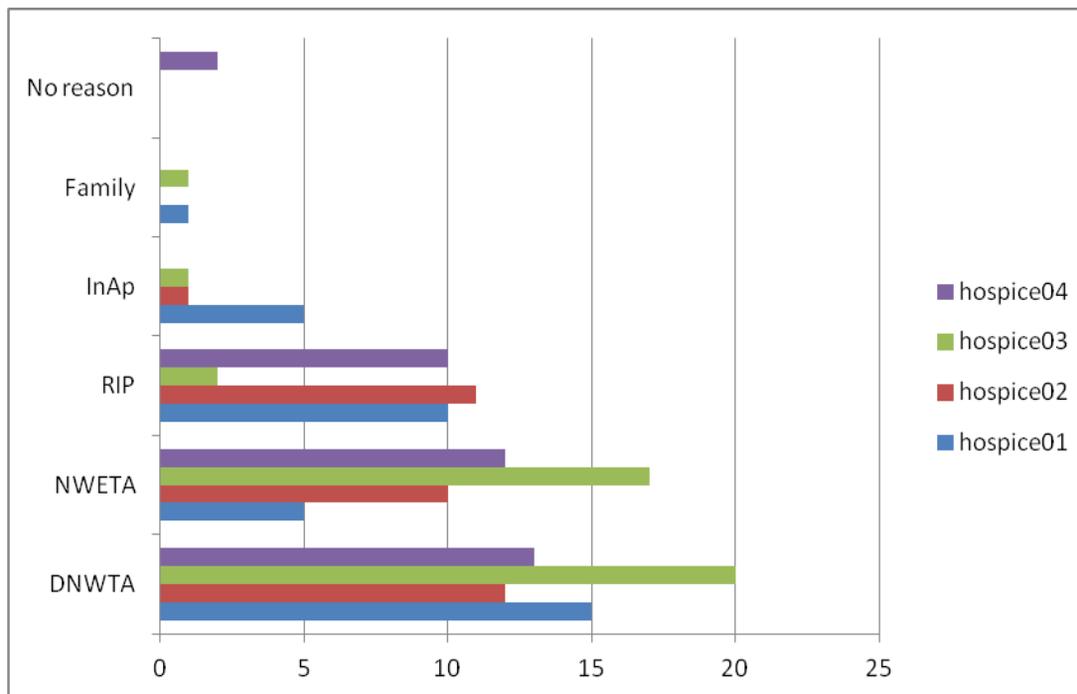
I was able to identify 18 factors which could be viewed as being determinants of access to APDC. These factors were found to be exerting barrier and or facilitator type effects on access, and were occurring as a result of the characteristics of individual users, the health system as well as complex social interactions. This chapter presents the 18 factors and the ways in which they were found to be related to each other. It starts by reviewing the characteristics of the study site and participants and then discusses the format for presenting the data. The actual structure for presenting the findings was arrived at after almost a year of critically considering various presentation formats. The models considered are presented in section 5.2.3 on pages 167-172. The final format chosen was one which grouped the 18 factors based on whether they were the result of a feature of the potential service user; the health system; or a mixture of variables. For each of the 18 factors identified the final format chosen also shows whether the factor acted as an inhibitor and or a facilitator of care (Figure 5.2, on page 172).

The presentation of the findings in sections 5.3 is supported by use of text data from interviews and comments on the documentary data<sup>78</sup>. In the interest of managing the word count and maintaining

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connectedness in the flow of the findings each identified determinant is supported by only one or two quotes. However, for some complex findings three or four quotes have been used. Quotes have been used from all categories of participants from across the network, and a labelling scheme was used which gives the type of participant, and the geographic area in the network which they worked or received services (section 5.2.2, pages 166-167). Details of the characteristics of each participant are given in Appendix 16 on page 329.

<sup>78</sup> Figure 5.1 Reasons for non-attendance to APDC for patients who were referred to day-care and did not attend July 01 2005- July 31 2006. Please see Appendix 6 on page 313 for more detailed data on the reasons which composed the emerged themes.



**Key:** DNWTA-Did not want to attend; NWETA-Never well enough to attend; R.I.P-patient died before being able to attend; No reason- no reason given for attendance; Inap-referral deemed inappropriate by provider of day-care; Family-family barriers recorded as the reason for non-attendance.

## **5.1 Brief summary of study site and participants**

### **5.1.1 Study site**

This study was conducted in a cancer network in the Midlands of England which served a population of almost one million people (sections 3.1 specifically pages 91-96). The network contained 5 APDC (a sixth unit within the network had been closed just prior to the commencement of the study). Three of the units were stand alone units. The other two had direct relationships with inpatient hospice facilities (section 3.1.3, page 101-107). At the time of conducting the research all of the units were nurse led and provided care along the spectrum of social and medical models. The average utilization rate at the units in the period prior to undertaking the study was just under the national average (section 3.1. page 93). The trends of use in the network mirrored those seen nationally in that there was under use by patients with non-cancer diagnoses and those from ethnic minority groups. However, there was the possibility that the trends seen in the network were influenced by the possibility of there being overcapacity in provision based on calculation of need using a modified Tebbit model (section 3.1.3, pages 101-107).

### **5.1.2 Participants**

Interviews were conducted with participants from across the network, 19 providers of APDC, 13 referrers to APDC, 7 carers, and 11 patients. In addition the reasons for non-attendance for 149 patients between were analysed.

I was unable to recruit any patients who were referred but did not attend for an interview. Overall only one interview participant was from a non-white ethnic minority group (provider participant). One other

participant in the documentary analysis was White Non-UK (White-Italian) while two other participants had self-declared ethnicities of White-Irish. The implication of the ethnicity of participants on results is discussed in Chapter Eight while the findings are presented in section 5.2.

## **5.2 Results**

### **5.2.1 The presentation of results**

The results presented in the following sections are those from the analysis of the entire data set of interviews and reasons for non-attendance obtained from documents. The identified determinants of access are presented with support from the content analysis of documents and evidence (in the form of quotes) from various categories of participants from across the network.

In keeping with current convention for presenting qualitative data, one or two labelled quotes are provided which are representative of the data set supporting a particular emerging theme. As far as possible the length of quotes has been minimised. The labelling of quotes is described below.

### **5.2.2 The Labelling of quotes**

To preserve the anonymity of participants, quotes have been labelled with a unique code. Each code contains: 1) a participant number; 2) the participant category e.g. patient or carer; 3) and a capitalised letter from A-F representing the geographic location in the network area with which the participant interacts.

It is recognised that the study setting was the network as a whole; however, it was important to have a system for identifying results which are arising from specific subareas of the study site. Consequently, a marker of geographic location is maintained in the labels of quotes. Earlier in this thesis numbers (1,2,3,4,5) were used to represent the various APDC units by geographic location in the network (section 3.1.3, page 94-96), however, to use these numbers alongside other participant information, could result in the identification of some participants who would have been the only person in a particular post, in a given part of the network. Therefore, letters are used in the labelling of quotes.

A table summarising the characteristics of all the participants is provided in Appendix 16 on page 329.

### **5.2.3 The formats considered for displaying results**

During data analysis, and the period of finalising the format of the thesis, constant consideration was given to how:

- the factors found to be affecting access could be related or connected to each other;
- the results could be best displayed so as to increase their readability.

Ensuring that the data were displayed in an easily accessible and usable format was important as one of the purposes of the study was to inform policy and service development. Therefore, using a format which would allow identification and extraction of findings would be advantageous. To this end, three major organizational formats were considered. These are presented below.

### 5.2.3.1 Barrier vs. Facilitator format

Firstly, a two-part system displaying results was considered where results were grouped as either barriers or facilitators. This had the advantage of being a simple display format. However, it did not allow for a clear representation of the relationships that were found to exist between determinants.

Table 5.1 shows the summary titles of identified determinants that were found to be barriers and facilitators, and is an example of how results organised in this way could be displayed.

**Table 5.1 An example of a display format showing the classification of identified determinants of access into barriers and facilitators only**

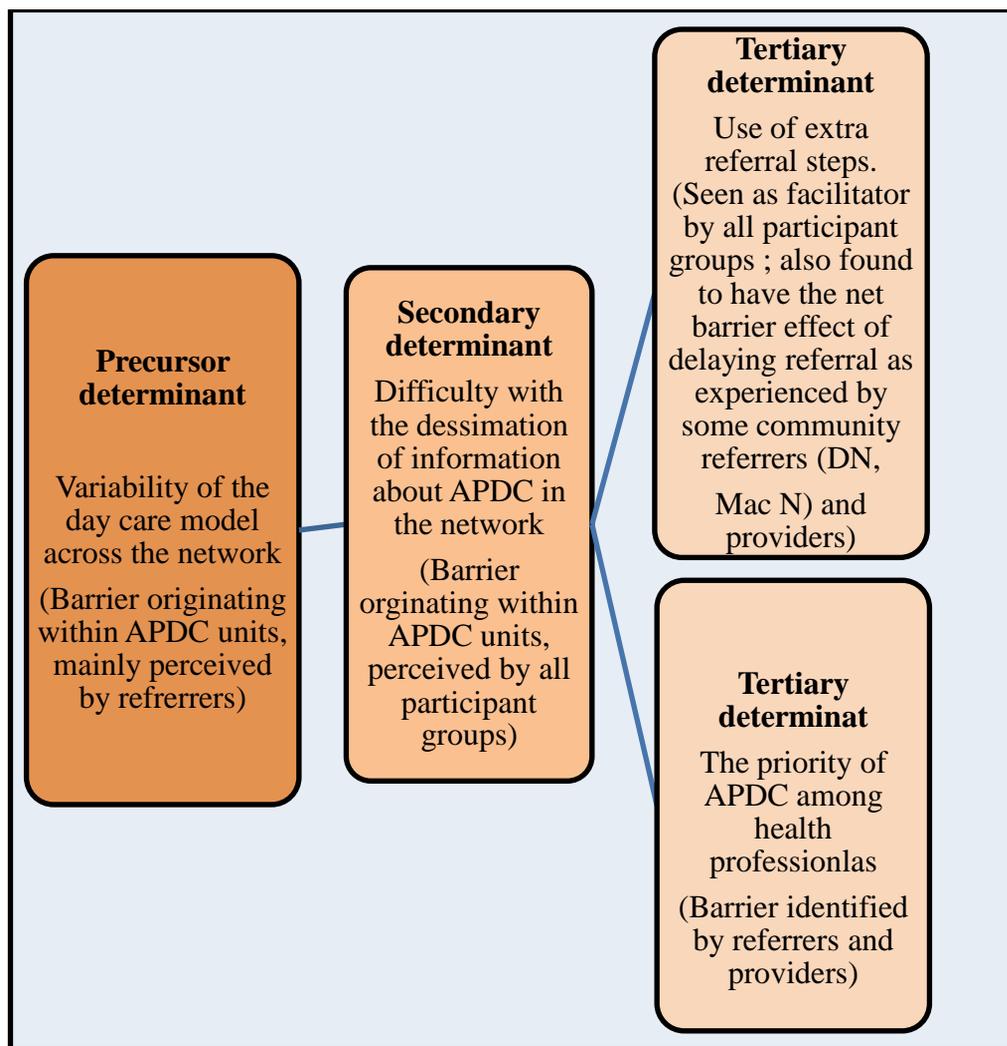
<b>Determinants found to act as barriers to accessing APDC</b>	<b>Determinants found to be acting as facilitators of access to APDC</b>
Variability in the service model across the network	APDC units using a mixed service model
Dissemination of information	Provision of transport
Use of the term hospice to describe APDC units	APDC units having an atmosphere of life

### 5.2.3.2 Hierarchical relationship format – (an adaptation of the tree-children-free node concept)

The second display format considered was influenced by the hierarchical tree coding system used in qualitative data analysis tools such as QSR International's NVivo qualitative data analysis software, 2008 (NVivo 8). In this study some of the identified determinants were interpreted as being *precursors* to others; where a precursor was defined as a determinant which contributed to the development of a

second determinant, or was vital in sustaining the existence of a second determinant). In this format the *precursor determinants* would be presented first, with the second or subsequent related determinants provided afterward.

**Figure 5.1 An example of a Hierarchical relationship display of identified determinants of access**



This display method was useful in showing the complexity of human experiences and interactions that were found to influence the decision making process in accessing palliative care. However, it was not

always possible to identify definitive hierarchies among determinants even when data suggested that they might be linked. In addition determinants of access were identified which were not clearly linked or grouped with other determinants identified (similar to free nodes).

In light of the above issues it became evident that using a hierarchical relationship format to display this type of text data could become very cumbersome. Further there was the potential for the display format to become even more complex as determinants which exerted both barrier and facilitator like effects would be presented simultaneously, without a clear divide.

Developing and manipulating this hierarchical display model was useful in that it emphasised the importance of using a simple categorising method that would allow the reader to have a quick overview of all the results, while balancing the complexity of showing how determinants were connected to each other.

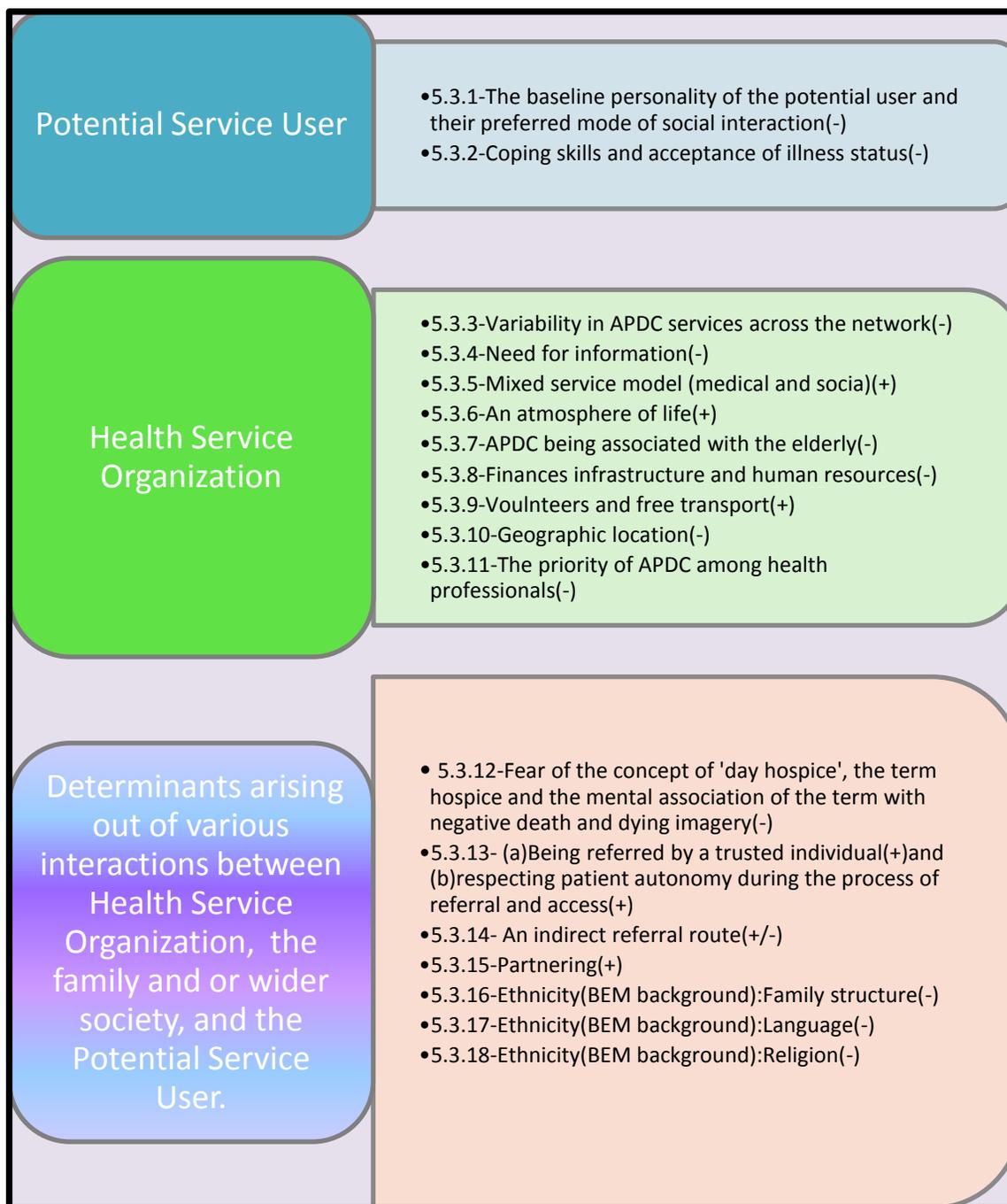
Finally a display format was formed which would allow for the reader to identify individual barriers and facilitators; while still seeing how groups of determinants were similar or dissimilar from each other. This display system arranged data according to the characteristics of the factors which influenced the development of the determinants.

### 5.2.3.3 Organization by the characteristics of factors which influenced the development of the determinants

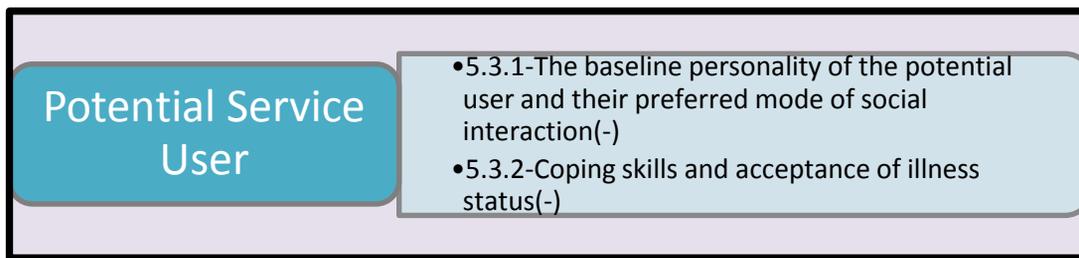
The static conceptual framework first proposed in Chapter Two used the categories of: patient, family and system characteristics; this final display format moved beyond this, taking into account the emergent determinants of access and how they were found to relate to each other. Therefore, determinants were seen as arising out of single or combinations of a new set characteristics termed:

- “potential service user”;
- “family and or wider society”;
- and “health service organization” e.g. the infrastructure, policies and institutional thinking or culture of the organization.

Figure 5.2 gives a summary of all the results showing their origins and their relationships with each other. In this figure factors which exhibited a barrier like effect, are accompanied by a minus sign, those with a facilitator effect have a plus sign, and factors which exhibit both barrier and facilitator effects are accompanied by both signs. This actual prose for the findings is presented in section 5.3. Portions of Figure 5.2 are used as sign posts (section graphics) between major sections of the prose. These indicate when the presentation is changing from one category of determinant of access to another e.g. from factors found to be arising from potential user characteristics to those arising from the characteristics of the health service organization.



**Figure 5.2 Identified determinants of access categorised by origin and effect. (A plus sign indicates a factor which acts as a facilitator while a minus sign indicates a factor which acts as an inhibitor of access. The section number in which the evidence can be found has been placed before each determinant e.g. 5.3.1)**



### **5.3 Determinants of access arising out of the characteristics of potential service users**

#### **5.3.1 The baseline personality of the potential user and their preferred mode of social interaction (-)**

It emerged that the personal characteristics of the patient, were important in determining whether access actually occurred. Here personal characteristics refer to a combination of the base line personality of the patient combined with their preferred mode for interacting socially.

This determinant was identified at all study sites, and by all categories of participants interviewed. It was reflected in documentary analysis by reasons for non-attendance such as “not a mixer” which was documented as a reason for non-use by persons who were referred to APDC but did not attend. I could not quantify how much input the barrier of personality played in the development in the theme that emerged from the documentary data of not wanting to attend (NWTa) which accounted for 40% of persons who were referred but did not attend (Appendix 6, page 313). This determinant (of baseline personality and preferred mode of social interaction) was found to be significant in that, the potential user’s personality formed the reference point which influenced whether and how the potential user would choose to access or use APDC. This is illustrated in the quotes below relating the experience and perspective of a community-based referrer and APDC provider.

**P32: GP-F**

*He was not keen to go along initially. He felt that he was quite a private person and that it would not be quite the right be thing for him. He was quite happy enough to sit at home and get along with things*

**P40: Management level provider-A**

*We have to remember that day-care is not the cup of tea of everyone. There are some people who do not like mixing with people particularly if they have got an illness*

These findings support the work of Cramond (1972, p. 661) in which he states that “Our dying involves our personality as much as our living”. When personality is seen to encompass or influence such issues as coping skills then further links between the personality of potential users and decisions to access APDC become more apparent.

### **5.3.2 Coping skills and acceptance of illness status (-)**

It was found that referral to APDC and the decision to use the service represented a significant milestone with respect to patients’ and family members’ acceptance of the state of wellness of the patient, and likely clinical outcomes. This psychological decision making milestone was identified by all categories of participants, and was not found to be related to any given model of service. In addition being referred to the APDC unit was found to involve confronting realities about the ability of patients and **relatives** to cope without assistance and decisions about how the patient should spend their remaining time.

**P5: Carer-A**

It was something he had to accept – that he was ill and he didn’t want to accept that he was ill. ....but once he was accepting he was ill he was easily able to accept going to the day-care unit... (later in the interview)... I’ve had two or three friends that have [been] unsure about the day-care unit ... in that “I’m trying to ignore the fact that I’m ill and if I go there it’s in my face and they are going to treat

other people in the same situation” and once they got their head around that and that it was there to help them, they’ve been sure.

**P41: Hospice nurse/Allied health professional-E**

People who are in to a certain degree denial and they come along and it’s taking a lot for them to come ...and then they come and say it’s not for me, at that particular time they are not ready to come ,... a lot of people have a lot of fear and anxiety about entering into an hospice and that really is facing up to the fact that their disease is not going to be cured and some of them can’t just accept that, and they find it very difficult to accept it and it can be hard , and yes they come because it has been suggested to them but it’s not actually something they are ready to accept.

The work of Hirabayashi et al. (2007, p. 24) (though a quantitative study, with the potential validity and generalizability limitations of having a low response rate and being conducted in a different cultural context from the UK) is significant in that it indicated that the patient’s own wellness status and **ability to cope** affected whether they decided to stay at home or use a palliative care service. It is possible that a similar effect could be experienced in the APDC context of this study, in the mind of the individual person.

In addition the ability of potential users to confront issues regarding their mortality, was also found to be interconnected with personal fears regarding what a service which caters to those with life threatening illness must be like. For potential users day-care seemed to represent a border place of sorts, an “unknown entity” between living and dying, which they were uncertain about entering. This is reflected in the quotes below describing barriers to accessing care.

**P48: Hospice volunteer-C**

[I] think it's the unknown, they have a fear of what sort of conditions people are going to be in there... how am I going to deal with somebody who is dying of cancer?

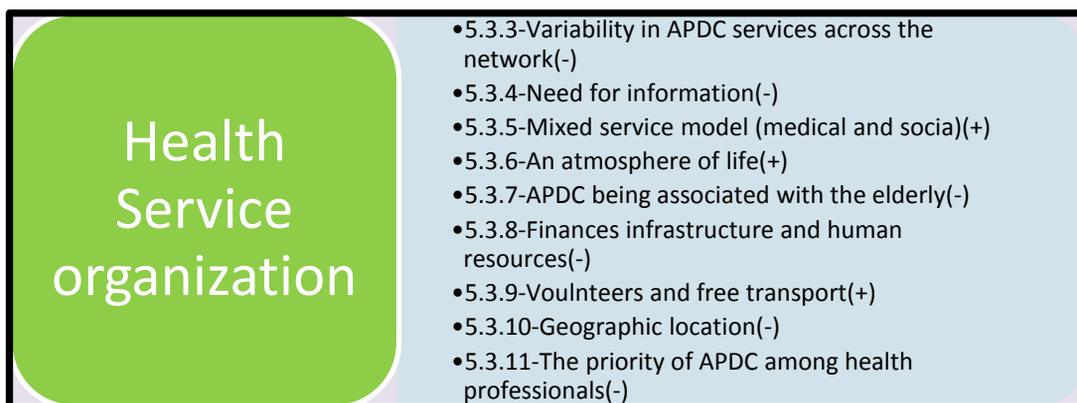
**P1: Patient-A**

It's fear. It's fear of the unknown, I think...

**P 28: Nurse/ Allied health-F**

Yes there are patients who are reluctant to attend the hospice , most of that is because of how they view it, ...fear of the unknown, fear of what the hospice could mean to them... In a sense it's a statement of where they are at in the stage of their diseases,

The above view was expressed across the network by all groups of participants, and was not found to be related to location or service model of units. The above fear of the unknown as shown above seemed to be more related to existential issues, and therefore “unknown” has not been interpreted as resulting from a lack of factual information about services. The need for information did emerge as a separate determinant of access and is discussed as arising out of the characteristics of the health service of organization (section 5.3.4, page 178).



**5.3b Determinants of access occurring as a result of the characteristics of the health service or organization.**

**5.3.3 Variability in APDC services across the network (-)**

Previous research has indicated that there is variability in the services provided by APDC units within the UK (Kernohan 2006, p. 463, also see page 61). Early observations made during the design phase and periods of negotiating access to units for this study, indicated that such variability was occurring in the cancer network being studied (section 3.13, page 101-107). The results of the work indicate that some referrers were aware of the variability between units. However, only a few referrers who had previous experience working at more than one unit were able to identify exactly how the units varied.

***P25: Macmillan nurse-D (E, A)***

*I know all three, and I know that their patients can be quite different, and the reasons why the patients come can be quite different. [Name of APDC unit] used to have quite a big alternative therapy remit at one point... [Name of another APDC unit] because it does quite a number of different medical interventions will again have a different clientele*

The variability in services offered was found to have affected the referral practices of health professionals. However, this was not exactly as first theorised in Chapter One (section 1.8, page 65); in that variation did impact negatively on referrals but the effect was only relevant to those professionals

who would had concrete knowledge of the extent of variation by having previously interacted with more than one unit.

***P25: Macmillan nurse-D (E, A)***

...the three that I know are all very different. So in a way you have to define the patient's needs by what day-care can offer. There is no point in me saying that the patient needs to have clinical needs to come to this day-care because there is no medical input and no clinical cover... Having referred patients to three different day-cares some of my reasons for referring were different in all sorts of cases; and the way I looked at the patients and my reasons for referring and prioritizing my referrals has been different for all three.

