UNIVERTSITY OF SOUTHAMPTON
FACULTY OF HUMANITIES, ARTS AND SOCIAL SCIENCE
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Exploring The Complex And Dynamic Construction Of Care Within Palliative Care: An Ethnographic Study Of Care Within And Across A Specialist Palliative Care Service In England

by

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ABSTRACT

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EXPLORING THE COMPLEX AND DYNAMIC CONSTRUCTION OF CARE WITHIN PALLIATIVE CARE: AN ETHNOGRAPHIC STUDY OF CARE WITHIN AND ACROSS A SPECIALIST PALLIATIVE CARE SERVICE IN ENGLAND

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This thesis explores the multiple and dynamic constructions and processes of care that inform how care is provided, experienced and conceptualised within an NHS integrated palliative care service in England. Drawing upon the literature and research from palliative care and the debates about care within the philosophical, sociological, health and educational domains, a wide range of constructions were revealed. How these constructions have influenced and continue to influence care within palliative care was explored guided by a philosophical position that values multiple truths and ways of knowing.

An holistic ethnography was undertaken over a period of six and a half months within the palliative care service that provided a combination of hospice, community and hospital palliative care. Observations of care were undertaken in each of the three areas of the service focusing on care practices, care talk, care processes and documentation. Semi structured interviews were undertaken with staff, people being cared for, family members and stakeholders. A thematic and hermeneutic analysis of the data was undertaken to reveal and interpret the emerging constructions of care, and how these informed and shaped palliative care practice.

The palliative care services had a democratically shared leadership which valued the multiple voices, knowledges and processes within and across the service enabling it to adapt to the centralising and hierarchical pressure of the NHS, whilst retaining a service that provided personalised responsive holistic and supportive care.

This thesis argues that care can be conceived of as a set of complex, multidimensional, temporal and dynamic processes informed by multiple knowledges and shaped by personal professional and structural values within society. Care within palliative care is constructed by these multiple processes and influences. Care is relational and can only be an ethically just process when the multiple voices are heard, respected and negotiated within the processes. Care is therefore not concrete, but shaped and reshaped over time.

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Care is a two way process, it is a choice made by the person to offer care and a choice by the person to receive care. Caring for and caring about are not as easily delineated, as some writers would suggest. Thank you all for your care during this process.

Say not, 'I have found the truth,' but rather, 'I have found a truth.'
Say not, 'I have found the path of the soul.'
Say rather, 'I have met the soul walking upon my path.'
For the soul walks upon all paths.
The soul walks not upon a line, neither does it grow like a reed.
The soul unfolds itself, like a lotus of countless petals.'

The Prophet
Kahlil Gibran (1972)

Contents

Chapter 1 Introduction and Outline of Thesis

This thesis seeks to explore how care is constructed and understood within an NHS integrated palliative care service that provides hospice, community and hospital palliative care. Palliative care now finds it self repositioned back in the mainstream of the modern NHS and accounted for in recent Department of Health policies and initiatives (NICE 2004, DoH 2000b). Yet despite the changes and redefinition of palliative care since the 1960's the same guiding principles and philosophies have been drawn upon to guide practice and shaped care. Whether these still serve the same function or whether other values and philosophies are now more influential will be considered. This thesis will therefore analyse these and other contributing factors that may be shaping and reshaping care within this area. What this thesis offers is an exploration of palliative care and care theory, and will therefore offer something to both the understanding of care specifically within palliative care and also the wider understanding of care.

Before the outline of the thesis is described, it is important that I contextualise myself and the style of the work. I have worked as a palliative care nurse and nurse specialist within voluntary hospices, the community and an NHS hospital. My journey began in 1989 when I began working at St. Christopher's Hospice in Sydenham as a young idealistic staff nurse. I chose to work there because I had felt impotent in my previous ward which regularly had people dying from cancer and leukaemia on it. Many people suffered because we didn't have enough knowledge to control their symptoms or work with their distress and that of their families. Many people were told too late that they were dying, and unrealistic promises were made by some of the doctors.

Years later I was prompted to seek answers to questions I had in my mind about the changing nature of palliative care from my experiences working in different hospices and within a district general hospital. I experienced a move from care with a holistic focus, to one in which the main focus was symptom control, despite our understanding of our work being shaped by palliative care within its holistic definition and framework.

Chapter two explores the literature that has shaped the development of palliative care from the early hospice movement to recent research across a range of palliative care services. Some of the early writings of Dame Cicely Saunders are considered in relation to the increasing redefinition of palliative care during the 1990s. The current socio-political context is discussed in relation to the increasing standardisation and regulation of services. The discussion then turns to consider how care is written about and described in the palliative care literature and what the research undertaken has explored in relation to the care provided, before discussing work that has begun to conceptualise care within palliative care. The aim of this review is to identify what further information needs to be sought about the construct of care within palliative care.

Chapter three continues the discussion about the different concepts of care, taking a broad and generalised perspective, drawing upon philosophical, sociological, nursing and educational literature. The different conceptual theories of care are discussed in relation to each other, before considering the role played by knowledge in shaping care and care practices. This chapter identifies multiple theoretical and structural influences in the conceptualisation and construction of care, rather than prioritising one theory as more important than another.

Chapter four explores the philosophical underpinnings that have shaped the study and the choice of methodology to explore the world of care. The discussion focuses on the debates between the different ways of knowing that exist, and how these can be explored and captured. Because undertaking research in the areas of palliative care is fraught with ethical dilemmas and debates, these are discussed in relation to the application made to the Local Research Ethics Committee and the very influential way the Data Protection Act (1998) is beginning to shape and define research practice.

Chapter five introduces the reader to Chaffinch Palliative Care Services before discussing and analysing the Socio-political context of the research setting and the culture and values informing the structure and organisation of the service and the care provided. Funding sources are explained which are important in the analysis of trail of accountabilities and also the structural organisation of care in chapter five.

Chapter six analyses the structural organisation of care. It commences by focusing on the non-clinical organisation of care by democratic management and decision making processes and the importance of balancing the needs of the NHS with the needs and values of the Hospice Trust before discussing and analysing the organisation of clinical care by spatial location: the Hospice, Community and Hospital. Discussion then turns to the clinical organisation of care through an analysis of leadership, multidisciplinary teamwork the role of regular meetings and how these are shaped by the care across the different locations of care.

Chapter seven introduces the reader to an analytical exploration of the multiple processes discovered to be informing and shaping the care provided across the different locations of the service. This is a long important chapter exploring the complexity and dynamic interrelationship between different processes of care. A range of examples from the fieldwork are drawn upon for this purpose. The processes of care are shaped and influenced by the socio-political contexts and values of the service, and by the organisational structures discussed in chapter five. The interrelationship between chapters five, six, seven and chapter eight can not be emphasised enough.

Chapter eight explores and makes explicit the multiple and often assumed knowledges that underpin and inform the different processes of care identified in chapter seven. Examples previously used in chapter seven are revisited to explore the processes of care from this alternative perspective and to identify the different knowledges within the processes. The different knowledges underpinning the processes of care and how these influence and shape the care provided across the hospice, community and hospital settings are discussed. This chapter requires the reader to appreciate the relationship between the preceding chapters as dynamic rather than linear.

Chapter nine draws the thesis together and discusses the findings in relation to the previous understanding of care within palliative care and in relation to the conceptual theories of care. The discussion argues for care generally and for care within palliative care to be conceptualised as range of interactive dynamic processes, which are shaped and informed by multiple concepts of care; organisational, professional and personal values; organisational structure and frameworks and the multiple knowledges used to inform and guide these processes.

It is important to note that throughout the writing of this thesis I have chosen to use the term, person being cared for to identify the people being cared for by the service. I choose not to use the word patient, which objectifies and positions that person within a range of hierarchical discourses. The guiding philosophy behind this study is the recognition and valuing of each individual, their experiences and their truths as informative and participative in a human endeavour of research, rather than as objects of health care and objects of this study. Because a person requires care does not make them any less of a person, as was revealed in the personalised care I observed in and across the palliative care service.

It is also important to ask the reader to remember to consider chapters five, six, seven, and eight as interrelated and not linear progressions. Care in this thesis is conceived of as multidimensional, however, the protocol for writing a thesis requires that a linear approach is taken. Therefore I had to decide in which order the place chapter six and chapter seven in the text. I chose to discuss processes of care because there was a more natural link from the last discussion in chapter five about clinical care and a greater inclusion of knowledge in chapter six to lead into chapter seven. This is a false situation, and is not representative of the reality of care and caring.

Chapter 2 Palliative Care Literature Review

2.1 Introduction

Palliative care has become an increasingly well established area of modern health care provision for people with cancer across the United Kingdom, the United States, Australia and increasingly so across Europe and some parts of Asia, Africa and South America since its inception and development in the late 1960's (Clark, Hockley, Ahmedzai 1997). These developments in the United Kingdom have been strongly influenced by changes implemented through successive health policy directives over the decades between 1987 and 2001 (DoH 1987, 1990, 1995, 1997, 1998, 2000a, 2000b, 2001). The implementation of the Framework for Cancer Services (DoH 1995) and more recently the modernisation agenda including The NHS Cancer Plan (DoH 2000b, 1997) are defining access to palliative care in the UK as an essential component of care available for people with cancer.

Concurrently there have been rapid developments in available treatment options, the rise and regular use of audit, the requirement for evidence based practice and the involvement of user groups (Clark and Seymour 1999, Gott 2000, NCHSPCS 2000). The Commission for Health Improvement (CHI), through the implementation of clinical governance and the evidence base for supportive and palliative care being established by the National Institute for Clinical Excellence (NICE), will, in conjunction with the requirements of the NHS Cancer Plan be used to create a set of national minimum standards for palliative care practice and provision. Although, it must be said, many people with other advanced life threatening illnesses continue to be disadvantaged in terms of palliative care provision it is hoped that palliative care and supportive care will increasingly be available to people without cancer (NCHSPCS 2002, 1998).

Palliative care continues to respond to these changes. The call for a 'seamless service' has seen joint consultant posts in palliative medicine developed across the different services, thus developing a more integrated and perhaps more complex network between the acute care and primary care sectors. The different funding bodies, as provided by the NHS and Primary Care Trusts, Macmillan, Marie Curie Cancer Care and voluntary contributions to local services for hospice, community and hospital palliative care services provide new possibilities as well as added tensions and constraints to working practices.

Current understanding of what palliative care means and what palliative care services offer in terms of care remains at times poorly understood by the people who access services and by those who commission services (Payne and Sheldon et al 2002, Seymour, Clark and Marples 2002, Jarrett and Payne et al 1999, Fallon and Dunlop 2002, Prail 2000). This may perhaps have something to do with the changes that have occurred over the last three and a half decades in the naming, defining and diversity of palliative care services available (NCHSPCS 2002, 2001, 1999, 1995 WHO 1990, DoH 1987, SMAC 1980). Also the differentiation of palliative medicine from palliative care, created when palliative medicine became a sub-speciality of the Royal College of Physicians in 1987, may have paradoxically contributed to this lack of understanding whilst at the same time raising its profile. There may, however, also be other sociological influences which have influenced the construction and perception of the care provided by palliative care services.

The early hospices through to the current day array of different palliative care services have continued to draw upon the original philosophy and ideals of total care, multidisciplinary team work and the inclusion of the person and their family, as the unit of care, with the aim of ensuring a good death (McNamara 2001, Seymour and Clark 1999, Aranda 1998, Saunders 1993). From out of this philosophy a set of ideological beliefs have been drawn upon which, according to Aranda (1998), have hidden the realities and complexity of the care provided. Perhaps these complexities and hidden components of care within palliative care also explain in part why palliative care and the care provided was not always so well understood. She suggests the ideology and guiding philosophy should be explored since palliative care has undergone such change. Hospices and palliative care services have adapted enormously to provide care to people at home, in hospital, in hospices, day care services and more recently in nursing homes.

Concerns have also been highlighted about potential attrition of the philosophy base and the ideals of holistic and multidisciplinary care in which the different areas of provision and different understandings of 'care' between team members have become the focus point of debate and challenge. Perceived medicalisation, bureaucratisation and mainstreaming of palliative care services and the lack of sensitivity of audit to measure the informal quality of care continue to be discussed. (Lawton 2000, White 1999, Rumbold 1998, Hockley 1997, Corner and Dunlop 1997, Biswas 1993, James and Field 1992,). There is concern in some quarters that palliative care is becoming little more than symptomatic management, a concern that was initially raised over a decade ago by Kearney (1992). The potential and perceived changes to practice, despite the referral to palliative care rhetoric, also raise concerns over the power of influence by palliative medicine, in terms of perpetuating the mainstream hierarchy at the loss of the more equitable status of the early multidisciplinary teams (Field and James 1996).

This chapter will consider and explore in more detail the many influences shaping the care offered and provided within palliative care. By considering the initial aims and guiding philosophy; exploring the roles and effects of social and health care policy specific to palliative care; the changing nature of the language used to describe the care and services provided, including the increasing specialisation and the contentious issue of the medicalisation of palliative care, this chapter aims to explore some of the constructions underpinning the care and how it is understood. It will do this by drawing on available research and literature.

2.2 *Initial Aims and Philosophy of Palliative Care*

The modern hospice movement was founded on a history of long established Catholic hospices and Marie Curie homes, which was acknowledged by Saunders in describing her learning whilst working in these places (1991/2). Coming at a time of medical advances, the rise in interventionist and technical approaches within the hospitals meant that the majority of deaths also occurred there, but did so in an environment that began to focus more on disease than the whole person. Care of older people and of those with cancer was also deemed poor and impersonal and the rising power of the medical profession began to be questioned. Those with cancer epitomised an almost societal fear of death through a disease that could not be controlled making it even more of a taboo. Where loss of control was identified with loss of dignity the opportunity was ripe to offer an alternative approach to providing end of life care, one which was holistic and valued the people it was involved with (Rinaldi and Kearl 1990, James and Field 1992).

The initial aims of the hospice movement were on improving care for people dying from cancer and their families, to provide whole person care, improving and opening up discussion and awareness of dying and to develop specialised skills and techniques to control symptoms for those working in the area to take back into the NHS (Seymour and Clark 1999, Parker and Aranda 1998, James and Field 1992, Clark 1993, Saunders 1993, 1981 Twycross 1984). Research and the development of high standards were central but were not to be achieved without skilled care and compassion. Inherent in the philosophy of care was the central belief that staff would stay alongside patients and their families through their pain and distress.

In a published article taken from a talk by Cicely Saunders to members of the Annual General Meeting at St Christopher's Hospice before it opened, she stated clearly a philosophy which values the individual and values the importance of human relationship as a means of therapeutic care. She explains:

> *"Watch with me' means still more than all our learning of skills, our attempts to understand mental suffering and loneliness and to pass on what we have learnt. It means also a great deal that cannot be understood... watch with me' means above all, just 'be there'... Certainly we are going to see hard things, but we are also going to see rewards and compensations and insights given to our patients here and now we will see an extraordinary amount of real happiness and even light heartedness...So much of our communication with people is done without words but I think this is especially so with the very ill"* (Cicely Saunders 1965)

It is clear that individual contributions of those working within the hospice should be valued without a 'hierarchy of importance in what is done', thus suggesting a levelling of the traditional hierarchy in favour of respecting and valuing the different contributions by members of the multidisciplinary team. Also evident was the expectation that those working in the hospice would use themselves and sense of personhood as a therapeutic tool in which to approach and meet the people being cared for and their families in their need or distress. That often there are no words but non-verbal communication plays an important role. Cicely Saunders returns to this almost thirty years later when considering the challenges facing palliative care and reminds the reader that the 'gift of listening' can be undertaken by any member of the ward team:

> *'It is a question of time – and timing- a readiness on the part of all staff to stop and listen at the moment this particular area of pain is expressed and to stay with it... Only as a team becomes more experienced and confident do its members find it easy to allow or even encourage the expression of anger and other negative feelings that may express this inner pain and the frequent question 'Why?' (p82 1993).*

This required the development of a supportive community within the hospice to offer a relaxed and homely environment so that people could be themselves and accepted as such, and that the staff supported in their work. Underpinning this was a very strong and steady belief in Christianity and the values held within its teachings. The sense of valuing people and learning from them was foremost in her aims and philosophy of care (Saunders 1993a 1993b, Du Boulay 1984, Twycross 1984,).

Through the philosophy of holism and the striving for a better understanding of skills and knowledge through care, listening and scientific rigor was taught and passed on alongside a strong commitment through faith. Looking back Cicely Saunders wrote:

> *'We began to develop the appropriate way of caring, showing that there could be a place for scientific medicine and nursing... terminal care is part of a continuity of treatment, not a sudden soft option. Care and treatment should*

> *be given throughout, as we aim to enhance the patient's quality of life' (1991/2)*

In 1993 after the acceptance of palliative medicine as a speciality and the change in terminology she added:

> *'We are concerned with how people live and we are concerned with how they die. Terminal care is part of palliative care and may extend over only a few days, bringing new and more difficult problems' (Saunders p78 1993a).*

This was as recognition of a change in the earlier aims from a total focus upon death and dying to care, which had a broader perspective. There were several constant themes in her early writing; 'being there' and 'watching', research, teamwork, communication and support and, importantly, working with the distress and suffering, both physical and mental, of patients in their care, spirituality and faith. The focus on symptom control and research to improve the methods and approaches was to be carried out but not at the cost of care and compassion. The care offered within hospice and palliative care was considered as part of the wider process of care over the duration of a person's illness rather than as something separate, or as a last resort for patients (Saunders 1991/2 p22).

It was from the early stories, work and books giving guidance on symptom control and emotional, social and spiritual aspects of care, that the notion of 'total pain' became established. That pain and suffering was not just a physical experience but one which included the emotional, social and spiritual aspects of that person in the time of facing their own death. Always referring to stories of patients that she had cared for set a trend of learning from a person's story and the reflective experience and the retelling by the staff about what was learned and the insights gained. Society has also become more secularised and the Christian tradition no longer remains appropriate for the provision of palliative care that is sensitive to the needs of multicultural and multi-faith communities (NCHSPCS 1995, 2001).

What we begin to see is a process of maturation, from an early vision of what care should be and how it should be carried out to a process of review and reflection in which there is a slight shift in focus, but where the stories of early patients remained as the inspiration to improve care. There is, however, also a notable change, the recognition that to go any further, and to be more formally accepted, palliative care would have to adapt to the requirements to define itself as a speciality.

2.3 Changing Language and Changing Definitions

The language and terminology used to describe palliative care has changed, as has the focus and remit of care. The term 'palliative care' became synonymous with and then defined this new speciality. The word hospice in the UK signified a place of care for travellers and had a positive connotation to it as a place of hospitality. However, this was not so in Canada where it implied something rather more negative (Saunders 1993). Already the influence on care, even through the language used can be seen to have been influenced by wider sociological concerns. Although the term 'palliative' was chosen as early as 1975 in Canada, it wasn't incorporated into the UK until 1987 by the new speciality of palliative medicine.

This language change and verification has not been without concern. Questions were raised as to whether the terms 'palliative care' and 'terminal care' were at all synonymous with one another and whether the focus on death and dying was about to change. Also, development and defining of palliative medicine as its own medical speciality (Doyle 1993) might alter the previously egalitarian nature of the work, changing not only the power base but both the nature and manner of the care to be carried out (Biswas 1993). These concerns were strongly disputed by Ahmedzai (1993) who saw new methods and medical techniques having the potential to improve quality of life as vital to be incorporated into the care offered. He also questioned who should hold the position of power and lead the team. The concern over the role language has on changing the nature of what is being named has continued. Not only were concerns that the change in language were to be the start of a creeping medicalisation (James and Field 1992, Biswas 1993) but also a more subtle way of masking death and removing the focus away from dying (Biswas 1993, McNamara 2001). Perhaps this move away from the development of open awareness is seen in the changing patterns of communication and the return to conditional and negotiated awareness (Field and Copp 1999, Johnston and Abraham 2000)

According to Foucault (1980, 1972) language plays an important role in constructing our knowledge and understanding of the world around us. The language or naming of things, which are identifiable, informs the development of knowledge. Knowledge is power according to Foucault, each are intertwined. Therefore, the language used to describe hospice care; palliative care and palliative medicine have shaped the developing discourses about the care and treatment of people with advanced cancer and those who are dying.

2.3.1 The Good Death Discourse

The construction of the discourse of a 'good death' is now the ideal the care people want at the end of life and what palliative care health care professionals seek to achieve. That is a death that is pain and symptom free, where people accept what is happening, there is family involvement and the person dying is peaceful (McNamara 2001, 1994, Kristjanson et al 2001, Lawton 2000, Clark and Seymour 1999, Payne et al 1996). The change in discourse over time is clear when comparing the findings of Glaser and Straus (1965) in terms of predominantly closed levels of communication and awareness (Sudnow 1967) in terms of the social, procedural and perceptual aspects of the care of dying people in US hospitals and Field (1989) in a UK hospital, in terms of perceptions, procedures and increasingly more open communication. The changing notions of 'good death' saw nurses on the medical ward preferring, where possible, that someone did not die alone. In James's study in a continuing care unit, death had become shaped by the discourse to the extent that anyone who raged 'against the dying of the light' (Dylan Thomas) and did not die peacefully was seen to be at odds with the normalising process of the carework (James 1986 p297). The normalising clinical gaze in conjunction with the development of particular knowledges has developed disciplinary practices that shape language, expectations and actions (Foucault 1973, 1977). Hockey (1990) questioned whether it was possible to focus on both living and dying as a continuum, and reveals the careful use of time and space to manage living and dying. Lawton's challenging critique of the dying process challenged the discourse of a good and dignified death. She suggests these are ideological concepts which actually mask the hidden and complex realities of bodily disintegration and social death, which rather than offer dignity actually contribute to a loss and denial of personhood (Lawton 2000). Rhetoric does not always appear to describe reality.

2.3.2 Changing Definitions of Palliative Care

The change in focus from the language of care to medicine is, therefore, not without implications in developing alternative discourses and practices. The change of language from 'hospice care' and 'terminal care' has enabled the focus to move away from death (McNamara 2001). The redefinition of palliative care over the last ten years has seen a change in the definition of palliative care from the WHO (1990) definition to a more inclusive definition in which the word 'cancer' has been removed to make it more inclusive to people with illnesses other than cancer. The definition also makes it clear that palliative care can be offered earlier in the course of a person's illness. The function of the most recent definition (NCHSPCS 2002) is aimed to explain and make clear the differences between palliative care needs which can be managed under the general palliative care definition by general palliative care services, and needs which are defined in terms of specialist palliative care and require specialist palliative care services (NCHSPCS 2002, 2001, 2000,1999, 1995). In many respects it is unsurprising that there has been a lack of clarity on behalf of service users and commissioners, as previously discussed, because of the alterations and refinements of definitions and service provision. There is also a language shift from multidisciplinary to multiprofessional team, which is also about to become defined in terms of its core participants, and core specialist palliative care services.

The changing language and legitimisation of palliative medicine has sanctioned the development of the medical gaze, the development of specialist knowledge, technologies and control and thus the professionalisation of the field. Considering Foucault's work, I would suggest the increasing observation or 'clinical gaze' has not only developed the specialist knowledges of palliative care and palliative medicine, it has been used to create a body of evidence which is drawn upon to exert influence and provide power within the multidisciplinary team (Foucault 1977, 1973, 1972, James and Field 1992). Interestingly, the definitions continue to refer to palliative care and specialist palliative care, and so it could be said that it is care that is the focus of the redefinition. An exploration of what the frequently used term 'psychosocial care' was undertaken. It was concluded that, although the term was widely used, it did not actually represent the care predominantly provided which was physical care and psychological care. Field writing on behalf of the NCHSPCS suggested the separation of the term into psychological care and social care, so that each might be accounted for. Here language is both definitive and descriptive, both masking and unmasking the lack of social care within palliative care (NCHSPCS 2000).

There has been a move away from the hospice as the central location of care to care provided by a range of different palliative care services found in a variety of locations and configurations. Perhaps the change in terminology does not matter. On the other hand, however, by changing the language the focus of the service changes. What then of the initial aims and philosophy in the care that was provided by hospices and palliative care services. Habermas (1984) suggests language and the use of particular words or speech acts provide meaning through a process of shared understanding. If the words or speech acts change, then understanding and knowledge also alter over time. Part of the influence of these definitional changes and focus in palliative care has been the effects of health policy.

2.4 The Effects of Health and Social Policy on Palliative Care

2.4.1 The Influence of the Market Economy and Business Values

Health and social policy over the last decade has had a profound effect on drawing palliative care back into mainstream NHS care. The analysis and predictions of James and Field (1992) have been fulfilled and surpassed due to the developments in health policy since 1990, but predominantly since 1995. The NHS and Community Care Act (1990) completely changed the face of providing care for people at home, in independent health care and in the NHS. Suddenly those services that were independent and had set themselves outside of the mainstream were required to make allegiances with the health service and develop interdependent partnerships. Those services and units established within the NHS were already subject to the routinisation and standardisation that came as being part of the NHS, with shared staffing costs and lower staff to patient ratios; adaptations had already been made to the original vision due to their position within the NHS framework (Clark and Malson et al 1997, Clark, Neal and Heather 1995).

The driving philosophy behind these policy changes was cost effectiveness and efficiency. Thus the new contractual arrangements would also be monitored and so the process of audit and contractual obligation could be seen as a challenge to the previous autonomy of many services and a reining in of this previously antiestablishment movement.

Clark et al (1993) suggested that hospice care was at a crossroads. Hospice care and palliative care either adapted or those voluntary services would struggle to survive. This had implications not only in terms of long term funding but for the growth of bureaucratisation and the sustainability of the original aims. From 1987 there had been a rapid increase and diversification of services, which had remained ad hoc rather than strategic (Wilkes 1993, Clark 1991). The new reforms introduced the notion of needs assessment. This meant assessment for the number of and nature of services for a given population, yet what this threw up was a question of definition. What was a palliative care need?

Thus began not only a defining of need but a redefining of palliative care services, which differentiated between different levels of palliative care needs, from a palliative care approach to general palliative needs, and to specialist palliative care needs catered for by a specialist service (NCHSPCS 1993, 1995). The focus of need was now to be determined by population rather than by the individual, ‘economy, efficiency and effectiveness, and possibly less equity than equality’ (Robbins p13 1997). Franks and Salisbury et al (2000) conclude that it remains difficult to evaluate fully a palliative care needs assessment, and that despite predictions based on cancer patients, there are many more people without cancer who have a very high proportion of unmet needs and who also require good symptom control and palliative care. In fact this reflects earlier work by Robbins and Frankel (1995) about the lack of planning by health authorities, Higginson (1997) and discussions by Clark and Malson et al (1997). The balance perhaps to be considered is the balance between the needs of individuals and the needs of the population.

The increasing use of the new definitions of need and of palliative care informed the changes, although research by Addington-Hall et al (1998, 2000) suggested that symptom severity, age (being under 85 years old), dependency level and site of cancer played a part in deciding whether someone should be admitted for inpatient care, yet it remained somewhat governed by chance. Access to specialist community palliative care tended to be lead by symptom severity and dependency and the need for support. It was also recognised that this needed further study. Grande et al (1998) in a review of research relating to home deaths also revealed that, although there is a strong wish among many people to die at home, this is not often possible as it often depended on the level of support at home from informal carers and statutory services. Socioeconomic status meant that those who could afford to pay for extra help were also the ones able to stay at home. Age was a contributing factor for older people, especially for women, who could only manage to stay at home if they had access to community palliative care services. Concerns are being raised about the increasing transfer of people to nursing homes from hospices because they are not dying quickly enough, or they are no longer deemed to have specialist needs, and the effect this is having on the person and the perceptions of palliative care by the public (Fallon and Dunlop 2002, Prail 2000, Porock et al 1997).

2.4.2 Return to Mainstream Health Care: The Standardisation and Regulation of Palliative Care

Small (2001) said that as a social movement hospice and palliative care had achieved its aims. Through innovative thinking it has embraced new ideas and creative therapies in order that quality of life and death and bereavement may be improved for patients and their families in an environment of open discussion. It could be argued that palliative care is about to become a fully integrated service within the NHS. The integration brings with it the potential for both opportunities and losses, and it could be said that by becoming more aligned to mainstream health care palliative care will be required to negotiate its own values and structures with those driven by the NHS.

The review of the Expert Advisory Group on Cancer, the Calman-Hine Report (DoH 1995) raised the profile of cancer care within the NHS and set in motion a series of developments aimed at improving communication, interdisciplinary team working and access to palliative care services in an attempt to create a 'seamless service' for patients between the different care providers. This was seen as an opportunity for the profile of palliative care services to be raised.

The National Council for Hospices and Specialist Palliative Care Services have been integral in raising the profile and understanding of palliative care in its advisory capacity to the Department of Health and Local Health Authorities. Thus there was an ever increasingly formalised link and mode of influence between the independent advisory body and the Department of Health.

The drive of the modernisation agenda through the work of the Commission for Health Improvement (CHI), National Care Standards Commission (NCSC) and the National Institute for Clinical Excellence (NICE) has focused on improving the evidence, effectiveness, efficiency and evaluation of treatments and health services (DoH 1997, 1998). The NHS Plan set out the agenda for the redevelopment of new partnerships with the social services and the involvement of service users in the evaluation of and future development of services (DoH 2000a). The Cancer Plan and Manual of Cancer Services (DoH 2000b, 2000c) places palliative care as an essential component in the provision of cancer care. Hospices and palliative care services have finally found themselves as central players in the development of new cancer and palliative care networks informing and developing cancer and palliative care services. However, in what appears as an opportunity for palliative care to reach wider populations, it is important to note that it remains entwined within the cancer policy despite calls by both the NCHSPCS and others that palliative care should be available to people with other life threatening illnesses such as heart disease and people dying from old age (Seymour 2001, Froggatt 2001, NCHSPCS 1998, Higginson 1997)

This is a time of great uncertainty for palliative care services. Unlike the changes in the early part of the 1990's these structural changes see the cornerstones and boundaries which have held services within the NHS and the voluntary sector being reshaped. The balance of power of commissioning services is moving entirely into the hands of the Primary Care Trusts. How palliative care engages in the process of the new structural changes, policy developments and consumerism will be crucial to how it make best use of the opportunities and threats ahead of it.