One might have expected that knowledge of the variation in service models across the network would have been more widespread. However, it was found that this was not the case. Instead there was a widespread need for fundamental information on APDC in general, which if available could then facilitate health professionals referring more patients to APDC. So that while variation in service model did impact negatively on referral, this was only perceived by a smaller number of participants as compared to those who were affected by a more general lack of information on services.

#### **5.3.4 Need for information (-)**

It is interesting to note that the need for further information on APDC as a determinant of access itself was expressed by **all** categories of referring health professionals and potential users across the study site.

***P 36: GP- B, A, C, E***

I don't think I've got any information about day-care services which I think, I find that quite amazing really. You know when I saw the thing about [name of the cancer network] I realized how little

information we had, nothing filtered through to us at all... I think one of the barriers might be in terms of us. You can't offer something that you don't know about or what gains you might anticipate really,

***P5: Carer- A***

There's no information in the doctor's about them. There is nothing in the surgeries about them. You go for your treatment but they don't...there's no information about it at all...We're quite close to where we go...until we were actually involved ourselves we weren't even aware that that facility was there.

***P50: Macmillan nurse- B, E, A, C***

I don't think that we have a good enough idea about what is going on really, and all the changes really... I need them to sell it to me really, you know, say why would I refer my patients to you, what can you do for them?... "why can't we get more people into day-care?" but If I knew more,...I need to know what is there before I can show it to somebody, so that would be a huge improvement for me. If we could have that information, and it's not two years out of date because things change....

The need for information was described as possibly being even greater among ethnic minority populations.

***P: 40- Management level provider- A***

They are not aware of what is going on very often or maybe they are aware and have some misconceptions, well if you have people in this country who have misconceptions about palliative care you can well imagine people who are not relatively well integrated,

In the presence of these calls for more information, my study revealed the paradoxical accounts of labour intensive efforts by providers across the network to educate referrers as to what day-care services provide. The aim of these efforts revolved around increasing awareness of the APDC product, including its role in relation to other palliative care services.

***P35: Management level provider- E, C***

I wrote to the GPs, I wrote to the district nursing service, I went to see the hospital matron and said “this is what the day-care was all about, it’s a really good service and you can refer to us”

***P46: Management level provider-F***

Well one of the earlier things that we did was to trawl about every GP practice in [name of PCT area] ...We went to each one and did a talk, presenting ourselves as a team, as opposed to this is Hospice, and this is the Macmillan and we don’t speak to each other...we are writing to every GP at the moment saying you need to get away from the idea that **a community** Macmillan is really what every patient needs to have, because actually that’s not a very cost effective way of running the service, there are a lot of people who the Macmillan nurses are going to see at home, and it would take them three times as long as it would take for them to come here.

The strategy for marketing APDC described by day-care staff was similar to those described by Cassaret and Abrahm (2001, p. 2059) in the marketing of a new pre-hospice or “bridge” programme in Pennsylvania USA. Cassaret and Abrahm do not comment on the success of their marketing campaign; however, in my study site the methods and efforts used for disseminating information APDC were limited in their effectiveness and did not meet the felt information needs of referrers and potential users.

Referrers, patients and carers all expressed a need to have more specific information on the details of when services would be available. However, a difference occurred in that patients and carers had a felt need for information on what the units actually looked like inside, and who were the other clients that were likely to attend. On the other hand professionals felt that they needed further information on the referral criteria and pathways for accessing services.

**P 1: Patient- A**

I found my way in and I thought ‘Gosh, what’s it going to be like? I don’t know anybody’ and nobody had told me what degree of illness people had got.

**P39: Hospital consultant- E, C**

I’d like to know who to direct my query to... and with respect to criteria, I’d like to sit down with someone and discuss this criteria...I would want to have advice on, and information on what was open and available to them,...whether or not.... they could come into day-care and be reviewed on a regular basis,

These results show that APDC still has the status of, or is possibly being perceived as a new innovation (Rogers 1983, p. 163); with the answers to such questions as “What is APDC ; and how does it work?”, still being unclear in the minds of potential users and referrers. It is evident that from the perspective of providers, activities targeted at “decreasing and reducing uncertainties about the innovation” as described by Rogers (1983, p. 167) are occurring. However, given the unmet information needs described across the network by referrers and users, the question has to be asked as to what might be contributing to or causing the development of such pervasive perceived information deficits. Possible answers emerge from the data itself. These are discussed below.

5.3.4.1 Mode of disseminating information

It was found that although the preferred mode of dissemination might vary from person to person (e.g. written versus oral), modalities which would take into consideration the work pressures of referring health professional recipients and the mind set and communication preferences of patients and their carers, were more likely to be successful.

**P 8: Carer- E**

just a little brochure or a little book or something just to...just very basic things really and then I can ring up and find out more myself then.

**P14: Patient-C**

the very first time I came I was interviewed by one of the nurses who gave me booklets...which said about various things that happened...although one might have been told these things. When there's a lot of information going on you can't always retain it,

**P3: Carer- A (discussing being introduced to APDC)**

I: would you have preferred the information in written form?

R: I think that this form is probably better because in that state of mind statements can become confused. Well, it would have done in my mind because obviously, you've got so much else to think about.

**P37: GP- B, A, C, E**

You have to remember that we get inundated with enormous amounts of information every day virtually and a huge amount of paperwork, so sometimes important stuff passes us by because of the volume, ...People would have to get past the high volume of stuff.

In this study one deviant<sup>79</sup> case was identified where the patient participant thought they did not require more information about the APDC services at the site from which they were recruited. Importantly it was found that this patient had previous exposure to another APDC unit and inpatient hospice within the cancer network. Although the participant noted the differences between the units, it was noted that acceptance of a second referral to APDC was influenced by exposure to a “day-hospice” in an inpatient unit.

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<sup>79</sup> Deviant in this chapter refers to atypical cases which emerged and were analysed as part of the process of enhancing the validity of the study (Silverman 2007, p. 294-295, 303).

**P15: Patient- E**

There were nurses of course in the unit and if there was a need they would always call a doctor. That was something that was available there, which is not available here....Well, as regards to the day unit I already knew a bit about it because I had two weeks as an inpatient here and I used to come to the day unit on occasions, so I knew something about it...,I had no problem about coming here because I suppose partly because I *did* know something about the set up and also, because I'd spent quite a few months going to the unit at [name of another APDC unit].

In the literature APDC has been described as a step up facility, the use of which facilitates the future use of inpatient hospice care when this is needed (Spencer and Daniels 1998, p. 220, Olson as described by Kernohan, 2006, p. 462). In the case described above we see that the reverse is also true. This is perhaps evidence for the need for further research regarding the use of one palliative service (whether specialist or generalist, community or hospital based) in facilitating the uptake of other appropriate palliative care interventions.

In the hub-and-spoke model of end-of-life care organization proposed by Help the hospices, in contribution to the national End-of-life care strategy, it is suggested that the co-ordinating hub of the model could be a hospice service (Help the Hospices 2006, p. 6). This example of inpatient hospice use facilitating access to day-care is perhaps a small example of an inpatient unit fulfilling this role. Although the hub and spoke model did not specifically mention stand alone APDC units, it is not improbable that an APDC unit with a "wide ranging understanding" of generalist and specialist palliative care (Help the Hospices 2006, p. 6) could fulfil such a coordinating or facilitator role.

The positive effect of prior exposure to palliative care services in facilitating access is echoed in another method used by referrers and providers. A “just have a look” or “come and see” strategy as illustrated in the quotes by participants P: 31 and P: 41 in section 5.3.14, page 214, was adopted by referrers and providers located at or referring to all of the APDC units studied. However, it was seen as a particularly valuable part of the referring process for health professionals who felt that they did not have adequate understanding of the services provided by APDC. The “just have a look”/ “come and see” strategy was found to be a composite determinant arising out of factors associated with health care organization and the characteristics of potential users therefore it is discussed further in section 5.3.14, page 212-215. The presentation of determinants of access arising out of health service organization is continued below with determinants of access which were related to the service models of APDC units.

### **5.3.5 Mixed service model (medical and social) (+)**

Health professionals and volunteers expressed the view that there was benefit in attending the hospice with respect to having what were described as psychosocial needs being addressed. However, it was found to be important to patients and carers for the APDC units to have the capacity to address medical needs.

#### ***P1: Patient- F***

I saw the nurse every week on a one-to-one basis. She wasn't the same one every week but they are there to see how I am if I've got any ...when you've got cancer you can get all sorts of funny feelings and aches and pains in your body and you don't know what to expect and whether there is anything wrong you see, whereas you need someone to ask you “Have you got any problems?” or if there's anything happening, which makes you uneasy. That's why I like to see a nurse because I feel if anything occurs that I'm not quite happy about then I can talk to her and she can either say 'Well see the doctor' or 'Go to a hospital' or put my mind at rest, so I think it is really quite important to see a nurse really.

**P12: Carer- E**

R2: In the last twelve weeks I've seen my dad really, really make huge progress psychologically. ...I think that's a big thing. One-to-one for me was a wonderful thing because you can't go marching in the doctor's surgery every week and say "I want to see the doctor"...I think the other part about it though is that they were able to what I call "manage" the medicines, so you'd be taken off this pill and put on that one, change this and increase the dosage of that....that one-to-one he's been making with [identifiable info removed-name of nurse] has allowed him to feel much more confident and comfortable and if he's having a little ache or a pain or whatever, he's had someone to talk to and explain it to.

Therefore, a day-hospice model which was able to address both medical as well as psychosocial needs appeared to facilitate access as it was more likely that the varying needs of potential clients would be met. However, it was important for care to be provided in an overarching atmosphere of life.

### **5.3.6 An Atmosphere of life (+)**

When potential clients and their carers made the important step to visit the hospice during the process of obtaining further information about the hospice, it was found that potential clients encountered an "atmosphere of life and wellness". This is a composite term being introduced to describe the physical and social aspects of the APDC units, which resonated with potential users understandings of life, wellness, and community, thereby facilitating access. Common experiences were reported of the APDC units being cheery, with a sense of happiness and care guiding the general approach to addressing the challenges associated with death and dying. No elements of cultural acceptability related to religion were found to be related to this determinant of access.

**P3: Carer- A**

The surroundings are beautiful. The atmosphere is so calming. It's superb and everybody is so good – so friendly and helpful.

**P24: Hospice nurse/ Allied Health professional- A**

Most people who come are pleasantly surprised by what they find here, that the place is live and airy and there will be a lot of laughter that goes on, but not sitting around feeling sad for ourselves. That it's rediscovering life...

In fact what emerged as introduced in the last quote above were descriptions of potential clients and their families being somewhat “surprised” at the reality of what the “day-hospice” actually was.

**P13: Patient-D**

I came to the hospice and I was very pleasantly surprised, because I thought it was going to be like a hospital... found that coming to the hospice was a better experience than I'd ever imagined, you see... sometimes you don't feel so well, but there's is no gloom and doom about it all... I mean its home from home...

**P6: patient-F**

You get a feeling that it's a sort of place of gloom and doom and it isn't. It's such a friendly, happy place... I thought it would probably be very depressing, but it isn't...

**P33: Management level provider-D**

I've never known anybody that hasn't come and said “Oh, isn't it lovely I did not expect it to be like this”,

**P48: Hospice volunteer-C**

You get people who when they come they are *frightened*. They don't come right away; they come for a look around first. But when they come they're so surprised, they say “I didn't know that it was like this, everyone's so nice, and there's no beds and things...”

From the above data it can be seen that the atmosphere which facilitated access to APDC is one in which sickness isn't obvious and that is not stereotypically clinical. However, as presented earlier in the chapter in section 5.3.4 (page 184) access was also facilitated by APDC having the ability to address both medical and psychosocial needs. The co-existence of these two determinants illustrates

the complexity of current APDC service remit; *in that effective service designs need to be capable of responding to the varied health and health care needs of potential users, and to do so within the context of the existential issues which may actually consciously or subconsciously govern decision making of potential clients.*

### **5.3.7 APDC being associated with the elderly (-)**

At the time of commencing this study, the day-hospices were opened to clients an average of six hours per day four days a week. With the exception of one hospice these four days were similar to the format described by Wilkes et al. 1978, p. 1054; where patients used the service one day a week for approximately five hours. During this time the patient would spend time socialising with staff and other patients as well as accessing allopathic, and complementary therapies as well as having their hygiene needs addressed.

This all day model of care is still predominantly used at many of the APDC in the UK (section 1.6.2, pages 55-57). However, it emerged that this model of service use was particularly not acceptable to the needs of younger patients (age 50 or less); or patients with a pre and post disease lifestyle which could be described as active.

#### ***P25-Macmillan nurse-D (E,A)***

Quite often the young ones are the one who are too busy living their lives....patients say, *"I'm not ready to sit and wait for God yet"*,

#### ***P24: Hospice nurse/ Allied Health professional-A***

medical professionals are saying, it's a lovely day out, go and be pampered, go and have a nice day out and if you are young person you still imagine doing all those things to yourself, you are not going to be drawn to that, you're going to want practical advice, practical support...you don't need to be bathed because you could probably do it for yourself.

The relative unattractiveness of this model of service use with respect to time was acknowledged by both providers and referrers across the network. The paradox in this situation however was in the fact that though providers realized that the all day service model was unattractive to certain patient groups, there still was relative resistance to patients using the service in a non-typical manner, with typical being defined as one day a week for six hours.

***P 38: Macmillan nurse- A, E***

I think sometimes flexibility of access to it. I think sometimes that there is rigid access, ... [participant relates personal history of a young patient] But if she didn't come to day-care, then she couldn't come. An hour is all I wanted and she was really keen... but that was not possible... you can take her if she comes for a day but you can't take her if she comes for an hour

***P 50: Macmillan nurse- B, E, A, C***

One of them was a young man 40 something who really needed day-care and he needed the respite, his wife needed the respite, and he needed some where to go and he really wanted to access alternative therapies and there was a block there because he didn't want to spend the whole day, as he just wanted alternative therapies...

However, it should be noted that this research did identify that some providers and referrers to day-care were actively changing or thinking about ways to overcome the barrier posed by the "all day service model", so as to make their service more responsive to the needs of their clients (especially younger active clients).

***P 26: Management level provider- A***

[Specific day of the week] is more of a drop-in day so patients don't come for the whole day, They are given an appointment time and they will come for a couple of hours... we get some [in the] 30, 40, 50 bracket we are getting more and more, [specific day of the week] tends to attract that kind of patient because they can drop in and that's where we are aiming at; so that they can drop in rather than spend a whole day, because some of them are still working.

***P 33: Management level provider- D***

For the younger person maybe it needs to be at weekends or maybe in the evening because some of them go to work... you would access the young ones who don't want to come and sit in a day-care for 5-6 hours

The inflexibility regarding models of use (i.e. all day versus drop-in) also affected typical patients who were already accessing day-care, but who may have wanted to use day-care, on the occasion in an atypical manner. Though this finding does not relate to access it does appear to be related to continued service utilization once access has been achieved and is perhaps an area for further research.

***P8: Carer- E***

She forces herself to go even if she's not feeling great, but maybe possibly have a flexi-day where she can't get out of bed, because she doesn't like to miss it now...And she goes just on a Friday, so it would be nice if she didn't want to go on a Friday just to go on a different day if she wanted to.

The evidence base for the perceived benefits of the all day model may be in terms of respite given to carers, and increased social interaction for the patient (Goodwin et al. 2003 p. 211, Wilkes et al. 1978, p. 1055, Kernohan et al 2006, p. 465-466) but as evidenced by this data if access to younger groups is to be expanded, there must be a willingness and resources to changes traditional usage patterns.

**5.3.8 Finances, infrastructure and Human Resources (-)**

Financial limitations was found to have acted as a barrier to accessing care, affecting the variety of services, the staffing levels and infrastructure of the individual day-care units. This was found to affect

not only the number of patients who could attend the service but also the wellness status and the diagnosis category of patients who were able to access APDC.

***P 24: Hospice nurse- A***

We are overly aware that the non-malignant diagnosis, everybody has a life-threatening illness should be able to access effective, palliative supportive care and at the moment we have neither staffing resources, financial resources, or the knowledge to care for other patients at the moment,

***P 30: Management level provider- D***

I [would] like to employ our own GP or Doctor, even for one session a day but that's a lot of money. We are looking at further developing our hospice at home service and that needs more people, and more money, so it really does not stop us providing what we currently doing, it does not stop us, it makes us more cautious about taking on additional services

Participants expressed the view that if the financial limitations were able to be addressed more services could be bought, and new mechanisms implemented to assist in staff training in “specialist areas”. The limitations placed by finances on delivery of palliative care in the APDC setting in the study site is similar to that experienced in palliative care services in other countries. The work of Casey et al in the United States though focused on examining geographical differences in hospice care, clearly shows that in addition to the usual funding mechanisms for hospice care in the US (Medicare and insurance), all of the rural hospices studied faced significant financial constraints, which necessitated “fundraising and donations” to “cover operating expenses” e.g. travel expenses for home care (Casey et al. 2005, p. 364).

In my study financial limitations were cited as the reasons for closure of one of the day units which previously existed within the network. The closure of this unit resulted in patients from this specific geographic already using APDC having to relocate to other locations.

**P15: Patient-E**

When they closed the one in [name of location] they gave us the option of either going to the unit at [name of location], or coming here and because I live in the [name of location] side of [name of location], this was the obvious option for me.

This presented difficulties with accessing care relating to the wellness status of some patients as well as the ease with which health professionals could refer. The effects of distance and geographic location are considered in the determinant of access termed “Volunteers and Free Transport”.

**5.3.9 Volunteers and Free Transportation (+)**

Field and Briggs in their study of patients accessing General Practitioners’ surgeries in Northampton found that 3% of patients who lived in a 1-3 mile distance from the surgery perceived distance as a hindrance to accessing care. This is compared to 19% of patients sampled who lived 4-5 miles away (Field and Briggs 2001, p. 294- 308). They noted that the relationship between distance and access is also influenced by mode of transportation. The issue of transportation and distance to be travelled in order to receive services was found to be applicable to palliative day-care patients who had limited mobility because of their illness or treatment.

**P25: Macmillan nurse- D (E, A)**

I: Do you have situations where persons may be affected by transport?

R: Yes we do. They’ve got a very [good] voluntary transport network here but some people find the journey too much if they coming from the outer reaches of [name of location] it can be half an hour each way, and some people feel that they don’t want to make that journey so they don’t come to day-care.

Typically as described by Fields and Briggs and illustrated above, there is a direct relationship between geography and transport, and an indirect relationship between these and access. That is, the greater the distance between the service and the potential service user, the greater is the potential need for transport and the greater the likelihood of there being difficulties in obtaining such transport in a reliable way, resulting in decreased likelihood of access. For the most part, however, the above relationship between geography and transport appears to have been nullified because of the provision of reliable, free transport by the APDC units. This transport is possible because of the operation of an extensive voluntary transport system, as well as units liaising with the NHS to facilitate patients with special transport requirements.

***P 6: Patient- F***

A volunteer picks me up every week and a volunteer takes me home, because I couldn't get there otherwise because I can't get to the bus stop or anything.

***P4: Patient- A***

When you actually go to the day-hospice do you have to drive yourself?

R: No, because it's spread to my brain and I'm epileptic now and so I have one of their drivers

I: OK, is that very useful do you find?

R: It is because I wouldn't be able to get there

***P10: Carer- C***

It's not really that far from [name of location where patient lives] but it would be the expense of the petrol and things like that. We're both retired and obviously the ambulance service picking her up and bringing her back is a big plus. We had a letter from [name of APDC unit] when we first decided that we would go and they explained to us that they would lay on the ambulance and give us the times ...they've done that ever since day one, so we don't need to bother about it. We just wait until they come, which is good.

The work of volunteers in independent hospices in the UK has been well described by Hoad (1991 p. 239-246). Although his work seems to focus on inpatient hospices with no distinct mention of

palliative day-care, his category of volunteer termed “direct carer” in which the illustrated case was involved with “the transport of patients to and from the day centre” resonates with the above finding of my study, where it is clear that free transport to day-care for clients is invaluable factor in achieving being able to access services.

In addition to barriers which might be posed by distance and the logistics of travel, geographic location was also found to be a determinant of access.

### **5.3.10 Geographic location (-)**

As was discussed in Chapter One, review of the literature on palliative day-care reveals that many units were established as a result of the initiative of local community groups and other members of the voluntary sector (Hern and Myers 2001, p. 5). Therefore, in some communities where such finances were not available a unit may not currently exist. This raises the possibility of the development of circumstances which can give rise to inequalities of access (section 1.6.2, pages 55-57). In this research it was found that the provision of transport to palliative day-care does not appear to be an insurmountable problem as all the units commonly provide free reliable transport. However, from my data it was seen that geography still acted as a barrier in that patients may have a decreased chance of accessing care if:

1. the day-care unit to be accessed is located outside of the area in which they (the patient) received their usual primary health care e.g. GP, or District nursing services (This was found to particularly affect those who are referred to day-care by a third party. In this case the patient may live in the catchment area of the day-care unit but the day-care unit may not be in the area

served by the referrer);

2. they receive or received their diagnosis specific treatment e.g. radiotherapy in a geographic location outside of the catchment area of the adult palliative day-care unit. This effect was observed when the location of disease-specific treatment was both in and out of the cancer network;
3. they had a non-cancer diagnosis.

**P33: Management level provider- D**

We take patients from [name of location] and [name of location] provided that their GP is based in that area

**P46: Management level provider-F**

There are a lot of people in [name of location] who go to [name of location] for their treatment and that group possibly are a group that we would miss out on at that earlier stage anyway...There is small group of people who live on the [name of location] side of our boundary. I suppose that would be sort of south [name of three locations] those sort of places, so it's actually geographically nearer for them but usually the geography does not play a part it's more the site of the cancer, and cancer therapy

**P39: Hospital consultant-E, C**

The only criterion is that the patients have LVSD [If] they have that we will pick them [up] whatever their condition and take them and as long as they have a [name of location] GP.

**P38: Macmillan nurse- A, E**

Down in [name of location] they will take cancer patients, but they won't take palliative patients with COPD and they have taken them to [name of another APDC unit]. So if you have COPD they have to travel to [name of APDC unit].

The situation described above is one in which the APDC services which a person receives is dependent upon their address, the location of their referrer, and the geographic location of where they may have

received hospital based cancer interventions. This creates a situation where postcode type inequalities of access can occur, particularly where referral to another APDC unit for a needed service may not be possible.

***Macmillan Nurse 25-D (A,E)***

I: Do you still have admitting privileges to all three hospices?

R: No, when we worked in [name of location] we could use those two; up here we can use this.

I: So what happens to patient who has a need that may be best suited to another unit as you may see it?

We don't refer across the units, say a patient with a medical need at this end, say some needed a blood transfusion say if they are down [name of location] in [name of Hospice] they can't get that here so we will get them to the oncology unit to get that.

This situation of variation in services across geography is not unique to palliative day-care in the study site; or in the UK, and has been reported in other palliative care services and or initiatives around the world (Greaves 2010a, p. 19). Specifically with respect to developed countries the work of Virnig et al (2004, p. 733, 2006, p. 1293, 1297), in the American context, and McGrath et al (2007, p. 105-113) in the Australian context show variation in access to palliative care services across states, between rural and urban areas as well as smaller geographic units such as zip codes. The variations in palliative services in all the above mentioned countries have been argued as being inequitable. However, as shown by Phillips et al (2006, p. 374) these inequities are perhaps routed in the “historical” lack of a theoretical base to guide palliative service development. Although the comments of Phillip et al.'s are related to the development of palliative care services in Australia, they are relevant to the APDC context in the UK given the previously documented unplanned growth in services (section 1.6.2, pages 55-57).

### **5.3.11 The priority of APDC among health professionals (-)**

Referring health professionals from across the network expressed that they understood and believed: in the provision of end-of-life care to patients in the UK; and that APDC could benefit their patients (particularly those with psychosocial needs). However, despite holding these apparent positive views of APDC referrers did not see the improvement of access to APDC with possible expansion of services as a priority to be addressed in the development of palliative care services as a whole. Providers highlighted other palliative service development needs which in their view were more pressing than the broadening of or improvement of access to APDC. These needs were found to involve challenges with afterhours care, including: lack of night care givers (night sitters); access to hospice/ or beds for emergency after-hours admission; access to beds for respite care; access to medication after-hours.

#### ***P31: District Nurse- C***

R: I would say that access today-care is fine. What is needed more than day-care at the moment is care for patients during the night and out of hours the availability of people with appropriate training. I would say that for us we don't need more day-care we need more out of hours support. We *need* support for patients during the night.

#### ***P30: Management level provider- D***

The huge issue with regard to [ name of location of the day-hospice] is with the regard to inpatient care, with regard to getting them here [day-hospice] is not a problem with regard to palliative care patient in [name of location of the day-hospice] if they need impatient care then it is an issue, because they are either at the moment going to [name of a town within the cancer network] or going to [name of a hospice **outside** of the cancer network] which is a distance away and because of lots of them being very rural areas, the public transport is not attainable and because the population is predominantly elderly they don't always have access to their own car.

#### ***P32: GP-F***

R: I think access to palliative day-care in [name of location] is good. The one wider area which I would look to tackle at the moment which is not about day-care, but our ward services and the availability of a 24 hour ward cover service for the north of the county which does not currently now exist. And one of my recent very, very big frustrations was someone on a Friday evening when I was still working who I needed to get admitted to the empty bed on the palliative care ward in our community hospital because there was no palliative care trained doctor to be able to admit them to the bed. So my patient who needed it could not have it and the facility that was there was wasted, because there was no one who could admit them.

When compared to these basic necessities of sort, it emerged that APDC was viewed as a beneficial but somewhat luxury or add-on service. In addition it was expressed that if additional resources were to be spent in day-care, these could first be used to build the capacity of hospice at home or other services which could help meet the needs of afterhours care provision.

***P23: GP- A, E, C***

Inpatient care in hospices is an extremely valuable and scarce resource I would say...if there is spare capacity in the day centre side and that could be diverted, that would be certainly beneficial because there is no denying the need for beds in hospices.

***P 30: Management level provider- D***

I: Would you want the capacity to take more [day-care patients]?...

R: Somebody hands us a big bag of money no questions asked .....we would extend our hospice at home service....

It has been shown that referring health professionals may have a gate-keeping role in access to palliative care services, and that the attitudes, and knowledge of these persons have an effect on access and utilization rates (Casey et al 2005, p. 364, Taylor 2004, p. 294-295). However, beyond such referrer attitudes of being “supportive” of hospice care as noted by Casey (2005, p. 364) this study

indicates health professional referring actions to APDC may actually be affected by an attitude which evolves out of a concept of essential and non-essential services in palliative care and other related clinical specialties.

***P46: Management level provider-F***

I think, it's very hard to get them to prioritize the kind of care that we give in the day-hospice. ... GP's and consultants and Oncologist and everybody who does the referring, thinks that the most important part of a palliative service is the part that supports people around the point of diagnosis and when people are dying at home and they want community Macmillan Nurses and they want a palliative care beds and they want a hospital team and they don't place enough value on that period in between when the day-hospice really come into its own, because all the other add-on sort of services that we have

***P20: Hospital Consultant-B ,A , E, C***

When you see the patients in the oncology clinic there is just so much else that you are addressing there... a things like day-care is relatively low on the list of an oncologist

In all of the above we see that health professionals are constantly making decisions about what are the essential services for their patients. This decision depends on what resources are available within in their local health care sectors. Based on their assessment of this, there is perhaps an unconscious lobbying or support of the long term viability of some services more than others by way of consistent referring to the service seen as being of higher priority.

There is the possibility that health care professionals probably don't feel a great need for APDC. Actually my research has found that APDC was perceived as having a limited clinical role; with there being a lack of clear agreement between providers and referrers about what constitutes a legitimate need for APDC across the network.

*Providers* from across the network expressed the view that APDC units were being perceived by some potential referrers as offering care packages that provided less clinical input than other palliative care services.

***P 24: Hospice nurse/ Allied Health professional- A***

time and time again particularly in the medical profession where we are seen as a nice day out, which yes we have in our endeavour to providing a nice day out for our patients who come here, but we do so much more than that, we are a team of dedicated trained professionals, with a range of experience and knowledge, who can make somebody's life much better with the knowledge that we have got... we have so much more than a nice day out

***P 46: Management level provider- F***

R; I don't think that they value the day-hospice, as highly as they possibly should...I don't think that they all quite see the point...we have absolutely as much experience and expertise as the community Macmillan nurses.../That's who they see as providing community palliative care, we have all of that and so much more. We have so much more that people can gain from coming here

The above experiences and perceptions of provider participants may be suggestive of the possibility that in the minds of potential referrers:

- 1) there is some hierarchy of value within (at least) community palliative care services, which acts to determine access;
- 2) and APDC is on the periphery of the medical clinical palliative care package;

There was *no evidence* to suggest that current referrals to APDC were based on any hierarchical assessment of the value, power or prestige of APDC in relation to other palliative care services e.g. Community Macmillan team. Also the data **did not** indicate that APDC was necessarily on the periphery of medical clinical palliative. However, it emerged that APDC care was seen **as a core** community palliative care service for addressing the **social and psychosocial needs** of patients and

carers. Of note **all** categories of non-provider participants<sup>80</sup> from across the network expressed the view that APDC was a valuable service in this respect. Further, it emerged that from the referrer perspective having a social or psychosocial need was in fact a key factor in determining whether a patient is suitable for referral to APDC (as shown in the quotes below where referrers are discussing the concept of what is an appropriate client to APDC).

***P31: District Nurse- C***

First the relatives, there must be a need for respite, then the patient must have some social need they need to get out-all some people have is four walls really. If they have psychological issues, if they're down, they need you know- some relief, there should be that psychological need. ...If a patient has a more physical need I would refer them to the Macmillan service.

***P38: Macmillan nurse-A, E***

I think the cancer must be having an impact on how they live, they can just about manage at home but not as well as they used to, they are becoming more isolated and potentially finding it more difficult to talk to people about how they feel.

From the above quotes it can be seen that in the minds of referrers having a social and or psychosocial need was a key factor in determining suitability of referral to APDC. This suggests that the belief in the ability of APDC to address the social objectives of care<sup>81</sup>, as categorized by Payne (2006, p. 441-445) had been established within the referring health professional community. However, the study data also indicated the decision making process regarding what constitutes a need for and suitable referral for APDC, went beyond an assessment of social and psychosocial need to include the consideration of factors such as the patient's diagnosis, age, and the services offered by day-care units.

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<sup>80</sup> Patients, carers and referrers.

<sup>81</sup>The social objectives of APDC as categorised by Payne's review of palliative day-care literature (2006, p. 441-445) include, emotional care, social care, family support and creative arts.

**P38: Macmillan nurse-A, E**

I think the cancer must be having an impact on how they live, they can just about manage at home but not as well as they used to, they are becoming more isolated and potentially finding it more difficult to talk to people about how they feel,

**P 32: GP-F**

We felt the GP team and the Macmillan team that in fact he was quite isolated and that more social contact would actually be quite good for him and that would, also offer extra care for him, to be observed every week

**P20: Hospital consultant- B, A, E, C**

it depends on how an individual day-care unit is set up, but I tend to see them as having a big psychosocial role, so the people I am talking about who weren't appropriate were young people who hadn't got cancer and who did not have or need that psychosocial support so therefore I wouldn't refer them.

As stated before, referrers saw APDC as being suited to addressing the social and or psychosocial needs of potential clients. However, while providers acknowledged the importance of meeting the social and psychological needs of patients, they noted that:

1. the appropriateness of a referral to APDC of a clients with a social need is dependent on the complexity of the need;
2. there was a role to be played by APDC units in meeting physical and medical needs of clients (notable exceptions to this being a decreased willingness to address the medical needs of patients with particular non-cancer diagnoses.

**P 26: Management level provider- A**

If the patient only needs social interaction then the patient should not be referred to us... If they are under control and there are no issues and all they want is a nice day out, and a bit of pampering and lunch because it not going to cost anything, then we are not where they should be coming. I think that people should have at least two needs whether that is psychological support and physical or psychological and social and they will have probably have social as one of their needs as opposed to

social being their only need. I think that can be served equally somewhere else and we are more specialist than that, and people need to be accessing the specialism that we can offer.

***P21: Hospice Nurse/ Allied health professional- F***

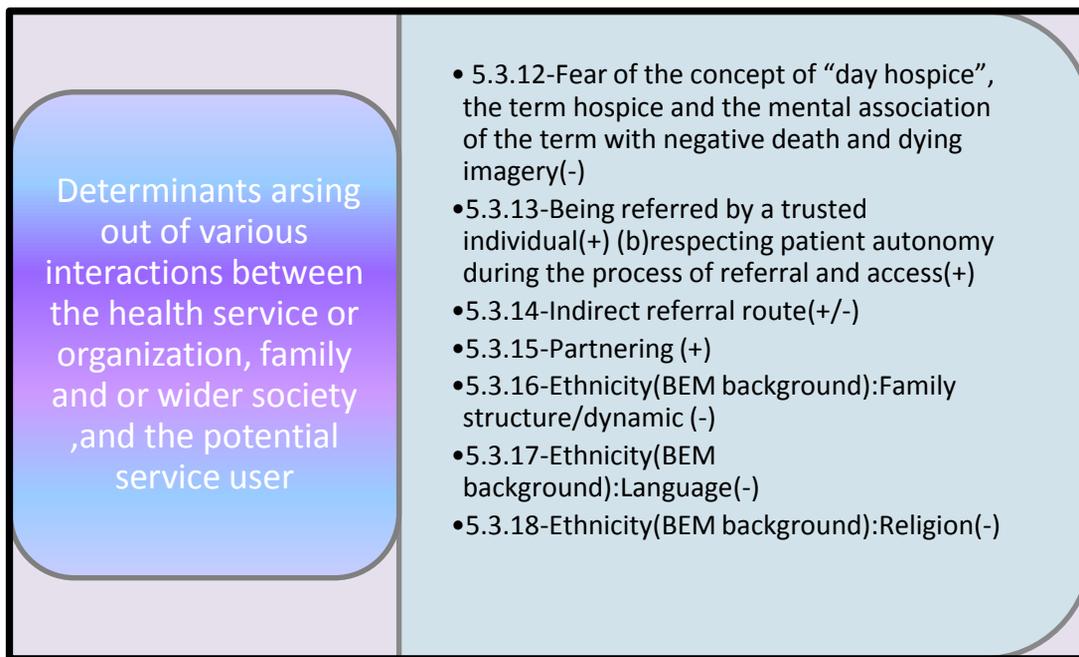
Inappropriate ...someone with extremely stable disease has adjusted to the disease; they don't need any support and want to get out of the house one day a week... There is a need for a support group for such people but not from day-hospice.

***P27: Hospice Nurse/Allied health professional-D***

Someone that's is not appropriate will be somebody who just come here for social needs to be honest, It has got a big part to play in the hospice, I mean it is a social gathering, I mean if it is somebody's really well then he has got nowhere to go on a Tuesday afternoon, he used to go to the pictures but now he doesn't well I'll have to say perhaps it's not the right place.

It is important to highlight that on the other hand patients and carers saw APDC as being appropriate for **mainly** addressing their social, and psychosocial needs while maintaining the capacity to address physical needs assessed by a clinician (as discussed in the 5.3.5 on mixed models of care). This slightly contrasting view between APDC clients, providers, and referrers is important because it raises the possibility that within the palliative care spectrum of services it is not entirely clear what niche APDC occupies or should occupy.

The discussion on whether APDC has a unique and relevant role in palliative care provision is important; and perhaps needs to be informed by theories of professional hierarchies within medicine (including ideas of what are less or more valuable forms of health care, particularly social versus physical or emotional, spiritual need). This is discussed further in Chapter Six.



**5.3 c Determinants of access occurring as a result of mixed interactions between potential service users, the family and wider society, and the health service.**

In this final section the determinants arise because of the complex interaction between, potential user, family, society and health service characteristics. The existence of such determinants of access serves to illustrate how difficult it may be to disentangle all the elements of health seeking behaviour.

### **5.3.12 Fear of the concept of “day-hospice”, the term hospice and the mental association of the term with negative death and dying imagery (-)**

The continued use of the term hospice as the title of and the main descriptive term for the services provided at palliative day-care units, emerged as a significant barrier to accessing care. The results indicated that potential clients of APDC perceived that the use of the term “day-hospice” indicated that a day unit was in fact similar to an inpatient “hospice”. This in their minds translated to a “day-hospice” being a place where only patients who were terminal, or actively dying, went to die

***P4: Patient-A***

I was very frightened about going to the hospice, because it’s the word “hospice” I think. It made it sound...you know...that you were going there to die basically,

***P 18: District Nurse-D***

A lot of patients are still afraid of the word hospice, they ask am I that ill then you have to explain to them that it’s not about being ill... cause they think it’s a place to die...

This notion that ADPC units were places where patients went to die was identified as a barrier to accessing care by all participant groups, across the network. The association between hospice, APDC and death and dying was found to be wide spread, affecting the actions of both health professionals and lay persons in the acts of both making and accepting referrals.

***P13: Patient- D***

Did you know anything about the hospice at all?

R: Well, we knew there were hospices but we thought of course, like a lot of people do, that you go there to die, which rather put you off.

**P24: Nurse/Allied Health professional- A**

I don't want to shy away from the word hospice but people, professionals are afraid to refer their patients to us if they are at diagnosis or expected to have treatment that is curative potentially because of that word hospice, they're afraid of freaking people out.

The basis for the development of the perception that day-hospices were akin to inpatient hospices and were places where people went to die appeared to stem from a combination of two factors which are discussed below.

*5.3.12.1 Factor one: The term hospice and the mental association of the term with negative death and dying imagery*

The first factor found to be contributing to the development of APDC being equal to “imminent death” was the societal association of the term hospice with negative images of death and dying. The negative images which were found to be particularly inhibiting access were the idea or assumption that day-hospices were dreary places, where persons (mostly with a diagnosis of cancer ) were most likely to be invisible pain.

**P32: GP- F (commenting on the interaction when referring patients to day-care)**

We gave the patient feedback on the perceptions you may have coming from the outside... giving them an appropriate perspective of what they might find in a hospice setting, trying to take away peoples negative presuppositions of what they are going to find, maybe they are going to find people who are in the advanced stages of cancer sat around the walls of a building miserable and moaning, obviously that's not what a hospice environment is about at all. It's about celebrating the life that remains rather than the death that is coming.

In addition to the negative image as the day-hospice as place of doom and gloom it was found that persons also thought that the model of care being given within the day-hospices would be in keeping with that of a traditional clinical hospital setting.

**P48: Volunteer- C**

I think people think that it's people with cancer just bedridden and things ...people are pleasantly surprised that the doctors and nurses are not in official uniform, all in gowns and so on, that people aren't dying

**P 6: Patient- F**

Quite honestly I didn't know whether I wanted to go to one of *those* places, as we used to call them... and anyway until I went myself, I think I got the wrong impression and thought it was all very clinical and people were very sick and all of that.

In addition to the negative mental images associated with the term and concept of hospice described above, referrals to the palliative day-care unit at site E were also being negatively affected by the societal perception that hospices provided care for the destitute. This negative mental image of a day-hospice providing care for the destitute was *not* found to be affecting access to other APDC units within the network and is perhaps related to an overflow effect of the close association of the APDC unit at site E with an inpatient hospice, the access to which was reported as being affected by the same issue.

**P38: Macmillan nurse- A, E**

R: I always start at people's perception of what a hospice is, there is a perception that you only go to a hospice when you are going to die...the older people will see it as the work house only very, very, poor people who can't afford things will go there, so that's one of the perceptions... and that's working class people that perceive it that way not the posh people.

I: Why would they be perceiving it that way?

R: That's the old way. You go to the work house to die. If you didn't have money to look after yourself you went into the work house, and they looked after you when you died...the stigma attached to going to the work house in the old days was pretty awful...You were really destitute to go into the work house... the poor ones think it's the work house and don't want to come. The ones in the middle are alright.

I: And that stigma not only affects the bedded units but also affects the...?

R: Yes! Can do, can do, can do, can affect day-care.

5.3.12.2 Factor two: Perceptions of hospice care which developed as a result of fundraising strategies used during the founding of current palliative day-care units

The second factor which was identified in two of the five geographic areas studied was related to the fundraising strategies which were used in local areas during the establishment of the individual day-hospices. Initially several of the APDC units were formed with intention of having beds, for the provision of inpatient respite and terminal care. However, usually because of financial limitations, some of these early plans were delayed or restructured.

These changes in service model and infrastructure of the "local hospice" do not appear to have been effectively and consistently communicated to potential patients and the community, resulting in the day-care units actually being seen as being inpatient bedded hospices, where people go to die.

**P30: Management level provider- D**

[Identifiable information omitted-names of individuals and location] applied to develop an hospice it was meant to be inpatient but the money was not sufficient so that its actually developed as a day-hospice and a couple of years later a hospice at home service... a lot will tell you that the hospice is where you go and die, a lot assume that we have an inpatient unit and even people in the hospital think we have an inpatient unit and that a hospice is where you go to die....

***P18: District Nurse- D***

I think most people know about it and would have given money to help start it but maybe they don't exactly know what they do or what it looks like inside. See the plan was to have a bedded unit but they didn't have enough money to run it, they get the wrong impression

***P22: Management level provider-A***

...I think the origins of the hospice are quite interesting .... The idea was to have beds because the general perception was that most hospices have beds and that was what (name of town) needed... the idea was to enable people to die well in a hospice setting as opposed to not dying well in a hospital setting. And what became obvious fairly late on in the process that the idea was not going to be viable as it became too expensive to run, so late on in the process the beds were dropped and the day-care remained. ... traditionally speaking hospices have been institutions where people go to die, which is no longer true anyway hospices at the bare minimum do that, on the other hand; that in parallel with the mixed messages that came probably during the initial fundraising meant that actually there was actually a lot of lack of understanding about what the hospice does.

Though the perception that day-hospices were in fact bedded units was found to be exerting a barrier like effect on access to day-care because of the association of bedded units with imminent death; the lack of beds was also found to be inhibiting access by reducing the perceived clinical role of day-hospices in the minds of potential clients and referrers.

This latter barrier like effect was identified by fewer participants, all of whom were referrers to or providers of day-care at sites which **did not have** a close geographic or management association with an inpatient hospice.

***P25-Macmillan nurse-D (A, E)***

R: I think people would probably take it more seriously as a clinical facility if it has beds

I: Is this the general population people or the referrers?

R: I think maybe every body

***P22: Management level provider- A***

I think that for some time the community in (name of place) has been labouring with the mis-apprehension that it isn't a proper hospice because it hasn't got beds

***P18: Management level provider- D***

The beds are seen as the attractive offer really

It is important to note that despite any misconceptions about what APDC might be like access was still achieved by some patients. My work has also shown that access was facilitated when a potential user was referred by a person whom they trusted and whom in turn respected their autonomy. These two facilitators will be presented together as they were found to be related, in that they both affect the health professional- client interaction when the concept of referral to day-care is introduced.

**5.3.13 Being referred by a trusted individual and respecting patient autonomy (+); and (b) respecting patient autonomy during the process of referral and access (+)**

From this study it emerged that access to APDC was facilitated when the health professionals introducing the concept of attending day-care was someone with whom the patient had an established relationship with, and whom they saw as a trusted individual.

***P31: Hospice Nurse/ Allied health professional- F***

The problems of the patients- it's very difficult to tell people who you are on the phone you lose them, being part of the community palliative care team, meeting them at their home. Meeting them on a safe territory. You can have several conversations, on the phone sometimes. Then they agree to come.

**P32: GP-F**

R:...once he was persuaded to go

I: Can I just ask you about that word persuaded- what did you guys do to persuade him...?

R: I suppose the better relationship that you have with people and chat quite well, and I respect this person who is visiting me, and if they say that I should give it a go then it's a good idea to give it a go.

The fact that the recommendation to attend day-care was being made by such an individual served to legitimize the service, with potential patients being more assured that the service was likely to be beneficial. In addition when the patient had an established relationship with the person recommending day-care, it emerged that the referral discussion was often able to reach a depth, where potential clients would be willing to divulge and discuss their fears and misgivings about attending the service. These disclosed misgivings could then be more appropriately addressed, resulting in the referral being accepted. This **was not found** to be related to professional status i.e. nurse >doctor etc).

It should be noted that even with an established trusting relationship, between the referrer and the potential client, the referral discussions could still occur in more than one session over a matter of days or weeks (see quotes below).

**P14: Patient- C**

Did you receive any information about the day-hospice?

R: I didn't from [T] but at first when she gave me the option to come I was still able to get out quite a lot and I didn't take that up probably. I can't quite remember. It was probably for about six weeks or so where I possibly didn't take up the offer ...I know I had [T] ringing up several times and coming to see me several times.

***P31: District nurse-C***

Sometimes I might not refer first off If I think that the patient could benefit. I usually tell them about day-care and the benefits and I encourage them to call and go and just have a look. If I've mentioned [it] once or twice and they haven't gone I encourage them some more.

***P27: Hospice nurse/Allied health professional – D***

We said to him- well look if you don't want to come for the whole day your wife drives you know-you come for hospital appointments if you just want to come over have a cup of tea and spend a bit of time that's up to you. He is going to do that and he said he is hoping he said by the end of November I will be able to come one day a week, so it all depends who it is.

In some instances this delay may have been related to the barrier posed by lack of information previously discussed in section 5.3.4, however, in other cases what may be perceived as an apparent delay in access is as a result of the operation of the facilitator of respecting patient autonomy.

***P 25: Macmillan nurse- D (A ,E)***

We give all those patients the information on day-care so that if they were to see it as an option at some point down the line, then they know what it's all about.

***P32: GP- F***

He was going on a trial basis. You know he went up one week and then he said you know I'll try it again for another week and then sort of got into a pattern that was acceptable to him

***P 41: Hospice nurse/Allied Health professional- E***

Once we get the application of the referral form we then make contact with the patient and introduce ourselves to them and make arrangement for them to come to day-care but not for what we term an informal visit which is just for them to come for half a day, either on their own or we can provide transport to actually come and see what we are what we do, the environment and if it is actually where they want to be

From this work it emerged that access was facilitated when referral to day-care was introduced in a non- paternalistic manner. In such cases, it was clear to the patient and their relatives that they were being given a choice as opposed to a mandate. This approach seemed to have the advantage of giving

the patients and their relatives the freedom to work within their own psychological trajectory, and to make the necessary social adjustments that attending day-care might entail. In essence this allowed the patient and their carers to become shareholders in the idea of attending day-care, thereby resulting in them becoming more comfortable and accepting of the referral.

It should be noted that the facilitator of respecting patient autonomy as well as the operation of other barriers which delayed access to day-care, may contribute to the trends reflected in the documentary analysis data where across the network 33% of patients died before being able to attend day-care, after having accepted the referral.

Also found to be affecting access was the speed and directness of the referral. These were found to be affected by what have been termed “Indirect referral route” and “Partnering”. These are discussed next in section 5.3.14 and 5.3.15 respectively.

#### **5.3.14 Indirect referral route (+/-)**

It also emerged that the referral route to APDC was somewhat indirect. It was found that referrals particularly those from community-based health care providers i.e. GPs and DNs often went first to the community Macmillan team, and then from the Macmillan team to APDC.

***P 23: GP- A, E, C***

I would rarely refer somebody myself to palliative day-care. I would usually go through the Macmillan service, ... I would then expect them to select the people who might benefit from day-care.

***P35: Management level provider- E, C***

The first point of call for someone in the community is the district nurse...so from that then the district nurse can then send her referral from through to us, what we might do is to see to it[that] one of the Macmillan nurse[s] come in and just to really look at this and see if it appropriate and the Macmillan

nurse come back to us and she is the one that would say yes, and may refer the patient to us,... when the Macmillan referral lands on the senior nurse's desk she then makes her own assessment, then the next process is that she rings the patient and she will ask the patient to come and look at the hospice.

The quotes above also show that, the indirect referral route was perceived as being a means of ensuring that patients were referred to APDC by a knowledgeable person who might be able to assess their suitability for the service. This in part reflects the uncertainty which some referrers have about the correct timing of their referrals.

***P46: Management level provider- F***

I've gone and talked to GP's in [name of location] trying to say that the Day-hospice is a little bit different from the Macmillan's and I would quite like it if you would think of us a little bit sooner...I could look after people better say if I get them say three months earlier than you might of referring them to a community Macmillan Nurse. But I wouldn't say that that has been hugely successful yet... They listen and they say oh yes, oh yes, but they don't really do it.

***P22: Management level provider -A***

We try to open our service from diagnosis onwards that's hasn't really happened, [we are] still tending to get referrals from people who are still fairly well on in their disease

***P37: GP-B, A, C, E***

It's not that easy to think of the right circumstances because if they're up and mobile and able to get here and sit across the desk, then they often...it might be limited as to how much useful day-care would be for them, because they're obviously able to get out and about and the alternative is people who are at the other end of the spectrum – people who are bed-bound.

This uncertainty regarding when to refer mirrors general problems which physicians have with prognostication regarding palliative and end-of-life care. However, it may also reflect a lack of information about services provided, as well as a disconnect in opinions regarding the stage of illness at which APDC and palliative care services as a whole should be introduced.

**P: 23 GP-A, C, E**

I'm not sure what the case is for bringing the day centres forward in the patient journey really.

**P 39: Hospital consultant- E, C (discussing referring non-cancer patient to APDC)**

It makes it very difficult to prepare for the very end-of-life with such patients. Obviously you don't want to be talking about the very end-of-life to a patient who is going to be 2 or 3 years down the line you want in the initial stages to giving them hope and focus on the positive things and live their life

In addition to the extra steps of having the appropriateness of a referral to APDC assessed by another health professionals, both referrers and providers saw the benefit of having potential clients visit the unit to see what it looks like. This “just have a look/ come and see” process was used at all of the units and by all categories of referring participants.

**P31: District nurse- C**

I usually tell them about day-care and the benefits and I encourage them to call and go and just have a look

**P41: Hospice nurse/Allied health professional**

Once we get the application of the referral form we then make contact with the patient and introduce ourselves to them and make arrangement for them to come to day-care but not for what we term an informal visit which is just for them to come for half a day, either on their own or we can provide transport to actually come and see what we are what we do

The two actions of being transferred between professionals to determine appropriateness, and visiting APDC units before use, were found to have the effect of facilitating access by reducing fears through correcting mis-information, and preventing the introduction of APDC services to persons who might not be psychologically ready to use a “ day-hospice”. However, extra referral steps also resulted in an extension in the total time it took for a patient to access APDC services. In addition it also increased the possibility that the involvement of multiple professionals would overwhelm the patient.

***P21: Hospice nurse/Allied health professional- F***

The GPs refer to the community Macmillan team, then the “Mac” team will pick them up and carry them for a while- sometimes they may give that referral right away but more often than not it is someone that they have been seeing for a while and then they say well actually this person will be more suitable for us.

***P34: District nurse- B, C, E, D***

If the Macmillan nurse is already involved then we would usually contact the Macmillan nurse, and then they would refer them onto the day centre, day-care...if we could refer into the services ourselves rather than going through other people because sometimes they may not be involved, like the Macmillan might not be involved anyway... it just making things more complicated for patients

During these periods of multiple transitions it was possible for the physical and emotional condition of patients to deteriorate / change. This is also supported by the emergent theme from the documentary analysis of persons not attending because they have died or were too poorly to attend (52% persons).

In-spite-of the potential drawbacks of using a referral route that involved more than one health professional and multiple steps, the ability of health professionals to work together did emerge as a facilitator of access. This emergent theme was termed “Partnering” and is described below in section 5.3.15.

**5.3.15 Partnering (+)**

This study found that access to APDC was facilitated by the existence of formal communication links or working relationships between referrers and, referrers and providers.