In the midst of the modernisation agenda palliative care, incorporated as a central theme within the NHS Cancer Plan, is therefore subject to the implementation of the national minimum standards within the Manual of Cancer Services, and those currently being developed specifically for supportive and specialist palliative care by NICE. Not only that but NHS cancer services will undergo regular accreditation reviews in order to meet these and other standards by CHI or NCSC for those in the independent sector based in part of on guidance from NICE.

The aim of this new standardisation is to improve quality and equity of services across the country. However, within this standardisation there is a regulatory capacity. What we can see is the development of a regulatory and accountability framework for the hospices and palliative care services. Clinical governance is providing the tools and methods of identifying best practice and assessing performance through risk management and the audit cycle and ensuring outcomes improve. However, it is not always easy to measure outcome within palliative care, which raises the issues of defining best practice and outcome and how such standards are initially set. Supportive and palliative care guidelines are currently being revised and assessed by NICE. However, it begs the question, how can one fully assess the evidence base for an area where it is extremely hard to quantify or qualify many of the outcomes.

Funding is being made available specifically for palliative care services aside from the money for cancer services. This will fund the education and training of more specialist registrars and consultants and nurse specialists. It also means that all palliative care services should receive at least fifty percent funding from the government. But how will the increasing standardisation and regulation of palliative care services affect the flexibility of meeting local needs and how will fair access be achieved if palliative care is becoming intertwined in a regulatory capacity into cancer services rather than a broader agenda. As can be seen from the National Service Framework for older people, there is only a passing reference to death, dying and palliative care.

Collaborative working across the different health and social care cultures is required if the Primary Care Trusts and palliative care representatives are to work together within the networks to meet local needs. This will require a sea change in thinking for most professionals. The networks offer opportunities for palliative care to have a key role in developing needs led services, responsive to local populations and co-ordinating palliative care across other services. The supportive and palliative care networks themselves are multiprofessional, with the group members including a partnership of health service commissioners, palliative care and bereavement service providers and local authorities to ensure a comprehensive palliative care service is available.

If one of Cicely Saunders original aims was to 'move out [of the NHS] so that attitudes and knowledge could move back in' (Saunders 1991), then it has been achieved, but at what cost to the original aims and values? If the move out of the NHS was so that only attitudes and knowledge would move back, then perhaps it has been overwhelmed by a political agenda underpinned by the resource implications from the public demand for symptom control and death with dignity. Can the hospices and palliative care services remain innovative, push the boundaries and try new ideas in terms of care if they are becoming bound by standardisation and regulation. Or perhaps as Douglas asked, their role is taken over for the greater good of the wider population in terms of resourcing and access.

As Rumbold (1999) suggests in light of the experience in Australia

> *'Accountability to government has also had the effect of reducing accountability to the local community. The community groups that established and funded the projects are now becoming more like auxiliaries that support mainstream institutions' (1999 p8).*

James and Field (1992) raised important and timely concerns, which remain even more pertinent today. The routinisation and bureaucratisation of palliative care has certainly occurred, with all that that entails. It also places an even greater focus on the early fears of Biswas about the medicalisation of the speciality. The closer alliance between palliative care services, the sharing of staff and funding will inevitably see a further cross fertilisation of ideas and perhaps values. Corner and Dunlop (1997) expressed additional concern over the reprofessionalisation of palliative care and a re-emergence of hierarchical structures to the detriment of multiprofessional team working and valuing the contribution of team members. The change in focus may also undermine the philosophy of holistic care and working toward a shared vision and concept of care, thus moving the focus back to the biomedical and away from the psychosocial (Corner and Dunlop 1997, Rumbold 1998, Clark and Seymour 1999).

In a climate that measures outcomes and evidence based practice, the social, emotional and spiritual aspects of care will be less easy to measure and define and, as Saunders said in her early work, so much care and communication is carried out through the relationship of the health professional and the patients and family and through the unspoken aspects of care giving and the 'being there' and listening.

Perhaps as Rumbold suggests hospices and palliative care services will need to further adapt, with the hospices retaining some degree of independence to retain the founding values and by specialising in holistic care within an egalitarian organisation where those being cared for are valued and leading care. This in contrast to palliative care services specialising in symptom control in which medicine is the core discipline and guiding focus. Aranda (1998), however, proposes an altogether different view. In her discussion about the role of ideology in palliative care she considers the guiding principles in terms of their social context and ideology. She suggests that because palliative care has undergone such change along with society's expectations, perhaps it is not about holding on to these beliefs and ideology blindly. She suggests that current day palliative care should develop and articulate in a new way the values, skills and realities of specialist practice which can more clearly demonstrate the complexity of relationships, skills, knowledge, attitudes and structures underpinning the work. As she says:

> *'The concept of supportive care often described and underplays the skills of the palliative care practitioners in negotiating care that meets the needs of people with divergent and often conflicting perspectives' (Aranda 1998).*

She suggests that in reworking the ideology and making transparent the complexity of palliative care practice, the hidden and often silent knowledge and skills used in caring for dying people should be acknowledged alongside the more visible aspects of care, such as symptom control, as a means of protecting and maintaining the vision of hospice care and the interdisciplinary nature of care from the effects of the mainstreaming agenda.

Through the pursuit and understanding of current hospice and palliative care practices, rather than focusing on an ideology, the specialist practice will be more clearly articulated rather than lost as an add on to other medical areas. Perhaps by refocusing it would be possible to ask the question 'what is the care that palliative care claims to offer', and how is it represented and constructed in the current climate of change?

2.5 Current Understanding and Position of Care Within Palliative Care

The discussion about the changing nature and definition of care within palliative care has also raised concerns about the current practice of palliative care and the possible rise in medicalisation with the increasing specialisation of services. These authors are concerned that there is already a change in the nature of care offered. Attention to working with people with increasingly complex needs, those who are seen earlier in their illnesses and the increase in the number of people moved into nursing homes from hospices to be cared for until they die, has caused concern and a fear that palliative care is losing some of its humanity and its focus (Fallon and Dunlop 2002, Froggatt 2001, Corner and Dunlop 1997).

Palliative care is provided by specialist hospital and community teams and by local voluntary and NHS hospices and day care services. Each has drawn upon the palliative care philosophy but it could be argued that this has required adaptation to fit the different foci of the services and make-up of the teams of care. In exploring the current knowledge about the nature of care within palliative care, a range of studies and discussion papers will be considered.

2.5.1 Studies Related to Care in Palliative Care Settings

2.5.1.1 Evaluation and Availability of Care

Most of the early writing about care and practices of care related to palliative care came from observations and studies from hospices. Several early comparative studies compared hospice care with hospitals (Parkes 1979, 1984), other hospitals or different palliative care settings (Hinton 1979, Seale 1989, 1991) and revealed greater satisfaction with hospice care and better symptom control. Later studies by Parkes (1984) and Kane (1984) revealed little differentiation in pain control between hospices and hospitals, suggesting better awareness of pain control in the hospital. Seale (1991) also found higher levels of satisfaction with care within the hospice due, in part, to the atmosphere and reduced number of interventions. Systematic reviews of published findings comparing different models of palliative care on quality of life revealed few comparative studies, but what evidence was available suggested inpatient hospice care provided better pain control than home care or hospital care. There are potential limitations with measurement tools, and this has not accounted for personal preference of those being cared for, or cost effectiveness (Salisbury et al 1999).

Most large scale studies, including the Regional Study of Care of the Dying, have surveyed what palliative care services are available and who receives these rather than focusing on the nature of the care available. Addington Hall et al (1995) found that the majority of family members bore the brunt of caring for people dying of cancer at home and this had restricted their own activities, although half found the caring rewarding. Symptoms were experienced by the majority of people dying. Those who received hospice in-patient care did so because of symptom severity, especially pain and constipation. The need for physical care, site of the cancer and being under 85 years of age were also indicative (Addington-Hall et al 1998). Drawing on the same data sample, people who received palliative care at home tended to have symptom control problems, were more physically dependent and under 75 yrs old. Breast cancer was an indicator for palliative care at home and in hospice (Addington-Hall et al 2000). Reports by Grande et al 1998 added some clarification to these findings in revealing that women were less likely to die at home, suggesting that men were less effective and able to cope as carers, but whether this was the perception of the health professionals or the family, men were offered more support. Older people were less likely to die at home or have access to home care. Socio-economic factors played a part in who was able to get access to increased support to be able to stay at home. These facts were supported by Higginson (1998), whose epidemiological analysis revealed older people and women were more likely to die away from the home than younger people and men. This is despite the findings that most people expressed a preference to die at home (Karlsen and Addington-Hall 1998). The studies discussed so far only tell us about who receives care and how this care compares with conventional services. They do not tell us what the care is like, and how it is undertaken, although we are offered a glimpse that physical care and symptom control are key factors.

2.5.1.2 Observations of Care Practices

In depth ethnographic studies revealed other aspects of care within palliative care services apart from the focus on symptom control. James (1986), using an ethnographic approach including participant observation and interview, revealed the process of hospice care as a combination of emotional and physical labour where the focus was on working with both the person being cared for and their family to improve quality of life and symptom control. Working with emotions and distress were an important component of the care which was often deemed an invisible aspect of everyday nursing. Both James and Hockey (1990) raised the issues of how care is socially structured with women the predominant carers undertaking often unseen care work. Hockey compared hospice and residential home care and revealed a holistic approach within the hospice which openly encountered and managed death as part of the life process compared to the residential home which masked it in its use of space. The hospice was flexible in its approach to meeting people's needs, providing more than just physical care. Hockey suggests the Christian ethos of care provides a form of loving care compared to care within secular residential homes, which was grounded in notions of control. Lawton's research within a hospice and the day care service focused on the process of people dying. Lawton (2001) revealed hidden aspects of nursing care, body care in managing the bodily deterioration and leakage of 'the unbounded body', and showed how these affected the person whose body was breaking down and the care that was provided. Although different it was reminiscent of Lawler's work on the body in nursing (Lawler 1991, 1997). Hockey also reveals how the process of social death, and withdrawal that occurs to people who are dying, is responded to by family and staff. In a philosophy that supports the notion of personhood, she suggests this is what becomes lost during the process of dying and the manner of the care provided.

2.5.1.3 The Work of Palliative Care Support Nurses

Davis and Oberle (1990) using a grounded theory approach described the supportive role of palliative care nurses as consisting of valuing, connecting, empowering, doing for, finding meaning and preserving ones own integrity. They suggested the characteristics of the nurse were essential in establishing trust which enabled connecting, empowering and finding meaning to occur and that valuing was the over arching concept as a pre and co-requisite to providing care. Work by Aranda (1997) has explored important aspects of how care is undertaken by nurses. She highlights the invisibility of the nurse's work, the lack of documentation and description of what occurs in practice as contributing to its lack of general awareness. Part of the nurse's work is in coaching, listening and responding as people want to talk. The care is person centred, developed through establishing a socially meaningful relationship. Focusing more closely on the nurse patient interaction Aranda and Street (1999) introduce the notion of being authentic and being a chameleon to describe how nurses adapt their approach to build and maintain a therapeutic relationship. They see this as an important skill, which enables the nurses to be responsive and provide personalised care and support. Nurses draw upon different aspects of themselves, different facets of their personality to present themselves in a manner that is sensitive to the personalities of the different people they meet. Thus they are authentic in their use of themselves, but are chameleon like, in that by adapting their approach and their language, they blend themselves into the context of the person they are meeting with, to develop trust and maintain their working relationship.

The findings of a large multi regional study, funded by Macmillan Cancer Relief between 1998 and 2000, revealed that the majority of people were referred to the community and hospital services for emotional care and pain and symptom control, but with increasingly more people in the community being referred for pain control and emotional support. The people in the community, therefore, were less likely to receive face to face visits compared to those in the hospital (Skilbeck et al 2002). Flexibility was important to the nurses enabling them to respond to the changing needs of people and changes in workload. Telephone and face to face communication enabled care to be organised and information transferred (Clark et al 2002). There was a lack of clarity and range of diversity in the roles of the Macmillan nurses. Hospital Macmillan nurses needed to be credible with ward consultants to be able to influence the direction of the care and change the working culture. For hospital based nurses balancing teaching, a clinical advisory role, supporting those being cared for and being a role model, created conflict where most felt their predominant focus should be in face to face contact with those being cared for (Seymour et al 2002). The managing of internal and external conflict produced out of a desire to serve others as well as continuously adapting ones role were also challenging components of palliative care support team nursing (McWilliam et al 1993), as were managing unpredictable and restricted time frames, balancing resources and working with psychosocial issues and working with families. The role is a complex one requiring a broad range of skills and abilities (Jones 1999, Dunne and Jenkins 1991, Nash 1990).

2.5.1.4 The Work of Social Workers

Social work is part of the founding history of palliative care. It was her work as an Almoner that made Saunders realise the importance of total care, paying attention to the social and psychological concerns of a person who was dying (Saunders 2001, and personal communications 2002). There has, however, been little research into the work of the social worker in palliative care. Sheldon (2000) studied the role of the social worker in palliative care. Drawing on the work of Davis and Oberle (1990) and using a constant comparative analysis, she revealed six key categories of the social role: a family focus, influencing the environment, being a team member, managing anxiety, values and valuing and knowing and working with limits. There are similarities in the themes but, where nurses focus on the nurse patient relationship, Sheldon suggests the social workers are predominantly concerned with the overall essence of the work of the team as a whole. Values and valuing are essentially central in both the Davis and Oberle and Sheldon models, as are self awareness and managing the wider context. Both Oliviere (2001) and Sheldon (2000) discuss the issue of role blurring and overlapping with other team members. Oliviere suggest the work of social workers in palliative care is contextually shaped, can differ depending on each organisation, and may partly explain its lack of understanding by team colleagues. Sheldon (2001) argues, however, that social workers have an important role in facilitating communication and counselling, working with psychosocial processes and concerns. The focus of social workers differs from nurse specialist in the level and knowledge of family work and working with children. Social workers work therapeutically as well as focusing on individual rights, access to resources and working with legal protective frameworks that offer protection to children and vulnerable adults. Bereavement care and education are also a major aspect of social work role in providing care.

2.5.1.5 The Work of Doctors

Care provided by doctors in palliative care is little researched, although a workload study of consultants was undertaken by Makin et al (2000) which analysed time spent teaching, clinical contact and indirect support. The study found that over half of the consultants were in solitary posts and were on call twice as frequently as other consultants. Bruera et al (2000) surveyed the attitudes of palliative care doctors towards communication in Europe, Canada and South America, and recommended more research in this area because of the diverse regional variations. One finding shared across the countries was that female physicians were more likely to support patient based decision making as compared with their male colleagues, which is supported by other studies about gendered nature of discussion and decision making (Brink Muinen et al 2002, Charles et al 2000, Roter and Hall 1998).

2.5.1.6 Community Palliative Care

Palliative care within the community relies on working within people's homes and often alongside General Practitioners (Gps) and District Nurses (DNs). As has been pointed out by Skilbeck (2002) people receive fewer face to face contacts with their nurse specialists outside the hospital setting, and are often contacted by telephone. Unlike observational research in hospices, there is little observation of how care is undertaken within the home. As previously discussed, Aranda used a critical incident technique to explore how nurses use facets of themselves to build and maintain relationships. We also know that the role of these nurses and of the multidisciplinary team that work alongside them is to assess and advise on symptom control and to work with the person and their family in a supportive way.

Studies about the experience and perceptions of services currently provide an insight into the care provided. Key aspects of palliative care that are appreciated by those being cared for and their family carers were expertise in symptom control, being listened to and having someone to talk to and time spent with the person. However, it is also clear that there is some misunderstanding about the role of palliative care and a reduced satisfaction with the infrequent number of visits by the nurses (Mcloughlin 2002, Jarrett et al 1999, Beaver et al 1999). Perceptions of the benefits of community palliative care by Gps and DNs is generally positive, but problems with communication and referral processes were highlighted (Mckenna et al 1999) which is an improvement in Cartwright's findings in which Gp's were less than enthusiastic (Cartwright 1991) .

2.5.1.7 Hospital Palliative Care

Palliative care provision in acute hospitals is the area of most challenge to palliative care staff, requiring the team to work across philosophical and, at times, organisational boundaries. The team is in a key position to coordinate care between the hospital and community. The presence of a palliative care service can improve symptom control, facilitate understanding of diagnosis, provide supportive care and facilitate future planning and placement (Higginson 1998, McQuilllan 1996, Ellershaw 1995). However, the success is dependent on the implementation of the advice offered, making evaluation difficult at times.

The hospital palliative care team often faced issues of resistance and rejection of their service (Ruszniewski and Zivkovic 1999, Dunlop and Hockley 1998). Nurses, however, face problems working within the acute hospital setting due to the power dynamics and traditional hierarchies with medical colleagues within palliative care, but predominantly within the hospital (Seymour 2002, James and Field 1996).

2.5.2 Communication as an aspect of care

Communication is seen as central in much palliative care literature and textbooks. Often chapters give advice about how to communicate with people, about breaking bad news, managing difficult questions or spiritual issues (Oliviere et al 1998, Sheldon 1997, Saunders and Sykes 1993, Doyal, Hanks and Macdonald 1993). Glaser and Strauss (1967) observed four levels of awareness in people dying from cancer about their diagnosis and prognosis. Since that time there has been a trend to improve communication and open awareness (Seale 1991b), although this openness about dying is now perceived to be more conditional or negotiated rather than open for all (Johnston and Abraham 2000, Field and Copp 1999). All aspects of improving care in palliative care are reliant on good communication (Wallace 2001). Haven and Maguire (1997) revealed that people being cared for were selective about who they chose to talk with and disclosed their concerns to, with two thirds of their concerns remaining undisclosed. Nurses registered only 40% of the disclosed concerns and only 20% were correctly identified. This suggested that nurses needed to improve their communication skills. Training models have been developed (Parle et al 1997) and the review of a longitudinal evaluation on communication skills training revealed people being cared for and their families were often dissatisfied with interactions with health professionals. Skills training, reflection and attention to knowledge and attitudes improved communication.

Research has revealed how nurses use defence mechanisms to prevent and block communication to reduce their own stress levels and the intimacy of the nurse patient relationship, resulting at times in poor understanding of a person's psychosocial concerns and distress (Wilkinson 1991, Menzies 1967). However, people who are able to discuss their concerns show that some problems can be resolved and some degree of relief felt (Bailey and Wilkinson 1998)

2.5.3 Multidisciplinary Working

Care from a multidisciplinary perspective is seen as an essential component of palliative care. Collaboration, common goals, valuing the contribution of team members and sharing the blurred role boundaries are considered important (Ajemian 1993). How is this achieved? Does the doctor have to be the team leader? Power dynamics which privilege the medical voice and decision making in preference to team collaboration and the nursing voice has been documented (James and Field 1996). Conflict and organisational factors within teams are the largest cause of stress (Hill 1998, Vachon 1987, 1997). However, what is evident is that there are many types of multidisciplinary teams with different structures (Donaghy 2002, Hill 1998, Sheldon 1997).

It appears evident that research needs to be carried out into how the increasing development and integration of palliative care services, the role of the policy developments and the understanding of those working in the field are shaping future provision and understanding of what 'care' means in palliative care. Much of the care provided in palliative care is more than providing good symptom control. How do teams work together? How is care initiated, support given and information shared? What concepts underpin the care and how is it achieved?

2.6 Concepts of Care Discussed in Palliative Care

Few theorists and writers have specifically considered the role of concepts of care and care theory in relation to palliative care. From her ethnographic study of care within a continuing care unit during the mid 1980's, James formulated a generalised theory of care work in terms of the gendered nature of care, its organisation and the role of emotion work. Drawing on some early sociological literature she suggested domestic care by women and care by nurses in hospice were interrelated, as was part of the focus on family care within palliative care. She suggested that the family model, however, represented the domestic and hierarchical division of labour between men and women and that hospice care had perpetuated this at that time. There are currently more women than men working as specialist registrars and consultants in palliative medicine now (Richards 2001). James highlighted the role of emotional labour as central to care work of nurses, which remains less visible than physical labour but is equally hard and demanding because it also requires the regulation of feelings and the use of particular skills (1993, 1992, 1989, 1986).

Pusari (1998) suggested that there are eight caring elements used by nurses in providing holistic care in nursing terminally ill patients. These are compassion, competence, conscience, commitment, courage, culture and communication. She draws predominantly on the work of the nursing theorist Roach (1993) but also draws upon work by Mayeroff (1971) and Leininger (1997) by adding courage, culture and commitment to create 'The eight 'C's of caring' to develop her theory for palliative care. Pusari, states that these eight elements can be used by nurses as a framework for care when nursing a terminally ill or dying person enables the nurse to remain alongside the person and meet their needs. Miller and Douglas (1998) again drew upon interviews with nurses in a hospice and those in home care in the States to reveal the concept of 'Presencing' as an essential component of nursing in which there is a commitment to care for the dying person, to maintain a relationship with the person and their family and remain alongside. They suggest this requires a shared vulnerability between the nurse and the person or family being cared for and draws on the palliative care philosophy of 'being with' during the dying process.

Prior (2001) explored the concept of caring in palliative nursing. She believes caring and care giving are integral to and underpin palliative care, but remain hidden due to the lack of value placed upon this in terms of research and professional dissemination in relation to innovations in symptom control. Drawing upon body care and cultural care as areas of overlooked and unvalued aspects of caring work which she believes should be reclaimed and valued by palliative nurses.

The concept of care within medicine generally, and palliative medicine more specifically, has been less well considered. Kearny (1996, 2000) has focused his discussions on the holistic care involved in working with suffering and soul pain. Drawing upon Greek mythology and using case studies he explores care through a process of 'conscious caring'. This is developed through relationship and creative techniques without relying specifically upon pharmacological medication. Kearny suggests two different but complementary founding traditions of medicine. The Asklelpian model of holism and healing, and the Hippocratic route of science, the medical model of cure which can be found in palliative care. Clark and Seymour (1999), however, drawing upon work by Morris, also discuss the linguistic divergence between cure and care in relation to palliative medicine in exploring the place of care. They suggest that this divergence is an important contributory factor as to how care is conceptualised in palliative medicine. That the rival histories between the root of the term palliative in which the Latin 'pallio' suggests a concealment or covering of the symptoms whereas the Greek 'pelte' is a more active and assertive term meaning shield and protect through action, thus raising the question as to the motivation behind the 'care' offered by palliative medicine.

How doctors learn to care and work within health setting is considered to be due to early socialisation within the medical culture (Soothill et al 1995, Macleod 2000, 2001). Macleod draws predominantly upon nursing care theory as he points out there is very little written on care by the medical profession in describing how doctors care. He suggests the concept of care or caring is elusive to medicine and is learnt as a process of socialisation and experience. From his study of doctors' perceptions about caring for people who were dying, he suggests a true sense of care comes from the empathy formed by the doctor through receptivity and a sensitive identification with the person's situation. These differences in how care is understood and whether it is conceptualised in palliative medicine may explain the divergence of opinion about the roles that care and cure play across the professions involved in palliative care.

How care is valued and written about informs how it is operationalised within a service. Clark and Seymour (1999) suggest the concept of care moves attention from paternalism in health care to that of participation, to holism with the focus on the individual. However, certain perspectives of care theory are not without their negative aspects. This includes the choice of the person being cared for to enter into relationships with health professionals where a particular theory requires the professional carer to form a unique bond with that person, or where the theory suggests the needs of the carer are met within the care relationship. Within palliative care there are a number of components that contribute to how the concept of care is influenced and understood and how providers, patients and carers understand, perceive and experience care. It is important that the provision of care reflects user needs but that the new developments are explored and their possible changes and working adaptations of the philosophy in different settings are revealed in order to optimise the breadth of palliative care. The construction of care and its meaning within the area is also dependant on which view is given greater priority and a louder voice.

Care is a complex concept (Fish 1999, Kuhse 1997). Care has not only been theorised it has become increasingly professionalised and consumerised. Care also constitutes ethical principles and encompasses deeply held social expectations, which will be explored in the following chapter.

2.7 Summary

This chapter has drawn upon a wide ranging field of literature in order to contextualise the current understanding and knowledge of care within palliative care. The chapter provides a historical view of the development of the philosophy guiding palliative care and discusses this in relationship to the recent changes and developments within palliative care provision in the United Kingdom.

The changing language and redefinition of palliative care has influenced general understanding of the care offered by palliative care services, whilst also creating misunderstanding through the specialisation of services across a range of settings in different ways. It is clear, that health and social policy has encouraged the movement of palliative care services back into mainstream healthcare provision. Also, the influence of regulatory and standardising frameworks and mainstream values are becoming increasingly influential in shaping care provision.

Current understanding of care within palliative care has been developed out of research considering the availability and nature of palliative care services to different people and by focused research on particular aspects of care such as communication. Communication is a central, yet complex component of care, and has been researched at the micro interpersonal level and the macro multidisciplinary team level by a range of researchers from different backgrounds, in order to improve care and support. Multidisciplinary team work is central to the philosophy of care, and yet requires much needed further study.

What this chapter reveals is a developing wealth of literature about the organisation of services, working practices of some multidisciplinary team members and different types of care practices, such as communication. There is a dearth of literature considering the construction of care within palliative, that considers the influences that shape and inform understandings of care, care practices, communication and teamwork. The following chapter will explore the multiple influences that inform, shape and guide how care is perceived and undertaken in palliative care practice.

Chapter 3 Exploring the Conceptualisation of Care from Philosophical, Health and Sociological Literature

3.1 Introduction

Current understandings of care are, in part, formed by our own ontological position and by the debates of philosophical, sociological, political, nursing care and educational theorists. Some theorists have focused on singular aspects of care, others have drawn upon wider perspectives and have considered some of the interconnected influences that inform how care and caring is understood and experienced. The conceptualisation of care remains complex and elusive. There is no one definition and no overall consensus about what care is, other than a general acceptance that care and caring are hard to define (Fish 1999, Kuhse 1997, Thomas 1993, Brykczynska 1992).

The conceptualisation of care remains complex because it is influenced by many factors. Care can be an action undertaken for a person or on behalf of a person; a labour of care in which the individual cares for another. It is also a thought or concern about an idea or person, perhaps through concern or love in which an individual cares about another (Held 1995, Tronto 1989, Graham 1983, Ungerson 1983, Mayeroff 1972). Concepts of care are rooted in historical contexts and are influenced through social, economic and educational discourses themselves informed by a range of different cultural, social, professional and personal values (Banks 2001, Hugman et al 1997). It is, therefore, important for this chapter to explore the different discourses about care and caring, so they can be drawn upon to illuminate the understanding and conceptualisation of care within palliative care revealed by the findings of this study.

3.2 Philosophical discussions of care

Care in some ways can be envisaged as a way of being, an ontological experience and as an intentional motivation or thought. In between the individual experience and the intention behind the action other notions of care can be located in a relationship that is rather more complex and dynamic than linear. The complexity enters in part because, although philosophical understandings can be free of context, the ontological and intentional notions of care cannot be removed from our everyday encounters, which remain influenced by socio-political, historical and economic influences. Interpretation and our phenomenological experience inform our own constructions of what care is. Understanding can only come from each interpretation at a moment in time, although we may call upon experience and the past to inform this interpretation.

3.2.1 Care Constructed Through Being and Time

From a philosophical perspective, care is said to be revealed within the essence or Being of each individual which is itself temporal in nature (Heidegger 1962). Each person's individual sense of self and the essence of who they are, their Being and how they experience being-in-the-world is inextricably related to time and to the concerns that each person holds. Self-concept and self identity appear to be shaped by how each person experiences and interprets their own sense of self through the past, present and future. Care according to Heidegger is expressed within the Being of each person and their concerns and through the meeting between people. Care is, therefore, both internally and externally experienced and becomes expressed concurrently within personal experience and through interaction with an-other, offering possibilities of relationship whilst informing the intra and interpersonal development of each person. Each interprets their understanding of the other and themselves through the expression of themselves and their concerns.

Care becomes both an existential and ontological phenomenon, which Heidegger suggests is too complex to be divided into its primal components which are not defined necessarily only in ontic terms of concern. Care, he suggests, continues for as long as it is in existence, which according to Heidegger would be as long as each person is alive. This does not, however, account for the sense of care felt for people after death, when a person's physical existence ceases but their existential selves live on in the memory, emotions and continuing interpretations and reinterpretations of others. Neither does it account for how that person understands their own identity when faced with death and when for them time and care ceases.

It could be argued that Heidegger only provides an ontological framework with which to view ourselves bringing the experience and existence of self, and what one cares for, into creation. However, because care is not just about being in the world, it involves understanding which comes from interpretation and from experience; I would argue that it does also inform the development of an epistemological understanding of care by revealing how personal knowledge of care is created. Care could then be seen to develop out from within the self, through being with others in the world, dialogue and interpretation and over time the creation of personal and shared knowledge which could be seen as making care an interdependent enterprise.