***P27: Hospice Nurse/Allied health professional-D***

We do have a multidisciplinary team meeting on a [day of the week] with the Mac, myself, chaplains whoever is involved with hospice and sometimes the Macmillan nurse will say well we've met somebody who's got, you know, so that's another way that we do find out about people out in the community....we are quite lucky in our area for the fact that they know us, it might be through the hospice at home, cause we have got a hospice at home team and they are in the community and they are often double up with the district nurses to do personal care and things so obviously they know about us through the fact that the hospice at home do go out with them.

Such relationships served to promote the timely sharing of clinical information, and decrease the number of transitions between health professionals which a patient would have to make before accessing day-care. It also served to foster an environment of trust among health professionals in the clinical expertise of each other.

***P18: District Nurse- D***

We are fortunate here to have some very good GPs, in that when they see a patient with cancer they refer to us very early, so that we become involved very early in the patient journey.

***P 46: Management level provider- F***

I started working very closely with the community Macmillan team in [location] You see that was the other issue there was lots of professional hostility they did not feel that [name of APDC unit] was providing a safe and appropriate level of palliative care so there was a lot of building up of relationships on that part of it....Now we work together, we tried to I suppose [to] change referral patterns

***P35: Management level provider-E, C***

we have multidiscipline[ary] meeting and all the professional comes together so we can discuss... we also got the Macmillan nurses so that we know the patient in the home, and then we know them here; so discussing together any changes is good for professional to professional which means that the patient gets the best care that we can possibly give,

As it relates to community level referrers it also emerged that in general the existence of national initiatives such as the GSF framework were positively affecting work practices, between health professionals. These were found to increase awareness and coordinated care of palliative care patients in the community, with possible subsequent referral to APDC.

***P29: District Nurse –F***

I: how do you find out whether or not a patient in your community is palliative?

R:... we have a meeting once a fort night as part of the Gold Standards Framework where we discuss our palliative care patients, so a patient may come up at that meeting

***P38: Macmillan nurse- A , E***

I: You mentioned previously [information about two patients] how did the GPs refer to the day-care?

R: I did

I: Ah-so the GP refers to you and then you refer to day-care

R: Yes I am very involved at that practice, we all work as a big team and I am involved with most of their patients and we have GSF meetings on a regular basis,

***P26: Management level provider –A***

With the District nurses in particular it think it's making sure that they are continually educated and aware about what we are about, and then kept up to date with how the hospice movement is moving; and then they [maybe] be more willing to share and I think that this will improve with more and more practices take on the GSF, because DN are involved in those meetings....

As was described in Chapter One and three, the utilization rates of APDC by ethnic minorities in APDC is lower than expected see pages 57, 58 and 60.

The quotes below reflect this.

***P4: Patient- A***

I: Are there any ethnic minorities who go to the hospice that you go to?

R: No.

***P28:-Hospice nurse/Allied health professional-F***

It tends to be a White British...I have been in palliative care for just over two years and I have seen one African Caribbean gentleman.

***P25: Macmillan nurse- D (A.E)***

We've got an Asian community, quite a big Asian community, not huge, and we did get quite a number of Asian patients referred patients, they take up "Mac" services, they have been very open to the services of hospice at home team when it has really been needed, but they don't avail themselves to the day-care services.

It emerged from the data that providers were aware of the low utilization trends, and had developed varying explanations as to why it might be occurring. Providers articulated that apparent under-access might be related to ethnic minorities taking care of their own family members. Other barriers to access identified included language, the day-hospice being perceived as a Christian institution, and lack of effective information dissemination to ethnic minority communities. The supportive text data for these factors is presented together; this is then followed by a combined discussion.

**5.3.16 Ethnicity: (BEM background) Family structure/ dynamic (-)**

***P44: Management level provider- D***

We get very few ethnic minority people as either volunteers or patients now whether or not it's a cultural thing I certainly think within some community there is a culture still that [they] care for their own.

***P41: Hospice nurse /Allied health professional- E***

A lot of ethnic groups have a very strong family support system and they don't use this environment.

***P38: Macmillan nurse-A, E***

...you should be looking after each other, they are very family oriented these people, the Asians are very family orientated aren't they, I think that they do access the beds much easier, but getting them to day-care is much harder, the families usually take care, and when the families know that they can't then they will take a bed.

### **5.3.17 Ethnicity: (BEM background) Language (-)**

***P 34- District nurse-B, C, E, D***

if they don't speak English, there might not be people there that they can communicate with the same...I think if the patient does not speak English then they must feel more vulnerable outside of their own situation.

**P21- Hospice nurse/Allied health professional- F**

Ethnic minorities- I wonder if some ethnic minorities even hit the radar palliative care in general, our literature is in no other language , staff don't speak other any language but English.

### **5.3.18 Ethnicity: (BEM background) Religion (-)**

***P28: Hospice nurse/Allied health professional-F***

I think one of the problems with the hospice, is that a lot of people say it as Christian because it was developed in this country in a Christian context, and it's finding ways to reach other religions or group of people. That in itself isn't neglect or an exclusion and it's difficult.

The belief that ethnic minority groups were potentially not accessing day-care because of family support systems was widely held among community health professionals, and providers of day-care. One management level provider did express the view that this common belief is not necessarily true.

***P40: Management level provider- A***

the Asian philosophy of family support and all of that is not always true in this country, I think that Asian families are going out to work, both of them, and you have people who are not getting the care that they deserve.

These two contrasting findings echo the work of Hirabayashi et al., in that they indicate that the attitude of the carer is linked to the decision of patients regarding whether to use palliative care services or stay at home (Hirabayashi 2007, p. 28). However, as has been shown in the work of Worth et al. (2009- BMJ 2009;338:b183doi:10.1136/bmj.b183), it cannot be held as a truth that ethnic

minority persons belong to families, and that these family units in the context of the western world are more family oriented than those of ethnic majority persons, and therefore might not have as great a need for day-care. The assumption is sometimes made that the presence of family is taken to mean greater than average career support. Hirabayashi et al. (2007, p. 28) show that it is important to differentiate the presence of a support system, from how the support system is coping. Therefore, in the context of improving access to day-care it will or is necessary to verify the presence of the support system and to assess how that support system is coping. This is relevant to all ethnic minority groups. However, in the case of ethnic minorities such an assessment might be even more important as these families may also be experiencing other social issues associated with being ethnic minority e.g. immigration status challenges, language barriers, lack of integration and being of a lower socio-economic background (Worth et al 2009, BMJ 2009;338: b183doi:10.1136/bmj.b183).

Across the network providers described measures that were taken or being undertaken at individual units to encourage access by ethnic minority groups. These measures included measures such as changing the physical infrastructure of the hospice to accommodate the likely needs of ethnic minorities, including changing the ethnic composition of the staff.

***P 46: Management level provider- F***

You know any hospice you go to will say that our door are open but they do promote this very white middle class Christian ethos and, and I hope that I've taking a positive step as I've just recruited a new [non-clinical volunteer post] who is from [name of country] and I hope that that in itself will actually start to give the place itself a different feel, and maybe then more acceptable for when patients come in cause we do have patients of various backgrounds who come through the door but they don't often want to come back again they say " it's very nice" but you can tell that they do feel a little bit out of place.

The above measures were not found to be effective.

#### **5.4 Brief Results Summary**

The results of this study have shown that there are inequalities of access to APDC although this was not concretely demonstrated by analysis of epidemiological need versus capacity data presented in section 3.1.3 pages 101-107. The qualitative arm of the work shows that there are factors which are operating to inhibit access to services by: persons with non-cancer diagnoses; who may be of younger age groups; and ethnic minority backgrounds. It is interesting to note that the factors found to be affecting access go beyond these groups; and were also found to be affecting persons who may want to use traditional 10 am-3 pm APDC, in an arguably “ atypical way”. In addition the work shows that ethnic majority populations in the UK are also experiencing very real barriers to accessing APDC. These barriers include continued taboos and fears about dying. It should be noted that these are persisting even in the presence of modern medicine, a modern health system, and a hospice movement that is now more than forty years old. The very human fear of suffering or having to see others suffer as death approaches continue to function as an inhibitor of access. Within APDC the continued use of the term “Hospice” to describe services was found to be contributing to the above fears. Alternatively, given that a significant number of APDC units are voluntary sector organizations and are funded through the charitable giving of local communities the use of the term hospice is likely to persist.

It was found that APDC units seem to have framed themselves as local hospices/charities; with the term “hospice” being firmly entrenched in the psyche of the population studied.

Other determinants of access identified hinged a great deal on the core philosophical questions of ‘What is day-care?’, ‘What does it do?’, ‘Is it truly a specialist palliative care service?’, and ‘Can it

address the multiple needs of all its potential clients in its current format?'. The earlier descriptions of day-care by Spence and Daniels (1998), Higginson et al. (2000), Hern and Meyers (2001) alluded to these issues. The results of this study suggest that in the context of this cancer network the current categorising of APDC as a SPCS may not be an accurate description of what the service provides or is able to achieve.

To gain “eligibility and acceptance” of APDC as a SPCS perhaps there is a need to define more clearly and perhaps even narrow what APDC units do, so that they are distinct from other SPCSs and other social services. Further, there may be a need for further work on defining the health and healthcare benefits derived from APDC (especially as there is increased lobbying for palliative care services to be involved earlier in the disease trajectory). Such data in the context of evidence based medicine may serve to increase the legitimacy, priority and subsequent referral of patients to the service. Finally, in the context of being an ambulatory palliative care service, the data shows that the model of APDC as a different type of hospital, which may be misconstrued as a partial hybrid of a social day-care centre, may not be viable in the coming decades. What constitutes community, for persons born in the latter half of the previous century, is changing. Further, the increasing multiethnic nature of UK society dictates that any service involved in palliative or end-of-life care will need to be emotionally intelligent and responsive to the varied needs of a diverse clientele.

It is perhaps the lack of the current ability of APDC to respond to the needs of atypical clients that is contributing to decreased access by ethnic minority patients and patients with a non-cancer diagnosis. This challenge with responsiveness was illustrated in this work by the barriers to access posed by financial limitations and evidence suggestive of the need to improve cultural competencies.

#### **5.4.1 Chapter Summary and key points**

This chapter does not have a summary box but flows into the final part of the thesis. In these final chapters I use the first person in keeping with discussion and reflexivity norms for reporting qualitative data.

**PART THREE:**

**DISCUSSION, REFLEXIVITY AND LIMITATIONS**

## **CHAPTER SIX**

### **Discussion**

#### **6.0 Introduction**

This thesis was concerned with understanding access to Adult Palliative Day-Care (APDC); particularly identifying factors which may act as determinants of access. In this work it was initially theorized that access to APDC could be approached by seeking to understand concepts of need (and the interpretation of need) along with understanding how unique features of day-care were actually affecting the ability of potential clients to use the service.

This work on understanding access to APDC was important as the services in the study site had “evidence” suggestive of underutilization both in terms of total occupancy levels and within particular patient groups e.g. patients with a non-cancer diagnosis.

A total of 18 factors were identified as possibly acting to influence access. This chapter does not present each barrier but seeks to further discuss the results in the context of current understanding of service organization and delivery, and new contributions to knowledge. It also makes recommendations on the potential implications of the findings to clinical practice and research in APDC.

## **6.1. Discussion of Results**

### **6.1.1 Is underutilization real?**

One of the first sub-questions stemming from the research question was a query as to the validity of the assessment that APDC units were actually experiencing underutilization as suggested by the literature (section 1.7, page 58).

Based on the quantitative data that informed the study design, along with the qualitative and documentary analysis data, it is very likely that APDC services were not experiencing underutilization but rather over capacity. All of the units in the study site aimed to offer 15 day-care spaces a day for most days of the week day (3.1.3, pages 101-107). When this level of provision was compared to their epidemiologic level of need it was found that all the units had more spaces annually than were required for their catchments. Further, from the documentary analysis I found that while 149 patients were referred to day-care but were unable to attend, only 5% were unable to so because of a provider declining a referral (Appendix 6, pages 313). The action of declining a referral in this study (using both datasets) was never found to be related to managing full occupancy: where full occupancy is defined as all 15 places being taken. However, provider participants did note that the dependency level of clients particularly that of non-cancer patients did serve as an indicator of maximum capacity. In that the more dependent the patient load, the fewer patients could be accommodated on a given day. So while it would not appear that APDC units were at “full” occupancy (from a purely numerical basis); they could however be at full capacity- when staffing to patient dependency level ratios were considered.

This is an important finding as it indicates that the method of measuring utilization based on numbers of occupants may not be an accurate measure for day-care services. In addition, palliative care patients are likely to have care needs which evolve as their symptom profile changes during their disease trajectory, and it is likely that their felt and demanded needs would change accordingly. Thus measurement of utilization in palliative care should take into account fluctuations that might occur in demanded need.

Perhaps standard calculations for measuring utilization of day-care should be developed which take into account and weight separately the number of clients which a service has, the dependency levels of these patients, and the number and skill set of staff. This kind of weighted measurement could then form the basis of a conversion calculation or formula which might give a truer reflection of how day-care is utilized. It may also provide a more objective way of comparing use between APDC facilities that offer the same model of care.

### **6.1.2 The concept of need**

Palliative day-care has grown rapidly in the UK since the opening of the first purpose built unit in 1975. The descriptions of this first service show that it sought to provide holistic care addressing social, spiritual, emotional and physical care (section 1.6, page 55). Since 1975, adult palliative day-care has been defined as a specialist palliative care service (Higginson 1997, p. 189-190). The documented perceived benefits of users of APDC are predominantly social and emotional and include:

- enabling patients to define themselves in ways other than the sick role (Douglas et al. 2000, p. 341);

- allowing persons to remain in their living environment longer (Douglas et al. 2000, p. 340);
- providing respite for carers (Wilkes et al. 1978, p. 1055);
- and empowering and enabling patients to cope with their illness and social challenges through the provision of information about other health and social services (Copp et al. 1998 p. 164, Davies and Higginson 2005, p. 614).

These perceived benefits were also identified by participants in this study. However, as shown in section 5.5 (page 198) access to day-care was facilitated when the units functioned to chiefly meet the social needs of participants while maintaining the ability to address medical palliative care needs should these arise. This may be evidence in support of the concept that day-care functions as a community with increasing social interaction being an important perceived benefit (Goodwin et al. 2003 p. 211).

Importantly this study found no evidence of patients or carers, expressing a felt need for APDC to have the ability to treat or directly co-ordinate *their complex medical palliative care needs*. This is paradoxical as APDC is defined as a specialist palliative care service; and so it would be reasonable to expect that patients would feel a need for and want to access this aspect of day-care. However, this was not the case.

The patient and carer view was notably different from the view of the providers who for the most part saw themselves as providing specialist palliative care services; and having a remit equal to that other SPCS with respect to addressing the likely range of complex palliative care needs, especially complex

physical palliative care needs. Therefore, the data showed that there was a disconnect between what patients valued and needed and what APDC providers felt it was their duty to provide. In addition this work also shows that there is actually a persisting difference in opinion between providers and referrers regarding what constitutes a normative need for day-care.

Most referrers expressed that appropriate referral could be on the basis of a social need only-with no emphasis on whether this social need was complex or not. In particular, referrers valued APDC units as they saw them as filling a void especially in terms of the time that could be spent in patient client interactions.

This difference in opinion between what constituted an “appropriate” referral to day-care was important as it served to inhibit access to day-care as patients were declined entry if they had a non-complex social need as their reason for referral.

The unwillingness to accept a person into care who does not have a complex palliative care need (even in times of lower than expected occupancy, and spare capacity) is perhaps a marker of medicalization of palliative day-care. It may be argued that in the descriptions of the first APDC unit in Sheffield there was a referral criterion of sorts. This resulted in the number of chronically ill patients being capped (Wilkes et al. 1978, p. 1055). This however, was not in response to any lack of “appropriateness” of the needs of these patients but rather was a means of insuring that space would be available for the patients that would likely need them most (Wilkie et al. 1978, p. 1055). In the case of this study, the management of occupancy levels was not identified as a primary driving force behind assessment of

inappropriate referrals but rather a need to protect the standards of day-care. The presence of this barrier<sup>82</sup> serves to illustrate the point that referral criteria to APDC will be affected by interpretations and implementation of the definition of specialist palliative care. To this end, it may be useful for mechanisms to be put in place that would facilitate the objective assessment of specialist palliative care need at a policy level. Such mechanisms may need to begin with revisiting the definitions of specialist palliative care, with specific modifications for APDC relating to the scope of practice and or complexity level of the user's need and or the providers skill set and competence. It may be useful for any new definition to build on and highlight evidence which supports the documented usefulness of APDC in addressing the psychosocial needs of clients. This may be a means of informing the users or potential users of the importance of this form of care. The following section discusses changes to the definition of palliative day-care.

### **6.1.3 A new definition of Palliative Day-Care**

As stated previously in this chapter, APDC is classified as a specialist palliative care service which by definition implies that it should be able to respond to clients with “moderate to high” complex palliative care needs (Watson et al. 2005, p. Xxvi). This study found however that day-care services are perceived by patients, carers, and referrers as having the niche of catering for complex psychosocial needs. The high value placed on this niche service as expressed by clients and referrers was not echoed with providers (section 5.3.5, page 184 and section 5.3.11 pages 196-202). However, whether recognised by providers or not, the work found that APDC is fulfilling a key unmet need of clients in

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<sup>82</sup> It is possible that although present in interview data from across the network, that the effect of providers assessing persons as not being appropriate for APDC was not as significant as other factors in determining access; as this accounted for only 5% of the reasons for non-attendance as collected in the documentary analysis.

the provision of specialist social palliative care for both cancer and non-cancer patients. Within the community, palliative care system it was found that it was perceived that specialist medical palliative care needs were being capably managed by other mechanisms such as Macmillan nurses (section 5.3.11, page 196-202). Therefore there may be benefit in APDC being redefined as a specialist social palliative care service, a role which it already seems to have. In the proposed reframing of APDC as a specialist social palliative care system, APDC would still have the remit of responding to basic generalist medical palliative care needs as this was valued by patients and found to facilitate access (section 5.3.5 page 184).

Having day-care positioned as a specialist social palliative care services may be perceived by some a possible loss in status; however, it should be noted that appropriate treatment of non -physical needs e.g. psychological needs is a vital part of the management of some physical palliative symptoms e.g. breathlessness (Bausewein et al. 2010 p. 1116). In addition, changes in definition may serve to increase the level of uniformity between services. Achieving some common service parameters could then make it more feasible to objectively compare the performance of individual services. This may be relevant to securing macro level financing from the NHS or other institutions that may award funding or payments based on the attainment of targets. This may be particularly relevant now in the UK given the interest on end-of life care financing by the DH (Palliative Care Funding Review, 2010, p. 5).

#### **6.1.4 Fear of the term “Hospice”**

Although the association of SPCS with imminent death has been identified in the literature (Parker 2007, p. 59), this study adds new insights into why such perceptions may be persisting in the case of

APDC. Importantly, I found that fear of the “term hospice” was very widespread; constituting a form of common knowledge-growing out of the fact that for many the APDC unit was an unknown entity. I found that APDC was perceived as a liminal border-land place from which a person might not return. I found that the marketing of APDC was such that there had been little or no emphasis on providing the general public with images of what APDC units looked like on the **inside**. Therefore, persons drew on a combination of factors to formulate in their minds what occurred at the “day-hospice”. Most of these images were negative- being connected with historical context of houses for the destitute, or pain and suffering as seen in the hospital oncology ward. Also I found that many persons not only associated hospice with death but also hospice with literal beds. This was particularly relevant to instances where APDC units existed because plans to have bedded units did not come to fruition because of lack of funding. Given the unplanned growth of palliative care as a whole in the UK it may be possible that similar situations (of APDC units being established as replacements for inpatient hospice services) are being repeated around the country.

I also found that the continued labelling of APDC as a “day-hospice” was serving to perpetuate the negative images mentioned in the previous paragraph. However, as was highlighted before at the end of Chapter Five, there is the paradox of the term “hospice” as a barrier to access and the term “hospice” as a facilitator of fundraising. The fact is, that funding of APDC is primarily driven by charitable giving; and using the term “hospice” is part of the established APDC brand. So while wanting to be associated with: life; the concept of fostering wellness; and improving/ maintaining quality of life; APDC units are literally connected with term that is understood as representing, pain, decreased functioning, and death.

There is a need for APDC despite its reliance on charitable donations to consider the effects that the continued use of the word “hospice” is having on access. I suggest that it is necessary to find more accurate ways of describing the service and to link these if needed with the idea of donating to a worthy cause. Further research involving potential service users may also be needed to guide in the identification of appropriate words or images to substitute for the “term hospice”.

### **6.1.5 Marketing and Ethics**

As shown in section above this study found evidence of competing forces between the need to ensure the financial viability of the APDC units and correcting an association of the day-care units with negative images of death and dying. The challenges of funding care are not unique to APDC (Palliative Care Funding Review, 2010, p. 5) and there is a need to consider increased partnerships and or pooling of resources among voluntary sector units and between the voluntary sector and the NHS as also noted in the Palliative Care Funding Review (2010, p. 25). Such partnerships may even be necessary to provide voluntary sector palliative care organizations with greater financial freedom. However, there is also a moral responsibility to market APDC services correctly so as to avoid the development of fear and unnecessary delays in referral because of patients and carers having misgivings which have developed from misinformation.

For many patients their palliative care disease trajectory will involve transitioning through various felt needs and through several health care providers. As shown in section 5.3.14 (pages 212-215), delays in referral can occur when there are too many transitions, or when a referral to an inappropriate health care provider takes place. The documentary data also indicated that 40% of persons who had been

referred to APDC and who were not able to attend would have been referred too late (becoming too unwell or dying before access could occur). Therefore it is from the view point of facilitating timely referral that I suggest that there is an important need for APDC to be marketed correctly and sensitively to patients.

### **6.1.6 Marketing and Psychological Trajectories**

My work has shown that a client's coping skills and willingness to accept a particular diagnosis or prognosis affects uptake of access and use of services. This has led to the formation of the concept of a psychological trajectory which referrers and providers should be willing to objectively assess, and understand. Understanding where a patient is psychologically can guide the ethical introduction of the patient to APDC, and might facilitate uptake earlier.

While my research gives evidence of the existence of a psychological trajectory, I have not as yet articulated what the points in the trajectory are, particularly for non-cancer patients whose physiological disease trajectory waxes and wanes (Murray and Sheikh, 2008, p. 959). Understanding psychological trajectories in non-cancer patients may be of particular importance given the possible effect that acute decline or improvement can have on a patient's mindset and willingness to accept a referral to APDC ( or palliative care services as a whole). Future knowledge about psychological trajectories<sup>83</sup> could be incorporated into elements of the palliative care education curriculae; including

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<sup>83</sup> ***The concept of Psychological Trajectories***

Psychological trajectory is the term being introduced to describe the mental and emotional journey which a person may be expected to traverse during the course of their illness (Greaves 2010c [http://www.bmj.com/content/336/7650/958.2/reply#bmj\\_el\\_240451](http://www.bmj.com/content/336/7650/958.2/reply#bmj_el_240451) (Accessed December 16 2010)). It is similar to the physical disease trajectory commonly used in palliative care to: comment on the physical wellness of patients, and

in the area of clinical assessments and communication skills. In addition, specific work is needed on coping skills and psychological trajectories with persons from ethnic minority given the effect of value systems and religious beliefs on a person's ability to cope (Worth et al, 2009 BMJ 2009;338:b183doi:10.1136/bmj.b183, Hirabayashi 2007, p. 28).

I am aware that skilled palliative care practitioners may already intuitively assess where their patient are with respect to their psychological trajectory by it may still be of use to objectify such clinical parameters using psychological tools. This may be particularly useful for less experienced practitioners who need help with identifying the ideal time for referral and or assistance with documenting care pathways or patient choice.

#### **6.1.7 The day-care model in times of austerity**

In my study I found that most APDC units were operating a mixed model of care with current emphasis on increasing the level of medical input which they offered. The work also indicated that the total operating cost would increase with further expansion in medical services to care for persons with non-cancer diagnosis. Providers expressed that the extent to which services could be extended would be limited by the available financial resources as these persons were thought of as requiring greater levels of nursing care and or specialised medical support equipment section 5.3.8 (page 189-191).

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illustrate the different illness course of palliative patients with non-cancer and cancer diagnosis (Murray and Sheik 2008, p. 958-959). It refers to a **projected** pathway and has similarities to the stages of grief identified and articulated by Kubler-Ross (1969). The concept of Psychological Trajectories sees the person who has been diagnosed with a life-threatening illness as starting on a journey which includes accepting a diagnosis and may lead to accepting and coping with the real possibility of imminent death.

As discussed in section 2.1 (page 72) there has been a call to broaden access to palliative care services. While it might not be possible for APDC units to expand care to non-cancer patients in an unlimited way some guided expansion may be possible- especially through the development of new delivery models of APDC.

#### *New models of care*

In 2008 one of the APDC units in the network piloted an evening service for non-cancer patients. The focus of the service was to provide social interaction for patients with clinical monitoring being provided by their heart failure nurse. It is possible that through partnerships like this one APDC may be able to expand care to non-cancer patients while controlling cost. Developing models of care that can respond to the needs of non-cancer patients may be a useful area of focus. Bausewein et al. 2010 (p. 1115) showed that breathless COPD and cancer patients have comparable symptom burden. In addition she showed that the length of time that the non-cancer patient has to cope with their breathlessness is longer than that for the cancer patient (survival time for COPD patients was 482 more days than that for cancer patients); therefore consideration would have to be given to the discharge and re-entry pathways for such patients given their typical disease trajectories.

As stated previously in the work of Goodwin 64% of APDC units rely on voluntary funding, therefore the limitations of funding found in this study is not likely to be unique. Given the relative vulnerability of the APDC funding supply it may be useful for providers to consider the benefits of: a) broadening their funding based or b) narrowing the scope and level of services provided. Previously in this chapter

we saw that patient, carers and referrers valued the psychosocial services provided by APDC and a specialist social palliative care model was proposed. Therefore, to facilitate continued operation through times of austerity or poor fundraising it may be useful for day-care units to perform local research and adopt financially viable forms of care that would be relevant to all/most categories of potential users. It is possible that a specialist psychosocial service would have cheaper start up and or operating cost. However specific health economic research would be needed to guide any such service change. (This study found that access to APDC services may be facilitated by the institution having a non clinical atmosphere<sup>84</sup>; with a “home away from home” feel. This has been described in Chapter Five section 5.3.6 page 186. This “home away from home” environment, consistent with a decor that life, should be continued regardless of an emphasis on medical or social needs).

So far I have discussed the study with respect to the interpretations and implications of the findings on access. I would now like to briefly consider the usefulness of the conceptual frameworks in understanding access.

### **6.1.8 A discussion on the usefulness of the conceptual frameworks first theorised in Chapter Two**

In Chapter Two, a dynamic framework was designed in which it was theorized that potential users are only able to utilize a health service if they are able to successfully negotiate a series of stages that influence access. These stages were termed firstly, the stage of potential access, secondly the point of

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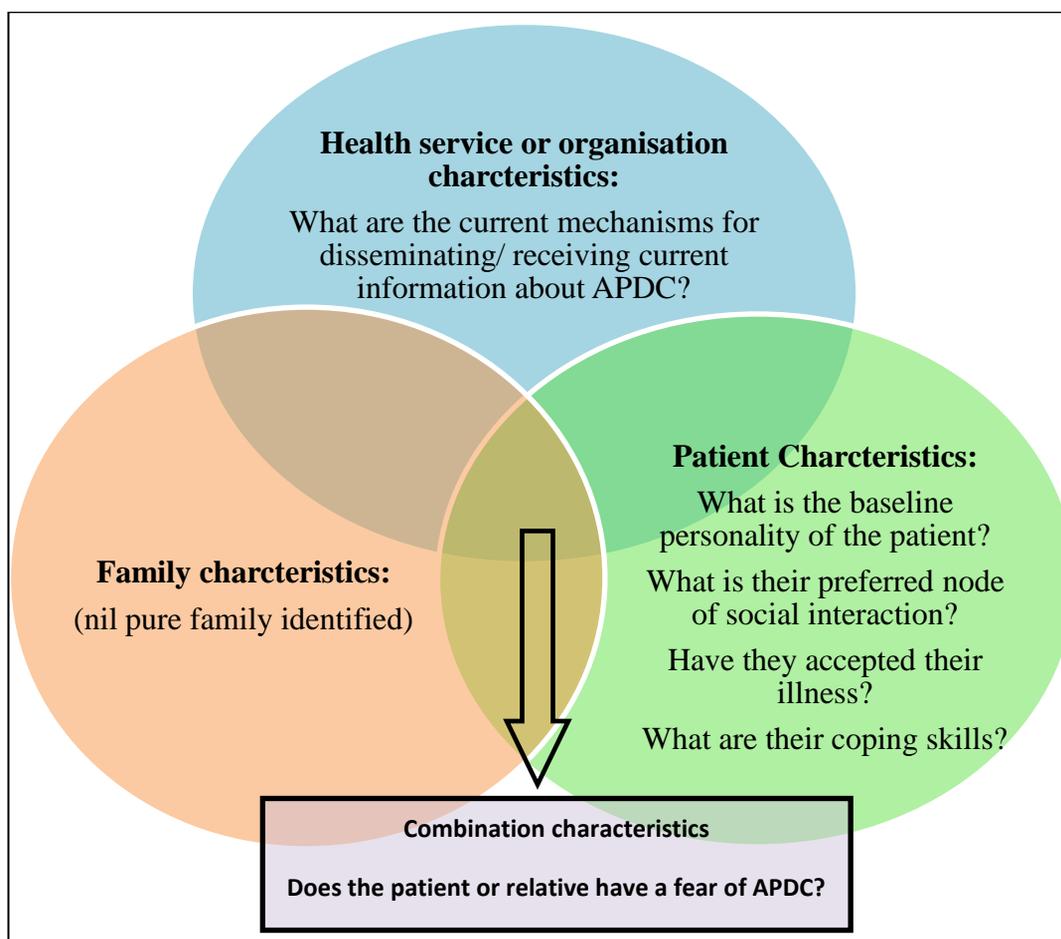
<sup>84</sup> It would be important to investigate aspects of interior design and its impact on different client groups' use of APDC units. This may be particularly as the specific elements of culturally competent care will vary between ethnic groups (Worth et al 2009, p. 7 BMJ2009;338:b183doi:10.1136/bmj.b183). Such information could be then used to guide future design of services in an increasingly multiethnic and multicultural society.

gaining access to the service, and lastly the stage of actual utilization. The study found that the factors which influence access can be framed and analysed in light of these three stages. In particular, the study was able to identify potential factors and interactions of factors which affect the direction taken along the theoretical access pathway by potential service users. Thus, the dynamic conceptual framework represents a potentially valuable new tool for investigating access in other APDC and palliative care services<sup>85</sup>. Figure 6.1 shows a modified static framework with sample questions that might need to be addressed in assessing the factors determining access.

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<sup>85</sup> While the two conceptual frameworks were designed to complement each other, the dynamic framework may be used alone if: there are already sufficient factors identified as affecting access. In such a case the dynamic framework could give insight into where and in what direction factors affect the access pathway.

**Figure 6.1 An applied static access framework (this could be modified to form a patient conversation map to identify factors which might influence access)**

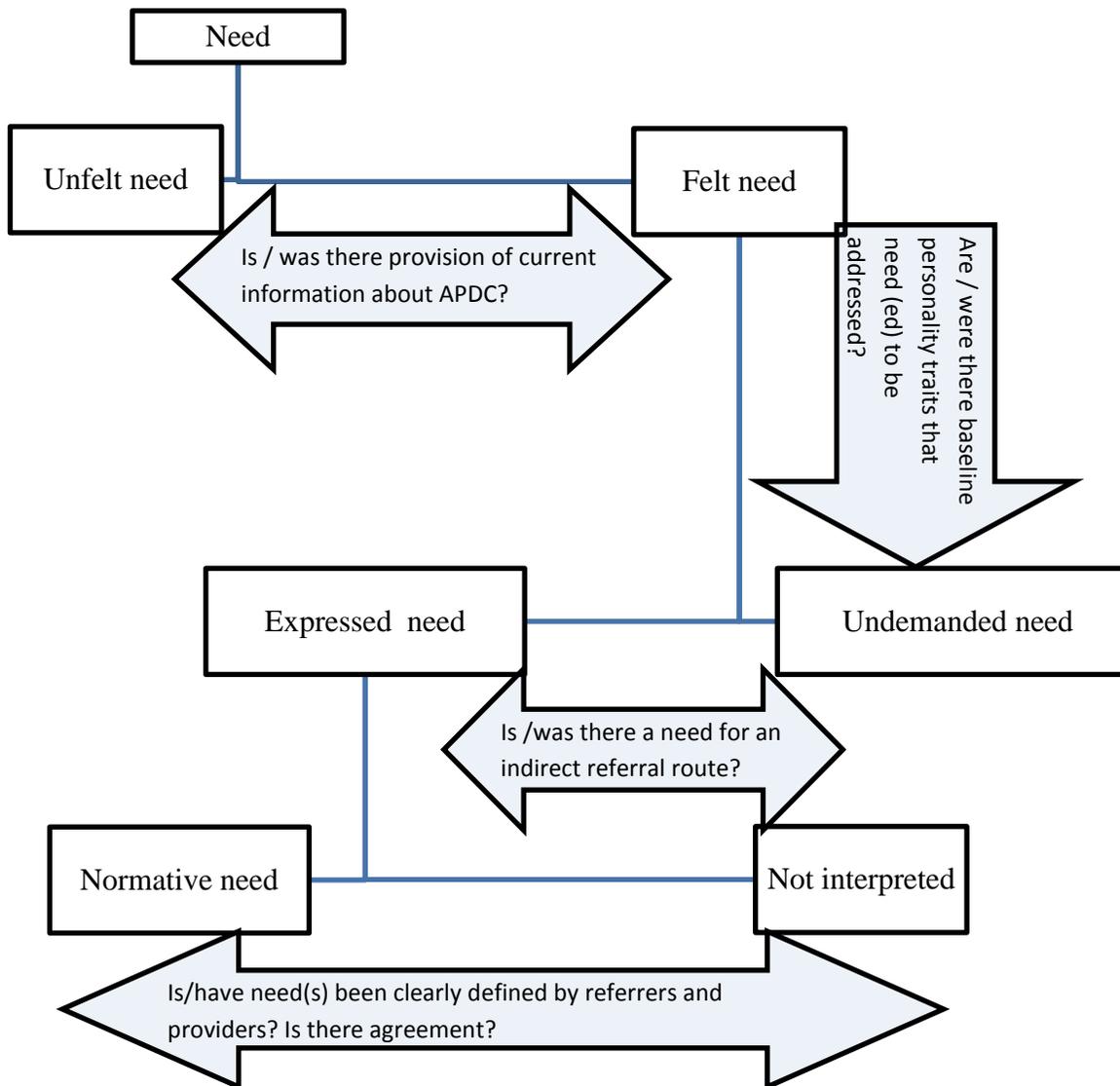


6.1.8.1 Possible practical application of the dynamic framework

From the study it was seen that all of the APDC units had or were considering policies outlining discharge criteria. A revolving door discharge plan was described, where although a person could be discharged, access would not be prevented if a need for the service reoccurred. In such cases of

discharge and re-entry, understanding and documenting the original dynamic access pathway of an individual patient, may serve to facilitate their re-entry by the avoidance of barriers, and use of facilitators that were previously found to affect a given client. Likewise, on an institutional or network level, using the dynamic pathway framework to identify where barriers or facilitators to initial access or re-entry are occurring may inform policy on improving access. An example of an operationalized stage one of the dynamic framework using some of the results of the study is shown in Figure 6.2.

Figure 6.2 Stage one of the dynamic framework integrating some results



The two conceptual frameworks have been valuable in providing a means for identifying and framing investigation of access to APDC, resulting in the identification of factors which facilitate and act as barriers to access, and may be of use to readers.

## **6.2 Chapter Summary**

This chapter discussed the study's findings on access in the context of what was known from the literature; the new insights added by the work, and suggestions for further work. The remaining chapters of the thesis provide the reflexive account and a discussion of the limitations of the study. This is done as a means of showing objectivity and to assist the reader with interpreting the results.

### 6.3 Key Points

- Access to palliative day-care is a complex process, affected by many determinants some of which act synergistically to facilitate or inhibit access.
- The two conceptual frameworks initially proposed for the investigation of the study may be of practical use to the individual practitioner and at wider system levels; assisting in the identification of determinants of access to APDC and other palliative care services.
- There was evidence supportive of arguments in the literature of there being inequalities of access. However, this may be occurring in the presence of over capacity versus underutilization. This study identified specific barriers to access faced by patients with a non-cancer diagnosis, and persons from ethnic minority background. In the case of persons with a non-cancer diagnosis this included decreased access as a result of financial limitations and the impact that these limitations placed on obtaining human and other resources that would be needed to care for non-cancer patients.
- Implications for clinical practice and medical education were identified. Suggestions for future research were also made. Some of the implications for practice are given below.

For referrers, implications relate to the assessment and understanding of patients fears and needs and improving their understanding of the APDC service; including their admissions process and or criteria.

For the APDC providers implications relate to developing clinical care that meets the needs of patients and their carers; including the need to have flexibility regarding how the services are accessed and used.

- Areas identified for further research include:
  - the need to understand the psychological trajectory of patients
  - the role of interior design in the process of achieving access to an APDC service that is sensitive and responsive to different user groups (age, ethnicity, social class etc), has been identified as areas for further research.

## **CHAPTER SEVEN:**

### **Reflexivity**

#### **7.0 Introduction**

Reflexive awareness was one of the methods used during this research to improve the reliability and validity of the work. As part of this process, I constantly reflected upon my activity, so as to monitor my impact on the research process. This was done through all stages of the research, but was particularly important during periods of data collection and analysis. This chapter gives an account of these reflexive awareness activities.

The chapter starts by first setting out the definition of reflexivity used in this work. It then proceeds to establish the importance of reflexivity and reflexive accounts to assessing the confirmability and interpretation of qualitative data. Specific reflexive accounts are then presented, followed by an analysis of how the reflexive process affected the ascribing of meaning to data.

In keeping with the presentation format of the thesis, the chapter concludes with a summary of the main contents of the chapter, presented in section 7.5.

## **7.1 Reflexive Awareness**

### **7.1.1 Reflexive awareness and its importance to qualitative research**

Reflexive awareness or reflexivity is a method which may be used by the qualitative researcher as a tool for improving the methodological rigor of the research process (Payne 2007 p. 128). As qualitative research is usually employed to understand the subjective experiences of human participants, it may sometimes involve increased levels of interaction between the qualitative researcher and the research participant and research material (Sword 1999, p. 270 referencing Daly 1992). Because of this often intensified relationship between the researcher and participants or data, qualitative researchers are advised to be aware of the effect which they may have on the construction and interpretation of data (Bowling 2002, p. 363, Sheldon and Sargeant 2007, p. 166-167). Therefore, as stated by Green and Thorogood, reflexivity represents the researcher's "conscious reflection on [the] process" by which data and its meanings are produced (Green and Thorogood 2005, p. 194).

From the interpretivist view point from which the study was approached I aimed to be aware of and to "account for the presence of self in the collection of data" (Sword 1999, p. 270-278). This process assisted me in data collection (Bloom and Crabtree 2006, p. 317), and in achieving analytical rigor, and in providing context to the reader of the work (Green and Thorogood 2005, p. 195). As stated by Sword 1999, p. 270:

"Reflection on the influence of self not only creates personal awareness of how the research is shaped by one's own biography but also provides a context within which audiences can more fully understand the researcher's interpretation of text data".

Within qualitative research, methods for achieving reflexive awareness and objectivity include: the keeping of research journals or personal notes (Payne 2007, p. 158); “memoing” (Payne 2007, p. 158, Miles and Huberman 1994, p. 66, 72-75); data summary sheets (Miles and Huberman 1994, p. 51-53); and in the case of observation based research, inter-observer comparisons (Bowling 2002, p. 363). On a less method-specific note, Green and Thorogood suggest that reflexive awareness might be attained through or by addressing the issues of:

“methodological openness; theoretical openness; awareness of the social setting of the research, and awareness of the wider social context” (Green and Thorogood 2005, p. 195).

I subscribed to this less specific school and sought to be open about the theories that were influencing the research and conduct. These can be found in the sections on philosophical paradigms shaping this research and the discussion around the choice of research methods that are provided in Chapter Four sections 4.1.2 (page 112) and 4.3 (page 118) respectively. In addition, I reflected on my initial motivation for conducting the research and presented this as an introduction to this thesis. In this second-to-last chapter I will present accounts of the social, and research setting and interactions between myself and research participants as influenced by Green and Thorogood 2005, p. 195 and Crossley 2007, p. 187).

## **7.2 Reflexive awareness of the social setting of this research: The interaction between the researcher and the researched**

In this section, the format used by Sword 1999 will be used to present the reflexive accounts of the interaction between participants and me. Sword’s work on reflexivity was based on her own research which sought to understand health seeking behaviour, particularly consumer-health system interactions

in the antenatal care setting in Ontario, Canada (Sword 1999, p. 270-280). Though she does not frame her accounts as interactions between the researcher and the researched, the “reflections on the presence of self” which she provides, are in fact compatible with this terminology as described by Green and Thorogood (2005, p. 195).

The research presented in this work is similar to Sword’s work, in that both studies share the theme of understanding aspects of health seeking behaviour. However, this commonality in theme is only a minor factor in commending Sword’s format for use in presenting the reflexive account of this study on access to APDC. In her three categories of: acknowledging emerging feelings; managing the role as researcher; and making meaning of text; Sword creates a classification system under which issues that should be presented in robust reflexive accounts may be placed. These issues facilitate the acknowledgement of social “differences” (Bloom and Crabtree 2006, p. 317) including the management of professionalism and power (Richards and Emslie 2000, p. 73-74).

At first glance, Sword’s category of “making meaning of text” may seem to be more in keeping with Green and Thorogoods’ issue of methodological awareness, as opposed to awareness of the interaction of the “researcher and the researched”. However, the process of analysis employed in qualitative research, justifies the process of interpreting or “making meaning of text” as being viewed as a continuation of the interaction between the researcher and the researched.

Qualitative data analysis, particularly the cyclical model used in this work (section 4.5, page 128 and 4.11, page 153), necessitates that the researcher be continually immersed in the data. The acts of

listening to tapes, reviewing transcripts, and making connections between various experiences, perceptions and views, all involve elements of reliving the interview interaction at each analytical step. This cyclical process represents a form of continued interaction between the researcher and the participant, of which the researcher also needs to be aware (Sheldon and Sargeant 2007, p. 166-167). So, it is with this understanding, that the process for making meaning of text is also being discussed in this chapter on reflexivity.

### **7.3 Specific Reflexive Accounts <sup>86</sup>**

#### **7.3.1 “Acknowledging Emerging Feelings”**

Prior to conducting interviews, I was aware of research which highlighted factors which may affect the conduct of qualitative research, for example, the choice of research setting, and personal characteristics of the researcher, such as gender, age, cultural background, and professional status (Bloom and Crabtree 2006, p. 317, Richards and Emslie 2000, p. 72-75, Sheldon and Sargeant 2007, p. 169-171). My greatest concern was with respect to the impact which my personal characteristics would have on the quality of data collected, particularly those characteristics which might cause me to be viewed as an outsider, or which would act in some way to inhibit the development of trust and rapport between myself and research participants.

Of note, I was aware that my relatively young age (28 years at the time of commencing the research), as well as my cultural (Barbadian) and professional background (medical doctor with non-UK clinical

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<sup>86</sup> The reflexive accounts will be presented in the first person singular.

experience in oncology and palliative care), might present a social disconnect, which might result in my having an outsider status. Sword in describing her own feelings towards the effect of her personal characteristics, describes having research anxiety. Though I did not experience anxiety, I did have a level of concern that my personal characteristics may be perceived negatively. This resulted in actions being taken on my part with the intention of; minimising the occurrence of any negative skewing of the research process because of my personal characteristics; and increasing the likelihood that participants would view my arguably outsider status as being beneficial to the research process. These actions are described below.

### **7.3.2 Managing the effects of being an outsider**

The mechanisms which were used for minimising negative effects were those which were found to be beneficial to other qualitative researchers, particularly those conducting cross-cultural research in sensitive research areas.

#### *7.3.2.1 Minimising Language/Communication Barriers*

With respect to minimising the effects of language barriers, I was aware that though my academic English language proficiency score (IELTS) was 8 that this did not necessarily translate into a guarantee of native fluent communication. I was conscious of the fact that the intonations, word contractures, and subject verb agreement in my native Bajan dialect could present difficulties to Standard English speakers. Therefore, in the 3 year period of conducting this research I made the decision to use Standard English as my first language, including in the home setting. Also, in my daily

interactions with fellow researchers who were British, I took the opportunity to learn and clarify the meanings of such distinctly British phrases as “swings and roundabouts”, “Joe Blog” and “porkie”.

During the actual process of interviewing, my awareness of the importance of my use of language in communicating continued. I adopted strategies such as speaking slowly, so as to minimise any problems relating to accent. In addition, to facilitate rapport building and minimise any issues of professionalism and power I employed active listening (Burr 1996, p. 174, Bloom and Crabtree 2006, p. 319) and avoided the use of medical jargon.

#### 7.3.2.2 Facilitating the development of trust

To facilitate the development of trust between myself and participants, I was conscious not to inhibit casual conversation before the start of the interview and freely answered or clarified questions which participants had about elements of the research and my personal characteristics. As I had anticipated most of the personal questions were about the origin of my accent, the answer to which resulted on many occasions on participants proceeding to happily describe holiday plans, or discuss cricket. Other discussions, particularly with health professionals, involved participants sharing their personal work experiences and asking about my experiences with working with palliative care patients in Barbados. Often in these discussions, participants spoke of their motivation for being involved in palliative care, burnout, and dealing with the death of patients. These pre-interview discussions were very effective, increasing participants’ comfort levels and creating a comfortable interview environment, and in the case of health professionals, a subtle form of kinship.

In situations where the pre-interview discussion included discussing issues related to palliative care, I was very careful not to discuss issues related to access or service delivery of palliative research, and to curb my enthusiasm for palliative care. These measures were taken to avoid priming the participants to the research questions, and biasing the participants to what they might think were right or wrong answers. Therefore, all pre-interview activities were carefully reflected on so as to achieve balance between creating a comfortable research environment and “contaminating” the research data.

It has been shown that patients who are approached regarding participating in research may not always recognise that they have the right to decline participation (Jubb 2002, p. 343), also they may feel the need to please the researcher, and not give factual accounts out of the desire not to jeopardise their care (Addington-Hall 2000, p. 221).

Establishing and maintaining this openness at the start of interviews also had the benefit of facilitating post-interview discussions. These were found to be particularly useful in maintaining a connection with participants who wanted to review the transcripts of their interviews; and also for facilitating closure of the research process for those participants who did not want to review transcripts. With respect to achieving closure, the post-interview discussions provided me with the opportunity, to thank participants in person (participants also received thank you letters, and in the case of a few health professionals, thank you e-mails), reassure them that their contributions were useful and appreciated, as well as restate information on the Participation Information Sheet (PIS). The reemphasised information included the confidentiality of their interview, the dissemination process for the research results, the

availability of post-interview counselling if they required such, as well as the availability of the contact information for the research team on their PIS.

### 7.3.2.3 The benefits of the researcher being perceived as an outsider

As was described in the earlier sections of this chapter, there were particular characteristics of mine which may have caused participants to view or categorise me as an outsider. Being an outsider or being viewed as an outsider does not automatically have a negative impact on the research process.

This benefit stems from the fact that the outsider researcher may be able to identify characteristics in the research setting which an insider researcher may have become accustomed or immune to because of the practices of the research site being part of their societal or cultural norm (Sheldon and Sargeant 2007, p. 174). I also found this to be my experience while conducting this research. As an independent, outsider researcher, I saw myself and sought to represent myself as an objective non-partisan researcher not affiliated with the cancer network or any given hospice. Also I saw that my previous international experience, as well as my not being part of the palliative care system in the network, added to my ability to identify processes in service organization and delivery which had been normalised within the network, which were acting as barriers to accessing services .

On a non-individual level, as it relates to the identification of emerging themes, two of the three members of the supervisory team which guided aspects of this research were also outsiders, i.e. as it relates to being involved in the provision of palliative care within the cancer network. This, I believe, also increased the ability of the research team to identify barriers to accessing care which might have not been identified if all the researchers had been indigenous to the network.

### **7.3.3 Managing the role as researcher**

It was important to be continually aware of the professional image which I was projecting to the participants, as this has been shown to affect the quality of qualitative research. Firstly, I was faced with the decision of choosing in which profession I should frame myself. Should I acknowledge to participants that I have a medical background, or should I, like Emslie (Richards and Emslie 2000, p. 73), present myself as the girl from the University who was conducting research?

Given that the research was in a sensitive area involving potentially vulnerable characteristics, I felt that it was important to inform persons of my medical background. I did this through using my professional title and qualifications on all correspondence, and when introducing myself at the time of first verbal communication, in most occasions this was by telephone. In addition to acknowledging my professional medical background, I also made it clear that I was a medical doctor; and was currently undertaking academic research at the University of Warwick, with the partial source of funding being the cancer network. These disclosures were a necessary step in adding to the credibility and the legitimacy of the work, which may have the advantage of reassuring participants that the research was safe and being conducted by professional and competent individuals.

In keeping with the projection of a professional image, on conducting interviews, I adopted professional attire more in keeping with my background as a physician than the perhaps more casual appearance which may be expected from a student researcher in a medical sociology related field (Richards and Emslie 2000, p. 73). In addition, when recruiting participants and conducting interviews, I ensured that my university photographic identification card was always prominently displayed.

### 7.3.3.1 Managing the role of researcher: Balancing power and status

It has also been shown that the development of rapport is negatively affected when there are perceived inequalities of status between the researcher and the researched. This may be particularly problematic where the researcher is seen as occupying the more powerful position.

In the case of the later, it has been found that disclosures of professional backgrounds can contribute to this shift in the balance of power in the relationship between the researcher and participants, including patient-physician relationships, where patients may have a desire to please the physician researcher so as to avoid negative impact on their treatment (Addington- Hall 2000, p. 222). On reflecting upon this possibility, a preventative mechanism was put in place, in that all participant information sheets clearly stated that decisions to participate would have no impact on treatment/employment of participants and or their relatives.

In addition to reflecting on the impact that my declaration of professional status may have on patients, I was also aware of the potential to complicate interactions with health professionals. Particularly as medicine and health care in general have been disciplines in which historical hierarchies have existed among various categories of professionals and specialities which could potentially complicate the development of a trusting relationship. Being aware of this potential difficulty, I sought to establish a peer type relationship particularly relating to use of titles. Though I used my professional title in correspondence, and in introducing myself at the time of the first verbal conversation, at subsequent phone calls to arrange meetings or when conducting the interview, I used my first name, which was the culturally norm for communication among professional peers.

I found that performing these steps, decreased the formality involved in the interviewing process, and resulted in interviews having the form of a comfortable, purposeful conversation. Reflecting on the potential balance of power in this case, also served to increase the depth of the data collected.

#### **7.3.4 Making meaning of texts**

The main aim of the reflective process which occurred while making meaning of text was as ensuring that at all times I was “[preserving] participant’s meanings while being aware of [my] personal and professional meanings” which I was bringing to the analysis from my background (Sword 1999, p. 275).

In addition to being aware of my limitations and potential biases, I sought to address possible theoretical limitations of my knowledge, by maintaining dialogue with other members of academic disciplines connected to the themes emerging from this work e.g. medical sociology, and business. I also attended research group meetings outside of my faculty, as a means of broadening my theoretical base.

As stated in Chapter Four, the data analysis process was conducted with the input from other members of the research team. Being able to discuss and challenge emerging themes as well as the conceptual framework with other members of the research team, was an important step in the robust conduct of the study. In one particular instance, other members of the research team were particularly valuable in challenging statements which I had made regarding the morality of inequities in palliative care. At that time, these statements could not be substantiated by previous theories or the data set, but were rather an expression of my past life’s experiences, and feelings about the provision of care for the dying. This

particular scenario served to reinforce my awareness that in my making of meaning with the text, it was essential to consistently compare and contrast the data set before concretising emerging themes, thereby avoiding arriving at conclusions too early .