Caring is seen as central to both an individual and communal humanity by Nursing theorists, who in comparison to Heidegger see care from a wider perspective than just the individual. Benner and Wruble (1989) suggest caring is '*The most basic way of being in the* world', Roach that *'Caring is the human mode of being'*. Care is, therefore, seen as central to human existence at an individual and social level. Whether it is instinctual or reliant upon intentionality or a moral imperative will be discussed in the next section.

However, if according to Heidegger both the essence of the self, as defined by one's Being and the experience or revelation of care through the interaction with an-other are temporal, there is always the potential for change and adaptation. This temporality of care and potential for change has been recognised by Watson when she states that:

> *'The now of human care and caring shapes the future and ontology of caring in time and space' (Watson p29 1988).*

Although Watson, considers the effect of the present on the future of care, care will, in fact, be continuously shaped and reshaped and reinterpreted by drawing not only on the present but the past, altering even within the moment and into the future, shaping both the ontology, the way of being, and the epistemology or way of knowing, of care in time and space.

Leininger (1986) also sees care as an essential human need, and central to nursing as a powerful means of enabling healing and way of supporting people in their life choices. But she states that care has to be placed within the cultural contexts of each society. Her model of transcultural care acknowledges that caring patterns may differ between cultures but that caring essentially has biophysical, emotional, cultural, social and environmental dimensions. This is a step away from care as instinctual and integral to Being in a related and existential sense and focuses less on the transcendental or spiritual components. Her 'Sunrise' model of care reveals the diverse and complex interactions between the cultural meanings and knowledge of care, the languages these are conveyed in and the dimensions within the social world view which influence how one understands care and caring actions (Leininger 1988).

It is an holistic approach to care, but one which draws upon that which informs the essence of each person, and interacts with it to create a Lifeway. Peoples' Lifeways are informed by their philosophical, religious, family and personal values, culture and society. Care is revealed through caring constructs which include: 'comfort, compassion, concern, coping behaviours, empathy, enabling, facilitating, interest, involvement, health consultative acts, health instruction acts, health maintenance acts, helping behaviours, love, nurturance, presence, protective behaviours, sharing, stimulating behaviours, stress alleviation, succorance, support, surveillance, tenderness, touching, trust', some or all of which are represented in the many different cultures she has studied (Leininger 1988 p 13). It is through the development of constructs, interpretation and understanding that we begin to understand what care means to us. Leininger importantly reveals to us some of the aspects of the world with which one's sense of self and Being interacts. How we then relate to this in terms of what we care about could be how identity constituting care (Edwards 2001) and intentional care (Noddings 1984) become informed and motivated. Benner (1994) sums this up when she says:

> *'Care sets up a world, and creates meaningful distinctions. Living in a meaningful world is the ground for perceptions and provides concerns and directions for persons' (Benner p44 1994).*

For Benner caring also has the potential to create meaning, shape language and set up the possibilities for knowing, which is grounded and guided by an ethic of care and responsibility (Benner 1994). Thus the notion of care is as an essential part of Being but it is only revealed in terms of caring for another, informed by society and cultural nuances. Therefore, care can also be seen as relational.

3.3 Care as Relational and Intentional

Noddings (1984) writes of care as a relational concept. That for care to occur there has to be an object or person to be cared for, so care is usually 'other' oriented, in which caring involves an appreciation of or empathy with the other person's reality and feelings, rather than a complete understanding of them. As with Heidegger there is a sense of the interpretation of the other person's expression. She also suggested that once the person caring has an appreciation of the care for a person's situation and experience, then one's caring must respond to meet the needs of the cared for person. This accordingly sets up the opportunity for reciprocity and also the development of a moral obligation. Noddings is not alone in considering relational care as central yet which is also guided by a moral obligation where the relationship fails (Edwards 2001, Watson 1988, Noddings 1984).

The care relationship is pivotally developed upon trust and receptivity, according to Benner. She suggests that the development of the caring relationship also requires understanding, knowledge and skills, which are not necessarily made explicit in the language used to describe care (Benner 1994 p46). Care according to Mayeroff (1971) occurs very clearly through relationships as a way of enabling the person being cared for to grow and develop, but which does so in terms of reciprocity. The reciprocity, he suggests, may indeed resemble friendship and create a deeper level of caring, but this form of care needs to be underpinned by both explicit and implicit knowledge.

The relational process of care perhaps combines Heidegger's (1962) existential notion of Being with Meyeroffs (1971) belief in the caring relationship, enabling some form of actualisation by the person being cared for. But which person is cared for in the interaction, and who gains most from it? Heidegger suggests care is revealed within the interaction between two Beings and, therefore, it could be surmised both parties reveal what they both care about. Noddings (1984) talks of care requiring both an object to be cared for as well as the carer finding completion through caring. For Noddings motivation is an important factor as to whether care is undertaken through an innate choice or obligation. Watson's theory of Transpersonal Caring commences at the point where the one who is caring, in her work it is the nurse, enters the subjective experience of the person receiving the care. It is this human-to-human care which responds to the spiritual, or existential being of that person, as well as the physical (Watson 1988). In the moment of caring, she suggests there is a union which transcends time, space and the history of each person. She suggests this transcendence of the physical, the soul and the spirit and which she describes as a 'mindbodyspirit' unity, provides the potential for helping a person find meaning in their illness, suffering or existence and is a way in which the carer can assist the other to gain self-knowledge, control and find some place of harmony (Watson 1999). The implication is that care is reciprocated and requires rather more openness and commitment from the carer.

However, this raises concerns about the implication of the goodness of the relationship as the central focus of care, and the role of carer motivation. Noddings and Watson suggest some form of union or self fulfilment are essential for the carer. Perhaps this seems a somewhat overwhelming or unrealistic burden to place on those caring professionally to consider and one that potentially denies the choices of those being cared for, who are equally obliged to enter into the relationship (Kuhse 1997). The notion that relationships are central and essentially good for care, even from the moral perspective, can fail to account for care that is abusive or oppressive.

Trust, reciprocity and choice as Benner (1994) suggests, create the possibility for some form of interpersonal connection. Such an interpersonal connection may lead to a possibility of meeting that person at a point in which they are able to reveal their subjective world, from which a therapeutic relationship can be established and perhaps a form of care-friendship. Roach believes that the human capacity to care is not achieved through an investment of the self in others but requires education. From a professional perspective, Campbell (1984), suggests the caring role of the paid professional is more like that of a skilled companion, in which there is sharing between the carer and person being cared for but without imposition of the carers will, so that the person being cared for can develop in their own way. It is less than friendship but more than a contractual obligation, offering a potential path between involvement and non-involvement at a personal level. It perhaps offers a greater balance than that suggested by Watson whose model places great emphasis on the connection of consciousness between carer and cared for and introduces a broader sense of spirituality and existential connection between carer and cared for (Watson 1988, 1999).

If care involves an appreciation of the other and a response, a sense of connectedness, obligation or moral pull, there will at some level be a degree of emotional involvement. For Noddings (1984) this implies a degree of intention where there are both emotional connection and an obligation to care which manifests when the emotional connection is not present. Edwards (2001) suggests the caring act stems from an awareness of the plight of a person and are thus needs related. He suggests intentional care requires three elements; a conception of the plight of the person being cared for, a response by the person caring to their needs and an emotional component (Edwards 2001 p123). Therefore, care has different levels of emotional involvement in intentional caring. Weak intentional care is where the one caring has a stronger sense of self regarding meeting one's own needs and strong intentional care, rather than meeting the needs of the other. Thus the degree of emotional involvement is regulated by the degree to which the person caring engages themself with the emotional subjective world of the person being cared for, and whether transcendence, as Watson suggests, is a possibility. It also implies that the degree of engagement of intentionality is also guided by a moral pull. The weaker intentional care has less emotional involvement and is less subject to the moral pull, or obligation (Noddings 1984).

A component of intentional care requires that the person caring to understands the plight of the person being cared for and their conception of what is significant to them. Thus a concept of self and understanding oneself becomes central. Self-identity becomes an integral component of intentional care, as Edwards describes it: 'identity constituting care', providing a basis for the motivation to care (Edwards 2001 p134). The relational aspect of care, the essence of care as part of one's Being meeting that of an-other, is, therefore, revealed through an intentionality which must account for the subjective understanding and notion of self identity of the carer and the person being cared for. There must be some choice as to whether the cared for person shares their concerns with the carer, and the degree of reciprocity between the carer and cared for person. This may occur through a process of transcendence at an existential level or from a moral obligation. Whether this obligation and moral pull be enough to form an ethic of care to guide the care that is provided is unclear.

3.4 Care as an Ethical and Just Process

Paley (2000) suggests that, since Heidegger has focused almost entirely on the ontological aspect of being in the moment, it is not possible to derive an ethic of care from his work to guide care in its wider sense. He suggests that because of the predominant focus on being 'with' the world, it prevents looking at the world from an alternative position, which offers a critique and from which questioning arises. Therefore, such an ontological focus potentially prevents questions about morality and self interest involved in care arising. Heidegger does, however, talk about conscience as the call of care, which may indicate a degree of personal morality or moral interpretation within care (Heidegger 1962).

There is an ongoing debate between theorists as to whether there can be an effective ethic of care. Care is said to be guided by the intentions of the people involved in some form of caring relationship from which obligations and moral pull or moral concerns arise (Gilligan 1982, Noddings 1984, Roach 1987, Leininger 1988, Watson 1988, Benner and Wruble 1989, Edwards 2001). The traditional ethics of Kant, Mills and Rawls rely upon a rational, objective universalisable and principled approach which the concepts of relationship and subjectivity play no part.

Kant's notions of duty to others, by respecting individuals as rational and self-determining, rather than as means for the other's ends are important aspects of current social and healthcare ethics. The Categorical Imperative states that, the only true moral action was that generated by pure motive. A truly moral act is not influenced by self-interest or by consideration of social benefit. Therefore, whether care can be seen as ethical in its identification and operationalisation through relationships appears uncertain since the intention to care can be questioned. Mill contrastingly discussed the notion of ethics in terms of utility, in which ethical decision making is dependant upon achieving the notion of happiness for the greater number, rather than the happiness of the individual and is based on the consideration of consequences. The significance of the action or non-action is the ethical crux within which the needs of individual and needs of the wider community can become divergent (Banks 2001, Seedhouse 1998, Sterba 1998).

This offers some perspective on the relational and intentional notions of care, linking with Rawl's notion of social justice and individual rights. Problems arise in relation to each person's right to liberties in relation to care. However, in that the positive liberties of one person can impinge on the negative liberties of another. The right of a person to go home to die, may impinge on the right of the person at home to choose not to act as the carer. Thus, creating an ethical dilemma, by which traditional Kantian ethics would weigh notions of self determination with notions of duty and utilitarian ethics would decide upon what outcome led to the greater good. In terms of fairness, whose rights are heard and who is deemed to have the duty to care become problematic, as does the notion of good (Willard 1999). Both the notion of rights and social justice have been challenged and problematised in their reliance and perpetuation of structural hierarchies of dominance and oppression, and their universalising and homogenisation of differences between people and groups (Banks 2001, Sterba 1998, Randle and Downie 1999, Lister 1997, Flax 1992, Young 1990, Noddings 1984). The questions raised are whether traditional ethics are sensitive to care, whether care requires its own ethic to guide decision making and whether this can be a just process.

Noddings suggests 'Ethical caring arises out of our expectations of natural caring' (1984 p79) and that this source of ethical behaviour develops from feelings experienced towards the other person and are inherent, so that where natural caring fails one resorts to ethical caring as a guide. What is clear is that an ethic built on care, according to Noddings, is dependant upon having a caring attitude developed through one's own experiences of being cared for in a relationship. The subjective is important. Whilst acknowledging the Kantian notion of duty, she insists the ethic of care is built upon striving for the caring attitude, rather than being undertaken soley out of duty. Benner talks in terms of an ethic of care and responsibility rather than obligation, suggesting that an ethic of care and responsibility is not only complementary to but offers far more that an ethic based purely on rights and justice (Benner and Wruble 1989, Benner 1994). Where Benner places this ethic in terms of nursing, Noddings sites her work in terms of a feminine ethic, although she is also clear that this does not speak for all women or exclude men. She says an ethic of care is a tough ethic in that it takes into account other aspects that are of concern to that person being cared for and the person caring, identifying the contribution of both (Noddings 1984).

Gilligan (1987) revealed the gendered nature of ethical thinking and makes evident that the moral judgements made by women are often based on partiality, context, relationship and consequence, rather than an impartial notion rights and duty. Gilligan sees this ethic of care as a feminine quality. She believes this difference comes from women's experiences of dealing with dilemmas and needs within relationships and weighing up the consequences of action rather than weighing up rights and duties. She is not alone in that Noddings also writes about a feminine ethic of care. However, Noddings sees her ethical caring as a dynamic, a process of reciprocity and mutuality and Gilligan highlights caring as interdependent.

The debate between justice and care that has been central in terms of feminist ethics, is important and should be looked at briefly within this debate about care. Part of the philosophical debate about care, as an alternative feminist ethic, has occurred because the different voices of women and their experiences which, until recently, were predominantly positioned in caring roles and relationships, had not been made visible or accounted for. The ethic and concept of justice and its associated impartial, detached moral rules and reasoning, have remained the dominant force, societally and within health care and so the moral decision making principles within the notion of justice have not always represented or validated those found within caring situations. Cooper (1991) suggests, within the ethic of care, moral responsiveness is individualised and guided by the private norms of relationship, friendship and care rather than the public norms of impartiality, reason and rights. The work of Gilligan (1987) and Noddings (1984) is important in revealing the different yet valuable knowledge about care, relationships and the importance of context. They have, however, been criticised by other feminist writers such as Tronto (1989) for supporting the essentialist view and thus reconfirming the 'natural' position of women as carers in society and perpetuating the social construction that has made women subservient to men and care subservient to science. Men are situated in public roles as knowers and validaters of knowledge, where impartiality and reason are the guides to decision making and where women are positioned in the private world of the home, knowledge subjugated and emotion and relational practices hidden and unacknowledged.

Within the debate between care and justice, feminist discourses have placed care and justice as oppositional, determined entirely by gender. However, Tronto (1993), suggests that the focus on gender hides the reality of care in ethical terms as shared across marginalized social groups and it should, therefore, be framed within a structural discourse rather than an essentialist one. Squires (1999) suggests that the narrow focus of justice generates and perpetuates hierarchical dualisms and dichotomous thinking which is unhelpful. Care and justice can, however, be clearly seen as complimentary, rather than as mutually exclusive. Botes (2000) suggests there is a communicative rationality, which underlies the ethic of care and which differs from the positivistic and modernist rationalism of justice. However, Young (1990) warns that both the ideal of care and the ideal of justice denies difference by universalising their ideals. It is clear that Gilligan generalises the ethic of care across all women, denies their rationality, diversity and differences and denies men the capacity to care, whilst both Noddings' and Gilligan's assumptions to naturalness assumes the capacity to care is unchanging across time and space.

Justice, however, remains an important aspect of care in terms of striving for equity, guiding decision making, balancing competing subjectivities and also challenging structural assumptions. Benner (1994), however, is concerned by the rise of the discourse of rights and individualism within the frame of social justice and health care as pervasive in beginning to dominate caregiving and the ethics of care. Care as interdependent and interrelational runs counter to the autonomy and independence discourse, which is currently dominating western societies. Phillips, considering professional caring warns that:

> *'A care system based on rights alone sterilises professions referred to as helping and 'caring'. It cultivates polarity rather than engagement. The honouring of rights and fulfilling of legal and professional obligations are essential to caregiving but they are the safety net, not the skilful artistry that itself warrants the net's protection. To overlook the caring practices, concerns and 'strong evaluations' of the caregiver is to miss what is significant' (Phillips p 8 1994).*

Who has what right and what freedom to chose or demand how, where and by whom they are cared for becomes central to care and caregiving in terms of social justice. The ethics of care are also being accused of failing to take account of the person receiving care. It is assumed that the caring relationship is good and not problematical. From a perspective of professional ethics Morse suggests it is unethical to care too much, in that over involvement can be harmful and not in the best interest of the person receiving care. Koehn suggests that the ethic of care

> *"rushes to judge an act or response 'caring', failing to ask further questions that might significantly affect the assessment of the act, of the response and what it means to have a good life" (Koehn 1988 p153 1998).*

Koehn (1998) raises concerns that care as an ethic can be equally rigid and can also be potentially manipulative or damaging to relationships. An ethic of care assumes that care is intrinsically good and fails to comprehend the power relations within the caring relationship, thus giving rise to potentially manipulative or damaging relationships. Power relations consist of competing needs between caregivers and those receiving care. There is a potential for denying agency in the person being cared for and denying the autonomy of both the carer and cared for in different situations (Armstrong 2001, 1983, Kuhse 1997).

Kuhse suggests that if care is used as the only guiding ethic, traditional ethical principles are rejected, leaving only a state of arbitrariness in decision making. An ethic of care, she argues, cannot provide equity or justice. Considering the debate between medical ethics and the ethic of care she proposes a 'dispositional notion of care' which 'emphasises the importance of receptivity and responsiveness' rather than relying on 'some kind of transcendental union with the patients'. This she believes places the relationship as exclusively important from the nursing perspective whilst denying the 'patient' the right to choose this, suggesting that minimally adequate ethics should give equal consideration to the interests and well being of all involved and affected by the carer's actions (Kushe p 150 1997).

Koehn presents 'dialogical ethic' built upon a set of principles which guide the dialogue and decision making, preventing arbitrariness. The dialogical ethic requires all participants to be involved in open dialogue enabling each person to voice their opinions. It is an ethic that acknowledges that different understandings of what is deemed good as well as negotiating individual rights whilst taking account of the context of the situation. It requires people to be engaged with the process in order to reach some form of consensus.

Jaggar (1995) argues that justice and care represent different aspects of moral reasoning, and that they should be recognised as distinct practices of moral thinking which complement one another. Gould (1997), however, sees them as complimentary rather than conflictual and that some conception of equal rights is implicit and essential for democracy and social justice. She uses the notion of reciprocity to extrapolate from the two person relationship, as valued by the care philosophers and ethicists, to an institutional level. The notion of social reciprocity and the reciprocity of respect are born out of the relational aspects of care and are important in the democratic decision making process and for the process of political and social justice.

Rather than focus on individual rights, the focus falls on respect for persons as social individuals, who are an independent part of a democratic community in which a notion of co-operative reciprocity is involved. A non reciprocal notion of relational care is acknowledged for the very vulnerable and sick where not only nurturance but also the implicit power relations of the carer over the cared for are acknowledged and where the individual is unable to make an autonomous choice. Here perhaps the ethical notions of beneficence, non-maleficence are called upon. Randall and Downie (1999) draw up a framework of medical ethics which requires attendance to beneficience, non-maleficience, autonomy and justice, but they state that attention to principles only does not take enough account of feelings and call upon the use of compassion as an essential component of ethical decision making. Compassion can be seen as both a physical and emotional moral dimension of care (von Dietze and Orb 2000).

Allmark (1998) discusses the relationship between ethics of care and ethics of virtue as alternatives to bioethics. An ethic of virtue according to Allmark focuses on the nature of care and how it is expressed whilst the ethic of care focuses on care itself suggesting it is good to care. Virtues are also judgements about the character of a person. Virtues, such as compassion, are considered to be qualities which are valued in terms of the potential for goodness and benefit. In terms of virtues as a constant character this is not entirely possible since virtues are learnt from guidance and observation. They are socially constructed and, therefore, change over time. (MacIntyre 1998, Gastmans 2002). Therefore, certain qualities or virtues are sought as aspects of care and caring which change over time. Care, according to Allmark, cannot be considered a virtue because it encompasses more than the notion of goodness and rightness. Over involvement or too much care can, in itself, be unethical, in that it can deny the autonomy of the person being cared for (Morse 1990). The values that underpin care, particular virtues, intentions and the ethics remain implicit rather than explicit (Banks 2001).

Whilst the ethic of care remains valued through the modernist lens it will continue to suffer attempts at invalidation and it will continue to be placed within a hierarchical structure of moral theories in which care will remain marginalised in relation to justice. Writers such as Flax (1992, 1990) and Young (1990) argue for the valuing of diversity and difference, for listening to the different voices outside of the established hierarchy of power and knowledge. Orme (2002) suggests plurality is vital in representing the different voices of care and justice and complicated ethical choices that occur during care. Flax (1992) suggests the process of justice should include a reconcilliation of diversity; reciprocity through the sharing of authority; recognition and acknowledgement of the legitimacy of the other person and judgement as a process of balancing the evidence and reflection, whilst drawing upon care and its central tenets of relationship and obligation. This approach synthesises the feminist discourses about care and post-modern discourses on social justice, offering a complementary way forward. There is certainly a need for justice within care, because of the complexity that arises out of human relationships and the complex negotiations required to balance the competing discourses of rights and self determination with the contested notions of community, relationship and obligation, which are essential in considering how resources are made available for care.

3.5 Care as a Gendered Construct

From the previous discussions it becomes clear that gender has an important role to play in how care is understood and constructed, who it is carried out by and how it is valued within the caring professions and society. The gendered notion of care has been discussed by Graham (1983, 1991), who described care as a labour of love, predominantly undertaken by women within the home, which is reinforced by social policy and social care systems (Orme 2001, 2002, Ungerson 1983). The inability to value women as different and equal as citizens denies them their rights and the freedom to choose to care (Pascall 1997, Pateman 1992). Significantly, Graham highlighted the interrelated multiple dimensions of care as expressed through feelings and through practical work. A key factor in the gendered nature of care has been the separation of care and household labour from public life and the economic means of production. She challenged the essentialising of care as integral to women and their identity suggesting this perpetuates patriarchal constructions of women and care. James (1992, 1989) developed Graham's initial theory and focused on professional care, revealing the significant yet unacknowledged aspect of care in general and nursing care specifically as incorporating not only physical labour but also emotional labour. She suggested that the organisation of care and division of labour within healthcare represented that of the family.

However, the professional focus of care tended to be on physical labour, which is what justifies the economic commodification of carework in terms of physical labour, rather than the unacknowledged emotional labour. The emotional labour is about more than love, it is the work required to build and maintain relationships and to work with people in distress. As Davis (1995) suggests, professional carework remains predominantly female work, which remains largely unvalued. The lack of public recognition and lack of language to describe the work and process of caring can be seen to be part of the lack of public recognition and development of knowledge about care. However, it is also important to note that class, age, race and sexuality also play an important structural role in shaping care (Orme 2002, 2001, Evans 2002, MacDougall 1997, Dominelli and Gollins 1997, Tronto 1994, 1989). Because care has been situated within the private domain of the home, the knowledge about care and caring practices have been subjugated and remained unvalidated. Hekman (1991) suggests that knowledge has, since modernity, been validated by those who are positioned within the public space : white, middle and upper class men. Care and caring practices remain situated in a structural hierarchy that validates the public, scientific, technical rational knowledge above that of the private, subjective, interrelational and partial knowledge that comes from caring. This is played out in society through welfare policy and through the historical gendered and class stereotyping of medicine, nursing and social work (Orme 2001, Kushe 1997). James suggests that the repression of female voices prevents the development of the self-esteem that women need to participate within the public sphere. Women, its is argued, are denied independence and autonomy through the political and fiscal power of the state and are still not treated equally as citizens because their civil, political and social rights continue to be denied (Lister 1997, James 1992,). However, this does not account for the number of men who are carers within the home, and who also become structurally disenfranchised. Housing and living arrangements, class, cultural difference and sexuality influence and challenge the gendered assumptions that care is essentially female and undertaken by women (Orme 2001).

Socialisation through policy of gender roles perpetuates the belief that men can care about their families. That is, they have emotional input without having to carry out the physical tasks of caring. Whereas, women are expected to show that they care by carrying out the tasks of caring. Women remain trapped in a discourse of duty and obligation, whilst providing continued unpaid informal care, which in turn affects their position structurally (Tronto 1994, 1989). This fits neatly into policy by providing the unpaid and unseen labour force for community care in which people are cared for (Griffiths Ch 3.6 1988). This stereotyping is, in itself, restrictive for both men and women. MacDougall (1997), writing about caring from a masculine perspective, suggests that men enter nursing with a desire to care. Later in their career they experience conflict between being in a female dominated profession and maintenance of their masculinity. Williams (1993) suggested that public care work was still associated with being homosexual, therefore heterosexual men had to maintain their masculinity through their choices of working in more technical areas of care, their interactions with colleagues and people being cared for. Men are thus prompted to follow traditional male paths where technical expertise is required, moving into positions of power with a higher income which, MacDougall suggests may have a negative impact on care.

A criticism of the work of the care theorists, finds much of the early work centred around the experiences of white western women, and universalised across different cultural populations (Graham 1991). It is argued that by not focusing or considering other structural influences such as power, class and sexuality, the complex influential constructions of care become hidden and unchallenged. The low salaries, lower status and positions of power and influence within care work and the sexualisation of care by men have important contributory roles in influencing why men and women enter professional caring. Thus, suggesting that gender is not the only discourse pertinent in shaping care (Evans 2002, Orme 2001, MacDougall 1997). Rather that discourses of power should be equally considered (Wilkinson and Miers 1999).

3.6 The Professionalisation and Disciplinisation of Care

Carework takes place in a range of different settings and within a range of different interpersonal relationships. The professionalisation of carework, has seen a systematisation and formalisation of training within a system in which care has become consumerised and commodified (Parker 1999, Davies 1995). The professionalisation of care has required the systematic acquisition of an identified knowledge base (Wilkinson and Miers 1999, Davis 1995). The development and use of discreet and identifiable knowledge bases has increased the degree of surveillance and power by held by the health and social care professionals over the objects of their care (Mowforth 1999). This is in turn set within a hierarchy or power relationships within the health system, in which medicine has been hegemonic.

The historical distribution of legal sanctions and power between nursing and medicine were also seen as a natural distribution of ability and knowledge, in terms of gender and class and are now a cause for reconsideration. Medicine historically held power through gender and class dominance. This is now being challenged by nurses who have become experts in their areas of speciality, and by recruitment of female medical students. The boundaries between nursing and medicine are becoming increasingly blurred and there is now a great overlap in some areas in the skills and knowledge of doctors and nurses. Kuhse (1997) suggests that we should ‘reject the idea that professionals have fixed natures and instead view them as changing and changeable social institutions’ (p43). Like gender, professionalism is in fact socially constructed and fluid in nature reinforcing the structural power with which it is associated.

There is an increasing requirement and desire by nurses to have technical skills, where formalised knowledge is drawn from scientific, medical technical rationalism rather than from the invisible and subjugated subjective knowledges of care (Woodward 1997). Phillips and Benner (1994) describe this as a ‘Crisis of Care’ in which the relational and spiritual components of care have given way to a rise in the technicalisation of medical and nursing knowledge and practices. Despite the recognition that relationship based care is important, professional care-workers learn to stand back having an objective knowledge of the situation whilst valuing that which is deemed valuable (Fish 1998). The current focus on effectiveness and efficiency increases the economic hold over what care is available increasing surveillance and control of care practices and bureaucracy (Traynor 1999).

Fox (1999, 1995) argues that through the professionalisation of care, care knowledges and practices, a paradoxical situation has arisen in that a vigil manifested in terms of surveillance has given authority and power to the professions whilst denying agency to those in need of care. The bureaucratic gaze of the health system has developed its own power through a sanctioned knowledge base, which excludes those receiving the care (Miers 1999). There has been a disciplining of care through both bureaucratic and professional bodies. The vigil becomes expressed through surveillance, standardisation and regulation of procedures. The power becomes enforced through increased scrutiny and regulation of these processes whilst those being cared for become objects of their own care with the medical/nursing gaze focused upon them in totality through constant monitoring, observation and recording of physical and psychosocial elements of care. That which is outside the norm may be disciplined and become a focus of the normalisation process (Foucault 1973, 1977). The needs of the authority are being met rather then the needs of those requiring care and therefore needs assessment become service led rather than client led (Ellis 1993).

Problems arise when different professions draw from different disciplinary knowledge bases, which can lead to increased surveillance and disciplining of those being cared for or too little or no surveillance and lack of care where there is little inter-professional communication. The balance is achieved only through interdisciplinary collaboration and teamwork (Miers 1999). However, teamwork and shared knowledge does not automatically offer resistance to structural hierarchies of power, and nurses can remain unacknowledged and their knowledge marginalized (Wicks 1998, James and Field 1996) This is also the case of doctors from disciplines lower in the medical hierarchy within general hospitals, such as has been the experience of palliative care physicians (Ruszniewski and Zivkovic 1999, Coyle 1997).

Fox suggests that care in itself seeks the person being cared for to resist this vigil and powerful gaze. The resistance of the vigil is the gift of care. The gift relationship is expressed through interest, concern, love, benevolence and commitment to enable the person being cared for to develop in their own way. It is a creative force not subject to technicalising and standardising forces, because it is dependent on the interaction of the two people and a certain degree of reciprocity. It is an empowering force. Resistance comes through this empowerment in respect of enabling the individual's needs and wishes to be met. This is the care that remains hidden behind closed doors and behind the screens that have remained unmeasurable and unsanctioned.

As Tronto states:

> *"Caring rests on knowledge completely peculiar to the particular person being cared for. Proper action for a nurse, faced with a patient who will not finish a meal, depends upon knowing the patient's medical condition, usual eating habits and tastes. There is no simple way one can generalize from one's own experience to what another needs" (Tronto p 105 1989)*

Care within health and social care has become increasingly regulatory, defined through a procedural process and a homogenisation of different needs. It is far more about containment and control than freedom, self-determination and difference. It preferences the needs, knowledge and the world of the professional caregiver rather than those of the person requiring care and often places the person receiving care as a passive recipient rather than an active participant, perpetuating structural dominance and oppression. Or places the family carer in a position as not knowing how to care. The professionalisation discourse has regarded certain technical and scientific knowledges related to care from across the disciplines as valid whilst continuing to disenfranchising the often hidden interpersonal and poorly defined and measured care.