#### **7.4 Reflexive awareness of the wider social context of this research: Funding and its effect on the shape of the data**

The work presented in this thesis was commissioned as part of the wider research agenda of the cancer network. Though I was cognisant of the fact that the core topic of interest was access to palliative day-care, it was important that the scope of the research was not unnaturally hindered by the topic of interest of the funders. Firstly, this research had a large exploratory function. Therefore, it was important for me to avoid any attempts to narrow the scope of the research which could have prevented the investigation of issues which on the surface might not have appeared to be relevant to the core research topic.

In addition to the above engaging with other researchers and academic processes such as upgrading from MPhil to PhD were useful in ensuring that the full theoretical scope of the project was pursued.

Although I would have been actively reflecting throughout the research process, and would have had input from my supervisors no research is without limitations. Therefore the last chapter of this thesis presents my assessment of these. This chapter concludes with a chapter summary in the form of a text box.

## 7.4 Chapter Summary in the form of Key Points

### Chapter Seven: Main Points

- Reflexive awareness was one of the means of addressing validity in this research.
- During this research I reflected on such issues as my personal characteristics which may have resulted in my being viewed as an outsider, or as being in a more dominant position to participants, because of my professional background.
- Pre-emptive measures were taken to address the above issues, so as to ensure the collection of good quality data.
- During the data analysis process I also reflected upon and was aware of :
  1. the impact of my personal background on the conclusions drawn from the data;
  2. the limitations of my theoretical knowledge;
  3. and the impact which responsibilities to funders might have on the conduct of research and the results were produced.

Measures were also put in place to minimise or avert any negative outcomes during the data analysis process.

## **CHAPTER EIGHT:**

### **Limitations**

#### **8.0 Introduction**

##### *Purpose of the chapter*

The work presented in this thesis was conducted in an attempt to further the understanding of accessing APDC. In Chapter Six the results of the work were presented and their relationship to existing knowledge discussed. This chapter (Chapter Eight) provides a systematic critique of the research process, in which the limitations of all the major sections of the work are discussed.

##### *Organizational structure of the chapter*

This discussion of limitations is done in a sequential manner, starting with conceptual phases of the work such as the literature review stage, and continuing through to data analysis. In addition consideration is given to the impact which limitations may have on the interpretation and application of the results.

## **8.1 Limitations**

### *Introduction*

This section as stated in the introduction presents the limitations of the research process. It describes the challenges encountered, and where relevant compares these to those experienced by other researchers who have conducted similar work. The measures taken to address limitations or challenges are described, and where appropriate, explanations are given as to why the existence of some limitations are not seen as reducing the quality of the research.

### **8.1.1 Limitations of the literature review process**

The literature review process was started in September 2005 (section 1.5, page 41) with the general remit of identifying the gaps in knowledge so as to focus the research on understanding utilization of APDC. Therefore, the literature review could be described as being for “knowledge support” (Mays et al 2005 p. S1:8).

On planning starting the review I realised that in order to meet my general aims, it would be necessary to collect data which would provide insight into: health seeking behaviour; palliative care and APDC history and services descriptions; as well as evaluations of service design and delivery<sup>87</sup>. It therefore,

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<sup>87</sup> Review of the literature of health inequalities began in May 2006 after the upgrade.

became evident that small but broad searches would need to be conducted. These early search strategies<sup>88</sup> ( in the areas of access and palliative care, and palliative day-care started) were limited by possible overreliance or selection of biomedical databases, such as MEDLINE, Cochrane database of systematic reviews, and American College of Physicians (ACP) Journal club. This would have resulted in the retrieval of more quantitative type research; including more US based evidence with specific reference to MEDLINE (Egger et. al 2009, p. 626).<sup>89</sup>. Therefore a search strategy which would have included databases CINAHL and PsycInfo, and EMBASE (in addition to MEDLINE) from the outset may have yielded more relevant data sources.

In acknowledgement of this limitation a further narrative review with a focus on palliative care with an expanded search strategy was conducted in March 2010, to identify any missing evidence in this area. The results of the scoping search of this review were significant as it identified only 5 relevant articles.

The literature review process was also limited in the process for selection of articles.

It is acknowledged that the results of literature reviews may be influenced by the quality of the evidence which they include (Gray 2001, p. 107); with their being various criteria for assessing the quality of quantitative and qualitative research (Centre for Evidence Based Medicine-Critical appraisal sheets <http://www.cebm.net/index.aspx?o=1913>, (Accessed 21 December 2010), Tong et al. 2007, p.

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<sup>88</sup> In addition to the use of databases the search strategy also involved, searching the bibliography of retrieved articles, as well the publication and project list of palliative care and policy research organizations e.g. The King's Fund. Evidence received from personal communication with policy makers in the cancer network was also included in the literature review.

<sup>89</sup> The Scopus data base was used to facilitate the retrieval of social science work, including qualitative work.

349). However, as this review was likely to include both qualitative and quantitative data, and was being performed to gather knowledge in a particular area with the aim of developing theories (to guide investigation and understanding of accessing APDC), it was seen as advantageous to not exclude studies on the basis of particular methodology or study design components (Mays et 2005, p. S:1: 9). Instead, broad exclusion criteria were used, with the strengths and weaknesses of individual studies being noted, and presented in the prose of Chapter One when the work was referenced.

As the work was focused on adult palliative day-care, evidence relating to studies reporting on services with a target clientele under 18 years old was excluded. Also excluded were studies reporting on single patients. The evidence informing the literature reviews was not limited by language.

Finally, the narrative literature review process may perhaps be limited by the fact that I was primarily responsible for the process. Such situations are not uncommon in supervised student-led research. However, given the broad inclusion criteria, and the easily applicable exclusion criteria, and the presence of supervision, this limitation is not seen as a limiting factor which would result in diminished quality of the work.

The limitations of the study relating to the study design will be discussed in the sections below (8.1.2-8.1.7).

### **8.1.2 Limitations of the study design relating to the study site and recruitment of participants**

A cancer network which is located in the Midlands region of England was chosen as the study site.

Although the decision to base the study in this location was influenced by funding, it is also important to note that the decision to choose the study site was also purposive and informed by the literature. As previously stated the aims of the research included understanding access to APDC, therefore, it was necessary to choose a location that would allow insight into this process from a wide a variety of perspectives, and experiences. As was described in Chapter Three (pages 91-108) the study site was seen as being appropriate for investigating access to APDC as it:

1. Provided the opportunity to study access to APDC in areas;
  - a. described as urban and rural areas;
  - b. with low and high levels of deprivation;
  - c. with different ethnic compositions<sup>90</sup>.
2. Contained APDC units which:
  - a. seemed to be experiencing issues of under-access seen nationally.
  - b. offered services similar to those described in other parts of the UK;
3. Contained varied health care sectors and infrastructure. This would allow for the collection of views from wide cross section health professionals who would theoretically be involved in the referral of patients to APDC.

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<sup>90</sup> When taken as a whole the network had a non-white ethnic minority population which was in keeping with the national average. However, at the time of undertaking the study the specific areas in which the APDC units were located had lower than national average non-white populations (see chapter three). Therefore it may be argued that the palliative population being studied would be relatively ethnically homogenous. However, it should be noted that within the network, there was one area with an ethnic minority population that was more than double the national average; with referrers and patients from this area having the potential to access four of the five APDC units in the network.

Despite these advantages of the study site and the use of methods aimed at sampling to achieve maximum variation it was not possible to recruit participants from all the groups identified for purposive sampling during the study design phase.

Firstly, there was difficulty with recruiting hospital consultants and General Practitioners as result of their work constraints and time pressures. There was also limited participation in phase one from provider professionals at sites 4, and 5. This was a result of significant internal restructuring occurring at this site during the time of conducting the study. Also, “it proved impossible to interview potentially eligible patients who were non-users because of non-take up of a referral” (Greaves et al. 2010d, p. 20). Ethical issues, together with poor health or death, prevented their recruitment. This limited the extent to which determinants of access could be identified from the first person accounts from this subset of potential users (Greaves et al. 2010d, p. 20).

The challenges of conducting research with palliative care patients or carers and some possible solutions for overcoming these have been noted in the literature (Addington-Hall 2002, p. 221-223, Jubb 2002, p. 345, Payne 2007, p. 241, Pessin et al. 2008, p. 628). These were taken into account during the design of the study.

Engaging with APDC staff during design and recruitment was invaluable to the research process. Firstly, it served to foster trust between myself and the APDC providers regarding the safety of the work. Secondly, it allowed providers to function as knowledgeable local research facilitators, being

able to confidently address questions regarding the study design and research protocol. This engagement process also in turn facilitated the recruitment of patients and carers into the study.

Despite the above mechanisms and relationships being in place difficulties were still encountered with recruiting patients. These were related to: delayed ethical approval; relative protection of patients; and attrition due to ill health. The experience of this study shows the importance of researchers not only engaging with potential clinical gatekeepers, but also of designing new ways to safely obtain the voice of and experience of “vulnerable” participant groups. In this work the use of documents allowed for some insight to be gained into the experience of patients who were referred to APDC but did not attend. Engaging palliative participants in the role of co-researchers in the day-care has also been reported (Wright et al. 2006, p. 821-822, 824). This however, as noted by the researchers created “atypical dynamics” in the focus group that was conducted as participants “had known each other” (Wright et al. 2006, p. 824). While the methods used in the work of Wright et al. were not directly suitable for this particular study, there may have been a role for the participants especially those who were found to be more inaccessible to act as co-researchers (had they been recruited). Such a study design could allow patients’ greater autonomy in their individual data collection process by occupying the role of both interviewer and participant, e.g. using self-controlled video/ audio diaries guided by research protocol based interview schedules.

In relation to palliative care research it might be expected that there may be difficulties with the recruitment of patient participants due to relative protection by ethical processes and attrition secondary to health or death (as presented above). What was perhaps more unexpected was the difficulty with recruiting hospital consultants and GPs because of work and time pressures. Altering

the data collection methods to include telephone interviews did improve the recruitment rate (of General Practitioners in particular). Whilst this might be seen as a solution to overcoming recruitment issues, it should be borne in mind that this added another layer of complexity, as data analysis then involved interviews collected using different methods. However, by analysing preserved words through transcripts (Dickson-Swift 2007, p. 330, Silverman 2007, p. 203-205), and adhering to the principle of saturation (Green and Thorogood 2005, p. 180-181), it was possible to obtain legitimate insights in-spite of the varied collection methods.

In addition to those limitations regarding recruitment already discussed there was an under-representation of participants from ethnic minority groups. In the documentary analysis of 149 reasons for non-attendance only 1 represented the view of an ethnic minority person (1 White Italian); of interviews with participating health professionals only one person was an ethnic minority (a provider of palliative day-care). I was also unable to recruit any patients or carers from ethnic minority groups. Further, all of the participants were English speakers.

In light of the above, although saturation was reached, the results of the study have to be interpreted bearing in mind that the study participants were relatively homogenous with respect to ethnicity and language and, perhaps by extension, culture. Also because the theory of key informants was applied, the results of the work need to be interpreted in the context of participating referring health care professionals having been more informed about palliative care services than their colleagues serving the same area.

It should be noted however, that the usefulness or applicability of the results to the wider population or other research settings is not necessarily diminished by the use of key informants or arguably homogenous nature of the participants. As stated earlier, this study used purposive and theoretical sampling (Clark 1997, p. 163, Turato 2005, p. 4) and as such was not designed to achieve statistical representation of the population as a whole, as may have resulted from random sampling used in quantitative study (Sale et al. 2002, p. 45, Green and Thorogood 2005, p. 197). Instead, this study (like other research which uses qualitative methods) may be applicable to wider populations and other research settings because:

- a) of the concepts it generates that are not context specific ( Clark 1998, p. 1246, Green and Thorogood 2005, p. 198-199, Popay 2006, p. 571);
- b) of its potential to [sensitize the reader] to new ways of thinking” (Green and Thorogood 2005, p. 197).

As a result of the work being conducted in a single cancer network, there were certain challenges to the protecting the identity of participants. These challenges as well as the effect they may have on interpretation of the data are described in the following section.

### **8.1.3 Limitations of the study design relating to ensuring anonymity and the effect this may have on the reader's interpretation of results**

The cancer network studied contained 5 APDC units, with only one person occupying certain post at individual units at any given time. This created a situation where it might have been possible to determine a person's identity if both their post and the geographic location of the APDC unit at which they worked were stated. As a result a system of coding participants was created as a means of preserving anonymity. In this system a single term was used as a label for several posts. Therefore, a person identified in the data as being a management-level provider, may have actually occupied the post of Chief-Executive Officer, hospice manager, or board member. This process of preserving anonymity by using a single term to represent multiple posts, was necessary for the protection of the rights of participants ((Statement of Ethical Practice for the British Sociological Association (March 2002) [http://www.britisoc.co.uk/equality/Statement+Ethical+Practice.htm#\\_anon](http://www.britisoc.co.uk/equality/Statement+Ethical+Practice.htm#_anon) (Accessed September 20 2010))).

It is acknowledged that the anonymization system used in this study could potentially limit the analysis and interpretations and applications which readers of the work may be able to perform (as findings which may be peculiar to individual post might not be easily apparent). However, it should be noted that this problem posed by anonymization is not unique to this study (Buchanan and Bryman 2007, p. 493, Payne et al. 2007, p. 243). Despite any limitations on interpretation of data which it might pose, in this work I felt that the overriding responsibility must be to uphold conditions and assurances relating to confidentiality and anonymity which would have been made to participants during the recruitment process (Statement of Ethical Practice for the British Sociological Association (March 2002) [http://www.britisoc.co.uk/equality/Statement+Ethical+Practice.htm#\\_anon](http://www.britisoc.co.uk/equality/Statement+Ethical+Practice.htm#_anon) (Accessed September

20 2010), World Medical Association Declaration of Helsinki 2008, p. 3

<http://www.wma.net/en/30publications/10policies/b3/17c.pdf> (Accessed December 21 2010).

Other limitations relating to methods and methodology are discussed in section 8.1.4 onwards.

#### **8.1.4 Limitations of methodology and methods**

This study was approached within a framework of guiding principles which have been influenced by my clinical background and philosophical persuasions regarding the nature of reality and how reality can be known. These have already been described in Chapters Four and Seven which provide descriptions of the methodology, methods and the reflexive account. However, it may be valuable to begin discussions on the limitation of methods and methodology by revisiting these guiding principles, and then discussing limitations relating to specific aspects such as data collection methods.

##### 8.1.4.1 Guiding principles

One of the major guiding principles of this study related to the notion that it is useful to categorise knowledge, ways of generating knowledge, and understanding of morality, under the caption of philosophical paradigms (section 4.1, page 113). It was viewed that paradigms by providing compartments, offered the advantage of potentially simplifying the thought processes relating to approaches to research and theory (especially when viewed as being accompanied by particular methods for data collection) (Clark 1998, p. 1243). In this study it was held that it was important to be aware of the philosophical paradigms shaping the work. However, a moderate view was held; with a

pragmatic approach being taken to conducting the research. To this end, the work was positioned in an interpretivist paradigm, but methodologies and methods were used which would best answer the research question.

#### 8.1.4.2 Limitation of an interpretivist philosophical paradigm

An interpretive philosophical paradigm is sometimes viewed as being directly opposed to positivist paradigms (Avis 2003, p. 996). This paradigm like others associated with qualitative methodologies places importance on understanding human interactions, experiences, and perceptions. Also the emphasis, and means for achieving, reporting and confirming results differ from those in positivist research (Silverman 2007, p. 288-290, 302). These differences may at first seem to decrease the usability and potential value of this work. However, understanding social action, involves capturing how multiple participants view and experience what may be arguably the same phenomenon or process. To this end the ability to confirm results is enhanced through illuminating and reflecting reality from varying perspectives (Denzin and Lincoln 2003, p. 8), and trying to understand the overt and subtle commonalities and differences (Silverman 2007, p. 303).

In Chapter Four, categories of participants were identified, whose actions were theorised to affect access and utilization of APDC. Participants were selected from these groups by a process of theoretical- purposive and random sampling. The main data collection methods for gathering experiences and perspectives were semi-structured interviews and the review of documents; with there being natural periods of observation, particularly during the initial stages of negotiating access to the study site and the recruitment of participants. The limitations of the data collection methods are reviewed below.

#### 8.1.4.3 Limitations relating to data collection methods

##### *Observation component*

As described in Chapter Four (section 4.5, pages 128-131), the periods of observation in the study were mainly at the times of negotiating access and recruitment of participants. This was seen as the most ethical way of obtaining observations of the day-care units in their day to day operations while limiting the effect of the research on the day-care environment. During these times, observations with respect to the physical layout of the units were obtained as well as the activities of patients and their interactions with each other and staff members. The observations at the units contributed to the descriptions in section 3.13 pages 101-107. However, at one of the study sites, a longer period of natural observation and rapport building was possible, as this site was a partial funder of the research and served as, co-headquarters of the study, in the early stages of the project. In addition after phase one a report of results was presented to the board of directors of this hospice.

It is recognised that the greater level of observation and interaction with the patients and staff at this study site (in the early stages of the work), may have created deeper insights into the social interactions, at this site. This could have potentially skewed the interpretation of data at this APDC unit and across the entire network. Reflexivity was an important part of the research process, which prevented any possible skewing of the data. Early reflexive activities lead to changes in the project management, and I was based full-time at the university as opposed to using office space at the APDC unit. This allowed me to be viewed as un-biased, independent person from the university who was conducting research that could benefit the entire network and not just one APDC unit.

Constantly reflecting on the research process and taking an iterative approach to data collection, also lead to the implementation of greater flexibility in the way in which semi-structured interviews were conducted. These led to General Practitioners, hospital consultants as well as patients and carers being given the option of having their interviews being conducted via telephone. As previously mentioned in the case of health professionals these changes occurred in response to prospective participants citing work pressures and subsequent time limitations, as reasons for non-participation. In the case of patients and carers additional options in interview format were provided as a means of: increasing participants' comfort during the time of interview (especially in light of the general physical condition of patients), preserving autonomy, and allowing participants greater privacy. It is perhaps significant to note that the majority of patients chose to have their interviews conducted by telephone. This was unexpected, and perhaps reflects a greater than anticipated need by palliative patients to control their physical in addition to mental and emotional privacy while participating in research.

In total 18 participants chose to have their interviews by telephone. It is recognised that though the interview schedules and other research procedure were unchanged that the dynamic involved in verbal, as compared to verbal, plus visual, plus physical communication (shaking hands at the start of interview) could have impacted on the nature of the data collected. However, research skills such as rapport building before the start of the interview were used to minimise any differences.

The challenges relating to documentary analysis were related to aspects of the data collection process. Firstly, the documents analysed were naturally occurring across the hospice so I could not handle them directly as I was not a clinical APDC employee who would ordinarily have regular access to this patient information. This meant that the data extraction could not be performed first-hand by the

members of the research team. However, hospice facilitators who were management level providers were provided with clear guidelines for the process for extracting the data, and this was then transferred to me. There was a standard guideline for extracting the data at all sites as well as a standard data extraction record form/ sheet (Appendix 5, page 297). There was no evidence to suggest that the research procedures as stipulated in the guidelines were not followed.

The documentary data was naturally occurring and at one of the hospice sites self-declared ethnicity was not routinely recorded, at the time of negotiating access, and collecting the documentary evidence it was noted by the site facilitator that none of the referred persons were of ethnic minority groups. However, in the absence of documentation of this, this could not be verified by the research team, and therefore was not included in the demographic profile for documentary analysis.

The documentary analysis was conducted during phase one of the research along with interviews of health professionals and volunteers. Phase two was composed primarily of interviews with patients and carers. The rationale for limitations of this two-phased approach is presented below.

#### **8.1.5 Limitations relating to the use of a two-phased research process**

This study was subject to review by the local research ethic committee (LREC then COREC) and then subsequently by the research and development departments of the relevant PCT and NHS trust, as well as the board of management of the individual hospices. In 2006 permission was granted by the LREC for conduct of the study on the condition that the work be conducted in two phases. Phase one would

be limited to documentary analysis and the conduct of interviews with health professionals. The rationale of the committee was that only after conducting phase one could it really be assessed whether or not it was necessary to interact with palliative patients (Buchanan and Bryman 2007, p. 492- 493). The two-phased approach had the net effect of prolonging the study with two applications to the then NRES being necessary. However, the data from phase did prove that attempts at understanding access to APDC would be enhanced by understanding the experiences and perspectives of patients and their carers. This allowed for convincing arguments to be made to the NRES with the relevant ethical approval being obtained 2008.

Although this research was not designed as action research it was funded as part of a service improvement initiative; therefore, feedback was given to individual hospice managers, as well as one board of directors. Therefore, there was the possibility that some elements of service design and delivery would have changed in response to the feedback given. This leads one to consider that there is the possibility that the service experience of patients might, have been different from that described by providers and or referrers during phase one.

Despite this possible above disadvantage, the data collected during phase one assisted in the development of a more targeted semi-structured interview schedule of patients and carers. As a result the interview process might have been more efficient, thereby reducing the likelihood of patient participant fatigue during the interview.

The potential limitations of aspects of the research design which were implemented to ensure patient participant comfort and safety are discussed in section 8.1.6.

#### **8.1.6 Limitations relating to the recruitment of patient participants during phase two**

Due to the changing clinical, emotional and physical status of palliative patients it was seen as an advantage to have clinicians more familiar with patients to perform the actual selection of patients. The clinical team responsible for the care of the participants at each APDC unit was responsible for the assessment and identification of suitable patient participants. The Karnofsky performance scale was used to assess the physical well-being of patients as a means of identifying patients who might be too unwell to participate in the study. (All management level providers confirmed comfort with applying the scale). The research team had no physical interaction with patients before they were recruited into the study. Such measures for safeguarding the well-being of patient participants have also been used in other palliative care research (Bausewein 2010, p. 1110). It is possible that the assessment of patient's suitability may have created greater opportunity for protection of patients by their clinical assessor, and might have reduced the number of patients suitable for recruitment (effective sample size). However, any reduction in sample size was seen as a less significant consequence of this recruitment method with the overriding responsibility being towards ensuring the safety of participants over research outcome (World Medical Association Declaration of Helsinki 2008, p. 3 <http://www.wma.net/en/30publications/10policies/b3/17c.pdf> (Accessed December 21 2010)).

The relative protection of palliative care patients was seen on a larger level in the case of hospice site 02 with respect to patients who were referred but did not accept care. This unit chose not to participate

in this arm of the phase 2 research; citing that approaching such patients and their carers could be seen as intruding upon the person's privacy and rights to deny use of the health care services that might have been offered to them (Addington –Hall 2002, p. 222, Buchanan and Bryman 2007, p. 489-490).

### **8.1.7 Limitations relating to the conduct of student research**

The work presented in this thesis though part of a larger research agenda of the cancer network, was undertaken in fulfilment of the requirements for a Doctor of Philosophy degree. As such there was initially a small study team of two academic supervisors, and one student, later expanded to three supervisors. As with other examples of student research at doctoral level, the student was responsible for study design, project management, as well as conducting all field research. Having a small team with one field researcher, may have prolonged the total time needed to conduct the study. However, maintaining a small team size was an important part of operating within the project budget. In addition, having one field researcher was advantageous, as recruitment and interviews were conducted by a researcher who had an in-depth knowledge of the study design, as well as a clinical background with experience in the field of palliative care (Clark 1997, p. 167).

As described in Chapter Four this research used a cyclical approach to data collection and analysis. Having a small team with me being the only field researcher facilitated my having uninterrupted contact with the data, thereby allowing deeper immersion (Clark 1997, p. 167), and correct identification of the data saturation point.

It may be argued that there is the possibility of researcher errors being compounded in small research teams where members responsible for study design are solely responsible for data collection. There is the possibility that in this research a methodological blind spot could have remained unidentified. To avoid this specialist qualitative supervision was sourced and regular academic supervisions held.

## **8.2 Summary of limitations in the form of Key Points**

- Like other research this study was not without limitations
- It is likely that the theories and conceptual frameworks were formulated on literature review which might have been too medical in its scope.
- In-spite- of efforts to sample for maximum variation the study there were only a few participants who were of ethnic minority background. Therefore it may be argued that the study population was homogenous in terms of ethnicity and perhaps by extension culture.
- Flexibility in the data collection methods, increased the recruitment rate of busy health professionals, and palliative care patients, however, this resulted in the need to synthesize text generated from face-to-face and telephone interviews. The synthesis of interview collection methods may be interpreted as a potential limitation.
- The relative protection of patients by the ethics committee, and some clinical providers was experienced during this study, with the effect of; extending the study time, and increasing the challenges with recruiting one category of patient participants from one study site.

### **8.3 Summary of the thesis**

This thesis began with an account of personal story which outlined the motivation and background on undertaking this work on understanding access to APDC. It is perhaps only fitting that the thesis ends by returning full circle to address what has been accomplished on a personal level and in the context of addressing the research question and contributions to knowledge. These are presented below in sections 8.3.1 and 8.3.2.

#### **8.3.1 Summary of the contribution of the conduct of this study to my personal development and career goals**

As a result of undertaking this work, I have gained an understanding of the scope of palliative care. Given the changing disease, mortality and demographic profile of the global population (section 1.3, page 38); I have been affirmed of the relevance of palliative care services to current and future populations in the UK and Barbados. To this end, with respect to Barbados, I have been able to increase awareness of the relevance of palliative care in Barbados and advocate for this form of care through engaging with the Ministry of Health there.

Through researching the arguments informing the debate of inequalities of access to health care and palliative care services more specifically I have seen the importance of services being designed on the basis of appropriate needs assessment, so as to avoid geographic related inequalities. In addition to the value of initial needs assessments, this study has shown that capacity building in palliative care service is likely to be most effective if it contains elements relating to: continued education and service monitoring and evaluation (including reviews of funding mechanisms in the context of the macroeconomic environment). In Barbados this process has been operationalized in the form of The

Barbados Palliative Care Needs Assessment Project, which has completed two phases (Greaves 2010 a and b). In addition the island was able to have its first palliative care conference in March 2011 which was facilitated by myself, my supervisor Dr Paul Ong and Dr Anna Towers of McGill university (<http://www.barbadosadvocate.com/newsitem.asp?more=local&NewsID=16139>, [http://www.gisbarbados.gov.bb/index.php?categoryid=13&p2\\_articleid=5374](http://www.gisbarbados.gov.bb/index.php?categoryid=13&p2_articleid=5374))(Accessed April 23<sup>rd</sup> 2012). The island now has a national palliative care association which is actively involved in educating the public and health professionals about the scope and clinical practice of palliative care (<http://www.barbadospalliative.org/index.html> Accessed April 23<sup>rd</sup> 2012).