3.7 Knowledges Informing Care and Carework

Professional knowledge in health and social care has been built upon empirical-analytic objective and measurable facts and theories. However, a growing area of knowledge is being developed which considers the understanding and experience of illness and social problems from the hermeneutic-phenomenological paradigm. Van Manen suggests that there are three distinct ways of knowing what influences how knowledge is valued, sanctioned and operationalised: the empirical-analytic, the hermeneutic-phenomenological and the critical-dialectical (Van Manen 1977). These different epistemological underpinnings are concerned with the production and sanctioning of different forms of knowledge by the 'cognitive interests' of those involved in knowledge development and use (Habermas 1974). Therefore, the different knowledges drawn upon within care are not without the implicit assumptions and values that influence how the knowledge is used. These biases can perpetuate existing knowledge and professional hierarchies and can also provide the holder of the knowledge with a degree of power and a vested interest in how that knowledge is used (Corner 2001). Knowledge that is not valued or verified by academic and public sanctioning becomes subjugated and hidden (Hekman 1990, Hagell 1989).

Specific and specialised knowledges have formed the base of professional disciplines, bringing with them different degrees of power which have either a normalising or standardising function as well as a disciplinary one (Foucault 1980). However, the differences between the professional knowledge bases offers the opportunity to resist standardisation and generalisation with a focus on the particular and the personal (Fox 1995).

The knowledge of care and the knowledge to care is more complex than the original distinction made by Ryle (1949) between 'knowing that' and 'knowing how'. Eraut (1994) suggests this simplistic distinction denies the synergistic nature of the development of knowledge that occurs between the two, which becomes lost in the language used to describe knowledge within professional practice. However, 'knowing that' and 'knowing how' are helpful concepts upon which a body of literature has developed, using a range of terminology to describe similar components of knowledge. 'Knowing that' has been associated with technical, scientific and factual knowledge, where 'knowing how' has been predominantly associated with practical knowledge.

3.7.1 Technical and Scientific Knowledge in Care

Technical, scientific or propositional knowledge is the predominant form of knowledge used by health and social care professionals, managers and policy makers

(Fish 1998, Kennedy 2002, Taylor and White 2000). This knowledge encompasses written theories, concepts and scientific enquiry, which are codified and form systematic descriptions of protocols, procedures and techniques to be undertaken. Schön (1983) describes this as technical rational knowledge which is based on objective rules used for problem solving and as a means to an end, which when carried out should, in theory, provide consistently high levels of care. It is 'a one size fits all' approach, in which findings and techniques can be generalised offering consistency and measurability.

This approach to generalising knowledge and practices has been challenged by Rolfe (1998) in nursing and Eraut (1994) in education, since standardised and generalised procedures and application of principles do not create a consistent response from either patients or students since it denies the differences between people, their contexts and the setting. Rolfe describes nurses as gardeners treating each plant differently, individually tailoring their approach and the procedure or behaviours used rather than being agriculturists. This for Schön (1987) is the swampy lowland, the place outside of the technical high ground in which most engagement with the messy problems and experiences occur. Even the use of empathy, a component of relational aspects of care, is seen as a technique to be used when it is deemed to be most needed, rather than from a point of understanding, which may impair judgement (Levasseur and Vance 1993)

Biological scientific knowledge has been the cornerstone of health care. Knowledge of the body and scientific enquiry into how best to treat particular conditions has placed this knowledge as fundamental to how decisions are made and care provided. Placed within the empirical-analytic paradigm, this knowledge has been endorsed as objective, factual and truthful, providing the medical profession with its unique power. Nurses also draw on scientific factual and descriptive knowledge, described by Carper (1978) as 'empirics' or 'empirical knowledge', although they have had no separately established scientific base, relying on medicine to provide the information. This knowledge provides the basis for analysing and assessing patient's problems and needs and evaluating the effectiveness of treatment and care. It has followed the facts and diagnostic categorisation of medicine. Most practitioners within palliative care know that pain is a complex physiological and emotional phenomenon which often requires a range of different approaches to manage it (Kennedy 1998).

However, the hegemony accorded to the medical profession by the status of their knowledge has, until recently, excluded nurses and other health and social care professionals from full participation in decision making based on scientific technical and biological knowledge, and ignored the knowledge of caring and attending to an individuals needs (Corner 2001). A study by Jordan and Hughes (1998) revealed that where nurses had increased their bioscientific knowledge they were more able to participate in inter-professional discussions and team decision making. It also enabled the nurses to evaluate the doctor's decisions and pick up errors. The common knowledge and linguistic understanding gave access to this previously boundaried knowledge of professional practice.

The technical rationalisation of caring practices and processes into identifiable practical tasks and competencies denies the complexity involved in understanding and operationalising the techniques or the knowledge used in practice within all professional domains (Adams 1998). Schön (1983) suggests practitioners do not reflect on this knowing-in-practice, since repeated actions become automatic and, therefore, the knowledge becomes taken for granted and is used uncritically. This is, however, the approach dominated by the current health and social care system in which competencies rather than understanding are measured and valued (Adams 1998) and where empirical-analytic knowledge is valued in relation to the hermeneutic-phenomenological.

3.7.2 Practical Knowledge of Care

Practical knowledge, or know-how, is learnt by observing others and by gaining experience through repeated practice. It is the knowledge of how to put the technical procedures into practice and developing skills or skilled behaviour (Eraut 1994, Titchen and Ersser 2001), such as giving a bed bath, setting up a syringe driver, building trust or comforting someone who is distressed, or using knowledge that is specific to a particular situation. The behaviour or the procedure does not necessarily have to be understood. Unlike technical knowledge, practical knowledge is difficult to describe and requires the interpretation and application of theories and technical procedures into practice often at an individual level, where adaptation occurs (Eraut 1994, Benner 1984, Schön 1983). The practice of particular actions and thought processes over time become repetitive, routine and automatic, even though they adapted to different situations and individuals. This practical knowledge can become both embodied, remembered by the body rather than the mind, and tacit to the extent that the professional can no longer remember how they know what they know or how to put it into practice and as such it becomes embedded within the context of the practice (Schön 1983, Benner 1984, Benner and Wruble 1989, Lawler 1991, Eraut 1994, Higgs Titchen and Neville 2001).

The synergistic and contextual nature of the development of practical, technical and propositional knowledge was apparent in Benner's study of nurses, but applies equally to medicine, social work and other health related therapies in which technical skills at accessing information and undertaking procedures also often requires an ability to communicate and to pick up visual and verbal clues (Benner 1984, Titchen and Ersser 2001). Such practical and embodied knowledge about how to relate to and identify and care for 'the self' of others, has continued to be subjugated. It is difficult to teach in the predominantly technical empirical model of health care and has only been recognised and valued by its omission (Corner 2001)

3.7.3 Personal and Experiential Knowledge of Care

Personal knowledge is acquired through life experience inside and outside of the professional world of work. Each informs the other. Within professional practice the personal and experiential knowledge is embedded in the continuous flow of experience, in which discreet experiences become meaningful when reflected upon. Over time multiple experiences become subsumed providing a rich pool of experiential knowledge out of which meaning can be built up in relation to specific remembered and recalled events and experiences (Eraut 1994). Personal knowledge, is also knowledge of the self in terms of knowing one's own skills and abilities and knowledge of how to use oneself in a therapeutic encounter (Carper 1978) and knowledge of what one does not know, or an awareness of unknowing (Heath 1998) .

Personal knowledge draws on objective and subjective knowledge, which includes both factual information and personal feelings. Heiddeger (1962) describes these as the difference between knowing and understanding. Previous experience and understanding, based on both knowing and understanding, create preconceptions or pre-understanding. Gadamer (1975) suggests that pre-understanding is used to interpret new knowledge, be that propositional or experiential through a 'fusion of horizons', a merging of information to create new knowledge and meaning, which in turn informs the next cycle of learning, knowing, understanding, application and interpretation. It is a dialogical process, where the meaning, understanding and interpretation are continuously interpreted and reinterpreted in light of the new knowledge or experience. This can be seen as central to the influence, development and embodiment of practical knowledge and skills over time. Lack of critical reflection suggested by Schön would suggest personal experiential knowledge becomes subsumed into the professional's lifeworld without thought, or reference to alternative perceptions. However with the addition of reflection, alternative perceptions are considered and new knowledge and experiences considered before integration, creating an awareness of antecedents and consequences of different situations (Radwin 1998)

Titchen and Esser (2001) suggest there is a difference between personal and experiential knowledge in that experiential knowledge is not dependant on personal knowledge, that is knowledge of the self. Cioffi (2001) proposes that nurses use their past experiences in the form of heuristics or representations which become intrinsic in the decision making process, which suggests there is a little reference to personal knowledge at least in emergency situations. The heuristics are built up over time, developed through comparisons between patients and situations and then drawn upon, as a time efficient way of sifting through what would be a phenomenal amount of related information. However, this can perpetuate bias, if critically unchecked. (Ciofi 2001)

These aspects of personal and experiential knowledge are important in relation to care and what Watson (1988) describes as 'carative' practices in terms of learning and knowing how best to approach and undertake an aspect of care, offering insight and understanding about how this may affect the person being cared for and providing an awareness of a range of potential responses. The hermeneutic-phenomenological paradigm endeavours to explore and make visible embedded meanings through interpretative processes rather than through technical rationalisation (Van Manen 1977) and is the paradigm out of which much of the knowledge and exploration about the phenomenon of care has emerged and theories have been developed (Watson 1988, 1999 , Leinenger 1988, Benner 1984).

3.7.4 Intuitive and Tacit Knowledge of Care

Intuitive (Benner 1984) and tacit (Polanyi 1967) knowledge are exceptionally difficult for people to describe. They 'just know' whether it is a 'gut feeling' or unconscious response that brings the knowing of a situation to mind. Intuition and tacit knowledge are informed by an amalgamation of propositional, practical, personal knowledge and experiential knowledge. Tacit knowledge has often been aligned to personal and practical knowledge, 'knowing how', and intuition has been aligned to 'knowing that' (Kennedy 1998, Herbig, Bussing and Ewert 2001, Titchen and Ersser 2001). Although they have been written about as separate entities, they could be considered complex interactive sides of the same coin. For Polanyi tacit knowledge functions as a background dimension, which draws on the integrated multiple knowledge fragments in a form of meta knowledge. In some respects this is similar to Gadamerian process of the influence of pre-understanding, and yet occurs so rapidly that the knower 'just knows'. It is a lightening speed response, a meta awareness and understanding bought into consciousness from the unconscious synthesis of multiple knowledges. Polanyi suggests:

> *'It is not by looking at things, but by dwelling in them, that we understand their joint meaning' (Polyani p18 1967).*

This also clearly describes the use of intuition within clinical practice, where expert nurses' intuitive knowing is situated within the depth of experience and context specificity of their work (Benner and Wruble 1982). It is not exclusive to nursing but found across diversity of health and social care professionals and situations (Fish 1998, Taylor and White 2000).

The use of tacit and intuitive knowledge within nursing has been problematic in its acceptance by professions submerged within the empirical-analytical paradigm since intuition cannot be easily rationalised. Therefore, nurses have often had insights and judgments overlooked (Benner and Tanner 1987). Yet this intuitive knowing in action (Schön 1983) enables responsiveness and adaptation to a situation that appears to need a different approach (Eraut 1994).

Intuition and tacit knowledge can be unreflective, leading to reliance and an acceptance of assumptions and decision making processes based upon this knowledge preventing consideration of potential alternatives (Eraut 1994, Schön 1983, White and Taylor 2000). Deliberative decision making and team discussions provide the opportunity for similar and different assumptions and perspective to be discussed and alternative perspectives incorporated and reflected upon (Eraut 1994).

3.7.5 Use of Ethical Knowledge in Care

Ethical knowledge informs the daily activities and decisions of practitioners, weighing up the rights and wrongs of moral dilemmas, particular judgements and situations (Kennedy 1998, Titchen and Ersser 2001). Carper was the first to identify ethical knowing as a fundamental aspect of knowing in nursing although, as with the other aspects of knowing, this is not mutually exclusive and not just dependent on codified professional ethics. In palliative care ethical knowledge and decision making has been written about extensively (Randall and Downie 1996, 1999 , Webb 2000, Thorns 2000a, 2000b, Henk Ten Have 2002). Ethical knowledge is drawn from a combination of ethical theories, personal values, morality and experiential knowledge. Within the clinical environment how ethical knowledge and judgments are made has depended on the discursive nature of the teams and the traditionally assumed ethical leadership assigned to the dominant group, medicine (Kuhse 1997). This relates to the previous debate between partial and contextual ethics of care (Gilligan 1982, Noddings 1984, and Tronto 1989) and the Kantian ethics of impartiality and duty, which has seen the position of the impartial rational ethics of duty and justice, predominant in the medical profession, management and policy delivery as dominant in informing decisions about care.

The influential role of professional ethics and values is raised by Carper (1978) in her discussion about the value placed on promoting and maintaining independence in health care. The point she raises is whether it is ethical to promote and strive for independence at the cost of focusing on and facilitating adaptation to increasing dependence. A salient point in the care of some people receiving palliative care. For Carper ethical knowledge is within the partial context specific aspects of care. Ethical knowledge can be seen to be shaped by the different contexts of care yet guided by different professional codes and values. For Bishop and Scudder (1985) dialogue between the different aspects of caring, curing and coping would offer a step forward in appreciating different ethical knowledge used in practice.

3.7.6 Aesthetic Knowledge of Care

Aesthetic knowledge informs the art of practice, be that the art of nursing, the art of medicine or social work. Fish describes this as professional artistry which is:

> *'a holistic view of practice, encompassing skills, and the visible and quantifiable elements of performance, but also attending to what lies beneath this visible surface' (Fish p37 1998).*

Carper (1978) suggests that aesthetic knowing involves the perception and awareness of subjective experiences informed by drawing on other knowledges and information available. The interaction of subjective experience, knowledge and information offers the nurse further insight into particular aspects of care. Titchen and Ersser (2001) suggest that aesthetic knowledge acts to mediate between other forms of knowledge available to practitioners within and informing their work. The art of care becomes that which is expressed within the therapeutic spaces between carer and the person being cared for, which has the potential for creative possibilities.

Aesthetic knowledge is not confined to only learning from propositional and practical knowledge within the care situation. It is also informed by drawing upon an individual's response to art, literature and hearing the narratives of others. Knowledge informing care, from an aesthetic perspective, requires the integration and mediation of information from the senses and subjective experiences. Using observation, listening, sensing, touch and the subjective reactions to a stimulus such as a piece of art work or a story informs the carer within the care situation and external to it. Aesthetic knowledge is an encompassing aspect of holistic care (Fish 1998).

3.7.7 Knowledge of Processes

Knowledge of processes is an important aspect of experienced professional knowledge, and according to Eraut (1994), consists of five identifiable processes: acquiring information, skilled behaviour, deliberative processes, such as decision making and planning, giving information and meta processes, used for informing and controlling one's own behaviour. This knowledge has not been identified in the nursing literature (Titchen and Ersser 2001, Fish 1998), but appears to be a core component of professional practice and knowing how to care. Eraut suggests a knowledge of how to acquire information and use this to inform behaviour and the decision making process are aspects of professional behaviour. In health care gathering and interpreting information it is a deliberative process, important in diagnosing and understanding identified problems, their solutions, planning the action and making decisions . Understanding and knowing the processes within care enables planning and evaluation to occur. There is an awareness of what to expect, how long changes usually take, what else and who must be included in the care.

3.7.8 Reflective Knowledge

Knowledge gained through reflective practice and insight has been welcomed by nursing and social work. Schön suggests reflection can act to correct over learning and challenge assumptions and biases developed over time and through the reliance on tacit and intuitive knowledge Reflection enables exploration of the pre-understanding that informs the cycle of understanding and knowledge development. Reflection according to Schön can occur in action and on action. Reflection in action is reflection in the moment of the intuitive judgment or knowing, enabling the responsiveness to change and alter direction. Eraut (1994) suggest this is problematic because it is not clear what is entailed in the process, since time appears to be a vital factor in the rapidity of the reflection in action as compared to reflection on action, which is less of an immediate meta cognitive response. However, reflection on action, does appear to provide thoughtful and deliberate sense making, from which taken for granted knowledge and practices can be considered in light of new information.

The identification of and exploration of professional practice knowledge, which is elicited from reflection, can be used to bridge the theory-practice gap, informing present and future practice. Critical reflection has a transformative potential not only to challenge the taken for granted knowledges, but the socially constructed hierarchies that surround their acceptance (Fook 2000, Brechin 2000, Adams, Dominelli and Payne 2002). This can offer transparency to decision making, thereby challenging hegemonic dominance of professional knowledge which has denied the particular and specific knowledge held by those being cared for and their family carers, about themselves and their needs (Schön 1987, Sheldon, Turner and Wee 2001).

3.7.9 Local and Cosmopolitan Knowledge

The knowledge held by people being cared for and their families about their specific needs and problems is rarely written about or acknowledged. However, the concept of Local and Cosmopolitan knowledge has been proposed to take account of the relationship between the unique knowledge provided by people being cared for and their families with that provided by health professionals (Harvath, Archbold et al

1994). Local knowledge is the unique and rich knowledge of the skills held by the person and the family about their particular situation and circumstances learnt through life and through the trial and error of experiencing, managing and coping with illness. Knowing what is or is not normal for that particular person. Maybe how they are most comfortable lying in bed or what they have discovered works best in terms of managing their pain. This differs from the cosmopolitan knowledge of health professionals derived from generalised theories, scientific facts and practice knowledge and applied broadly to a range of different people and situations. As patients progress through their illness they begin to know more about their own condition and wish to make choices and decisions. The importance of incorporating both local and cosmopolitan knowledges has been identified as the only way to provide satisfactory care, rather than seeing only the incorporation of the patient and carer's perspectives as part of the initial assessment or planning for service (Sheldon, Turner and Wee 2001).

An important point raised by Field et al (1995) is that there will also be differences in the knowledge held by patients and their carers and, therefore, incorporation of these knowledges, with the cosmopolitan knowledges of professional health and social care, will require professionals to draw on their own personal and practice knowledge of working with people and their use of negotiation skills. Although the knowledges may vary they are valid, representing the different perceptions of the situation, especially where there are different levels of awareness about the person's illness (Glaser and Strauss 1965). In a recent paper Morris and Thomas (2002) highlight the fact that carers of terminally ill people are active participants in the illness experience and life world of that person but continue to remain unrecognised resulting in a failure to use their knowledge and a failure by health professionals to supply enough information leaving their needs unmet.

'Knowing the patient' is increasingly referred to within nursing literature (Radwin 1996, Luker , Austin et al 2000, Kennedy 2002), and draws upon an holistic understanding of the person and their context and an attempt at understanding the life world of the person in their care and not just their physical bodily needs. Knowing the person receiving care focuses on recognising and understanding their feelings, behaviours, attitudes, values, expectations and wishes, which Titchen (2001) suggest occurs in two stages. Gaining knowledge of the immediate situation and personal responses is the first stage before developing a more in depth personal knowing through the therapeutic relationship. Titchen continues to describe components of this knowing relationship, which is built upon skilled companionship, reciprocity, mutuality and graceful care, in which all aspects of 'the self' of the nurses are used.

This is compared to medicine, which can be said to subsume knowing the patient in terms of their biological condition and rational objectification of their needs (Seymour 2001). Knowing the patient has developed a centrality in district nursing, enabling the identification of patient and family needs which are mediated through the development of a therapeutic relationship. By getting to know the patient and family the nurses are able to develop a sense of continuity and trust necessary for continued access into the home, especially during a period of palliative care. However, they also recognised that this increases the degree of emotional labour on behalf of the nurses through the development of a sustained relationship (Luker , Austin et al 2000, Kennedy 2002).

The focus of nursing away from the scientific objectification of patients has seen an increasing focus on the social and emotional worlds of people in their care. The focus on inter-subjectivity and the therapeutic relationship is to provide highly individualised care, unique to each person, which contains two components - the nurse's understanding of the patient and the selection of individualised interventions. Also the nurse's experience of caring for patients, chronological time and sense of closeness between nurse and patient are central to the concept (Radwin 1996).

However, knowing the person being cared for does extend the clinical gaze into extended areas of the person's emotional and social experiences rather than just their body, which extends the power of normalisation and disciplinary practices (Fox 1995, Armstrong 2001).

3.8 Summary

This chapter has explored key discourses and constructions informing care from philosophical, political, sociological, nursing and educational theory. From this exploration it is apparent that care is constructed from multiple perspectives and is shaped by individual and structural process over time and space. The role of the self as the point from which care begins and is then revealed within a relational and obligatory perspective is central. Care as a process of each person's concerns is also reflected by the motivations informing each carer's actions. Competing discourses between care and justice have served to essentialise the debate, ignoring the structural inequalities and dominance of objective, rationalistic, universal, and homogenised ways of knowing, estranging care, social justice, ethics and knowledge. However, post modern debates offer a discursive and just process to care, which values the difference between people, knowledges and discourses but also the complementarily between care, justices and ethics, which serve to balance arbitrariness, and competing notions of good whilst negotiating the multiple voices, perspectives and rights. The importance of multiple knowledges informing and guiding care is revealed and discussed. Multiple knowledges are valued as essential to care, and in guiding decision making.

The following chapters will discuss the findings of this study in relation to the palliative care setting. The discourses have informed both the preparation and design of the study and will also be drawn upon to inform the final discussion.

Chapter 4 Undertaking the Research: Epistemology, Methodology and Methods Involved

4.1 Introduction: Epistemological and Methodological Issues Informing the Research

The literature review has revealed a complex picture involving a range of theories, values and concepts about care in general and a range of factors influencing palliative care. There is little research that has studied how integrated services provide a combination of inpatient hospice, community and hospital palliative care and how the guiding principles of palliative care adapt across location. This study, therefore, aims to explore how social constructions, values and palliative care philosophies influence the care across these different locations. This chapter will consider the epistemological or philosophical framework informing the methodology and the methods chosen to undertake the study.

Care cannot be considered without confronting the constructions surrounding it. These constructions delve deep into the social psyche and subsequently individual and organisational constructions. Care and caring have been constructed as essential female and feminine attributes, something initially carried out within the private domain of the home, and within care institutions. As a concept care can be deconstructed and deemed an arbitrary construction within a post modern context. Today, it is not only women who can be defined as 'caring' or who provide formal and informal 'care' to people. However, because care is both a complex range of concepts and a complex set of actions, an epistemological and methodological framework will be necessary that can best reveal them. Also the epistemological and methodological framework will need to acknowledge and value the creation of truth and knowledge that is located within and formed out of complex conceptual constructions which are multiple, temporal, and contextual.

4.1.1 Epistemological Understanding and Underpinning

Epistemology has been described by many writers as the philosophical understanding of the nature and condition of human knowledge. It is a theory of the knowledge of the social world. This knowledge is validated in terms of its origin, its nature and limits and, therefore, supports and defines what is understood as truth. Yet, what is validated as knowledge and as evidence of the truth; that is, how the social world is known is contestable (Lincoln and Guba 2000, Hekman 1999, 1990, May 1997, Van Manen 1977).

Dominance of a positivistic, scientific hypothetico-deductive and rationally driven epistemology has validated and maintained the power of particular forms of knowledge since the Enlightenment. This has perpetuated the mind-body dualisms upon which Western societies have been structured; the privileging of associated male attributes: rationality, impartiality, objectivity and morality, in relation to those associated with the female: emotion, partiality and subjectivity (Hekman 1999, 1990, May 1997, Van Manen 1977). Fox (1999) suggests that modernism, therefore, denies difference whilst seeking to define and compartmentalise knowledge.

It has been argued that the hypothetical-deductive epistemology produces research that objectifies human respondents whilst ignoring their subjectivity, thus alienating them from the process. This hegemonic epistemology denies the opportunity for truth and knowledge to be located in different ways and for such truths to be partial, contextual and personal and, therefore, meaningful. It denies the voices of those involved from being heard and, in denying the humanness, it fails to consider the complexity behind the understanding and creation of different ways of knowing and the meaning and values which inform them (Guba and Lincoln 1989, Fine 1998, Geertz 1973).

Challenges to this dominant epistemology have been raised by constructivist (Guba and Lincoln 1989), feminist (Usher 1997, McNay 1994, Stanley and Wise 1993, 1983), interpretivist (Schwandt 1998, Denzin 1989, Gadamer 1975, Geertz 1973) and post-modern debates (Hekman 1999, 1990, Foucault 1972). This shift in paradigm away from positivism has enabled the development of new paradigms which see truth and the development of knowledge as multiple and not contingent. As Reason and Rowan (1981) observe there are now many ways of being in the world and yet there appear to be few ways of sharing these. They recommend that the most important task is to learn and to think in new ways in order to be able to see and communicate these many ways of being.

The discourse of constructivism runs through hermeneutics and interpretivism, in that social reality is seen as a meaningful construction and not as an objective reality (Gadamer 1975, Geertz 1973). Therefore, one explores the social world. We are all caught within 'webs of significance', as Geertz describes it, that shape experience and the on-going interpretations we make to understand the world around us. Gadamer (1975) like Geertz believes it is not possible to transcend our contexts and our histories and deny our values and biases, as is asked of the researcher within the positivist objective paradigm. Understanding is seen to come through a fusion of these different perspectives, it is a dialectical process in which there is a fusion of past knowledge or experiences and biases with what is being interpreted in the present, a fusion of horizons.

"Interpretation is not an occasional, post facto supplement to understanding; rather, understanding is always interpretation, and hence interpretation is the explicit of understanding' (Gadamer p306 1975)

Through the development of feminism the social constructions surrounding gender and power were brought to the fore, revealing the privileged nature of knowledge and the constructed hierarchy of being male compared to female. The early guiding epistemology behind feminism, that of critical emancipation, the research on women for women was accused of perpetuating the dominant positivistic male dominated paradigm through buying into the positivistic research methodologies and perpetuating the position of women as 'other' in relation to the androcentric norm. It also homogenised all women, perpetuating further disenfranchisement of Black and Asian women, lesbians and other groups (Fawcett and Featherstone 2000).

Hekman (1999) suggests that feminisms are now moving towards an acceptance of all knowledges as situated and discursive and away from the universal or relative. Feminist research offers a more emancipatory approach to research in which the unequal power hierarchies within the research relationship can be challenged and more participatory approach taken (Wolf 1996,Usher 1997, McNay 1994, Stanley and Wise 1993, Reinharz 1992). Although, as Finch recognises, unless the researcher uses reflexivity there will remain a potential for abuse, simply because some women may identify with a female researcher, more so than with a male researcher, where they share similar interests and backgrounds, and may be more willing to talk about particular issues (Finch 1993).

Foucault's perspective corresponds with that of the Gadamer and the different feminisms which see power and knowledge perpetuated through language since it plays such a divisive but important role in the development of hegemonic and personal constructions within society (Foucault 1972, Gadamer 1975). Written text and spoken language can be deconstructed but also have to be interpreted to provide meaning and understanding (Fawcett, Featherstone, Fook and Rossiter 2000, Delanty 1997). The use of deconstruction challenges these normative foundations and the binary oppositions revealing the multiple realities and constructions which inform our thinking and understanding of reality (Usher 1997, Denzin 1989). However, one of the problems within the process of deconstruction is found in the way that it relies on the language and understanding of the prevailing system. By using the same language, we are at risk of repeating the story that we ourselves are critical of (Spender 1980, Poovy 1988, Rorty 1993). Foucault suggests that one should always consider the question *'according to what rules has a particular statement been made, and according to what rules could other similar statements be made?'* (Foucault p4 1972).

What constructivism, hermeneutics, the different feminisms and post modernist approaches share is the development of and legitimisation of partial, subjective knowledges and truths rather than a singular truth. Yet the different ontological positions that are within each of these paradigms would traditionally lead to more than one epistemological position. However Orme suggests that :

"Identifying a single epistemology is in itself positivistic and deterministic…and argues for a privileged position on the basis that it provides the correct version of how things really are' (Orme :119 1997).

Hekman (1999) suggests that social research is undergoing a paradigm shift in which epistemology is characterised by a movement from:

'the universal to the particular, from Truth to truths…In epistemology it solves or, rather, displaces the question of how universal truth is grounded, but it raises the equally difficult question how to justify particular truths' (Hekman 1999:23-24).

She describes this as the development of a new 'paradigm of differences' where:

'truth is plural and relative, historical and particular' (Hekman p24:1999).

Importantly she acknowledges that this requires a new understanding of how these truth claims are to be grounded, in order that when claims are made there is some way of judging these. Her challenge is:

'not how can we establish a metanarrative more to our liking, but how can we make our voice heard among the cacophony of voices' (Hekman p 89 1999).

Therefore, this study into how care is undertaken, expressed and conceptualised within palliative care, was guided by an epistemological position which aimed to value multiple truths and knowledges and, therefore, the different ontological positions, or ways of being in and experiencing the world by the participants.

4.2 Methodological Considerations

The epistemological discussions are important in that they raise important methodological issues for consideration in deciding which would be the most suitable methodology or methodologies to guide this inquiry. Therefore, in order to study the nature of care within palliative care it was important to find a methodology which could take a holistic approach. One that would enable care culture, care practices and care talk to be observed whilst also listening to the experiences and beliefs of participants about care and then placing these within the wider health and social culture. I wanted to be able to explore the micro and macro dynamics affecting care.

A methodology that recognised the different truths and experiences of participants was important, in that the majority of careworkers, professional or ancillary, are female in health and social care and particularly in palliative care. However, it was expected that within palliative care the professional and ancillary care workers would occupy a range of different hierarchical positions and bring a range of different values, knowledges and experiences into the working roles. To have chosen only a feminist epistemology would have been placed myself at risk of setting up the study in such a way that it would have reflected the dominant dualism, creating a process of feminist knowledge in opposition to a masculinist knowledge. This is certainly a criticism of feminist research by Hammersley (1992), although he appears to fail to consider his own hegemonic position within the criticisms. Gelsthorpe (1992) highlighted the use of feminist perspectives within a variety of methodologies as important since we are all more than our gender, whether male or female. She says *'women are never just women'* in that women, and men, have many different relationships and personal constructions and understandings about reality and different truths from these different perspectives (Gelsthorpe 1992:215).

To use a positivist methodology would strip away the values, context and subjectivity of those involved, would deny the personal and the humanness behind the beliefs and development of concepts and create findings alienated from the realities of those involved. Constructions are interdependent on the physical, social, emotional and cultural contexts from which they are created and situated. Similarly so is the founding philosophy of palliative care which draws upon an holistic awareness of the physical, social, emotional, spiritual and cultural contexts of pain and suffering.

4.2.1 Choosing an Ethnographic Approach

Ethnography is somewhat like care. According to Atkinson and Hammersley (1998) it is difficult to define and is subject to controversy. However, it does provide an holistic approach to research. Tedlock (2001) offers a very clear and helpful account of what she believes ethnography to be:

> *'Ethnography involves an ongoing attempt to place specific encounters, events, and understandings into a fuller, more meaningful context. It is not simply the production of new information or research data, but rather the way in which such information or data are transformed into written or visual form. As a result it combines research design, fieldwork, and various methods of inquiry to produce historically, politically, and personally situated accounts, descriptions, interpretations, and representations of human lives...Because ethnography is both a process and a product, ethnographers lives are embedded within their field experiences in such a way that all of their interactions involve moral choices. Experience is meaningful, and human behaviour is generated from and informed by this meaningfulness' (Tedlock p455 2001).*

This understanding of ethnography suggested that a holistic approach to researching the cultural, organisational and individual constructions of care was possible. It accounted for the possibilities of different interpretations and truths and placed me as the researcher within the process, thus supporting the epistemological underpinnings of the study. Hammersley (1992) raises concerns about the level of subjectivity inherent within the process and the potential of poor reliability of ethnographic analysis. He suggests that the inability to generalise from the findings is also seen as a weakness. However, when considering the contextual positioning of the knowledge gained, ethnography offers the potential to critique the culture being observed (Thomas 1993). In effect a post modern ethnography offers the potential to deconstruct the taken for granted language, symbols, routines and norms of the culture or the palliative care service that is being studied and to reveal the interaction between micro and macro level processes and structures (Schwartzman 1993).

In terms of this study, ethnography was to provide multiple methods to explore care, through the use of participant and non-participant observation, interview and documentary analysis. It enabled me to remain within the palliative care service for over six months developing relationships with participants out of which dialogue and collaboration was possible, checking interpretations and reinterpretations and the development of a certain amount of reciprocity. This reciprocity enabled me to give something back, a shared experience, rather than one in which I owned the data. The extended period of study ensured that rather than a snap shot of care was observed, the richness of the culture, taken for granted language, knowledges and process were to be revealed. Multiple methods used in ethnography enabled multidimensional analysis of the subject being studied.

Since palliative care and palliative medicine are often located in three main areas of provision, the hospice, the community and the hospital, the research was undertaken within an integrated service and looked specifically at each area as unique, yet interdependent. This deterred an undertaking of pure case study research, since a pure case study is bounded within its own system and remains explicit in its attempts to preserve the case. Case study does not usually consider in depth the cultural aspects of the setting and the meanings understood by those within the culture (Simons 1996, Stake 1994). Although the role of 'thick description' is central to both (Geertz 1973), by undertaking three case studies, studying the three locations of care separately, the different situational aspects of care would have been at risk of defining understanding in terms of comparisons rather than as components of a wider culture.

A multi-method approach is recommended by Ingleton, Field and Clark (1997) when undertaking research within the palliative care services to enable the multidisciplinary aspects of the work to be studied, as a range of methods are more able to tap into the complexities of palliative care. By using a variety of methods, participant and non participant observations, interviews and documentary analysis, these provide a more holistic collection of data and can then be analysed and compared to ensure the trustworthiness of the findings.

Hammersley and Atkinson (1995) are clear that there is no one way of undertaking ethnography because it is a practical activity which has to adapt and change according to the site of the research and the judgements required of the researcher in negotiating access and managing themselves throughout the process, rather than simply following methodological rules. It is an evolutionary process which offers a degree of flexibility and responsiveness that is required in the palliative care setting, where situations change daily as the conditions change of people being cared for.

4.2.2 The Inclusion of Hermeneutic Interpretation

Geertz (1973) suggests ethnography, or anthropology, requires a hermeneutic interpretative process to interpret the language, symbols and meaning of the cultural word that is being studied. Ethnography is underpinned by an interpretativist philosophy and is a dynamic process in which the questions originally formulated at the beginning of the study often change as it progresses (Roper and Shapira 2000). The use of hermeneutical interpretation not only informs methodology but is also used as a method in itself. Interpretations inform the gathering of observations, listening to the narratives and the questions asked during interviews (Hammersley and Atkinson 1995). A hermeneutical dialectical process (Guba and Lincoln 1989) or fusion of horizons (Gadamer 1975) enables the germination and development of the interpretation of personal and professional constructions and influences, beliefs and values. Delanty criticises the use of hermeneutic interpretation for ignoring the role of power in shaping meaning and emphasises cultural essentialism (Delanty 1997). However, Hekman (1990) disputes this suggesting that:

"Gadamerian hermeneutics entails a critique of prejudice and tradition as well as material for an attack on the gendered connotations of ways of knowing"
(Hekman p17 1990).

Therefore, during my fieldwork I engaged in ongoing dialogue with all the participants, using my pre-understanding of the range of care and palliative care situations, languages, symbols and practices to confirm or disconfirm my understanding and interpretations. Although not undertaking Fourth Generation evaluation, as this was not an evaluative study, I drew upon the principles within it to guide my inclusion of as many voices and perspectives as possible and drew upon its description of the hermeneutic dialectic process to guide my own interpretations (Guba and Lincoln 1989). I did this so that I would not be perpetuating only my own voice and judgements but rather a negotiated understanding, which would enable greater trustworthiness of the data and findings. To undertake such a study it is recommended the researcher needs integrity, an ability to communicate, power sharing, a reconsideration of their values, a willingness to change and to provide a commitment of time and energy (Koch 1994).

4.3 Undertaking The Study: Methods And Processes

4.3.1 Undertaking Sensitive Research with Vulnerable People

Undertaking research within the field of palliative care is a contentious issue for some who believe people receiving palliative care are too ill to participate and their time too valuable to be taken up by a researcher (De Raeve 1994, Kristjanson 1994). Other researchers suggest that this perspective actually denies the rights and the voices of those people who are receiving palliative care or who may be dying (Barnett 2001, Beaver et al 1999). The complex issues surrounding research with vulnerable people are well documented, especially in relation to palliative care (Rees 2001, Lawton 2000, Seymour and Ingleton 1999, Beaver et al 1999, Randle and Downie 1999, Bruera 1994, de Raeve 1994, Kristjanson 1994, Cassileth 1989).

The ethical issues involved in research within the palliative care settings are multi-fold. De Raeve (1994) raises these issues when asking such important questions as will the involvement in research be harmful? Does that person really have a choice, or do they feel obliged to be involved? Is the person able to withdraw if they do not wish to continue? As De Raeve also notes, there is an imbalance in the power of the researcher in relation to the participant, despite attempts on behalf of the researcher to negate this and maintain a comparative balance. Kristjanson (1994) suggests potential threats to a persons humanity may occur during involvement in palliative care research since the person may become increasingly fatigued, drained emotionally whilst attending to other personal issues and potentially suffering from increasing symptoms. Whether people could give informed consent was questioned. In fact

Lawton (2001) clearly discussed the problems of gaining and maintaining informed consent in a busy hospice when undertaking observations where people were admitted as emergencies and who were unconscious or unable to engage in discussion about the research due to the distress they were in.

Lawton suggests that ethnographers have to tread a fine line when undertaking research in such an environment. For her the dilemma was whether a person's consent remained valid after they became unconscious. She sees this remaining a thorny issue for debate. Seymour and Ingleton (1999) discuss the perception that qualitative research has been seen as potentially less harmful, and yet the face to face contact requires great vigilance and sensitivity on behalf of the researcher to ensure the participants make an autonomous decision to be involved and understand what they are consenting to. It is the researcher's responsibility to ensure participants are not harmed by participating in conversations that are potentially distressing and that their confidentiality is retained and their dignity respected.

The notion of informed consent and confidentiality are crucial considerations within palliative care research. However, ethical sensitivity and a focus on the process of informed consent can address some of these issues. The notion of consent as a process, rather than a one off event, ensures consent is renegotiated during the research process and is, therefore, sensitive to the changing situation of the person who is ill, or the member of staff who decides they no longer wish to participate (Beaver et al 1999, Seymour and Ingleton 1999). This offers the opportunity to be more respectful to the humanity of the individuals involved. A balance, however, has to be struck between constantly reminding each participant involved in the research and not disturbing the processes within the field, especially when undertaking participant observation.

Undertaking research within any health setting however does require submission to a Local Research Ethics Committee to ensure the research proposal reaches a rigorous standard that is acceptable to the committee before it can commence. The introduction of the Human Rights Act 1998, defined a set of rights each individual was entitled to have protected, including the freedom of speech and the Data Protection Act 1998. It set out clear principles about ownership of personal data and third party data, which came into effect during 2000. These required consideration when developing my research proposal for the hospital and local research ethics committees undertaking research. Most papers at the time of preparing the study discussed the implementation of the Data Protections Act 1998, the Caldicott principles (2001) and the Human Rights Act 1998, in terms of how they would affect clinical practice. Woogara (2001) discussed both the Data Protection Act and Human Rights Act in terms of patient privacy in UK hospitals and McHale et al (2001) discussed the implications for nursing practice. Diamond (2000) discusses the 'duty of confidentiality' in terms of the Data Protection Act, and how the processing of personal data would now apply to manually held records. In terms of research the only papers written were speculative as to how the Data Protection Act would affect access to patient information and access to participants (Stroble and Walley 2000, Warlow 2000). Warlow suggested the requirement for explicit consent was unrealistic in observational medical research and audit, and that the enforcement of the Acts may be seen as unethical in terms of hindering important medical research in the future. There were no research papers about undertaking research with these Acts in places.

The final aspect of managing research with vulnerable people is the researcher's responsibility as to how to leave the research area without causing harm to the participants. Relationships are built and maintained over the time of an ethnographic study and it is naïve to consider the researcher would not have an effect within the community being studied. Meaningful relationships can and were created within the palliative care service from which an abrupt exit could have been highly damaging. It was, therefore, important to leave in a manner that was responsive to those being left behind. It had to be planned and provision made to retain some level of contact.

4.3.2 Preparing and Planning the Research

It was important to put together a research proposal before locating a potential site for my study. I was aware that to approach a service I would need to be able to present my proposal, having considered a range of potential scenarios and concerns that might be raised by the potential services. I knew I would also need to be ready to debate the use of my chosen methodology, since health care remains an area where positivism is the guiding epistemology behind research. I, therefore, put a research proposal together using the guidance available from the Local Research Ethics Committee in Southampton before making contact with any of the services.

4.3.3 Choosing the Research Site and Negotiating the Initial Access

I chose my research site from within pragmatic parameters. I wanted an integrated palliative care service, which offered traditional hospice inpatient services and also a community and hospital palliative care team. This was to allow me to observe and record care practices across the different arms of the service and see how they are adapted from the inpatient unit. The site ideally needed to be in commuting distance from my home base due to the pressure of costs. I was prepared to commute for up to two and half hours a day.

I located Chaffinch Palliative Care Services through the hospice directory (2000) as fulfilling my criteria for selection. I then wrote an introductory letter to the Lead Nurse. I chose the Lead Nurse, rather than the Medical Director, as I wanted to approach via the nursing route, since this was my background. This could be seen as attempting to use a route in which the dominant cultural power structures were used not only for my own benefits, but also to take advantage of the fact that I also did not want to get into a position where the doctor had ultimate power over my ideas and requests. I felt that this would be a project that would appeal to nursing, perhaps more than to medicine. My own bias I realise was in considering doctors to be less interested in care and caring and more interested in the science. However, by taking the route I did it meant that my position as nurse and student were in some way protected from an instant dismissal and my perception of the power divide.

Although my initial letter was sent out in March 2001, due to the absence of the medical director, KL, who was away on leave, the first meeting with the service was not until May. However, during this hiatus I had had the opportunity to talk to EG the Lead Nurse. She expressed her own interest in the study, and explained that their other Consultant, IS, had expressed some reservations. EG explained, however, that she had suggested to him that perhaps they should not let his worries and concerns about the length of time and commitment prevent them from considering participating. I thought that this was an interesting sign since the Lead Nurse obviously had certain powers of persuasion over her medical colleagues. We arranged a time to meet when KL, the Medical Director, would be back.

Prior to the meeting I sent them a copy of my research proposal. When we met the thing that took me by surprise was the interest they both expressed. Both were very open and friendly and, despite asking many questions about the research, there was no sense of power dynamics at play between them, although they both held the power to deny my request. I wondered if it was because we were all women, and that interestingly the one person who had raised concerns was male. Although IS, the other Consultant, was not at the meeting he left questions about the scientific rigor of the research and whether it was objective. This led me to discuss the difference in paradigms and to position my research. I also suggested that I would be happy to adapt my approach to include anything they thought pertinent or to remove aspects they were not happy about in an effort to create a degree of participation.

What was clear was that both KL and EG saw the research as looking at 'the essence of palliative care', as EG described it, which was what I had wanted to explore. What became clear was that they had an agenda. They wished to evaluate their own service and my research provided them with an opportunity to do this. I negotiated that I would spend two months within each location the service provided, and that the first two months would be on the Hospice Ward, the next two months with the Community Team and the final two months with the Hospital Team. I had anticipated that achieving the consent of hospital Consultants to involve the people under their care would take time. In hindsight there were no problems with the hospital Consultants.

4.3.4 Meeting the Requirements of the Local Research Ethics Committee (LREC) and Hospital Management and Data Protection Committees

The following day I arranged to meet a member of the Hospital Research and Development Department to look through my research proposal before submitting to the LREC covering that particular hospital. It was during the subsequent meeting that the minefield created by the Data Protection Act was made clear to me and of the alterations I would need to make in light of the requirements of the Data Protection Act 1998, and Human rights Act 1998.

Once I had rewritten my proposal and protocol it had to be submitted to three committees: the Local Research Ethics Committee (LREC), the Hospital Research and Development Management Committee and to the Data Protection Officer. The LREC and R&D committee only met monthly, which meant a rejection or minor correction would have to wait a further month for approval. My first submission to the LREC and Research Management Committee required minor alterations, which were achieved through a conversation with the chair of each group, and the document resubmitted.

When applying for ethics approval I found I needed to debate the competing rights of patients in the hospice and hospital ward in terms of the right to privacy and protection of their personal information with the right to free speech. To obtain informed consent and process consent in order to carry out ethical research I had to ensure the participants would be made aware that their right to privacy might be jeopardised because it was not always going to be possible to provide a private and secure room on a ward in which to hold an interview in terms of maintaining confidentiality.

Freedom of speech meant that I could not deny anyone the opportunity to participate, unless they were unable to give informed consent. Therefore, this provided me with the opportunity to invite participation by people who were close to death, since gate-keeping could be seen both as a protection and a denial of a person's right to speech. I was surprised, expecting the involvement of people close to death to be problematic. I had to ensure that the participants retained the right to withdraw their consent at anytime, and withdraw their interview data if they chose. Clear and informative information sheets were provided as part of the research protocol.

The crux of the Data Protection Act 1998, that caused me such angst, was how to address the issues of first and third party data. According to the Act, unless a person's name is in the public domain, as a researcher I have no right to know this unless the person consents to me knowing it. This was to be the same for people being cared for by the service, their family members, the names of Ward Sisters/Charge Nurses and Consultants, General Practitioners, District Nurses, and hospital ward staff. The advice I had been offered by the Research Department was felt to be not practical by the LREC Committee. However after a discussion with the Chair of the LREC it was agreed that a general letter could be sent to the health professionals who may also be involved with some of the participants receiving care.

I spoke with the Lead Nurse and Medical Director. Together we drafted a short letter to be sent out in their names to members of staff and the people being cared for by the service. This letter explained that there would be a research study taking place and it requested their consent to allow me to know their name and details so that I could contact them with some information about the study, before I stepped into the service to commence the research. People were being admitted and referred to the service throughout the six months and so each new person was presented with this letter authorising the release of the person's name and contact details. (See Appendix 1 for the process of gaining ethical approval, Appendix 2 for letters and Appendix 3 for information sheets).

4.3.5 Anonymity, Confidentiality and Data Security

For my study to be sanctioned by the Data Protection Officer, I had to plan how to anonymise my data, ensure confidentiality was maintained and protect the data. It has, however, been questioned whether some data can be truly anonymised. Ethnographic reliance on 'thick description' can create the potential for a site to be identified by someone who chose to investigate the local descriptions. Small numbers of participants, different gender and professional occupations can also lead to potential identification. However, the omission of gender or occupation would deny the reality of the situation. Anonymisation can also create the potential for confusion unless careful tracking of codes is maintained and can deny the humanity of participants, placing them once more as subjects (Kite 1999b, Brannen 1988). I chose to use an alphabetical coding system for participants, which had to be altered once to ensure anonymity of participants, and names of birds and plants for the research site, and local services.

Confidentiality was maintained by using the codes and not repeating what had been said to me, either on or off the record. I had to make a decision prior to commencing the study as to whether to abide by the UKCC Code of Professional Conduct for Nurses, which would require me to bring to the attention of managers unsafe practices, or offer complete confidentiality to all participants, which could then not be broken. I chose the latter, since the Research Department were very keen that I made a clear decision to be there as a researcher and not as a nurse. Data was protected on site using a locked brief case into which note pads and audiotapes were put to keep them secure. This was kept in the Lead Nurse's office and the Senior Sister's Office. Observation notes, cassette tapes and typed transcriptions of interview recordings were kept in a locked filing cabinet away from the research site. Computer files were password protected.

4.3.6 Entering and Negotiating Access

After the research protocol was given final approval, I arranged with the Lead Nurse, EG, to introduce myself and present my prospective research to the members of staff at their weekly meeting. This was arranged for the middle of August 2001.

The Ethics Committee required the information sheets to be sent out at the same time to all potential participants. The first problem I encountered was that I could not actually address the envelopes for each member of staff or person being cared for myself, because I did not know their names, unless I was given permission to do so. I realised there was going to have to be some delicate balancing and negotiation if this was going to work, without me being seen as taking up undue time and being a nuisance. EG offered to write the envelopes for the staff letters. I left a box in her office for the returns to be put in. 65 members of hospice staff and key stakeholders received forms over the course of the study, 62 chose to participate. 60 staff and stakeholders were observed undertaking care or in meetings; 51 were interviewed although one interview was withdrawn from the study by the participant and the tape destroyed.

I started in the hospice during the first week of September 2001 before joining the Community Team in November and then the Hospital Team in February 2002. In my first week RT, the Senior Sister, introduced me to people, and EG gave me information about the service, the layout, the general running and routine of the place. During the first week I began collecting the returned replies, observing and slowly introducing myself to every one.

I had chosen not to wear uniform, but wore dark trousers with pastel coloured tops so that I did not stand out as completely different, but also could not be mistaken for a member of the staff. The ward nurses wore uniform, as did EG and LN when working on the hospital team, and AA and AZ in day care but everyone else wore smart casual clothing. I signed an honorary contract with the Personnel Department, and was given an identity badge.

As I got to know people by name I began to ask them to think about if they would be interested in participating. I answered any questions they had and when someone expressed interest I gave them an information sheet and then followed up with a conversation about the study and offered a consent form to those who were happy to participate. I tried to avoid working on the shifts or in the environment of the staff and people being cared for who chose not to opt into the study. With the staff this was difficult at times, as I found myself sitting in the same handover meetings or being on the ward at the same time. I chose to manage this by positioning myself in another area when possible, interacting respectfully and not mentioning them in the observation notes.

KL agreed that the medical staff would talk with the people being cared for either on admission or very soon afterwards to let them know I was on the unit. I discussed this with the different doctors on the unit, as this did not happen initially, and was often a little sporadic depending on who was on. The aim was that in trying to remain guided by Data Protection, I would be able to listen to the shift handovers and ward meetings and with the authorisation of the majority of people allowing me to know their names and, if I was lucky, their consent to knowing more of their details. I had provided several matt laminated posters, which explained why I was there and what I would be doing, and these were placed on the walls on the ground floor.

As I developed relationships with members of the unit staff, I tried to find a point of reference to talk with each person. I drew upon the skills I had previously developed as a nurse to build and maintain working relationships. I needed to present my self as non-threatening, and I needed to gain the trust of those around me if I was to be able to observe both their interactions outside and inside the rooms and within the meetings.

4.3.6.1 The Community Team

Before entering the Community Team, I met with their team leader, CS, and the team to discuss any concerns they might have during the six weeks prior to my move into their area of care. I had met all of them on the hospice ward and at the weekly multidisciplinary team meetings (MDT) I attended. However, I had not had the opportunity to develop relationships with them as I had with those on the ward. The meeting with the team threw up some unexpected issues. I explained that in order to try and work as closely to the Data Protection Act as possible, I felt that we would need to send out the letter requesting access to people at home asking for their authorisation for me to know their names so that they had a chance to respond, and that they were made aware of my presence within the team. The aim was to ensure I could validly listen to conversations between team members, telephone calls and attend discussions in the meetings. Concerns were raised by the Community Palliative Care Team (CPCT) about the logistics of doing this because they felt that by sending out this information it would make some of the anxious people more so. I asked them for suggestions as how to best handle this, as I needed to be able to at least sit in with them when I was due to join them, rather than wait a couple of weeks for the forms to go out.

This was my toughest negotiation by far, and one that left me really concerned, because the team did not appear initially to want to engage with it. In the end we agreed to send out the letter and an information sheet. Once again I could not address the envelopes, and the team said that they certainly did not have time.

It was suggested I ask the volunteer co-ordinator, which I did. She suggested that I get the Community Team to write a list the names of the people on their books and then she would arrange for a couple of volunteers to address the envelopes. The team raised concerns about the amount of time it would take for them to write a list, and again I asked for suggestions. I remained calm and flexible and kept negotiating gently but persistently, whilst acknowledging their position. In the end it was agreed that the folders which contained people's names and addresses would be made available to the volunteers, but that each member of the team would make clear which people were not to be sent the letters.

The following week I met with two very helpful volunteers who addressed and stamped the 144 envelopes and inserted the letters. This took them a whole morning but the letters went out. However, only 18 people at home participated. I had labelled and stamped the return envelopes so they could be clearly identified from the Medical Director's regular mail. I provided two trays, one for the 'yes' and one for the 'no' letters. However, there was some confusion and I ended up with both then 'yes' and some 'no' letters. Some went to KL and some to CS, the Community Team leader.

The nurses stapled the return slips to the back of the front cover of each person's case notes, once I listed who had agreed to me knowing about them. The negative replies were also stapled into the notes. As new people came into the service, it was agreed that the CPCT Nurse would use her discretion about handing out the letters. I then began the process of getting to know people. It took a long time to break down some of the initial barriers and be accepted. The team agreed for me to attend the regular weekly case meetings, but not their team meetings.

4.3.6.2 The Hospital Team

The Community and Hospital teams shared CS as Team Leader. LN was the other part time member of the HPCT. I spoke with both CS and LN a month before crossing offices into the Hospital Team about how we would tackle the problem of the authorisation letters. LN gave me a list of the hospital wards she tended to be involved with and I sent a letter introducing myself as the researcher to them, explaining my attachment to the team. LN, CS and I agreed that they would take the authorisation forms with them when they went to see patients and would endeavour to inform the people in their care about my presence in the team and ask if they would be willing to sign the authorisation form.

4.3.6.3 Authorisation Forms

The authorisation forms were not consent forms, they only allowed me to know that persons name, so that I could approach them to talk about the research and ask if they would consider participating. I am sure the added bureaucratic level dissuaded some of the people, and the Community Team reported that people at home found the amount of information too much to take in. It was easier in the hospice ward, as most people signed authorisation forms, although only 21 people consented to participate. When I attended handovers and ward meetings I would hear information about some people who had not authorised my knowing their names so I ignored this focusing on those who had given authorisation and consent. However, in the Community Team this became almost impossible since most people had not signed authorisation forms and only 18 people consented to participate. I made a decision to focus my listening to the nurses' responses and the content of this rather than any other details. This meant I still heard a lot of information about people who had not consented to this. However I resolved to remain ethical with this information and disregarded it when specific identifiable information was discussed.

The hospital team was equally problematic from this perspective, because CS and LN both told stories about people they had encountered and their situations. In fact, most of the staff did. This was something they all shared. However, this raised my concerns over third party data. In theory the person being talked about would need to give permission for me to know the information. The issue of third party data was complicated and in a sense nonsensical in terms of carrying out observational research. In theory I would need to inform everyone about the research and acquire their authorisation so that I could observe all the people within the area.

I discussed this problem freely with everyone. I was the one who was most concerned about the ethical implications, since most members of staff were quite unaware of the Act in terms of their working world. I acted as the gatekeeper on many occasions reminding the staff that I could not just go and see someone without their consent or read their notes, even when they were offered to me.

4.3.7 Obtaining Consent from Participants

4.3.7.1 Obtaining Staff Consent

With the members of staff obtaining the consent involved me in discussing the study and answering the questions people raised as I gradually met them all. Most of the members of staff throughout the service signed the consent forms during the first month. However, members of the Community Team were the most reticent but I was able to talk through it in detail with them on several occasions and explain what the study involved and address their concerns.

4.3.7.2 Obtaining Consent from people being cared for on the ward

Obtaining consents from the people being cared for by the ward, community and hospital teams was more complicated. The doctors on the ward spoke a little about the study when asking each new person whether they would allow me to know their names so that I could approach them about the study. The reply slips were returned to me and I would then ask the ward staff how that person was and whether they minded if I went to speak with them. Only occasionally did the staff suggest that I might want to wait, as perhaps the person was less well since signing the form or had recently had some medication for their symptoms. When I went to talk with people I explained who I was, and most said they had heard about me. I talked about the research and gave them the information sheet. Often I found that people wanted to talk there and then. However, I suggested they read the sheet first and I would return. I realised the information sheet was too lengthy for most people to take in. I adapted my approach and took to reading through the sheet and then asked if they had any questions. I also made it very clear that the study was optional and they could withdraw from it at any time.

4.3.7.3 Obtaining Consent for People being cared for in the Community

In the community the logistics were more difficult. Of the letters and information sheets that were initially sent out to people, 48 gave authorisation for me to contact them, although I eventually only saw 18 people. On discussion with the nurses they said people felt the information was too much for them to deal with, and many did not have the energy to participate. The nurses preferred that I check with them before contacting anyone, which I agreed to do. It was also agreed that the nurses would take out the information sheets and letters to people to gauge whether they would be prepared for me to see them and answer any basic questions about the study. Often people's conditions deteriorated before I was able to see them, as the forms were originally sent before I began with the team.

The nurses agreed to take authorisation forms out with them when they saw new people, but often chose not to ask for the person to consider the study feeling that the timing was not right, or the person was too anxious or too ill. In the end it was negotiated that the community nurses would take me with them on a pre planned visits, agreed by the person at home. I would then talk through the information with the nurses present. On most occasions consent was obtained before the meeting commenced.

4.3.7.4 Obtaining Consent for People Being Cared for in the Hospital

In the hospital the issue was more of a case that people were so ill, or were transferred in and out very rapidly, that either their condition or position changed overnight. Once I was with both teams the nurses agreed to take out information sheets and the letters with them and to talk through these with the people to gauge whether they would be prepared for me to see them. I joined CS and LN when going to see each person, and discussed the study and obtained consent at the time. Only three people consented to participate.

In an ideal situation people would have had the opportunity to think about participating over a period of time and be able to talk about it with family members and in the hospice ward this was what tended to happen.

4.3.7.5 Different Levels of Consent

Because of the frailty of some of the people receiving care I had developed two levels of consent for the participants: consent to have their care observed and to read the documentation written about this, or, where the person felt able, a separate consent to be involved in an interview. I felt I wanted people to have the option of participating at a level they felt able. For some an interview was too much but they were happy to have me assist and observe their care. I explained the different levels of consent before asking if people wanted to be involved. I also made it clear that if they then chose not to participate I would leave there and then.

4.3.7.6 Did People Feel Obliged to Participate?

People in the Hospice did not have another member of staff present when I undertook the consent process, however the 18 people I saw at home and 3 in hospital agreed for me to join them with their community or hospital nurse present. However, many other people did not choose to have me join the nurses, which perhaps answers the question that would be raised as to whether people felt obliged to take part. I am certain that, because of the nurse's rigorous gate-keeping, and from listening to their telephone conversations giving assurance that people did not have to participate, the people I eventually saw had made an autonomous choice. I was always very clear to ensure people that this was independent of the service and that the findings would be published. Interviews were always held separately from the observations, without members of staff present. Often these occurred with people lying in their beds, and I always explained the problem of maintaining a level of privacy in an open ward. At home this was a different matter. Although where the person being cared for had a partner they were also present and were asked to sign a consent form.