### **8.3.2 Summary of the thesis: The aims of the research and how these have been addressed**

As described in chapter one, reviewing of the literature has indicated evidence of underutilization of Palliative Care Services in the UK, with there being the possibility of inequalities of access to care. This trend of apparent underutilization is reflected in Adult Palliative Day-Care (APDC) (section 1.7 pages 57-66). As it relates to APDC there remain gaps in knowledge relating to the nature of underutilization and whether it is real or perceived (section 1.8 pages 66-67). In addition, it is unclear as to whether or not the documented underutilization is actually a reflection or result of the effect of other issues which are acting to determine access. I theorised that such unknown factors affecting access could be related to need, interpretations of the perceived benefit of APDC, and the characteristics of the service user, health system, or family (section 2.8, pages 88-89).

As such an overall research question was formulated, namely “What are the factors which act to determine access to APDC?”. Five other sub-questions for exploration were formulated relating

among other things to the perceived health care needs of users, the perceived and experienced benefits of using APDC, and understandings of the role of APDC as a palliative care service (section 2.8, page 88 and section 4.0, page 111).

From this study 18 factors were identified which were acting as determinants to access. These were factors found to be arising out of the characteristics of the potential service user (two), the health service or organization (nine), or as a result of mixed interactions between potential service users, the family, the wider society, and the health service (seven). These results are presented and discussed in section 5.3, pages 170-220, and Chapter Six, page 224-243 respectively, however a brief summary is provided below using the content of the research sub-questions as a structure for showing how the research aims were addressed in the work.

#### 8.3.2.1 Findings and conclusions related to health care needs, the benefits of, and the role of APDC

In answering the overall research and exploratory questions I found that that patients and carers identified social needs as their predominant health care need, and perceived APDC as being beneficial as it provided social interaction in a setting where there was a sense of belonging and community. APDC was also valued as a means of providing for the respite needs of carers<sup>91</sup>. In addition, service users valued the provision of services for monitoring of symptoms and the ability of APDC to address non-complex medical needs (section 5.3.5, page 184). I found that this view of the role and benefits of APDC as held by patients and carers was consistent with that of referrers who saw APDC as the ideal setting and the most well positioned service within palliative care and end-of life services for

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<sup>91</sup> These benefits have been identified previously in the literature see section Table 1.2a, page 50.

addressing social and psychosocial needs. This has led to the conclusion that APDC services could possibly be fulfilling a niche role in community based social and psychosocial palliative care. Greater identification, development and acceptance of this role by service providers may be an important step in ensuring the future relevance of APDC as a Specialist Palliative Care Service. However, such a formal repositioning or redefining of the remit of APDC would require discussion at many levels within local and national palliative care organisational structures; including at the policy and academic levels. In addition, any changes in the definition of APDC to facilitate occupying the role of a specialist social palliative care service would need to consider the concepts of hierarchies and professionalism which exist within medicine and between medicine and other allied health professions. It is possible that occupying a specialist social remit may not be acceptable to providers of APDC who value and aim to address medical palliative care needs as part of their current fulfilment of their role as a Specialist Palliative Care Service.

#### 8.3.2.2 Findings and conclusions related to the features of APDC organization which affect access

Although providers expressed the aim of addressing medical needs I found that that the current financial and human resources levels in APDC units are acting as barriers to fulfilling this need, and by extension are actually serving as barriers to accessing care, particularly for patients who have non-cancer diagnoses and or high dependency levels (section 5.3.8, pages 189-190). I therefore conclude that if APDC services are to continue to define themselves as Specialist Palliative Care Services (that are capable of meeting both complex medical and social palliative care needs) then it may be necessary for them to form greater alliances with other primary and tertiary health care services (both palliative and non-palliative). Such alliances could facilitate the safe provision of care and the broadening of access.

In addition to financial and human resources I found that other organisational features of APDC served to influence access (section 5.3.3-5.3.11, pages 171-196) these included a relative inflexibility in the way in which the service could be used, for example, a preference by providers for whole-day versus drop-in care, which seemed to inhibit access by young service users. However, other aspects of day-care such as the non-clinical cheerful atmosphere termed an “Atmosphere of life” also served to enhance access and continued service use.

Interestingly I found that the reality of the pleasant atmosphere present at day-care is opposite to the images of imminent death which potential users mistakenly associated with APDC units as a result of the use of the term “Hospice” in the units’ titles and marketing material (5.3.12, page 204-206). This has led to the conclusion that the use of this term is actually serving as a barrier to access. Perhaps using the term “Hospice” in association with APDC units would be appropriate if APDC units are to function primarily as precursors to inpatient terminal care. However, I did not find this to be the case with the emphasis in care being on living rather than focussing on approaching death. In addition given: a) the increasing chronicity of cancer and many other life threatening illnesses coupled with; b) the expanding remit of palliative care (to include persons in the early stages of illness, and non-cancer patients with complex waxing and waning disease trajectories); using the term “Hospice” may no longer be appropriate to describe a service which caters to persons in the non-terminal phases of their illness. The reality is that choosing an alternative term to “Hospice” is not likely to be easy given that the term is arguably an established part of the palliative and end-of-life brand across the UK, and a key factor in current fundraising strategies (5.13.12.2, page 207).

#### 8.3.2.3 Findings and conclusions related to the self factors of potential users

Factors were found to be influencing access which were related to the characteristics of the users themselves. I found that the psychological trajectory of patients as influenced by their baseline personality and level of acceptance regarding their illness and likely prognosis was a factor in the decision making pathway to accepting care and accessing APDC units (sections 5.3.1 and 5.3.2, pages 173-176). It is likely that the incorporation of regular assessment and documentation of psychological trajectories would decrease the number of late and indirect referrals to APDC units. This may be relevant to other palliative care services as well. The results of this work has shown that some experienced palliative care clinicians already use the concept of monitoring the psychological position and trajectory of a patient when making referral, but it may be important for this skill to be documented and improved upon for more inexperienced clinicians.

#### 8.3.2.4 Findings and conclusions related to the measurement of need

Finally, as it relates to the question of underutilization in APDC this work found that while factors determining access exist (both barriers and facilitators), the recorded underutilization may not actually be real, and also may not be a marker of under-access. In fact it is possible that current means of measuring utilization are limited as they do not take into consideration factors such as the dependency levels of patients and staffing ratios, therefore it is possible that while utilization methods suggest underuse, some day care units maybe functioning at their maximum capacity, while still having theoretical unoccupied/ empty spaces. Therefore, given the changing disease trajectories of palliative care patients along with features of APDC such as its ambulatory outpatient setting and the call to expand the remit of APDC to include patients with possible higher dependency levels, it is perhaps

necessary for a new model to be created for specifically guiding need assessments in the Adult Palliative Day-Care service setting.

Adult Palliative Day-Care Services:  
An investigation of the factors influencing access to services using the case of a cancer network in the  
United Kingdom

(Appendices, References and Bibliography)

by

Natalie Sharnell Greaves, MBBS

A thesis submitted in fulfilment of the requirement for the  
degree of

Doctor of Philosophy in Primary Health Care Management

University of Warwick, Health Sciences Research Institute

June 2012

## Appendix 1

### Training undertaken in the process of acquiring or strengthening research skills

<b>Course Title</b>	<b>Research skill set</b>	<b>Project year</b>
MH900-Epidemiology and Statistics-Warwick Medical School	Review of quantitative research design, Quantitative software-SPSS	Year one-2005-2006
MH918-Research and Evaluation Methods for Primary Health	Qualitative research design	Year one 2005-2006
Introduction to NVIVO-IT Services University of Warwick	NVivo 2 software	Year one 2005-2006
Qualitative interviewing training course- DIPEX, Department of Primary Health Care, University of Oxford	Qualitative interviewing Techniques-Individual and focus group	Year two 2006-2007
Qualitative data analysis- DIPEX, Department of Primary Health Care, University of Oxford	Qualitative Data analysis	Year three 2007-2008

## Appendix 2

### Interview schedules for phases one and two

(Spacing and font adjusted for thesis, content the same as originally given to participants)

a) Interview schedule for **health professionals** and **volunteers** involved in the **provision** of palliative day-care.

#### Introduction

In our study we will be conducting semi-structured interviews; the interview will be relaxed resembling more of a conversation. In our interviews we would like to discuss your experience with and views on issues regarding access and referring to adult palliative day-care services in the cancer network. It is our hope that by interviewing you and persons like yourself, that we can better understand the organization of referral pathways to palliative day-care and what factors affect patients accessing this service.

As stated in your participant information sheet we would like to audiotape your interview, whatever you say during this interview is confidential, please remember there are no right or wrong opinions. We expect this interview to be approximately 50 minutes long and we can stop interviewing at any time should you wish to do so.

#### Topic Guide

In our interview today, we will be exploring some topics listed below. These topics are a guide and we may not necessarily discuss all of them or in the exact order outlined here.

- Issues surrounding referral routes and criteria (e.g. which health professionals refer most often to palliative day-care, which routes of referral do they use, which routes of referral are most efficient, what would be your ideal route?)
- Issues surrounding patients (e.g. are there patients who might benefit from palliative day-care services but who are unable to attend?)
- If you could change or add one thing to day-care which would enable patients who need palliative care to get it, what would you change or add?
- Closing

We the members of the research team would like to thank you for taking the time from your busy schedules to assist us with this project.

You may review a typed transcript of your interview if you wish. If this is your desire you may feel free to indicate this to the researcher who has conducted your interview, who will arrange a suitable time with you.

If at any time you have any further queries, you may feel free to Dr Natalie Greaves at

n.s.greaves@warwick.ac.uk.

b) Interview schedule for **health professionals** involved in the **referral** of patients to palliative day-care

### Introduction

In our study we will be conducting semi-structured interviews; the interview will be relaxed resembling more of a conversation. In our interviews we would like to discuss your experience with and views on issues regarding access and referring to adult palliative day-care services in the cancer network. It is our hope that by interviewing you and persons like yourself, that we can better understand the organization of referral pathways to palliative day-care and what factors affect patients accessing this service.

As stated in your participant information sheet we would like to audiotape your interview, whatever you say during this interview is confidential, please remember there are no right or wrong opinions. We expect this interview to be approximately 50 minutes long and we can stop interviewing at any time should you wish to do so.

### Topic Guide

In our interview today, we will be exploring some topics listed below. These topics are a guide, we may not necessarily discuss all of them or in the exact order outlined here. Some questions that we may cover in our discussion under these main topics are listed as well.

- Referral routes
  - 1) Have you ever made a referral to palliative day-care services?
  - 2) Which referral route do you use most often?
  - 3) Which referral route do you find most effective?
  - 4) Why do you find this route most effective?
  - 5) What would be your ideal route of referral?
  - 6) In your opinion how might referral routes be improved?
  
- Information Sources and suitability of day-care for patients
  - 1) How did you first come to know about Palliative day-care services in the network?
  - 2) What is your current source of information about palliative day-care services in the network?
  - 3) Would you say you have enough information on what services palliative day-care offers and how you can refer patients to them?

- 4) Do you think that palliative day-care is suitable for the palliative patients that you meet in your practice?
- 5) Given your past experiences what would you say might prevent a patient from choosing to accept day-care?

### Closing

We the members of the research team would like to thank you for taking the time from your busy schedules to assist us with this project.

You may review a typed transcript of your interview if you wish. If this is your desire you may feel free to indicate this to the researcher who has conducted your interview, who will arrange a suitable time with you.

If at any time you have any further queries, you may feel free to Dr Natalie Greaves at  
n.s.greaves@warwick.ac.uk.

## Appendix 3

### The possible role of observation methods in this work

Observation is one of the commonly used methods of qualitative research. It is employed when the researcher wants to obtain an understanding of what persons do, opposed to what they think or say they do (Silverman 2007, p. 69). It should be noted however, that there is the risk that during the process of observation the researcher may alter the phenomenon being studied (Green and Thorogood 2005, p. 139). It is recognised that with respect to interviews, persons do change their accounts, especially where they perceive moral judgements are likely to be made. This also occurs with observations, where the challenge is to observe a naturally occurring phenomenon without impacting, and thereby changing it. In particular when observing social relationships, the researcher needs to be aware of, monitor and document the impact that his or her presence makes.

This research aimed to identify and understand the factors acting to determine access. From the conceptual framework presented in Chapter Two, three characteristics have been theorized to affect how access occurs. These are family, patient and system characteristics. By using this framework, it was considered that observations of interactions in various settings might be able to give insight into the access process. The interactions are presented below in Table Appendix 3.

**Table Appendix 3 Interactions and their settings which, if observed, may theoretically give insight into the access process of accessing adult palliative day-care.**

<b>Interaction to be observed</b>	<b>Possible setting for observation</b>
Patients, their carers and the referring clinician at the time of referral	Office of the health professional or home of the patient
Patients and their carers at or around the time when the patient and their carer were deciding whether to access the palliative day-care service	Patients and or carers home or usual place of residence
Patient and the staff of the palliative day-care unit to which the patient was being referred.	Palliative day-care unit
Interactions between health care professionals, when arriving at decisions as to whether or not they should accept or make a referral to a palliative day-care service.	The offices of health professionals' as well multidisciplinary team meetings

In deciding whether to adopt observations as a method in collecting information regarding the above interactions in their likely natural settings, three factors were considered. Firstly, the relevance and suitability of the information likely to be obtained to the answering of the research question. Secondly, the reliability of the information obtained, and thirdly, the ethical considerations and pre-existing legal stipulations that would prevent observations from occurring in the settings identified in Table Appendix 3.

No pre-existing legal stipulations were identified which would prevent observations of the various interactions in the proposed settings. There were, however, ethical considerations particularly relating to respecting patient's and carer's privacy.

It is recognised that non participant observation of patients in their homes while they are having discussions with their families regarding whether to accept palliative care, may be an invasion on participants' privacy. Importantly, such an invasion would be occurring at a time which is already emotionally challenging for the patient and their carer. In the case of using the participant observation method, the invasion maybe more acute if the researcher is not a health or social professional who is already acquainted with the family and has gained their trust. In the case where the researcher is not already acquainted with the family, they may see the researcher as a new addition to perhaps an already too large number of health and social professionals with whom they interact. To the patient, this may represent a loss of privacy (Sheldon and Sargeant 2007, p. 165).

Observing the interaction of patients and carers at the time of being introduced to the concept of accessing palliative day-care service by the referring health professional also has its limitations. Firstly, this interaction may represent only a single "snap shot" in time which may not necessarily give full insight into the referral and decision making process. In addition, what is observed will be affected by how the patient relates to the physician. Performing a series of observations may pose the same problem as that with performing observations in the person's home. In that having repeated consultations with their clinician in the presence of the researcher or researchers recording equipment e.g. video cameras, the clients may feel that their privacy is being encroached upon and that too many persons are involved in aspects of their care and or private lives (resulting again in possible feelings of intrusion).

Another potential limitation of performing observations of clinician client interactions which occur in the physician's office etc., is that in situations where physician and their clients have a variation in power in their relationship, clients may alter their behaviour out of a desire not to offend their clinician, or out of a fear of jeopardising their care. Therefore, there is the possibility that deeper insights may be gained if patients and carers have the opportunity to interact with the researcher in the absence of the clinician.

The other possible location for observation could be the Multidisciplinary team (MDT) meetings where clinicians might discuss issues relating to what is an acceptable referral to day-care. These MDT meetings may occur among those referring to day-care and those accepting referrals to day-care. Therefore, observing MDT meetings was initially viewed as a way to gain insight into the access process. However, on further consideration, it was concluded that observations of these meetings might not permit observation of the natural discussion process as the research was being partially funded by the network, it was likely that the health professional participants may view the researchers' presence as a form of audit or performance review. Furthermore, as the research was concerned with issues of

inequity, there was the possibility that on observation, participants would alter their behaviour to what they thought was the socially correct form, so as to avoid being seen as disadvantaging particular client groups.

The discussion above presents the limitations of using observation as a method which were considered in this study. In addition to these limiting factors, such as potential invasion of participants' privacy, "snap shot" versus global observation of the phenomenon and the possible effect of the researcher, it was considered whether observation methods were the most suitable research methods to obtain valid and reliable results for the research question.

### **Observation methods and their suitability to answering the research question**

The research question and sub-questions of this work sought to identify the determinants of access to adult palliative day-care. Furthermore, the research aimed to identify these determinants of access through the examination of the perceptions, and experiences of participants, while taking account of the research context.

In the case of observations, there are limitations which exist because the observations may not necessarily give insight into actions which have occurred before the time of the observations having taking place. Therefore, there is the risk that previous experiences which have contributed to the development of the phenomenon under study are lost to data collection.

Also, observation methods while allowing the researcher to gain descriptions of actions or events concerning the phenomenon under study, limit the amount of information that can be gained regarding the thought processes and previous experiences which act to determine action. With respect to this, research observations therefore limit the amount of evidence that can be gathered concerning participants' thoughts and feeling and previous social and health care experiences which have interacted to determine whether access to adult palliative day-care occurred or not. Potentially, these limitations could have been overcome by a prolonged period of covert non-participatory observation with the researcher embedded in the health system or with covert non-participatory observation. However, both these methods are not ideal from an ethical view point (Wilkie 1997, p. 322-323, Green and Thorogood 2005, p. 139). It was also considered that to enhance the possibility of being able to gather participants' views and experiences, a combination of observation and interviewing methods could be used. However, the sequential use of these methods (observations followed by interviewing or vice versa) could have altered either the actions observed or the talk content obtained during interviews, as there might have been an increased chance of persons attempting to alter their behaviour and our views expressed in order to create what they think would be consistent, socially acceptable behaviour and accounts.

Given that the study sought to gather persons' views and experiences, interviewing data collection methods were used, which would allow for the collection of this type of information.

## **Appendix 4**

### **Participant Information Sheets (PIS)**

(All categories of participants)

(Spacing adjusted for thesis, content the same as originally given to participants)

a) Health professionals

#### **Accessing and referring to Palliative Day-care Services in the cancer network: the experiences of Patients and Health Care Professionals**

You are being invited to take part in a research study carried out by researchers from the University of Warwick. This leaflet will explain why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**Thank you for reading this.**

#### **What is the purpose of the study?**

This study is part of a PhD which aims at examining the palliative day-care services provided in the cancer network and how patients are able to access these services.

We would like to discuss the various experiences that patients have had when accessing day-care for the first time and the experiences that health professionals have during the referral process. By examining these experiences we hope to identify any factors which may be affecting access and to gather information which may help to make referring and accessing palliative day-care better if this is needed.

#### **Who is organising and funding the research?**

This research is jointly endorsed by the University of Warwick and the cancer network. It is being organised by Dr Paul Ong, Professor Jeremy Dale and Dr Natalie Greaves (Centre for Primary Health Care Studies) at the University of Warwick. It is being funded by the cancer network and is being administered by the [Name and Location of Hospice].

#### **Why have I been chosen?**

You have been chosen because you are involved or have been involved in the provision of care to patients who have or may potentially have palliative care needs. In our study of access to day-care services in the cancer network it is important that we gather the views of various types of persons who may be involved in the access pathway to this service. All experiences are important to developing our understanding of these access pathways.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do decide to participate you will be given this information sheet to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision not to take part or to withdraw will have no implications on your treatment as a patient, your role or employment.

**What will happen to me if I take part?**

If you decide to take part you will be invited to attend one interview lasting approximately 50 minutes long, at a time and place arranged by mutual agreement and convenient to you. The interview will be audio-recorded and typed up later by the interviewer conducting the research. You may review your transcript and a typed copy can be given to you if you wish. Your interview is confidential and tapes will be destroyed at the end of the study.

**What do I have to do?**

If you agree to participate you will be asked to sign a consent form at the time of the interview confirming that you are happy to participate in the study. You will be asked to keep a copy of the consent form together with the information sheet.

**How will confidentiality be maintained?**

All information that is collected during the course of the research will be kept strictly confidential. Audio-tapes of the interview will be stored securely at the University of Warwick, and will not have your name on them. Your name will not be transcribed or used when discussing the research material. Any identifying details in your transcript will be removed so that you cannot be recognised.

**What are the possible disadvantages and risks of taking part?**

If you are selected for interview you may find that talking about your experiences in palliative day-care is upsetting or you might realise that there are things you are not sure about and need to know more about. If this happens you should discuss this with the researcher who will talk with you about where you might be able to get help, information or support.

**What are the possible benefits of taking part?**

There may be no benefit directly to you. We hope that the information provided by your participation will contribute to findings that help us to better understand palliative day-care services how they can be organised.

### **What will happen to the results of the study?**

The results will be published in a document to the cancer network which can be used to inform further service development. The results will also be published as part of a PhD degree thesis and may be published in peer reviewed health care and other professional journals. The findings will be made available to all participants through these publications. As the study progresses it may be possible that other means of sharing results may become evident these may include conferences or Peer Review Meetings. If you want to see a copy of any report or article before publication, you can receive a summary of the findings by contacting me at the address below.

### **Who has reviewed this study?**

This study has been reviewed by the cancer network, The University of Warwick, and the Research Ethics Committee (future Jan 2006).

For further information or concerns about any aspect of the study please contact

Dr Natalie Greaves- 024 765 75132 (university)

[Contact details- postal address, e-mail and telephone numbers of all members of the research team]

Thank you for taking the time to read this information

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b) Patients

### **Accessing adult palliative day-care services in the cancer network: The experiences and perceptions of patients and carers**

You are being invited to take part in a research study being carried out by researchers from the University of Warwick. This leaflet explains why the research is being done and what it involves. Please take time to read it carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Please decide whether or not you wish to take part.

**Thank you for reading this.**

### **What is the purpose of the study?**

This study aims to examine the palliative day-care services provided in the and how patients gain access to these services.

We would like to discuss the experiences you and your carer had when accessing or deciding to access day-care for the first time. We hope to identify any factors which may be affecting access and to gather information which may lead to make referring and accessing palliative day-care better if this is needed.

**Why have I been chosen?** You have been invited to participate because you have been previously referred to a palliative day-care unit in the cancer network. The experience you had when deciding to access palliative day-care are important and can help us to develop our understanding of how this occurs.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do decide to participate, you are still free to withdraw at any time and without giving a reason. A decision not to take part or to withdraw will have no implications on your treatment.

**What will happen to me if I take part?**

If you decide to take part you will be invited to attend an interview lasting approximately 15-30 minutes, at a time and place that is convenient to you. The interview will be audio-recorded and typed up later by the interviewer conducting the research. You may review the transcript and a typed copy can be given to you if you wish. Your interview is confidential and tapes will be destroyed at the end of the study.

**What do I have to do?**

If you agree to participate you will be asked to sign a consent form at the time of the interview confirming this. You can keep a copy of the consent form together with the information sheet.

**How will confidentiality be maintained?**

All information that is collected during the course of the research will be kept strictly confidential. Audio-tapes of the interview will be stored securely at the University of Warwick, and will not have your name on them. Your name will not be transcribed or used when discussing the research material. Any identifying details in your transcript will be removed so that you cannot be recognised.

**What are the possible disadvantages and risks of taking part?**

There are no specific risks or disadvantages associated with being interviewed. Should the interview evoke any negative feelings, discuss this with the researcher who will talk with you about where you might be able to get help, information or support.

**What are the possible benefits of taking part?**

While there may be no benefit directly to you, we hope that the information you provide will contribute to findings that help us to better understand palliative day-care services how they can be organised and improve services as necessary.

**What will happen to the results of the study?**

The results will be published in a document to the cancer network which can be used to inform further service development. The results will also be published as part of a PhD degree thesis and may be published in academic journals and presented at conferences. The findings will be made available to all participants through these publications. You can receive a summary of the findings by contacting me at the address below.

**Who has reviewed this study?**

This study has been reviewed by the cancer network, The University of Warwick, and the Local Research Ethics Committee (Nov 2007). For further information about any aspect of the study please contact:

[Contact details- postal address, e-mail and telephone numbers of all of the members of the research team]

Thank you for taking the time to read this information

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## Appendix 5

### Guidelines employed during documentary analysis and all data extraction sheets

Accessing and referring to Adult Palliative Day-care Services in the cancer network: The experiences of Patients and Health Care Professionals. A pilot study

[Date]

[Name and address of hospice manager]

Dear [Name],

Thank you very much for taking the time to facilitate our documentary data collection for Phase 1 of the Accessing and referring to Adult Palliative Day-care pilot study.

In the aim of greater efficiency we invite you to view the collection of documented data as occurring in two parts:

- before meeting with the researcher and
- on meeting with the researcher.

#### Before meeting with the researcher

Before meeting with the researcher we would ask that you kindly collate the information outlined below, on adult patients who have been referred to your day-hospice between [start date- end date] but have not attended.

We recognise that within the cancer network there exists some degree of variation in the data storage systems used by the individual palliative day-care units (e.g. computer files vs. paper referral files etc). We ask that you use the data source that is most readily available to you and which will contain the most reliable information on:

- the age of the patient at the time of referral;
- their self-declared ethnicity;
- the diagnosis category of the patient (i.e. cancer or non-cancer);
- and the reason for non-attendance if this has been record.

Please note that our researchers will only collect the data stated above.

#### Meeting with the researcher

We would like for a member of our research team to meet with you at a time of your convenience. At this meeting the researcher will then record the information which you have collated. Please note that the members of our research team are not permitted to have contact with patient files or records, and as such you may have to verbally communicate the data to the researcher who will then copy (write) it onto the data storage form. As such it may be best if your meeting with the researcher is an area of your day-hospice which facilitates a measure of privacy.

Overleaf is an example of the data storage form which will be used by the members of the research team. You may feel free to use a copy of this form during your collation process. At the time of your meeting, we kindly ask that you have access to your primary data source(s) should you need to verify or query any information that may need to be recorded by the researcher?