Most contacts were one off meetings, and consent for that meeting was taken as a one off event. However, for people on the ward whose care I was observing, and for 3 people in the community whose care I observed on several occasions, I also rechecked that they understood and whether they remained happy continuing to participate. This led to my involvement with several participants until very close to their deaths.

The people I observed in the community were some of the least ill people that were being cared for at the time. Those less well were protected by the team from the intrusion of having a researcher alongside. However, in the hospice and the hospital I met people at different stages of their illness.

4.4 Data Collection

4.4.1 Participant observation

Previous researchers undertaking research within the palliative care services have chosen to be participant observers, since this enabled them to have access to all areas of the care environment (Lawton 2000, Seymour 2001, Hockey 1990, James 1996). I chose also to undertake participant observation on the hospice ward where I could work alongside the team members, but had to be a non-participant observer when spending time with the community and hospital teams, since their work is undertaken by Nurse Specialists or Consultants predominantly working alone. However, in reality

I was a participant observer in the sense that I was involved in ongoing conversations and discussions, rather than not interacting with the members of the two teams, but I was not involved in taking telephone calls or talking with clients.

4.4.1.1 Participant Observation in the Hospice

In the hospice, as a participant observer, I worked according to the shift patterns, choosing to try and avoid those visits to the people who did not wish to be involved in the study. I was involved in shift handovers, to hear how caring work was described and discussed and written about in the nursing and medical notes. I observed ward rounds and discussions between nurses, doctors and other health care professionals. In many respects I needed to maintain a close and constant reflexive frame recording all that appeared to me and all that I thought, in order that I might see things anew, but use my previous knowledge in enabling understanding and interpretation. I always carried a small notebook and a pen. I explained to everyone that I might at times be seen making occasional notes, although never in front of patients, and I also tried to go elsewhere to write them. However, this did not always occur and my notebook became part of a standing joke throughout the service.

In the hospice ward I spent the first two weeks quietly observing the comings and goings of the ward area. After the first couple of weeks I asked if I could begin to attend the ward round meetings and the handover meetings. I also began negotiations with the different members of staff about working alongside them. Some were more forthcoming than others. I began helping with bed making in the rooms of the patients who had signed authorisation forms. This also allowed me to introduce myself to them and open up a dialogue about the research. I began working full shift hours, which for an early shift meant getting up at 5.00 in the morning, something I had not done for some time.

After hand over I would ask the nurses if I could work with them, and I would explain which of the people being cared for had consented to being involved in the study. After several days nurses began to become familiar with which person was involved and those who were not, with comments such 'oh she's one of yours isn't she'. I would also talk on a daily basis with the doctor on duty about who was and was not involved and arranged over time to accompany them so that I could observe them with their patients. This was something I also did with the occupational therapist, physiotherapist and social workers.

I made sure that I avoided being in the same area as the members of staff who did not want to be involved in the study, apart from at handover time when it was almost impossible. I did the same for those being cared for who did not wish to be involved, or who were too ill to make a decision. What I was unable to avoid was hearing information about other people who had not consented to me doing so. For if I were to remove myself at the mention of every non consented or authorised person, I would have been in and out of the meetings like a fly buzzing in and out of a room, which would have been extremely disruptive. Once again I had to be guided by my ethical conscience and on many occasions, whilst hearing the information, I did not record anything. On others I did so in a way that followed the conversation interchange rather than identifying details.

When I was able to work alongside members of the staff, I asked them if they would check with the person being cared for first and then I did so as well, to ensure that it was alright. This gave me opportunity to remind them that they could always say no, that it would not be a problem and that they could withdraw at any point. I tried to remain sensitive to the person's needs and situation, and if a potentially embarrassing aspect of care was to occur I again checked if they minded me being there. I was very lucky to have the opportunity to help bath, and bed bath people, and assist with a range of other aspects of care. I began to be asked if I could help out, and became much more involved in moving and handling patients. However, I was never involved in handling medications or taking telephone calls or relating to family members on a professional level. I worked at a level of health care support worker.

It took a little longer building up the trust of the health care support workers, but through talking, and helping out, and working alongside them I gained their trust and reduced the level of the threat that I might have posed. I was then invited to work with them. We laughed a lot by the end of my time on the hospice ward, and I was involved in ongoing discussions, jokes and non-work related issues. This continued even after I left the hospice ward to spend time with the Community Team.

4.4.1.2 Non Participant Observation in the Community

Carrying out observations in the Community Team was more difficult. The office only had room for the team members and there was no spare space for me to sit if they were all in there together. In many respects it worked out because two members of staff were part time and only on one day of the week was everyone in. I would sit in whatever chair was vacant, which meant I moved position around the room and desks. I could not blend so easily into the background because there was so little space. I was there, very much present, even though I would try and be as unobtrusive as I could to begin with. As with the hospice ward, I spent the first couple of weeks quietly watching and listening and making notes. I then started to try and negotiate getting out to see patients with the nurses. This was not as easy as I had hoped. A matter of only having 48 slips returned meant there were different numbers of people for each nurse who had agreed to me knowing about them. A month went by and I had not been able to go out with anyone. I then asked in a slightly more persistent manner maybe I had not been persistent enough, but I did not want to put anyone's back up. It was a very delicate procedure being an observer who is trying building rapport and trust, yet who needs some access to the experience of community patients. Finally, I began to go out. Luckily there were 2 people I managed see on three occasions, and one person on two occasions. I always sat to the side of the nurse and tried to merge into the background, if only for a short while. Eventually I was also able to see some of the participants through different parts of the service. Most of the time I would go out with the nurses in their cars but on a few occasions I went on my own. By the end of my time with the team most of the barriers had fallen, apart from their team/clinical supervision meetings where a couple of the participants did not want me to be involved, and this I continued to respect.

4.4.1.3 Non Participant Observation in the Hospital

By the time I joined the hospital team, I had got to know CS and LN quite well, since the two teams worked so closely together and I did not have to start a fresh developing relationships and trust. However, the hospital threw up its own problems as far as access and authorisations were concerned. LN had more concerns about discussing the research with the patients but again I suggested that she should use her judgement. CS, however, was very keen for me to see as many people as I could, and so involved me more from the start. For both teams I produced a set of files containing the appropriate information forms, authorisation request letters and consent forms. By the time I had got to the hospital team, I had ensured that they had a set of forms in their folder every time they went up to the wards. The hospital situation was less planned and people were often very ill, and this became a focus in that often we were unable to get authorisation and so I could not watch the nurses or consultants at work.

At points my ethical radar was not sure what to do, and we adapted the approach used in the community. This time, CS or LN would go and see the patient, ask them if they minded me joining them and this I did when they consented. Only after they had their initial discussion would I talk more about the research, and ask if they would mind participating. Often this only led to me being able to record the interaction and notes, rather than going back for a follow up interview. Sometimes all I had was verbal consent as people did not want to sign the form or were too weak to write. Those who signed the forms were given a copy back.

I managed to observe 3 interactions between the nurse and person being cared for because the hospital posed the most difficult problems. The need to acquire the authorisation of the person on the ward, before they could be told about the study, and then be introduced to me to talk through the information, took up much valuable time often in very sick and weak people. A person's condition often changed in the course of a day and overnight and, therefore, the ideal of having enough time to contemplate participation was not achievable. I had to become just a little more flexible with time otherwise there would be no study. I retained every other aspect of ethical concern and at no time abused this. I observed the team's interactions with the ward staff, and I always introduced myself to them. In fact, on the oncology ward I got nicknamed 'the shadow' by the ward receptionist because I was there so much, often waiting whilst the nurses saw the people on the ward without me. So to a degree I was both visible and invisible at the same time because in each of the teams I became part of the furniture and was the one to remind them when I felt an ethical boundary was about to be hit.

4.4.1.4 Observing the Everyday Aspects of Work Throughout the Service

Throughout my time in each of the areas I listened intently and asked many questions which came from what I had seen, or from a point of reference from my own previous work. The longer I was there the more stories I was told about past patients and past experiences which were relevant to situations happening at that moment. In all the areas I participated in I was visible, because I interacted with everyone, chatted and listened, laughed and shared poignant moments. I was also entrusted as a confidant and had a supportive role for certain people.

There was always a power imbalance with me as a researcher within the clinical environment considering the power established and held by the Senior Nurse and the Medical Director and all other members of staff. This proved integral to my observations and the access I was allowed to have. I also needed to remain aware of how power was used within the areas, what the non verbal and verbal indicators were, the language used between different people and how positioning, space and time would be used. I entered into an ongoing dialogue with everyone.

4.4.2 Interviewing

I had chosen to use a semi structured interview technique to enable the discussion of themes related to care and palliative care (See Appendix 4 for the Thematic Interview schedule). The questions were developed from my experience, observations and interpretations of care. I aimed to interview both health care professionals and those being cared for and their family/friends. This was to provide a greater insight into individual understandings about how care and care within the context of palliative care is conceived. It enabled me to ask about what each person saw as an expression of care. Whether care was different for different people and what made it different. It also enabled me to ask those being cared for what they perceived as caring.

Most of the interviews were tape recorded, with the permission of the participants. Not all recordings were audible due to the quiet speech of some participants, background noise and occasional low battery power and had to be discarded. Flexibility was crucial, and so the questions were open to change as new themes arose or issues were raised. I ended up interviewing 51 members of staff within the service and stakeholders involved with the service and 22 people being cared for across the service (Appendix 5 has a list of participants).

The interviews of people being cared for usually came out of my previous contact with them in each area. Often on the hospice ward it was a case of carrying it out there and then, once the person had said yes. It was not my expectation but theirs. I had started with the good intention of allowing people time. However, sometimes there is no other time when you are very ill, and at that moment is the only time you have. So it was. On the hospice ward I also managed to interview 2 spouses and one family. This was not so easy in the community where I did joint interviews of 2 people and their spouses. I did not manage to interview any family members in the hospital. I always tried to ensure people were comfortable, and knew they could withdraw. Only one person decided they did not want their interview used and withdrew it. Interviews lasted from five minuets to two hours with one member of staff. People on the whole were able to be reflective. Many, however, found it difficult to talk about care and caring. This included both staff and people being cared for.

The longer I was with the service the more readily people were willing to talk with me. Interviews were carried out in any spare available private space. Prearranged times were made with staff and those being cared for, where possible. Sometime it was ad hoc, taking the moments as they arose. A date and time was set with people at home over the telephone, and I was warmly welcomed and offered refreshment. The hospital setting was not conducive to undertaking interviews, in part because of the poor state of health of participants and the business of the wards.

One man became upset when talking about his experiences during his interview, so I switched off the recorder and asked he wanted to stop. He gained his composure and asked to continue. We did so. I suspect because the focus was on care rather than on dying this may have tempered the potentially upsetting nature of the interviews. Some members of staff used the interviews as almost cathartic expressions of their frustrations with the state of care on the main hospital wards, which was not dependent on the location they worked in.

4.4.3 Documentation

The documents I studied included a combination of patient medical and nursing records, governmental documents, circulars and white papers, the occasional papers produced by the National Council for Hospices and Specialist Palliative Care Services held by the service, local health authority and hospice/hospital/community strategy documents. The notes recording the care that had been discussed and undertaken were my priority, to see how these compared with the care I had heard talked about and observed. I was able to copy the notes of participants whose care I had observed in the hospice and in the community and the palliative cares service recorded its own notes which were added to the main hospital notes. It was not possible to copy the hospital notes on the main wards, but copies were made of the notes written by the hospital team for their own keeping. I used the photocopier at the service and paid for the use of it. On a couple of occasions I was told that the volunteer who was going to be doing a large amount of copying would be able to also copy some notes for me, which was very helpful, and so it was all ready for me to collect the following day.

4.5 Analysing the Data

4.5.1 Initial Management of the Data

4.5.1.1 Observation notes

Observations notes were recorded into noted books, which we identified by date and number. Observations from the hospice were then typed up onto the computer. However, on commencing the community observations I decided not to do this as typing was taking up so much time and I was able to make good hand written notes and reflections in my notebooks because I spent so little time with people being cared for. The notebooks were clear and rich with information, reflections and developing themes. I continued this through to the hospital observations. Initial analysis, therefore, occurred on both typed transcripts from the hospice and in the notebooks using coloured pens to underscore and write a code name of repeating actions, processes and observations. Pieces of text were then copy typed into the computer creating newly formed documents, and themed folders were created to hold examples from each area of data and analysis.

4.5.1.2 Transcribing interviews

54 interviews were transcribed in total, which included representation from all staff groups and people being cared for. The volume of transcribing required me to obtain assistance to share the workload, since it was extremely time consuming. The interviews transcribed were chosen because of the clarity of the recording and the greater fluency of the person talking, and their ability to discuss care. This enabled the basis of analysis to begin, built upon with each successive interview. The remaining interview tapes were listened to repeatedly during the process of analysis to develop themes and constructions emerging from the transcribed interviews. Interviews were transcribed successively and, therefore, early analysis developed this way, commencing with the hospice team and people being cared for, then moving onto the

community and hospital. Only one person requested their transcript, although this was offered to everyone at the start of the interview.

4.5.1.3 Documentation

Documents were photocopied, including the case notes of people being cared for. These were placed in labelled files in a locked cabinet. Notes were made on each photocopied page in coloured pens as repeating patterns emerged, and the codes identified from the observations and interviews were used to identify developing themes. Examples and comparisons between different multidisciplinary team notes were copied, typed into the computer, and created new documents.

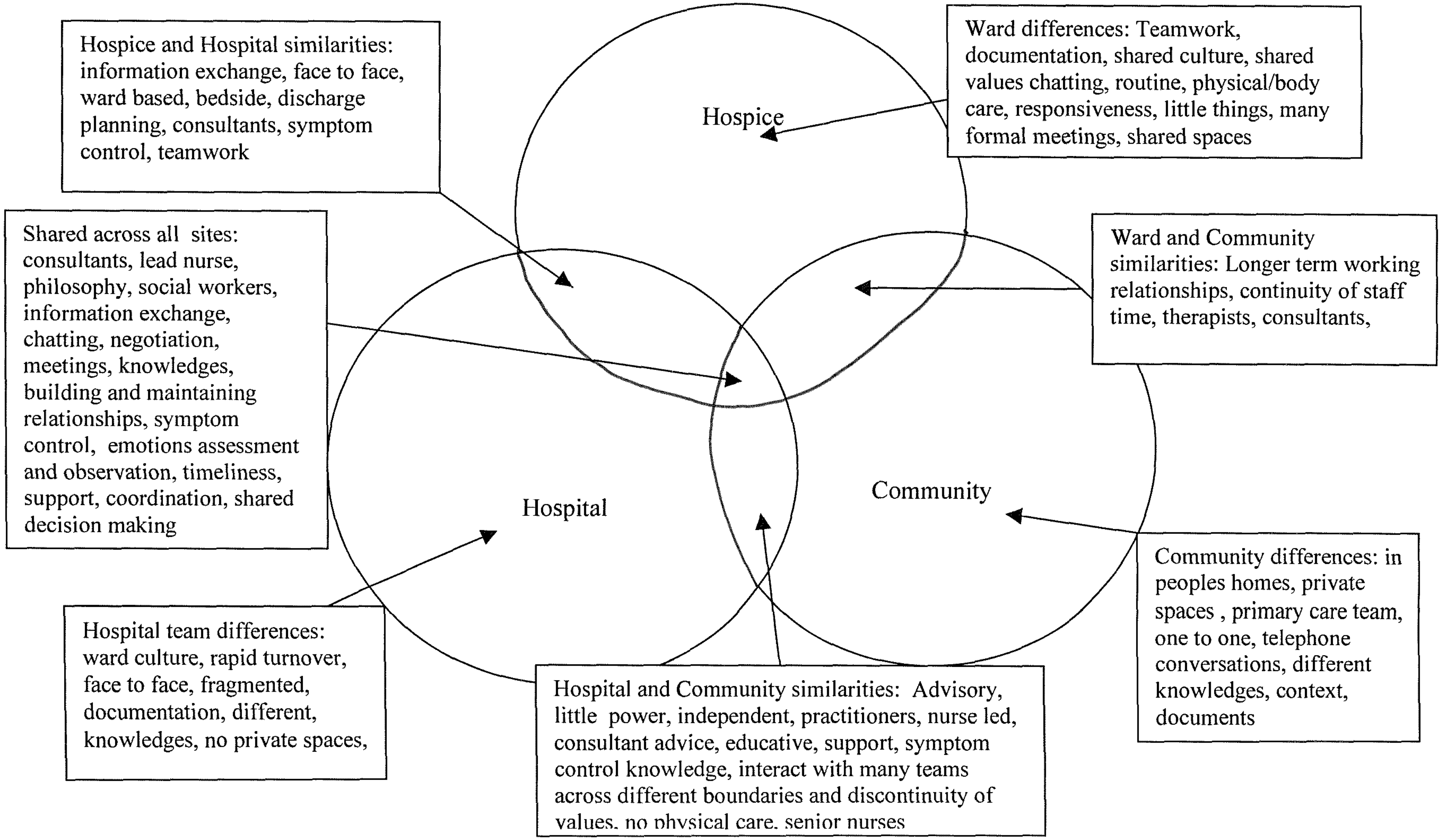
4.5.2 Analysis of the Data

Analysis of the data was emergent throughout the period of immersion in the palliative care service. As repeating and stronger patterns appeared these were noted within the notebooks, influencing further observations and interview questions. Formal analysis however began after the fieldwork. I decided not to use a qualitative data analysis package, due to the time it would take to learn, and because the Ethnograph software at the University was known for freezing and crashing unexpectedly. I decided to use MS Word to create files to contain developing codes and themes and examples from the data, which enabled me to work at home as well as at the University.

The analysis process was cyclical and reflexive, although it is described in a linear manner. Using a hermeneutic approach ensured that the interpretation of my own past understanding of palliative care in part informed my development of codes and themes, as did the concrete observations recorded in the data, the language and constructions of participants from their interviews and the way care was written in the documentation and case notes. I read and reread word document observations from the hospice, making notes in margins of printed pages of thoughts and developing labels and codes and underlining text examples. I made notes of recurring observations in new MS Word files, such as chatting, and labelled them on subsequent observation documents. When all documents were read through a list of labels and codes were collated and each typed repeatedly into a new MS Word document. The greater number of same repeating codes, and related codes, revealed the strength of key emergent themes developing. A list was created for each developing theme, along with the identifying code and labels. Examples from the observations were copied into new MS Word folders created for each theme. The documents were printed. Cross reference notes were typed or hand written into the themed files between the different locations. Therefore chatting on the hospice ward was cross-referenced to the community to highlight the predominance of the difference in style by the use of telephone conversations as a means of sharing information with community colleagues. The community observation notebooks were read and reread several times, and coloured pens used to make notes in the margins and underline text. Notes were made in a large spiral bound notebook, and examples written by hand stating notebook number, page and date. When all notebooks had been coded a list of codes and labels was drawn up, and this was where the greatest number of the same codes and associated codes were pulled together to identify emerging themes. The hand written examples were then typed into MS Word document files and separate themed documents created, with examples typed in. The same processes were undertaken for the hospital notes. The themes from each area were then compared, and the differences and similarities noted. Examples were looked at from each setting often revealing similarities and a complex interaction between themes, since often one example would contain more than one theme.

Throughout the process successive codes and then themes emerged as each area of data was analysed. This process was carried out for each set of interviews. The interviews were broken down into subgroups, such as leaders, ward nurses, doctors, people being cared for, family, volunteers, community nurses, social workers, hospice team administration, and stakeholders. These were analysed using the same process by their sub group and by location before being compared across the services. The themes were then compared. Cross-referencing occurred which often led to the data being reinvestigated to check a new finding or reinterpretation. The documentation of peoples' case notes underwent the same processes, and cross-references and links were made to the other data and analysis. Therefore, the connection was established between the importance and reliance on chatting as a means of sharing information on the hospice ward and the lack of clear personalised instructions in the nursing notes.

Throughout these steps thoughts raised and questions raised were noted in a notebook, and cross-links made between different data when very clear themes emerged, such as that of information exchange. The following diagram on page 108 shows an example of how observations were compared between the different locations. The themes and codes were developed out of both direct references to concrete examples and individual participant's constructions and from my own interpretations from previous experience, knowledge and intuition. The links were drawn upon large flip chart paper, as patterns emerged, enabling clear visual identification of similarities and differences, and links between themes. The visual linkage between initial themes and constructions, which were closely related, enabled the development of meta-themes and constructions about care to be identified. There was a continuous ongoing dialogue between my interpretation and the data. I took the interpretation back to the palliative care service on two occasions, and talked about it, to gather whether the participants concurred or saw the themes and constructions differently. Two helpful alternative interpretations were offered about the role of chatting and the intuitive knowledge involved in knowing when and when not to open a conversation with someone. Outlying examples, which did not fit into themes, were also considered. Examples of analysis can be found in Appendix 6.



Comparing observations developing across the sites informing broader theme development

4.6 Reflecting on the Process

4.6.1 Researching One's Own Culture: Insider-Outsider Perspective

To undertake this study and to get under the skin of the palliative care service and immersed within it, I identified a service and negotiated to stay with the service for just over six months. Ethnographic research study requires the researcher to spend time immersed within the area of study in which observations, interviews and documentary analysis are undertaken (Tedlock 2001, Atkinson and Hammersley 1998, Holloway and Wheeler 1996 Geertz 1973). This provides both benefits and challenges, however, when studying one's own culture. Coming from a palliative care background, I understood much of the language used by the participants, although local differences and symbols occurred, but it was easier to gain a degree of acceptance by the participants as I did not have to burden them with asking too many naïve questions. I also explained that I would at times need to clarify my interpretation of events and understand these from their perspectives. I discovered that asking simple clarifying questions about practice induced a process of reflective questioning by the members of the staff throughout the hospice and palliative care service. These questions were usually informed by my own previous experiences and knowledge, which situated me as an insider in terms of my knowledge base. This led to some people genuinely questioning their 'taken for granted' assumptions despite the open nature of the questions often beginning with 'why?'.

I was also more at risk than someone new to the field of not seeing the 'taken for granted' aspects of my own culture and becoming overly immersed, or going native, and only seeing the care through the eyes of a practitioner once again (Seymour 2001, Seymour and Ingleton 1999, Kite 1999a, Hammersley and Atkinson 1995, Field 1989). For me it was not strange to be working with so many dying people, to observe bodily deterioration or listen to staff conversations where, for other researchers such as Lawton (2000), this was shocking. It was not uncommon for me, once I was established within the service, to be observing and listening to discussions about care or problems with managing symptom control or other issues, to find my own clinical self becoming involved. Or, in fact, for some members of the different palliative care teams to ask me for my clinical opinion or for clinical advice. However, this was always countered by my research perspective but in the spirit of reciprocity, so that I would enter into discussions but avoid offering a decisive decision, preferring to facilitate the other person's reflections. An important aspect of having insider knowledge is that it can help uncover why people act as they do, enabling explanation and insight from the inside (Holloway and Wheeler 1996). Balancing the insider/outsider perspectives was an important aspect of this study, which was guided by the process of keeping field notes which combined both observations and personal thoughts and reflections.

However, I was an outsider to this particular service and it required the use of all my social skills to develop working relationships with everyone within the service. This meant taking time to develop trust, expressing genuine interest it their wellbeing and their work. I wanted to work as participatively and respectfully as possible. My outsider status, however, also made me shockingly aware of the complexity of the work I had previously taken for granted.

As an outsider I had to negotiate and consider how I spoke and reacted at all times. I had no rights of access to meetings and the spaces in which care occurred. But by developing trust, participating in conversations when invited, and helping out with making the drinks and undertaking small tasks for the teams gate keeping became less of a problem as the perceived threat of my presence reduced, and the people being cared for by the team felt more comfortable. I was then able to introduce them to the possibility of engaging in the research by asking whether they would let me know their names so that I could talk through the information about the study. When I was told that I had become one of the team, by members of the community team, I knew I had been accepted since they were the people feeling most threatened by my presence. When observing the Lead Nurse working for the Hospital Team, she completely forgot I was there in my research capacity and I had to explain my presence to the Ward Sister on one of the orthopaedic wards, who looked bemused as I sat down in her office.

4.6.2 Reflexivity and Tempering Bias

Steier (1991) describes reflexivity as a turning back on ourself in a way that reveals our own tacit knowledge about ourself and the world around us. This is important when undertaking any research but especially when following an ethnographic and hermeneutic interpretative methodology. Having an awareness of my own constructions and interpretations was important in order that I might recognise these as they informed my observations, the questions I formulated and how I read and interpreted the documentation. Without acknowledging my personal values I risked skewing, blocking or misconstructing interpretations. However, my experience and knowledge about care and caring in relation to palliative care were important in creating the fusion of horizons between my interpretation and those of the participants in reaching some consensus of understanding (Peshkin 1988) Gadamer 1975, Guba and Lincoln 1989). Reflexivity is an ongoing process, much like the hermeneutic circle, and required me to explore my own values, prejudices and presumptions, so that I could more clearly see that which was going on around me.

Reflexivity is important in managing and negotiating oneself in relation to the gatekeepers and participants. Awareness of presenting oneself as safe, ethical and with integrity is crucial to develop and build trust. It is also important in preventing any abuse of trust and power within the research relationship (Finch 1993).

Peshkin suggests that when investigators keep their subjectivity unconscious it prevents them clarifying their personal stakes. He sees one's subjectivities, the different 'I's, 'like a garment that can not be removed' (Peshkin p17 1988).

Before I was able to make my methodological aspirations reality, I was myself struck down with glandular fever, which resulted in my having to take seven months out and a further considerable period with chronic fatigue. It was a time of new and not necessarily invited experiences. Nias (1993) in her chapter 'Changing Times, Changing Identities: Grieving for a Lost Self' discusses the role of the 'situational self', which varies according to the context and the 'substantial self', the deeply embedded core of self beliefs, assumptions and values which construct and define us.

She highlights the powerlessness which comes with enforced change and the chaos that comes when one's meaning for one as a unique self, and one as professional/functional self is threatened by change and the process of bereavement one goes through when negotiating an altered identity. My illness, and the recuperation time needed, made me captive to the experience of being 'cared for' and 'cared about' challenging both my situational and substantial selves, the 'me' and 'I', by bringing the personal and professional/academic into sharp relief and perhaps collision. I was left for the final months of my illness and recuperation, wondering who I was any longer and how I fitted into the world anymore.

Bochner, talking about how the death of his father made him confront his academic self with his personal self, tells how he is no longer able to write his experience or values out of the research narrative any longer and says that 'Chance changes us' (Bochner p 420 1997). Nias (1993) suggests that the:

> *'crisis can be resolved by a reintegration of meaning in which neither the past nor the loss are denied, but, instead, meaning and purpose are reformulated in terms of the present and the future'(Nias p150 1993).*

When one of my supervisors underwent palliative treatment for wide spread metastatic cancer another subjective realm became involved during the fieldwork and process of analysis. It informed my interpretations on a personal and professional level and shed further insights on the data collection and analysis. I experienced the range of emotions and thoughts that accompanied each subjectivity. Seeing someone I admired becoming less well, observing the same processes in people cared for by the palliative care teams, watching the staff work with people in a way I had done made me ask more questions about how they did what they did. All of this informed my ongoing observations, interviews and analysis providing a clearer appreciation of palliative care from within these different subjective positions.

Supervision was an important part of undertaking the research. It enabled exploration of my own thoughts and expectations and challenged those that I was not consciously aware off. Supervision in palliative care research can focus on tasks and processes, which can be undertaken together or separately (Clark, Ingleton and Seymour 2000).

Whilst undertaking my field work, I chose to explore the processes through an arranged contact with the University Counselling Service for the period of the fieldwork, leaving the task centred supervision with my local supervisor. The important role of reflexivity and of the self within the research process means that my recent experiences cannot be written out because they are key to how I now see the world and my research. Chance changed me. Peshkin (p 20 1988) talks about a 'tamed subjectivity' and this was also part of my aim. By acknowledging my subjectivities, I hoped to be able to see beyond them rather than be shaded by them.

4.6.3 Awareness of Power Dynamics

The dynamics of power began from the moment the first contact was made with the research site. Throughout the process the power of the researcher has to be accounted for using a reflexive approach to practice. Research can be seen as threatening to participants due to its potential intrusion, positive sanctioning by managers and, therefore, seen as threatening at a practical and political level (Lee 1993). It is tempered by adherence to explicit and implicit ethical practice and a personal belief that I would not abuse the trust placed in me by those I observed or talked with. As I became accepted as an insider, and almost unseen in my research capacity, I became a listening ear and support for those who wanted to talk to me 'off the record'. My insight and palliative care experience placed me in a position similar to Finch (1993) in which I found myself able to explore issues because I was seen as familiar and with a shared background.

Those who acted as gatekeepers throughout the research process held the power to allow my study to continue or to stop it by choosing not to participate or by denying me access to observations or interviews. The leaders had their own agenda; by letting me undertake my study it gave them an opportunity to re-evaluate their service and use my insights to develop changes. The Community Team held a lot of power and I had to negotiate how to contact the people they were caring for. Obstacles placed in my path by their sense of threat and concerns for the emotional safety of the people they cared for, and some lack of clarity on my part as I tried to negotiate the best way forward to work within the Data Protection Act, lead to me being sat in their office for a month before seeing anyone working within the home environment. One conversation about a politically sensitive topic about who got transferred to nursing homes and who was allowed to stay for longer than average, led to a gentle warning by the lead nurse that she would be watching me. This was an interesting insight into the power dynamics and practices of the leaders, who preferred to watch and wait, rather than take direct action. It subsequently turned out I had asked the one person who had been the most resistant and vocal to changes in working practices and who the leaders had worked for a long time to manage through these. It was felt I was rocking the boat unnecessarily when I thought I was trying to understand the different perspectives about how decisions to keep people in the hospice were taken. Power is dynamic, and is constantly negotiated during fieldwork. It also continues to be negotiated during the analysis and writing of the research texts (Fine et al 2000, Hammersley and Atkinson 1995, Finch 1993 Reinharz 1992).

4.6.4 Trustworthiness and Crystallisation

Ensuring the trustworthiness of the data and findings comes through a process of triangulation or crystallisation. Triangulation, according to Denzin (1978) requires that data is drawn from different sources, that multiple perspectives are drawn upon to interpret the data and that multiple methods are used to study a phenomenon. This study has fulfilled these criteria. However, a process of crystallisation enables the recognition of the many facets within the methods and analysis that inform the findings to be recognised. It is the multidimensional approach which enables the complexity to be revealed (Richardson 1994). This study has taken different data sources from multiple perspectives: three locations: hospice, community and hospital settings. Interviews have been undertaken with staff, people being cared for, family members and some stakeholders, and documentation has been considered from each location. This provides a multiple and complex set of data from which independent and interconnected themes have been developed. The influence of personal bias has been tempered by the process of personal reflexivity and by taking the interpretations and findings back to the research site on two occasions after the fieldwork was completed.

The nature of the hermeneutic ethnographic study suggests, as looking through a crystal, that there are different perspectives to be seen from different vantage points. The interpretation never ends, but a construction of the findings has been created from which the reader will make further interpretations from their own perspectives.

4.6.5 Representation

Feminist writers have questioned issues surrounding fieldwork, such as representing the self, insider/outsider roles, friendship, power and voice (Fine, Weis, Weseen and Wong 2000, Fine 1998,Wolfe 1996, Lal 1996, Reinhartz 1992). Fine (1998) brings in the idea of 'working the hyphen', such as the hyphen often found between Self-Other, because she sees these to be entangled rather than clearly delineated. 'Working the hyphen' means creating occasions from researchers and informants to discuss what is, and is not, 'happening between', within negotiated relations of whose story is being told, why, to whom, and with what interpretation, and whose story is being shadowed, why, for whom, and with what consequence' (Fine 1998:135).

The writing of the findings over the next four chapters has, therefore, drawn on the voices of the participants at length in an attempt to ensure clarity, both my own and their own interpretations of the situations and their understandings about care are presented. Long extracts are used where processes and complex constructions are described by the participants. However, at times the voices have been shortened, and altered and are not always directly re-presented but represented through my own interpretations of situations and constructions. This is undertaken in the knowledge that each reader will in turn reinterpret what they read informed by their own constructions and knowledges of care, palliative care and research.

Chapter 5 The Cultural and Socio-Political Context of the Setting

5.1 Introduction

This chapter describes and situates the care within Chaffinch Palliative Care Services by exploring the multiple interrelated cultural and socio-political contexts within which the research was undertaken. Although the situational context of Chaffinch Palliative Care Services is important in locating the research in its totality, three locations - the hospice, the community and the hospital, where palliative care occurred - were studied in depth. Each location is contextualised and discussed separately and in relation to the others. The financial and political context of the service is elaborated and the implications these have for the care provided discussed.

5.2 Organisational Setting: Contextualising the Study

5.2.1 The History and Setting

Chaffinch Specialist Palliative Care Services were situated within an NHS District General Hospital outside of a small cathedral city in a rural county in England. The Hospital and the Palliative Care Services covered the urban population of the city and the large widely spread rural population of small towns and villages in the southern part of the county. The Specialist Palliative Care Services had their own purpose built building, referred to by most people as 'The Hospice'.

Chaffinch Specialist Palliative Care Services began in the early 1980's as a community based service supported by Macmillan funding until donations were raised for the construction of the hospice building and ward. It was initially known as 'The Macmillan Unit', losing this title as funding sources changed to being predominantly provided by Chaffinch Hospice Trust from 1987 when the building underwent an extension and the number of beds on the ward were increased and it was renamed 'The Chaffinch Hospice'.

Further changes in funding occurred in the early 1990's, when ownership moved to the Chaffinch District Hospital NHS Trust. There has been an increasing range of palliative care services developed since the late 1980's consisting of: the Hospice ward, the Community Palliative Care Team, the Hospital Palliative Care Team, the Social Work/Bereavement Service, Day Centre and the new Hospice at Home Service. The changes in ownership of the service from the community, in terms of monies raised through voluntary donations, to statutory ownership by the NHS reflects the increasing mainstreaming of palliative care services.

5.2.2 The Hospice

The hospice was situated in the hospital grounds beside a small car park and overlooked a garden with a pond and the local fields. Outside each bedroom window were bird feeders enabling people inside to watch the birds from their beds. The ground floor was open plan, built around a central courtyard. The 8-10 bedded ward, containing four single rooms and three double rooms, was on the far side of the courtyard. On the ground floor there was a small Day Centre, the ward Medical and Nursing Teams, the Occupational and Physiotherapy Team, the Volunteer Service, the Secretaries, a staff room, and an education room. Upstairs, across the entrance, housed the offices of the Social Work Team, the Hospital Palliative Care Team, the Community Palliative Care Team, and the Chaffinch Hospice Trust, including a second meeting room and staff room.

The main doors reflected the colour theme of the Palliative Care Service logo. The entrance was an important aspect of making the environment welcoming to people new to the service. On entering the building there was a corridor straight ahead and one to the right, with a reception desk where the two corridors joined. The reception desk was often the first point of contact for friends and relatives as they arrived and for bereaved relatives when they returned to pick up the death certificates, or returned with donations. There was a quiet room just beside the reception desk where people could go for privacy or if they were distressed.

The reception desk was also a favoured point at which members of staff congregated and 'chatted' during the different times of the day, as they signed in and out saying 'hello' and catching up on their way to doing something else. This might include going into the ward or day centre to talk with members of staff or people they usually visited at home or in the hospital. It was often the point at which those in the offices upstairs bumped into those downstairs.

'Chatting' and 'catching up' with one another was an important part of the everyday social and working relationships between all members of staff, regardless of position. It included catching up with one another on a personal level as well as sharing information about the people being cared for in the hospice, in the community or in the hospital, their families, current plans and future possibilities. 'Chatting' was often ah hoc and informal, although it was also sometimes in the form of conversation used during ward rounds and meetings, as will be discussed further in Chapter 6. It served an important function in passing on up-to-the minute information about people and their situations, whilst also providing a personalised touch and a level of support to working relationships.

The hospice was poorly signposted from the main hospital entrance and directions were required to locate it. The small signs that were visible referred to the 'hospice/palliative care unit', taking account of local knowledge of the hospice along with the less commonly understood professional terminology of palliative care.

5.2.2.1 The Ward Area-Public and Private Spaces

Because of the open plan layout, people would come from different directions, walk round the central square and congregate at the nurses' station, as they did at the reception desk. The nurses' station, which was a four-foot high fronted desk, only had seating for two people. Like the reception desk it was positioned where the corridors intersected. The nurses were aware of their open environment and their constant availability by not having an office, which meant families and friends of people being cared for or members of staff coming down from the main hospital would also come to the desk for information. It also provided a point for members of the multidisciplinary team to congregate and exchange information, 'chat' about work issues as well as catch up with one another on a social level, as well as making telephone calls or filling in paperwork. If the area was particularly busy the nurses would sometimes take their notes and sit in the day room to write when it was quiet.

The clinical room behind the nurses' station was often used for the more confidential conversations spoken in hushed tones, as only members of clinical staff were allowed to enter this room. The lack of private space required the nurses to find a free office or room to make confidential telephone calls or conversations. The other rooms on the ground floor included offices for the lead nurse, the secretaries, the senior sister and the doctors. There was a small cramped staff room, just off the ward, next to the door to the staff toilet. The education room was used for teaching and the weekly multidisciplinary and Tuesday afternoon meetings.

The bedrooms were situated along the corridors either side of the nurses' station, and the rooms usually had their doors open. Open doors worked in several ways. As staff passed they could look in and observe the person's condition or how the families were coping, and also the people in the rooms could see members of staff and other people passing by and hear the chatting and other everyday sounds. The doors were always closed when personal care was being undertaken, when the doctors were doing their ward round and talking with and assessing the person, or when the person or their family wanted some privacy. As observed on the 25th September 2001 and at other times, the doors were also closed after a person had died and their body was still in the room.

There were two small bathrooms adjoining three of the single bedrooms, with hoists, and a separate single shower room. However, on most days the two larger bathrooms, which had the variable height hydrotherapy baths, were mainly used as many people appreciated the opportunity to relax in the deeper warm water, as well as having their hair and bodies washed. A small kitchen contained equipment to store and make a variety of foods and drinks, for people who did not want to eat what was on the menu.

The hospice used its own cutlery and crockery rather than the hospital supplies to add to the homeliness. The volunteers made drinks, prepared the trays and took meals into people at lunch and supper times. The detailed presentation of this service was commented upon by YA and SS during their interviews, appreciating the little things that made a difference for them.

The volunteers took great pride in ensuring everything was not only presented nicely, but that the ward and locker areas were kept tidy and the flowers kept fresh. During an overheard conversation on the 16th October 2001 two of the volunteers were quite vocal about what they felt were slipping standards after one of the nurses had suggested using paper urine bottle covers as waste bags because there were no waste paper bags available to put on the lockers. This not only illustrated the pride the volunteers took in ensuring the ward environment was kept tidy and homely but highlighted the continuity of standards they provided.

The day room and garden room were used throughout the day and during the night when larger families stayed. The garden room had large windows overlooking the pond and garden and was a suntrap. The day room also opened onto the inner courtyard between the two corridors, and so natural daylight flowed in on both sides. For those who wanted to smoke, they could walk or be wheeled in their beds or in their chairs into the day room area, where the extractor fan would be turned on. This was not always ideal as the fan was noisy and some smell of smoke lingered. However, it was a compromise that was made in order to try and meet the individual needs of the people receiving care in the hospice.

The opposite side of the day room lead to a small visitors' room which was also used for outpatient consultations. The therapy room opposite was used as an office and treatment room by the occupational and physiotherapist, and also for aromatherapy massages and reflexology.

During the period of the fieldwork the day centre was completely refurbished and modernised giving warmth and brightness to the areas where people gathered. The room was used for socialising, and for artwork, creative writing and relaxation classes.

5.2.2.2 The Public and Private Spaces Upstairs

The first floor housed four small offices for the two Chaffinch Hospice Trust (CHT) Administrators, the two part time Social Workers, the five Community Palliative Care Team (CPCT) nurses, the two Hospital Palliative Care Team (HPCT) nurses and the two consultants. All of the office doors tended to be kept open and when the offices were full during the mornings it was quite noisy, as people talked on the telephones or to each other. Conversely it was also very quiet when the various team members were out. This appeared to reflect the open culture of the service in terms of access to one another, in that closed doors were rare unless something very private and confidential was being discussed. But it also revealed the lack of space available.

5.3 The Socio-Political Context

5.3.1 Funding and Management Accountabilities

Chaffinch Specialist Palliative Care Services had a complex funding arrangement and there was a blurring of the boundaries between the NHS and charitable status in the minds of most people. The Palliative Care Service had a very strong local appeal and identity. Most people identified the service as 'The Hospice', since this was the term the Charitable Trust used in its fundraising literature and at the fund raising events. This was perpetuated locally by the involvement of volunteers who talked about working at 'The Hospice'. The title 'Chaffinch Specialist Palliative Care Services' was referred to only on official NHS paperwork and on the front of the information booklets.

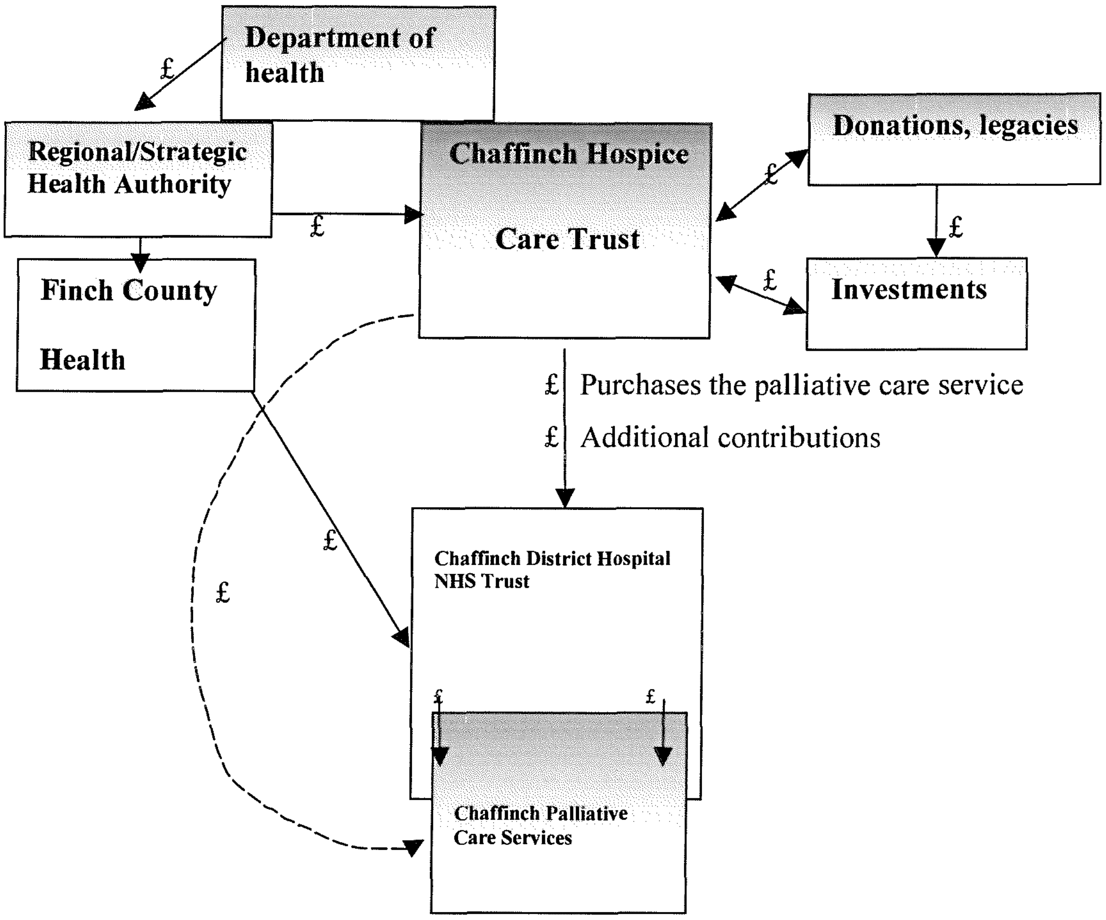
Chaffinch Hospice Trust purchased the Palliative Care Services from Chaffinch District General Hospital NHS Trust and the services and staff were purchased by the Charitable Hospice Care Trust from the NHS who paid their salaries. The Palliative Care Services' building and hospice were owned by the NHS, after having been donated by the Chaffinch Hospice Care Trust, and any changes that the Palliative

Care Service wished to make to its building and any routine decorating had to go through the NHS Trust. Funding, however, for the proposed changes to the service or building came from the allocated NHS budgetary allowance for the service and from the Chaffinch Hospice Care Trust.

The Chaffinch Hospice Trust raised funds from the local community and local businesses; it was also funded directly by the Regional Health Authority (RHA), which was to become the Strategic Health Authority. The remaining NHS money allocated by the RHA was paid directly into District General Hospital funding. On paper, the Charitable Trust provided approximately 50% of funding for the services with the other 50% contributed from the government, through NHS and direct RHA monies. However, it was calculated by the Palliative Care Services that the charitable trust topped this up by another 10% of funding through purchasing the 'additional essential extras', such as funding petrol for volunteer drivers, additional food items such as refreshments, sorbets, ice creams and soups, staff education and extra building and material refurbishment. This complex arrangement provides a sense of ownership by the local community, the NHS Trust and the RHA and Primary Care Trust. WB, the accountant to the Hospice Trust, explained the intricacies of the funding and went through the Report of the Financial Accounts for 2001.

Development of the service, such as the new Hospice At Home Service, was discussed and negotiated with all stakeholders, including the Area Health Authority in terms of current and future funding and the position of the service in relation to other agencies and the Primary Care Trust. This was illustrated by preparing for the development and trial of the Hospice At Home Service. The process of discussion was observed at the Trustees Meeting of the 6th February 2002 and was explored further in conversation with KL on the 5th March 2002.

Funding and purchasing map:



(£ = money)

5.3.2 NHS and Chaffinch Hospice Trust Accountabilities

The Lead Nurse and Medical Director were accountable to two separate management bodies, the Managers of the Medical Directorate of the Hospital and to members of the Charitable Trust Committee. Both the Medical Director and Lead Nurse worked closely with their hospital counterparts implementing NHS directives. However, they were able to independently run and manage the Palliative Care Services because of their separate identity and complex funding arrangements. They had to seek authorisation for any major structural changes in terms of internal reorganisation or external structural changes, such as the planned building work to extend the office space available from the NHS Trust.

Each attended the quarterly financial meetings with both the NHS Accountant and the Finance Committee of the Charitable Trust, where they gave account of their budgets and made requests for additional income. During the time of the research, the service was being requested to make savings of 1% from its NHS budget by the Finance Manager. Because of the 50% funding divide, this meant a cut of 0.5%, which was heavily negotiated at an observed NHS Finance Meeting on the 22nd March 2002 between KL, EG and the NHS Finance Manager, and then discussed at a subsequent Charitable Trust Finance Meeting.

The Medical Director attended meetings outside of the Hospital with the Primary Care Trust, and any changes to the service were negotiated with their Primary Care and Regional Health Authority colleagues, as well as with the NHS Trust. The Medical Director also represented the service at other local networks, as did the Lead Nurse, and they shared the responsibilities for attending external meetings, and both acknowledged that, in certain circumstances, the role of Medical Director carried more power and weight in negotiations on behalf of the service. Both attended the Cancer Services Meetings within the Trust, and occasionally IS would deputise for KL, as he did at the observed Cancer Services Meeting on the 20th March 2002.

All members of staff were on NHS contracts, including the two part time Social Workers, giving them access to the NHS Pension Scheme, Occupational Health Service and Personnel Department. The service, therefore, did not have to provide this layer of personnel, management and staff services, thus freeing it up to concentrate on providing care and managing day to day personnel issues. Although this offered certain freedoms it did also come with certain obligations, such as taking student nurses on placement during their training, which meant not all staff could be hand picked.

5.3.3 Increasing Standardisation and Regulation: The Political Context Within The NHS Affecting The Services

During the early period of fieldwork the Lead Nurse, Medical Director and colleagues from the Hospital Cancer Services undertook a Cancer Services Quality Assurance Assessment visit (CSQA) in October 2001 in which the standards were discussed for both cancer services and palliative care services with representatives from each department involved. Documents had previously been collated and submitted to the Assessment Board, and during the meeting these were referred to and the different representatives from the services had to respond to the questions being asked of them.

The CSQA visit reported that the Palliative Care Service had met the majority of the standards and had excellent links with primary and secondary care services including good 24 hour support, good bereavement support and detailed audit records of the service. The assessors' concerns were with the cancer network strategy document that had been submitted and the need for the palliative care drug formulary to be confirmed as acceptable by the hospital pharmacy, although it had been designed and used in palliative care services across the region and updated.

The importance of this was in the requirement of the services to meet the predefined structural criteria. Having observed three different cancer site specific multidisciplinary meetings, which were attended by the Palliative Care Consultants and members of the Hospital Palliative Care Team, there was an obvious difference in style and engagement in the process by the members of the different meetings. The Gastrointestinal Multidisciplinary Team Meeting (GIMDT) engaged a wide range of different disciplines, from the Pathologist, Consultants, Nurses and Palliative Care Team, although they largely appeared to work in a collegial manner. The second site specific meeting with the Respiratory Consultant appeared to play lip service to the notion of multidisciplinary meetings and engagement. The third, although also small, consisted of the Oncologist, Hospital Palliative Care Team and the Gynaecologist and was less formal than the previous two, but the inter team engagement and open discussion was on a respectful level footing with open discussion about people under the care of the different teams and a clear valuing of the expertise of the other.

This was followed-up, in January 2002, by the Commission for Health Improvements' (CHI) Assessment of Chaffinch District Hospital NHS Trust. The CHI team chose not to assess the palliative care services that day, but the Lead Nurse and the Medical Director were involved in attending ongoing meetings held by the Clinical Effectiveness Department to improve the effectiveness of services and to implement clinical governance.

During the previous year they had undergone an accreditation assessment for specialist palliative care services by the Regional Health Authority for cancer services in which a different set of standards were required to be met. Although commended for its excellent seamless service, it provided what was revealed as an intense period of surveillance, assessment and standardisation at a level previously not experienced by palliative care services. Similar to the concept of care as both vigil and gift by Fox (1995), the standardisation process was both organisationally a disciplinary process and a gift. Recommendations to increase day care services were being implemented and the recommendations to increase the medical input supported a bid for additional funding for a new specialist palliative medicine registrar training position.

There was a relentless need to respond to ongoing implementation required of the Modernising Agenda and the introduction of The Cancer Plan (DoH 2000) and 'Shifting the Balance of Power' (DoH 2001). The Lead Nurse held a joint Lead Nurse/Cancer Nurse post with the Senior Cancer Nurse. Both took responsibility for their specialities in implementing the changes and attending the cancer networks. The

Medical Director was also involved in meetings and negotiations with the Primary Care Trusts (PCT's), responsible for assessing needs, planning and purchasing health services from their community base and the new Strategic Health Authority in terms of it strategic planning of palliative care services and delivery agreements with the PCT in relation to the new monies available for cancer and palliative care services by the government. Throughout all of this, recommendations of the National Council for Hospice and Specialist Palliative Care Services were also being responded to.

This revealed the need for open, trusting and close working leadership, a continual responsiveness and political astuteness by the Palliative Care Service to Government led initiatives. The standardisation agenda, driven by national minimum standards of service delivery was enforced through regulation. However, there were opportunities to be seized to shape the future. Both Lead Nurse and Medical Director engaged with the processes whilst maintaining the running of the Palliative Care Services and sustaining their own organisational philosophy in the face of ongoing changes. Despite this workload, they maintained a clinical 'hands on' presence, attending ward meetings, supporting staff and working with the other areas of the service to ensure that staff were involved in the changes and the service continued to respond to the needs of the local population.

As EG, the Lead Nurse explained:

> *'I think I sometimes feel like a puppet of the government, um, and that sort of frustrates me sometimes. I think, sort of leading on to that, and sort of again answering the question about how things have changed or whatever, is the good news is palliative care has a huge profile now nationally, regionally, locally, when you think, and I think how I used to have to chip away on the wards. You still chip away. You should never be complacent but its so accepted now and, you know, from having gone sort of 'please use us, we're here' its now sort of 'whoa, hold on', um, you know there is the aspect of us jumping through the hoops um, you know, sort of, and trying to make them relevant to us without losing the roots of the philosophy'(EG Interview April 2002).*

5.4 Shared Leadership and Management of the Services

The leadership of the service was shared between the Medical Director, KL, who was designated as Head of Service and the Lead Nurse, EG. Although this appeared from the outside to present a typical hierarchy, this was not the case and leadership and management were collaborative, divided by the different roles and the different skills and abilities of both people. It was clear when observing the day to day running and management of the staff during the fieldwork that EG managed all members of the team. She was also the key provider of information about changes in hospital policy, implementation of Department of Health requirements and on assessment visits by regulatory bodies. EG led the weekly multidisciplinary meeting and facilitated the contributions from all multidisciplinary members, including the Consultants.

WB, the Finance Manager, in his interview spoke of EG being the key manager of the budget, having budgetary control of the service. This reinforced a comment made when meeting with EG before commencing the research and in a meeting on the 29th August 2001 when both she and RU, the Senior Sister, commented on organisation not being one of KL's skills as she was so busy balancing other demands of her role with her part time hours. This was confirmed during the observations.

KL independently identified this during her interview :

> *'...as regular on going management and budgetary control of this service I wouldn't ever pretend that it's me that does that, its really EG and I hope I give her some support but I wouldn't pretend to be the key player in that, but I hope we have a good relationship whereby we can chew things over...I don't necessarily want to be the leader of the team because often I shouldn't be. I think often its a majority nursing team and so in many respects often EG should be the lead or CS if it's the community team. Umm I don't have a need to be, I hope we have a flat hierarchy, I hope we have the leader there to make the decisions and take forward when it has to be' (KL Medical Director: April 2002)*

KL was clear in her interview that management was not the favourite area of her role or necessarily her strength, putting troubleshooting, working with patients' complex needs and supporting staff and colleagues, both in palliative care and in the hospital and community services, higher on the list of what her role entailed.

EG saw herself as having multiple aspects to her role and saw her work in terms of leadership, having an advisory and developmental role as she valued developing the service and members of staff working within it alongside integrating and developing the requirements of the Cancer Plan and searching for opportunities for palliative care that could be grasped along with the everyday running of the service

> *... it gives us the opportunity to think 'okay', how can we make this work for us in palliative care rather than just being dictated to by political policy, you know, and, um, and that sort of thing. Um, but another part of me finds the role very difficult and I think perhaps personally, I find sort of, strategic managerial hard work, more challenging (EG interview April 2002)*

What both leaders shared was a focus on and the valuing of their clinical skills, knowledge and experience and using these in ways which would ensure that the complex needs of people needing care were met, and that staff within and outside of the service were supported and developed. Both valued talking with people as EG states:

> *'I will not just use the e-mail because I think actual contact, verbal or visual, is so important. I might go out, sometimes I have a list of people that I want to collar or see, and I'll go out and lurk in the corridor and catch up with them. Corridor networking, meetings, cannot be under estimated or over estimated. Umm, most of the most useful work I've got done has been in corridors' (EG interview)*

Yet both had an ambiguous relationship with strategic management and constantly had to engage with new Department of Health directives and change.

5.4.1 Managing Internal Politics

When and wherever problems arose, the leaders were quick to open up a dialogue with colleagues who were concerned about an aspect of the service or an aspect of how the care of a person could have been better handled. Internal disputes between the different areas of the service were managed by creating an open or closed forum in which to solve the problems at the heart of the dispute. The Discharge Committee was set up to ensure discharges home went more smoothly and were better informed, after several discharges home from the Hospice had not, according to the Community Team, been planned and properly assessed beforehand. From December 2001 until April 2002 meetings were held to resolve and improve communication between the hospice ward and the community team. New documentation was developed, responsibilities highlighted and operationalised.

The introduction of unplanned changes into the working practice had unexpected outcomes across the service. An example of this was the introduction of the student counsellor to the ward and the day centre during November 2001. The student counsellor arrived through an informal invitation rather than as a service led initiative. The counsellor was welcomed with open arms by the ward staff, some of whom had said in conversation that they felt they needed a counsellor as they did not have the skills or time. They quickly made referrals to her on behalf of some of the people being cared for. This caused consternation initially with the social workers who casually bumped into her in the coffee room during February 2002. During a conversation on the 25th February 2002 the social workers spoke about how this caused them some concerns in terms of how they were being perceived by the ward and whether the student was being supervised. They also spoke about their concerns about the implications this had for the ongoing care of people and their families. During a conversation in April 2002, the social workers explained they had taken their concerns to EG, who chose to talk with all of the people involved.

For the medical director this also raised concerns about the overall picture and strategy of the service and the lack of broader thinking by the initiator of the invitation.

> *'I think an important part is to be aware of each other and that we are all part of one big service and I think that shouldn't be underestimated, I think we are so fortunate here among our strengths is we are under one roof, but I think we could easily loose it…its not to say that we shouldn't necessarily have a counsellor but I don't think they have liaised with the social workers who pursue their counselling role, with the psychologist and with staff who have an element of counselling and I hope I can be open minded enough and say 'we need to look at counselling', and may be we need to look again but what I really feel is that as my role as head of service is actually to put the brakes a little bit on people and say 'excuse me can we look at this across the service', because what has always been the problem is one branch of the service wants to do something and they don't realise the knock on effects across, and because the OK centre went and got the counsellor in suddenly its infiltrating elsewhere and actually could potentially cause some upset, and that's how you divide a service…I just want everyone to examine it and look at the strengths and weaknesses and then reach a consensus and reach parameters what we like' (KL interview: Medical Director April 2002)*

This supported the notion of a leadership that valued dialogue as a means to managing disputes and finding solutions. It also highlighted the organic nature of the separate processes occurring within the different areas of the service, which had the potential to have a large or small effect on peoples' experiences of care and the work carried out by members of staff. This episode also revealed the important role of EG and KL in keeping an overview of the service as a whole and the difficulties they experienced in not always being aware of the perceived needs of staff. Both tried to maintain an open door policy and were open to talking with any person working in the service, but they were both busy and this was not always possible each day. This openness to offering time to talk was reflected in how this was valued in the care provided to people and their families on the ward, at home and in the hospital. Each year an open meeting was held to discuss the service and future plans at which all were welcomed, to voice their concerns and opinions.