The meeting with the researcher is expected to be approximately 45 minutes. This is based on an estimate of the time needed to record data on approximately 50 patients.

Thank you very much for taking the time to read this guidance letter, please do not hesitate to contact Dr Natalie Greaves should you require any other information.

Thank you once again for your kind assistance

Natalie Greaves MB.BS

[n.s.greaves@warwick.ac.uk](mailto:n.s.greaves@warwick.ac.uk)

Tel 024 765 75132

Completed document storage forms -Phase 1 documentary analysis

Centre Number:

Study Number: 001

Title of Project: Accessing and referring to Adult Palliative Day-care services in the cancer network:  
The experiences of Patients and Health Care Professionals. A pilot study.

Pt #	Age	DC	SDE	Reason for non-attendance as documented -----
01	67	NC		Inappropriate Referral
02	54	C		Did not want to attend
03	34	C		Did not want to attend
04	61	C		Pt. R.I.P (patient died before being able to attend)
05	83		01	Too poorly to attend
06	-	-		-
07	79	C		Never wanted to attend
08	67	C		Pt. R.I.P (patient died before being able to attend)
09	54	C		Too poorly to attend

10	78	C		Never wanted to attend
11	55	C		Never wanted to attend
12	80	C		Too unwell to attend
13	55	C		Pt. R.I.P (patient died before being able to attend)
14	66	C		Pt. R.I.P (patient died before being able to attend)
15	70	C		Pt. R.I.P (patient died before being able to attend)
16	74	C		Never wanted to attend
17	69	C		Never wanted to attend
	-	-		-
Pt #	Age	DC	SDE	Reason for non-attendance as documented -----
19	74	C		Pt. R.I.P (patient died before being able to attend)
20	-	-		-

21	80	C		Pt. R.I.P (patient died before being able to attend)
22	69	C		Pt. R.I.P (patient died before being able to attend)
23	57	C		Pt. R.I.P (patient died before being able to attend)
24	61	C		Never wanted to attend
25	68	C		Never wanted to attend
26	80	C		Too poorly to attend
27	80	C		Pt. R.I.P (patient died before being able to attend)
28	85	C		Never wanted to attend
29	84	C		Inappropriate referral
30	82	C		Never wanted to attend
31	74	C		Never wanted to attend
32	62	NC		Inappropriate referral
33	78	C		Inappropriate referral

34	50	C		Too poorly to attend
35	71	C		Did not wish to attend
36	73	C		Unable to talk to patient. Wife very protective and concerned about hospice image i.e. death
37	71	C		No palliative care needs
38	54	C		Never wanted to attend
39	77	C		Never wanted to attend

Document Storage Form -Phase 1 documentary analysis

Centre Number: 02

Study Number: 001

Title of Project: Accessing and referring to Adult Palliative Day-care services in the cancer network:  
The experiences of Patients and Health Care Professionals. A pilot study.

Pt #	Age	DC	SDE	Reason for non-attendance as documented -----
01	84	NC		Not well enough to attend
02	62	NC		Does not want to attend

03	74	C		Not well enough to attend
04	82	C		Died before (commencing) attending
05	68	C		Not well enough to attend. Admitted to _____
06	-	C		Not well enough to attend
07	72	C		Not well enough to attend
08	74	C		Died before coming
09	86	C		Died before coming
10	65	C		Died before coming
11	79	C		Died before coming
12	77	C		Died before coming
13	82	C		Not well enough to attend
14	82	NC		Not well enough to attend

15	67	C		Died
16	72	C		Died
17		C		Did not want to attend
18		C		Died
Pt #	Age	DC	SDE	Reason for non-attendance as documented -----
19	72	C		Not well enough to attend
20	71	C		Not well enough to attend
21	77	C		Died
22	57	C		Not well enough to attend
23	83	C		Declined
24		C		Does not wish to attend
25		C		Died
26		C		Did not want to attend

27		C		Did not wish to attend
28		C		Did not wish to attend
29		C		Did not require day-care
30		C		Did not wish to attend
31		C		Did not wish to attend
32		C		Did not wish to attend
33		C		Did not wish to attend
34		C		Did not wish to attend

Document Storage Form -Phase 1 documentary analysis

Centre Number: 03

Study Number: 001

Title of Project: Accessing and referring to Adult Palliative Day-care services in the cancer network:  
The experiences of Patients and Health Care Professionals. A pilot study.

Pt #	Age	DC	SDE	Reason for non-attendance as documented -----
01	77	C	BW	Declined, said no
02	88	C	BW	Too unwell deteriorated died quickly
03	85	C	BW	Not a mixer I can't visit
04	81	C	BW	Refused all palliative care services – Macmillan and Day-care
05	77	C	BW	Was not well enough at the time of referral
06	64	C	BW	<b>Was not ready</b> for the day-hospice- family ill as well
07	65	C	BW	Not ready for hospice ( where you are at in your illness)
08	84	C	BW	Deteriorated very quickly ( refereed from the acute trust)
09	62	C	BW	Never well enough to come

10	70	C	BW	Never well enough to attend
11	37	NC	BW	Came looked “ It will take me away from my family”
12	66	C	BW	Visited (invitation visit). Absolutely hated it withdrawn, didn’t socialise
13	85	C	BW	Well enough but too far to come (hospice staff thought he could easily have come). Patient died a month later
14	62	C	BW	Absolutely declined referral refused to speak with the day-care team
15	82	C	BW	Not well enough to come
16	73	C	BW	* Previously came , then stopped , didn’t really like day-care ( staff thought the patient was in denial and did not want to talk)
17	64	C	BW	Inappropriate referral – very early curative treatment
18	71	C	BW	Declined all palliative care services felt __ wouldn’t benefit
Pt #	Age	DC	SDE	Reason for non-attendance as documented -----
19	75	C	BW	Absolutely declined
20	52	C	BW	Not ready to attend –“unsure of diagnosis”

21	54	C	BW	Lacked confidence to be away from family (noted to have be anxious)
22	50	C	BW	Accessed other hospice services “Day-care was not for her”
23	78	C	BW	Was not well enough
24	86	C	WO	Was not well enough
25	71	C	BW	Wanted to come, deteriorated, never made it
26	79	C	WI	Never well enough
27	57	NC	BW	Both patient and family declined palliative care treatment - they did not understand the diagnosis
28	78	C	BW	Referred and died 3 days later rapid deterioration
29	76	C	BW	Declined all services – could not see a need- need was being met other places
30	81	C	BW	Never well enough wanted to come
31	84	C	BW	Declined all palliative care services – well supported by oncology
32	47	C	BW	Thought about coming- declined all services “she wanted to pretend that it wasn’t there”
33	75	C	BW	Never well enough

34	80	C	BW	Declined all services – long way- very well supported in_____
35	76	C	BW	Not well enough
36	52	C	BW	Not well enough
37	69	C	BW	Worried about sitting in a group with very ill patients( nervous)
38	71	C	BW	Wasn't his thing thought by staff to have "forced jollity"
39	72	C	BW	Never well enough
40	84	C	WI	Never well enough
41	47	C	BW	Self referral-alternative treatment" treatment thought by patient not to be alternative enough
42	83	C	BW	Very keen never well enough
43	77	C	BW	Very late- essentially dying

Document Storage Form -Phase 1 documentary analysis

Centre Number: 4a

Study Number: 001

Title of Project: Accessing and referring to Adult Palliative Day-care services in the cancer network:  
The experiences of Patients and Health Care Professionals. A pilot study.

Pt #	Age	DC	SDE	Reason for non-attendance as documented -----
01	86	Ca	WB	Admitted to inpatient unit and died
02	82	Ca	WB	Too poorly to attend
03	79	Ca	WB	Admitted to inpatient unit and died before attending
04	59	Ca	WB	Finished DXT to REFUSED TO ATTEND
05	77	Ca	WB	Too poorly to attend
06	60	Ca	WB	Admitted to inpatient unit and died
07	86	Ca	WB	Too ill to attend
08	72	Ca	WB	Too unwell to attend
09	57	Ca	WB	Too unwell to attend
10	53	Ca	WB	Too unwell to attend

11	84	Ca	WB	Did not wish to attend
12	48	Ca	WB	Felt that it was not for her –did not wish to attend
13	90	Ca	WB	Did not wish to attend no reason given by patient
14	91	Ca	WB	Did not wish to attend no reason given by patient
15	76	Ca	WB	Not well enough to attend
16	86	Ca	WB	Did not wish to attend
17	79	Ca	WB	Not well enough to attend
18	55	Ca	WB	Was having DXT Never returned
19	72	Ca	WB	Not well enough to attend
20	67	MND	WB	Not well enough to attend
21	68	Ca	WB	Admitted to inpatient unit and died
22	63	Ca	WB	Admitted to inpatient unit and died
23	78	Ca	WB	Admitted to inpatient unit and died
24	62	Ca	WB	Did not wish to attend

25	78	Ca	WB	Did not want to attend
26	56	Ca	WB	Too unwell to attend
27	62	Ca	WB	Admitted to inpatient unit and died
28	46	Ca	WB	Admitted to inpatient unit then afterwards did not wish to attend
29	80	Ca	WB	Died at home
30	52	Ca	WB	Did not want to attend
31	80	Ca	WB	Did not want to attend
32	45	Ca	WB	Did not want to attend
33	79	Ca	WB	Too ill to attend
34	67	Ca	WB	Died before coming
35	96	Ca	WB	Did not want TO ATTEND
36	85	Ca	WB	Cancelled No reason given
37	68	Ca	WB	Admitted to inpatient unit and died

## Appendix 6

### Results of Documentary analysis

(This appendix is presented immediately after appendix 5 as it presents a summary of these results)

**Figure: Appendix 6.-Reasons for non-attendance to APDC for patients who were referred to day-care and did not attend July 01 2005- July 31 2006**

Reason for non-attendance	Hospice					Totals/%/theme
	01	02	03	04a	Cf	
Does not wish to attend	1	8	7	6	22	Felt/perceived need minimal Patient did not wish to attend DNWTA n=60 40%
Does not want to attend	2	3	0	5	10	
Declined referral	0	1	9	0	10	
Never wanted to attend	12	0	0	0	12	
Not ready for hospice	0	0	3	0	3	
Admitted to inpatient hospice, afterwards did not want to attend	0	0	0	1	1	
Distance cited by pt, hospice staff felt pt could have easily come	0	0	1	0	1	
Was having radiation treatment refused to returned-	0	0	0	1	1	
Not well enough to attend	0	10	3	4	17	Patients P.S at time of referral or within two days of ref poor NWETA n=44 30%
Too poorly	4	0	0	2	6	
Too unwell to attend	1	0	0	6	7	
Never well enough to attend	0	0	12	0	12	
Very late essentially dying	0	0	1	0	1	
Rapid deterioration	0	0	1	0	1	
Patient died before being able to attend	10	0	2	0	12	Patient died before attending
Admitted to inpatient unit and died	0	0	0	8	8	

Died before coming	0	11	0	1	<b>12</b>	R.I.P n=33
Died before coming- at home	0	0	0	1	<b>1</b>	22%
Cancelled-no reason given	0	0	0	1	<b>1</b>	n=2
Was having radiation treatment never returned- no reason doc	0	0	0	1	<b>1</b>	1%
Inappropriate referral	4	0	1	0	<b>5</b>	Inappropriate – Normative need
Did not require day-care	0	1	0	0	<b>1</b>	n=7
No palliative care need	1	0	0	0	<b>1</b>	5%
Unable to talk to patient protective family	1	0	0	0	<b>1</b>	Family Barrier
Lacked confidence to be away from family	0	0	1	0	<b>1</b>	n=3
It will take me away from my family	0	0	1	0	<b>1</b>	2%
<b>Total of non attendees over 12 month period</b>	36	34	42	37	<b>149</b>	

## Appendix 7

### Consent Forms

(Spacing adjusted for thesis, content the same as originally given to participants)

#### a) Consent form- non patient participant

**Centre Number:**

**Study Number:**

**Health Professional/ Volunteer Identification Number for this study:**

**Title of Project: Accessing and referring to Adult Palliative Day-care services the cancer network: The experiences of Patients and Health Care Professionals. A pilot study.**

**Name of Researcher: Dr Natalie Greaves**

1)

I confirm that I have read and understand the information sheet dated 31/03/2006 with Version number 02 from the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2)

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.

3)

I agree to participate in this study.

4)

I agree to have my interview with the researcher audio taped

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

**b) Consent Form-Patients**

**Centre Number:**

**Study Number:**

**Participant Identification Number for this study:**

**Title of Project: Accessing adult palliative day-care services in the cancer network: The experiences and perceptions of patients and carers.**

**Name of Researcher: Dr Natalie Greaves**

1) I confirm that I have read and understand the information sheet (2/11/2007, Version number 01) from the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without medical care or legal rights being affected.

3) I agree to participate in this study.

5) I agree to have my interview with the researcher audio taped.

6) I agree to my General Practitioner (GP) being informed about my taking part in this study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

## Appendix 8

### Letters of thanks

Hospice managers

Accessing and referring to Adult Palliative Day-care Services in the cancer network: The experiences of Patients and Health Care Professionals. A pilot study

[Date]

[Name and address]

[Name],

Thank you very much for your support in the facilitation of this study at the [name of APDC unit]. Your assistance has been invaluable.

Interviews with the selected health professionals and volunteers have now been completed and as such we would like to commence the collection of data on patients who have been referred to day-care between the periods of [date] but have not attended.

Enclosed are the guidelines which will be used by the researcher in the collection of this data. The completion of this documentary analysis phase will mark the end of data collection in this pilot study.

Thank you once again for your kind assistance.

Yours sincerely,

Natalie Greaves MB.BS

n.s.greaves@warwick.ac.uk

## Appendix 9

### Contact Summary Sheet

Interview # \_\_\_\_\_

Site#: \_\_\_\_\_

Interview Date: \_\_\_\_\_

Written by: \_\_\_\_\_

Today's Date: \_\_\_\_\_

- 1) What were the main issues or themes that struck you with this contact?
  
- 2) Summarize the information you got/or did not get on each of the target questions for this contact.

Question \_\_\_\_\_

Information

- 3) What research question in the framework did this contact focus on most and what questions need more exploring with this contact or at this site?
  
- 4) What issues remain unanswered?
  
- 5) What new speculations or hypotheses were suggested by this contact about the field situation?
  
- 6) What would I do defiantly in my next interview/ including what to improve or tone down?

## Appendix 10a

### Initial coding scheme

Name of Code	Abbreviation	Explanation of code
<b>Day-care Characteristics-DC</b>		
DC-care model	DC-CARE MOD	Refers to the care model present at the PDC units as described by participants- the code may be applied to descriptions of social medical or hybrid models.
DC-source of funding	DC-SOURCE FUND	Refers to (Rt) Sources of funding NHS/ Voluntary/Also Rt the proportion of funding, and at this stage methods of and factors affecting fund raising
DC-ethos	DC-ETHOS	Rt description of care ethos
DC-type of staffing	DC-TYO STAF	Rt descriptions of type of staff involved in palliative day-care and their levels of training
DC-patient to nurse ratio	DC-PT:NU	# pt: nurses- dependency ratios
DC-patient:-other staff ratio	DC-PT:OT STAFF	# pt: other staff- dependency ratios
DC-location	DC- LOC	Rt descriptions of geographic location of hospice, catchment area, references to transport
DC-history of formation	DC- HIS	Accounts of the history of formation of a PDC and development of care mandates
DC-preferred patient profile	DC-PPP	Preferred patient type, referral criteria
<b>Patient characteristics-PC</b>		
PC-ethnicity	PC-ETH	Self-declared ethnicity

PC-social class	PC-SOC CLAS	Rt descriptions of a patients social class/ occupation of patient
PC-age	PC- AGE	Rt accounts concerning age profile of patients
PC-diagnosis	PC- DIAG	Rt accounts concerning the diagnosis of patients (primary diagnosis and co morbidities)
PC-economic status	PC-ECO STAT	Rt the possible economic status of patient
PC-family support	PC-FAM SUP	Accounts of family support/ family input in treatment decisions
PC- coping skills	PC-COP SKIL	Accounts of mechanisms of coping used by patients
PC-stage of illness	PC- STAG O ILL	Documented stage of illness/ accounts of stage of illness particularly at time of referral (mark by asterisk)
<b>Network characteristics- NW</b>		
NW-dissemination of information	NW- DOI	Accounts of current and previous methods of Dissemination of information about PDC and day-care patients. Refers to communication between health professional, patients carers and communities at all relationship levels
<b>-ve perceptions of day-care-NPD</b>		Accounts of-personally held negative perceptions of day-care <sup>1</sup> Accounts of perceived negative perception of day-care held by others <sup>2</sup>
NPD-patients	NPD- PT 1 <sup>0</sup> /2 <sup>0</sup>	
NPD-community	NPD- COMM 1 <sup>0</sup> /2 <sup>0</sup>	

NPD-GP	NPD-GP1 <sup>0/2</sup> <sup>0</sup>	
NPD-district nurses	NPD-DN 1 <sup>0/2</sup> <sup>0</sup>	
NPD-consultants	NPD-CON 1 <sup>0/2</sup> <sup>0</sup>	
NPD-NON HOSPITAL CONSULTANT STAFF	NPD –NON CON 1 <sup>0/2</sup> <sup>0</sup>	
NPD-Macmillan	NPD-McM 1 <sup>0/2</sup> <sup>0</sup>	
NPD-hospice staff(new code)	NPD-Hos staff 1 <sup>0/2</sup> <sup>0</sup>	
<b>+ve perceptions of day-care-PPD</b>		Accounts of-personally held positive perceptions of day-care1 <sup>0</sup>  Accounts of perceived positive perception of day-care held by others 2 <sup>0</sup>
PPD-patients	PPD- PT 1 <sup>0/2</sup> <sup>0</sup>	
PPD- community	PPD- COMM 1 <sup>0/2</sup> <sup>0</sup>	
PPD-GP	PPD- GP1 <sup>0/2</sup> <sup>0</sup>	
PPD-District nurse	PPD- DN 1 <sup>0/2</sup> <sup>0</sup>	
PPD-consultants	PPD- CON 1 <sup>0/2</sup> <sup>0</sup>	
PPD-hospice staff	PPD- McM 1 <sup>0/2</sup> <sup>0</sup>	
<b>Description of referrals-DR</b>		
DR-source of referral	DR- SORef	Accounts of sources of ref
DR-frequency of referral	DR- FQRef	Ref number of referrals per unit time- referrals made, received and accepted
DR-route of referral	DR-RORef	Accounts of pathway of referral/process of referral

DR-timing of referral	DR-TimRef	Accounts of timing of referral as pertaining to stage of illness or prognosis of patient
DR –inappropriate referral	DR-INAPRef	Accounts of referral criteria, suitability for day-care or “inappropriateness”-particularly accounts of patient stage of illness and needs as described by health professionals
DR-appropriate referral	DR-APRef	Accounts of referral criteria, suitability for day-care or “appropriateness”-particularly accounts of patient stage of illness and needs as described by health professionals

## Appendix 10b

### Evolving coding scheme-additional nodes

Expanded tree node- **Description of referrals-DR and Network characteristics-NW**

Node	Nodal Code	Node Description
<b>Network characteristics-NW</b>		
NW-partnering	NW-PAR	Accounts of network partnering activities (all levels)
NW-power struggles	NW-POW STRUG	Rt any evidence of power struggles
<b>Description of uncategorised referral blocking</b>		Factors perceived by the researcher to be acting as barriers not previously classified
DR-BLK	DR-BLK	
<b>Description of uncategorised referral facilitating-FACI</b>	DR-FACI	Factors perceived by the researcher to be acting as barriers not previously classified

## Appendix 11

### Inferential and Interpretive codes

Code Name	Description	Higher order results
Autonomy	Elements of day-care which respect patient autonomy- facilitating both access and utilization	Related to: referral interaction, routes of referral, being referred by a trusted individual- also affects the stage of utilization- the antithesis to “forced jollity”- as identified in documentary analysis.
Liminality	Descriptions of day-care as a liminal place –where liminal relates to the following associated or overlapping term border/ unknown/twilight/ Nederland place	Found to be related to/ have origins in: patient’s coping, and acceptance skills. Existence supports the premise that there is a psychological trajectory which affects access
Negotiation	Referral to day-care of a negotiation type process for during the referral of clients to day-care.	Referral to day-care involved a negation type process between patients, and health care professionals, where disadvantages and advantages actively weighed by both parties- terms as “you have to sell it to them”. Involves waiting, respecting autonomy, persistence on the part of HPs both community and hospital based.

## Appendix 12

### Excerpt from a transcript coded in Microsoft Word

R: We do also have a lady that was coming on a Friday, and she said, I would prefer to come on a Thursday you know because I met so and so and she comes on and Thursdays, so we go back have a look at the books and say well actually so and so does not come in anymore so we can – if we have to....[PC-GENDER-NEW CODE]

R: Its 14 to 15 a day, it all depends, it's all to do with the table really for lunch, how many people we can get round table but at the moment well are hoping perhaps to have this extended- our dining area we can have something built out so we can extend our dining room so it can be a bit bigger[DC-MAX PT NUMBER REASON]

I...in terms of the numbers would you like to have more numbers coming

I think at the moment it is nice and manageable- it is at the moment, we did have four qualified nurses here but at the moment we are down to three for the fact that one us has gone away for a year... so we are down to three nurse at the moment but we are fine because they are full time now, but it is manageable- about 14 people[DC-PT:NURSE RATIO]

## Appendix 13

### Excerpts from a nodal report

(need for information-free node)

<Internals\update O1310706HMP\_D> - § 9 references coded [15.34% Coverage]

Reference 1 - 0.67% Coverage

I think also the medical professionals as a whole don't always understand that that is not the only thing that hospices are about, there is a major educational need out there

Reference 2 - 3.05% Coverage

Interesting term hang on- I want to make sure that I am understanding in that they might have a patient who is suitable for day-care but they might not refer?

Yes

Why would that happen?

I think that again the DN may not have a true understanding of what we can offer

<Internals\Part two 05120908SM-A> - § 2 references coded [4.00% Coverage]

Reference 1 - 1.90% Coverage

They offer this information but other people who don't have the Macmillan nurses into their houses may not know about it, so we were quite happy with the information we got and that type of thing.

<Internals\Mac > - § 16 references coded [15.72% Coverage]

Reference 1 - 0.29% Coverage

So I think accessibility is a the biggest stumbling block really, they don't know enough about it unless they go have a look

Reference 2 - 1.18% Coverage

Do you feel like you have enough, information?

No, No definitely don't have enough information and it's something that we are aware of, and unless it's you have explored it yourself things change, but no I don't think we have enough information



## Appendix 15

### Excerpt from table matrix of results

Overarching barrier	Sub-barriers	Category of identifying participant	Model of day-care participant exposed to
<p><b>1. Fear of the concept “day hospice”</b></p>	<ol style="list-style-type: none"> <li>1. Fear of Hospice arising from being seen as a place to go to die.</li> <li>2. Fear of hospice arising out of negative mental imagery about patients, and décor.</li> <li>3. Hospice being for the poor and destitute.</li> <li>4. APDCs being seen as bedded units where people go to die-related to fundraising and deficiencies in information about APDC</li> </ol> <ul style="list-style-type: none"> <li>• No beds also equalling low clinical usefulness?</li> <li>• Ward Structure.</li> </ul>	<p>No relationship between fear of the hospice and the day-hospice site i.e. whether the day-hospice was a standalone hospice, associated with an inpatient hospice or cottage hospice or a day-hospice situated at or on shared grounds with a hospital.</p>	<p>Medical, social and dynamic. Here predominantly medical or predominantly social day-cares are those which address primarily patient’s physical medical or psychosocial needs respectively. In both models medical and social needs may be addresses but these are not prominent or dominant services being provided.</p> <p>In mixed models both medical and social needs are equally addresses with equal importance and are provided based on the patient’s current need. That is the hospice has the capacity to address both medical and social needs.</p> <p>Dynamic model was one in which the hospice was in transition between wither of the three models of care described above being able even in a state of transition to meet the medical and social needs. Using the above descriptions this research identified that of the 5 day-hospices, three were of the predominantly social model, 1 mixed and 1 dynamic.</p>

## Appendix 16

**Table summarising characteristics of participants used to label the quotes in Chapter Five**

Participant number	Participant category	Geographic location with which participant interacts
1.	Patient	A
2.	Patient	A
3.	Carer	A
4.	Patient	A
5.	Carer	A
6.	Patient	F
7.	Carer	F
8.	Carer	E
9.	Patient	E
10.	Carer	C
11.	Patient	F
12.	Carer	F
13.	Patient	D
14.	Patient	C
15.	Patient	E
16.	Patient	C
17.	Patient	C
18.	District Nurse	D
19.	Patient	F
20.	Hospital consultant	B,A,E,C
21.	Hospice Nurse/ Allied	F

	health professional	
22.	Management level provider	A
23.	General Practitioner	A and E,C
24.	Hospice nurse/ Allied Health professional	A
25.	Macmillan nurse	currently site D previous experience referring to sites A and E
26.	Management level provider	A
27.	Hospice Nurse/Allied health professional	D
28.	Hospice nurse/ Allied Health*	F
29.	District Nurse	F
30.	Management level provider	D
31.	District Nurse	C
32.	General Practitioner	F
33.	Management level provider	D
34.	District Nurse	B,C,E,D
35.	Management level provider	C and E

**Appendix 16 Continued-**

**Table summarising characteristics of participants used to label the quotes in Chapter Five**

Participant number	Participant category	Geographic location (s) with which participant interacts/interacted
36.	General Practitioner	B, A, E,C
37.	General Practitioner	B, A, C, E
38.	Macmillan nurse	A and E
39.	Hospital consultant	A, C,E
40.	Management level provider	A
41.	Hospice nurse/Allied health professional	E
42.	Hospice nurse/Allied health professional	A
43.	Management level provider site F	F
44.	Management level provider site F	D
45.	Hospice volunteer	D
46.	Management level provider site F	F
47.	Hospice nurse/Allied health professional	D
48.	Hospice volunteer	C
49.	Hospice volunteer	F
50.	Macmillan Nurse	B,E,A,C

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