5.4.2 Devolved Leadership

Leadership was also devolved to the team leader of the Hospital and Community Palliative Care Teams, CS, and to the Senior Sister, RU, responsible for the Hospice ward and Day Care Services. Devolving responsibilities was part of EG's focus on developing team members by giving them a different dimension to their role. She saw this also as a way in which some of the emotional burden of the work was dissipated. The ward had two Junior Sisters leading and managing the two nursing teams, and one Junior Sister running the Day Centre, which ensured direct practical and clinical leadership. The social work team and the therapy team managed themselves on a daily basis, but had EG as their line manager. For the social work and therapy teams this was not always ideal as they occasionally felt isolated within the larger nursing team. During interviews in March 2002 and in ongoing conversations with ME and both Social Workers, both teams felt EG was generally fair when listening to and handling their concerns when they arose. However, in terms of supervision both teams preferred to have this from a facilitator away from the service.

5.5 The Values and Philosophy of the Organisation, Leaders and Staff

5.5.1 Organisational Values and Philosophy

The organisational philosophy and values held by the Palliative Care Service were presented to users through publicly available information booklets. The literature explained the services offered and was important in clarifying the type of care provided, and whom the care was for. These were found on the information stand in the entrance and included 'A welcome booklet' for anyone accessing the services.

The welcome booklet was written in a friendly down to earth and inclusive style. The language used in the introductory text and in the description of the hospice as a concept of care, its philosophy of care and its aims, introduced the service as person focused and family centred. How this was reflected in the experience and phenomenon of care provided in the different locations was established through interviewing people about their personal experiences and from the analysis of the observations.

The front page of the booklet introduced the service as caring and thoughtful, indirectly but inclusively acknowledging the different reasons for people's involvement with palliative care whilst wishing for them to 'feel at home':

> *'Whether you are with us for a doctor's visit or as a day patient – or for a longer period or as a visitor, we hope you and your family will feel at home here…Palliative care means continuing involvement and appropriate support for patients and their families who face the effects of any life threatening condition. The word hospice not only describes a building but more importantly describes a whole concept of caring that recognises the particular needs of patients and families/carers at this difficult time.*
>
> *We aim to enable each individual*
>
> - *To improve quality of life by control of troublesome symptoms*
> - *To help maintain independence and dignity*
> - *To give opportunities if desired for talking through feelings aroused by the illness'* *(Welcome booklet)*

This provided an important public message about the philosophy of the service. It reveals a service that publicly values care, that is individualised, inclusive and facilitative. A shared focus between symptom control, independence, dignity and listening to concerns of the person being cared for and their family or carer's values, a personalised approach to care in which the physical as well as the emotional aspects of care were integral.

The booklet for health professionals provided the definitions of palliative care, specialist palliative care, and the palliative care approach alongside a service description, which appeared to have an educative purpose. The different definitions provided an insight into what specialist palliative care needs were considered to involve, compared to general palliative care needs which were seen as the remit of all health professionals. The description of palliative care clearly positioned the service in terms of providing care for people with life threatening diseases other than cancer:

> *'PALLIATIVE CARE APPLIES TO PATIENTS WITH LIFE-THREATENING DISEASES OF ALL TYPE, NOT SOLEY TO CANCER PATIENTS'* [uppercase theirs]

> *'It is important to remember that not all patients requiring palliative care intervention will progress rapidly to death. Thus the numbers referred will be higher than the number dying. Those patients who have had their symptoms and distress relieved may be discharged from the service and re-referred at a later date when problems reoccur, with the primary health care team providing interim follow up' ('A guide for all health care professionals to the Chaffinch specialist palliative care services')*

Although the majority of the people admitted to the care of the teams within the service had cancer, a small number of people were referred or admitted each year suffering from a range of other life threatening illnesses. This openness to caring for people with conditions other than cancer was not found in neighbouring services, and posed a problem for the Hospital Palliative Care Team or Hospice Ward Team when transferring people out of the catchment area where there was little palliative care available. There were frustrated discussions in the Community and Hospital Palliative Care Teams' offices on 4th March 2002 about cases of people requesting care from outside of the area.

Valuing palliative care irrespective of disease type, or disease stage, enabled the service to be involved in the care of people on a needs basis rather than disease basis. This supported the concept of individualised or person centred care. The text clarified that people could be discharged from the service when their symptom control problems or emotional and family needs no longer required specialist input. This placed palliative care firmly as part of the ongoing process of illness, becoming more or less involved as a person's or family's needs increased or decreased, and was not just as a focus of care at the end of life. The inclusion of a focus on quality of life, dignity and listening to feelings, of the person and their family also suggested a concept of care which drew upon the experiential, relational and biomedical aspects of care. The lack of rigid criteria suggested a flexibility in defining needs.

The service definition publicly valued multidisciplinary working, collaboration, communication and education.

> *'Chaffinch hospice provides a base for a full range of specialist palliative care services and serves the whole catchment area of Chaffinch health care NHS Trust. There are key relationships between the primary health care setting and Chaffinch District hospital which foster collaborative care and communications. This includes multiprofessional case and peer review. A variety of education opportunities are also provided by the service on a uni and multidisciplinary basis'('A guide for all health care professionals to the Chaffinch specialist palliative care services')*

The degree to which this public positioning of service values and philosophy would be reflected in the day to day workings of the service could only be revealed by the fieldwork and ongoing analysis. The multidisciplinary work valued by the service was extended to working both within the palliative care services and out with the primary care and social service teams and the general hospital teams. This contributed to the developing picture of a multifaceted concept of care, which valued collaboration and dialogue as its central features across the different boundaries of care.

The concept of personalised or individualised care to those being cared for is reflected in the information for professionals offering to undertake reviews for teams to talk through difficult cases once again highlighted talking and listening as one key component of care for colleagues as well as those who are ill. The inclusiveness open to families is mirrored in the offer of education or case reviews for multiprofessional and uniprofessional teams.

Public documentation about the service, such as the information booklets contained both the logo of the NHS Trust and of the Chaffinch Hospice Care Trust, highlighted the position of the palliative care services as sponsored by both organisations. This combination was important in that the purchaser of the palliative care services, the Chaffinch Hospice Trust, also had a written constitution, policies and objectives which they aimed to achieve through the monies provided to the services. In the public 'Report and Financial Accounts March 2001' it is clearly stated that the Trust :

> *'aims to secure the highest possible standards of care to meet the physical, emotional, social and spiritual needs of our patients and ongoing support for their families and other carers both during their illness and beyond. Our care is about LIVING with cancer and other potentially terminal illness'* [capitals theirs].

The spending powers of the trustees and the decision making undertaken within the Financial Review Meetings were important in setting a budget thus raising the question of whether the level of funding of the service affected the care provided. If the Hospice Trust had a set of objectives that required 'the highest possible standards' from the services it purchased, how much would they be prepared to pay above the statutory NHS monies to achieve this? Would providing additional monies to top up that from the NHS be the only aspect that would make the difference to the care? This is debatable but may, in part, be the reason that high standards and an open and inclusive philosophy of palliative care could be aimed for, ensuring enough staff were available to be able to listen and talk through peoples' feelings. In a health service that values efficiency and effectiveness, this was an objective that could not be easily measured or an evidence base relied upon.

How the leaders of the palliative care services balanced their responsibilities to the NHS and Hospice Care Trust in ensuring that NHS and Hospice Care Trust requirements and objectives were met are important considerations. However, before discussing this, the role of personal values on providing care must be considered.

5.5.2 Personal, Professional and Working Values Informing Practice

Values held by members of the multidisciplinary team were influential in informing, care-giving and decision making. Working practices were informed by a combination of personal, working, organisational and professional values, which appeared to have a dynamic interrelationship. Personal values were informed by culture, experience and expectations and could be seen to influence the everyday working values of staff. A thematic analysis of the interviews undertaken with members of staff throughout the multidisciplinary team revealed a relationship between what was valued at a personal level and the values they expressed during interview and from the observations of care interactions in caring for others.

As table 1. shows, there were overlaps in what the staff valued for themselves, receiving care and what they valued in the care they gave. Personal values and preferences were informing the priorities and perceptions in the care offered to those in need of it. The working values expressed by the staff verbally and in their actions appeared to be a fusion predominantly of personal and organisational values.

Working values were the everyday values drawn upon and used by staff in the different areas of the service. Yet they were similar throughout the different teams and locations in which care occurred. In part this was due to the influence of the organisational values drawn from the service philosophy and the values the leaders, EG and KL, expressed during their interviews and observed in their practice.

Table 1. Values Informing Care Within Chaffinch Palliative Care Services

Personal values: What made staff feel cared for on a personal level	Working Values: what staff valued as important in caring for people using the services
Being known	Enabling /empowering others
Being listened to	Feeling one has given good care/doing ones best
Being loved	Giving something of oneself
Being supported	High standards
Being valued	Holistic care
Feeling cared for	Individual and family focus
Having someone to talk to	Knowing – the person/family
Little things personal to you	Listening and talking
Relationships	Relationships
Time and attention	Self determination
	Supporting others
	Symptom control
	Time – Making, giving, pace
	Teamwork
	Working with families
	Valuing others
Organisational values: what the organisation states it values in providing care	Professional Values: Expressed in professional guidance (BASW GMC UKCC.)
Collaboration across services	Collaboration and teamwork
Communication	Communication
Competence	Competence
Dignity	Confidentiality
Highest standards	Dignity
Holistic care	Education
Independence	Equity
Individual and family focus	Individual
Listening	Integrity
Multidisciplinary teamwork	Knowledge
Quality of life	Personal worth
Relationships	Respect
Self determination	Self awareness
Support	Self determination
Symptom control	
Valuing others	

The working values of the members of staff from different professional disciplines were also informed by the professional values enshrined in particular codes of practice for each discipline. There were similarities between the values supported by these codes of practice, although only the BASW Social Work Code of Practice valued family involvement as well as valuing the individual, and clearly discussed values as a component of practice (BASW 1996, GMC 2001, UKCC 1992)

The care provided by individual members of staff and by the service as a whole was informed by a dynamic relationship between personal values, organisational values and professional values, which appeared to be expressed practically in the everyday working values of the staff. The working values appeared to be the synthesis between personal and meta level values. Therefore, part of the construction and conceptualisation of the care provided was developed out of this dynamic and expressed through face to face interactions with colleagues and the people being cared for.

5.6 Multidisciplinary Teamwork

All teams within the service worked closely with one another within the same organisational philosophy. Although the hospital and community teams often worked independently of the other teams they also worked interdependently to ensure an holistic approach to care and a seamless transition of people being cared for between the different locations. The ward, community and the hospital palliative care teams shared the same Consultants, worked with the same Social Workers and the Ward Team and the Community Team worked closely with both the Physiotherapist and Occupational Therapists. This provided a centralised notion of the service as a whole with the different parts of the service leading out like threads from a central point which were then linked together, much like a spiders web, but in a more three dimensional way. Innovation or change in one area of the service had an affect on the other services, which led at times to inter-team tensions and creative resolutions.

Within the service the culture of openness and collaborative working was supported by the central working philosophy, which valued each person in their own right whether a member of staff or a person being cared for. Effort was made to get to know both new colleagues and to get to know those being caring for. This was seen when the staff members were chatting with each other about general and specific enquiries, about one another's families as well as of the people being cared for, no matter what role that person had in the service.

The multidisciplinary team members held open dialogues and worked together discussing options and possibilities for people's care, without traditional hierarchical boundaries interfering in the process. There was an emphasis on sharing knowledge and learning from others. The service had a large collective memory, which was drawn together from all of the experiences and recollections of the teams. It was dipped into or revisited on different and varied occasions and served as a well of reflective information and shared experiences which could be drawn upon for difficult or rare situations and complex problem solving for current situations.

The emphasis that was placed on exchanging information and negotiation, ensured close working with Hospital Consultants and Ward Nursing Teams as well as General Practitioners and District Nurses. The Community and Hospital Palliative Care Teams, were integral participants in multidisciplinary teams outside of the Hospice. Therefore, there was a complex matrix of inter and intra team positions, perspectives and knowledges. The Community Team Nurses would drop into the Health Centres and General Practices that they worked with to maintain a face-to-face contact with both the GPs and the District Nurses. There was a well established weekly meeting of the Community Palliative Care Team with the Hospital Oncologists, which provided an opportunity for both teams to exchange information about people at home and those in hospital receiving treatment, keeping both up to date with events, facilitating a degree of awareness about the person's coping and response to treatment and the shared thinking about future plans. The Hospital Team attended and there were members of three Cancer Site Specific Multidisciplinary Meetings within the Hospital each week.

The advisory role of the palliative care service relied on good working relationships and the Hospital and Community Teams fostered collaboration through working together rather than working in isolation from one another with the teams in the hospital and community. The attendance of meetings revealed an openness to share and participate in the cultures of the hospital and community. One form of collaboration in the community was seen in the sharing of the care of people at home. They were visited on alternate weeks by the District Nurse and the Community Palliative Care Team Nurse and during the care of a person dying at home there was close working between the Palliative Care Teams, the District Nurse and the General Practitioner, so that the aims of the person being cared for could be achieved.

5.7 A Socially Focused Culture

The collaborative working practices in the different areas and across the sites were mediated by the inherent social based interactions, sociable chatting and the valuing of the voices of those contributing. It transgressed hierarchy positioning each person as equal social beings as well as being an informer and receiver of information and knowledge within the team. Social dialogue appeared the mediator of care, which attempted to normalise interactions between the professional carers and those being cared for, taking the focus away from their health needs to the world around them and the everyday aspects of life and family. Most people chatted and when they were not able to engage verbally the manner was still adopted as the nurses chatted to the person about what was happening on the ward, with their families and in the news. It was part of reducing the professional barriers and building relationships, guided by a humanistic psycho-social framework rather than a professional-technical framework.

The friendly informal culture of the service was also revealed by the sending of signed cards from as many people as possible in the service celebrating each member's birthday over the year and other events such as childbirth. When people left there was always a sociable event, a night out, a collection and presentation of thoughtful and very personalised gifts and a card. Even as a researcher this custom and personalisation was offered to me. Care and support was extended to staff on sick leave or experiencing personal bereavements, cards and gifts were sent. With members of the team closest to the person visiting to offer support, and keeping colleagues updated.

The majority of the staff working across the Palliative Care Services were part time apart from the Lead Nurse, Team Leader for the Community and Hospital teams and the Senior Sister for the Hospice and several staff nurses. One Doctor was also a part time GP and one Consultant worked part time in a neighbouring Palliative Care Service. Much effort was put in to ensure the services were covered on a daily basis, but occasionally this was not possible.

5.8 Summary

In setting the context for the care provided by Chaffinch Specialist Palliative Care Services, the history and present day context are important in considering how the service has been shaped over time. The move into the NHS has seen the implementation of Government policies, which has increased regulation and standardisation of care to an extent never seen in palliative care before. It has increased the focus by service leaders in trying to manage the demands placed upon them in responding to what appears to be a relentless bureaucratic demand.

However, the shared funding of the service appeared to provide the opportunity to resist some of the financial burdens associated with being in the NHS. The service had a degree of independence and was able to provide an aesthetically pleasing environment through the use of voluntary donations to develop the service and the building. Volunteers provide additional support for maintaining the aesthetics. This appears to enable the philosophy and values of the service to remain person focused, with an emphasis on holistic care. A synthesis of organisational, professional and personal values shaped the culture of the service and the way care was understood. A culture of sociable collaboration and dialogue, gave the opportunity for all voices to be offered the space to be heard. Everyday social interactions were at the core of developing relationships with colleagues and with the people being cared for. There was recognition that everyone was a social individual in a network of social relationships so often the focus of conversations was inclusive of the everyday life world of each person. However, it is important to consider how the culture and context of the service shapes the organisation of care.

Chapter 6: The Organisation of Care

6.1 Introduction

The culture and socio-political context of a service shapes how it provides care. This is, in turn, informed by the values and guiding philosophies of the service and the professional and personal values of those within the service. However, how the care is experienced will be shaped by how the care is organised along with the expectations of the people being looked after. Care is revealed through the physical actions and inter-relationships between the person or family being cared for and the health professional. Care and caring actions are also influenced by different non-clinical structures of an organisation. For Chaffinch Palliative Care Services the clinical face-to-face interactions and the organisation of the service were essential components in enabling and facilitating the care across the hospice, the community and in the hospital. There were several organisational structures, especially regular and informal meetings, across the different areas of the service which contributed to and facilitated the caring processes and the experiences of care by the people being cared for. This chapter will, therefore, discuss both the formal and informal organisational structures influencing care, leadership, teamwork and importantly the role of exchanging information within and outside of meetings.

6.2 Non-Clinical Organisation of Care

6.2.1 Management and Accountability Structures

The non-clinical organisation of care is by the management and accountability structures within the services that provide the framework within which care is provided. The structures are essential components for guiding and protecting decision making and future planning.

6.2.1.1 The Trustees Committee: Management by Consensus

The care offered by the service was directly and indirectly affected by the decisions made at the meetings of a series of committees designed to ensure collective responsibility and accountability in the financial management and future planning of the service. The service was guided by decisions undertaken and agreed upon by the Trustees Management Committee, the Sub Committees for Finance, hospice arts and fundraising. The influence of the NHS on the organisation of care was made visible through the adherence to procedural guidelines and standards. The Hospice Trustees Management Committee, of which KL and EG were members, was a democratic decision making body upon which trustees from the Hospital, The Primary Care Trust and local community discussed and planned the future of the services, managed the finances, projects and problems. From observing a meeting on the 6th February 2002, in which financial projects were discussed, the Hospice Trust appeared extremely influential in ensuring the palliative care services received adequate funding to finance the staff education and new initiatives, such as The Hospice At Home Service. The Chaffinch Hospice Trust sanctioned the release of extra monies to the service above that which it paid to the NHS in purchasing the service. The Trustees Management Committee also provided the forum in where problems affecting the service could be discussed and ways of managing such situations could be discovered.

The Trustees included two Consultants and a Nurse Consultant from the main hospital, and a GP from the community. They had the capacity to influence how palliative care was perceived and positioned within both locations and their involvement ensured appropriate referral of the people they were caring for when required. This was certainly observed in the case of the Consultant who also attended the weekly Oncology/Gynaecology Multidisciplinary Meeting with the Hospital Palliative Care Team. The GP also shared the care of several people at home with one of the Nurses from the Community Team.

The shared management by the Hospice Trustees added to the perception of shared ownership between the Palliative Care Service, the hospital and community, ensuring current and future developments were negotiated and discussed with stakeholders before they were implemented. This assisted the reputation of the service as well as the experience of seamlessness between the locations of care.

6.2.1.2 Finance Committee

The shared approach to financing the service by the NHS Trust and the Hospice Trust enabled the negotiation of higher numbers of nurses caring for the people on the ward compared to the main hospital wards. The construction of the budget as observed at the quarterly meeting held on the 25th January 2002 valued the employment of experienced nursing staff within the hospital and community teams, as well as on the hospice ward. The regular meetings with the NHS Trust Finance Managers and the quarterly Hospice Trust Finance Committee facilitated the negotiation of the service needs between both Trusts. The Hospice Trust monies enabled access to additional funding for staff education, and added extras, such as additional and alternative food for those being cared for, petrol for volunteer drivers to bring people in to the day centre or to bring frail relatives to visit the person being cared for, which was not available from the NHS budget. The additional funding for staff education and conference attendance was debated and discussed by EG at the Finance Meetings with the committee members. Consensus decisions were made in terms of the benefits the higher education course, study day or conference attendance for staff would bring to the level and quality of the care and knowledge within the service.

The additional finances and the democratic process of the committee enabled both KL and EG to focus on meeting needs within the service and the care provided by both clinical and non-clinical staff. The extra resources provided by the Hospice Trust above the basic NHS funding did make a difference to the aesthetics and increased numbers of nurses on the wards and the number taking educational courses, but as to whether this is entirely what makes the difference to care provided is questionable.

6.2.1.3 Hospice Arts Committee

The use of the arts as an integral component of care within the Hospice revealed a philosophy that valued working with the wider essence and inner world of individuals. The aim of enabling each person involved with the creative work was to explore their experiences and discover new or old interests. The Arts Committee, part of the Chaffinch Hospital Millennium Arts Project, met quarterly in the Hospice. The members included the Senior Ward Sister, a member of the Hospice Trust and the Arts Programme Director. They met to plan and discuss the incorporation of art work within the Hospice, and the purchasing of creative therapies which included sessions with a creative writer, a music therapist, an art therapist and the local theatre company, who undertook reminiscence work, and the creation of poems, prose and plays. There was also a visiting clown, who came into the day centre and onto the ward and played and spoke with anyone open to his approach.

The focus of the Arts Committee was to facilitate care from a creative, expressive, emotional and non-verbal level, as a complement to the physical and clinically focused care on the ward. Plays and poems were created, written jointly by the people in the day centre with the actors of the theatre company. These were read and reproduced and enacted publicly using the words and experiences of the people attending the day centre, valuing the personal contributions of those who contributed, revealing the profound, painful and also the fun aspects of the life journeys people had reflected upon. It also provided an opportunity for people to pass their stories and experiences onto their families. The pictures hanging in the corridors and in all of the rooms were chosen carefully by the Committee. Contributions and donations were considered on merit and visual appeal by the members.

The Arts Committee and the Hospice Trustees were important democratic decision taking bodies and were drawn upon by EG when the donation of a very expensive gift caused some controversy. During January 2002 both Committees discussed the merits and potential diplomatic approaches in resolving the issues with the group that had donated the gift. At the meeting of the 28th January 2002 the Trustees took the final decision after weighing up the diplomatic problems caused in relation to future fundraising, goodwill in the community and ongoing maintenance costs to the Hospice. A letter was presented to the Committee for approval, which diplomatically explained to the donors that the significant amount of money spent on the gift would be more welcome in cash terms to pay directly for care and the running of the service. Decision by consensus and by Committee shared the responsibility between the Trustees rather than it being held by one person.

The role and incorporation of the Finance and Art Committees in expending and supporting the different manners in which care was offered underpinned the working palliative care philosophy that valued care from a holistic person centred perspective in its engagement with the experiential aspects of life threatening illness, as well as the physical aspects. The democratic decision making processes also mirrored the collaborative and dialogical respectful decision making undertaken between the staff and the people being cared for.

6.2.1.4 PR and Fundraising Committee

The Hospice Charitable Trust relied on developing and maintaining good public relations with corporate businesses and individual donors to raise the profile of the Hospice and bring in the money that would pay for half of the running costs and the aesthetic feel of the hospice in terms of decoration, atmosphere and hospitality. The quarterly meeting on the 23rd January 2002 was attended by the Chair of the Trustees, the Accountant to the Trust, RU and members of the Charitable Trust administration team. Planned fundraising events were discussed and organised, future proposals and ideas were considered and debated. Fundraising events were both local and linked with national fundraising campaigns by Help the Hospices. Fundraising was seen as integral to the continuation of high quality care since the number of legacies previously relied upon was decreasing. An extension to the building was planned to provide more office space for the Charitable Trust Accountant and the fundraising team who had been working predominantly from home, away from the Trust administration staff based in the Hospice.

6.3 Administrative support

How the secretarial and administrative staff of the Hospice and the Hospice Trust related to the people being cared for, their families, the health professionals and fundraisers influenced how the service was experienced as a caring organisation. The answering of telephone calls and the acceptance of donations from bereaved relatives or fundraisers required good, perceptive social and people skills. The Hospice Trust office kept a record of all the people who died under the care of the different areas of the service, the choice and place of death of the person who had died and the names of next of kin. This was the file that EG filled in at the beginning of each Multidisciplinary Meeting. This enabled the Hospice Trust administrators to place the person who had died in context and have a little knowledge about them so that this could be referred to when talking and listening to the person with the donation. When the person at the front desk rang up to tell the Hospice Trust personnel that there was someone with a donation, they always explained who the donation was in remembrance of, so that information about the person could be retrieved before the meeting occurred. This was important in that it focused the interaction as specific and personalised, ensuring each person was made to feel important, the person who had died was remembered and their donation valued.

The perceptive supportive listening skills were also important in ensuring that people who were distressed or who were requiring information were handled carefully and put through to the appropriate member of the different palliative care teams. As they were at the front line of answering the telephone during office hours and their manner and approach was important, the administrative staff were offered access to communication skills courses. One member of the secretarial team had attended a course run by the training centre in the hospital.

The role of the administrative staff could not be underestimated in terms of ensuring that up to date information was retrieved from relevant sources, which included finding and acquiring hospital notes and passing information on to all health professionals involved in each person's care, including the typing and distribution of medical letters to the GPs. As will be discussed later, the importance of a wide base of available information was essential in facilitating the process of care and ensuring care was contextualised, individualised and personalised.

6.4 Bereavement Support Service

Bereavement support was provided and managed by the social work team and a dedicated group of bereavement support volunteers, who had undergone a minimum of 60 hours of training by the social workers. This form of care and support was extended to family members and family carers after the death of the person close to them. For those who were offered ongoing support, bereavement care was an almost seamless continuation from the previous clinical services, but was an almost invisible aspect of the service as it generally occurred outside of the Hospice by a group of volunteers who were rarely seen by the majority of the staff in the service.

The level of support was structured to assess how key family members/friends were coping before the person close to them died, during the first few days after the death and 6-8 weeks later. Remembrance cards were sent on the first year's anniversary, most often to people whose relative had been under the care of the community team. The act of sending cards sent out a message suggesting the service still cared and was thinking about the bereaved person. One bereavement support volunteer regularly organised the anniversary cards and gave them to the nurses who had been involved in caring for the person and family.

Where people were assessed to require on-going bereavement support they were allocated a bereavement support volunteer. The two social workers took the complex issues and supported children when they were involved. The person centred nature of the palliative care service philosophy extended to the support offered during bereavement. One of the social workers, DE, explained during her interview that it was important that the bereaved person was able to begin a new relationship with the bereavement support volunteer with a clean slate, that is without there being any pre-knowledge and, therefore, pre-judgement of themselves and their relationship to the dead person getting in the way of the process. The aim was to enable the bereaved person to reframe their experiences within their current situation and context.

6.5 Clinical Organisation of Care

The clinical organisation of care occurred mainly within three locations: the Hospice; on the ward and in the day centre but also in the community, in people's homes, in nursing homes, and in the hospital; on the wards and in the outpatient departments. The division of the care by location required collaborative engagement with members of the different disciplines within the palliative care service and collaboration across the locations of care. The organisation of care was intimately associated with the process of care, as there was a complex interaction between them. There was often an overlap between the different services. People being cared for move between the care of the different areas of the palliative care service during the varying periods in their illnesses. This provided an almost seamless transition between the sites of care in terms of palliative care knowledge, knowledge of the person and of their situation and history.

There were similarities and differences between the different locations as to how care was organised clinically. Some of the central organisational components will be discussed prior to considering the similarities and differences between the locations.

6.5.1 Care By Location

6.5.1.1 The Hospice

The direct care in the Hospice occurred predominantly on the ward. It combined physical and bodily care in terms of symptom control and personal care, with time spent providing support through listening to and talking with the person being cared for and their family. This was undertaken by developing a relationship with each person and trying to gain some insight into the essence of that person, their needs and wishes. The ward team consisted of the nurses, the doctors and consultants, the social workers and the occupational and physiotherapists and the occasional input from the visiting psychologist. The care in the day centre was predominantly psychosocially focussed. People came in from home in the morning and returned the same afternoon. Social interactions and the use of different art and complementary therapies were integrated into the timetable for different weekdays. Some people were able to have an assisted bath when they attended, but physical care was not the prime remit of the day centre service.

6.5.1.2 The Community

The community was the term used by the palliative care service to broadly combine the concept of palliative care provided at home, in nursing homes and the local community hospital. Predominantly the care provided in the community referred to individual nurses being invited to work in an advisory or consultative manner taking palliative care into peoples homes, and differed from palliative care provided on the hospice ward and in the hospital. The team were invited guests of the person being cared for and of the GP who sanctioned their involvement. Rarely did the palliative care consultants make home visits. They worked predominantly in an advisory and consultative capacity with the nurses. The nurses did not carry out physical or bodily care, unlike those on the hospice ward. This was undertaken by the social services carers, district nurses or family carers. Although the nurses did, on occasions, set up syringe drivers. They assessed people's physical symptoms, functional ability, emotional wellbeing and coping. Much of the work involved listening to people's concerns, talking and offering advice, assessing needs and co-ordinating services and information on behalf of the person being cared for.

6.5.1.3 The Hospital

Working within the general hospital environment required that the hospital palliative care team be invited to participate in the care of people on the hospital wards by the consultant. The team worked on the different busy, noisy and predominantly short staffed wards assessing people's situations, symptoms, emotional wellbeing and listened to and talked through people's concerns and wishes for the future. They offered advice to the Doctors and Nurses, acted as advocates for the person and assisted in helping arrange complex discharges when someone was imminently dying and wished to die at home. The hospital team also maintained an awareness of when hospital ward staff were stressed and were having difficulty coping with particularly difficult and complex palliative care and offered support to the ward staff and opportunities to review and reflect upon the situations.

6.5.2 Leadership

Leadership was both part of the structural organisation of care and also an important part of the process of care. Leadership was organised, in terms of an organisational perspective, which defined roles, responsibilities, and accountabilities and provided incentive, motivation and vision to other staff members. The leadership of the service integrated managerial, motivational and visionary aspects of organisational development whilst balancing the standardisation and regulation requirements of the NHS with the Charitable Trust's plans to maintain a service sensitive to the needs of the local community.

Multiple layers of leadership were observed in the nursing teams located within the different areas of care. Delegation of managerial responsibility and motivational leadership was shared in the day to day running and management of care between a senior core group which included KL, EG, and CS, the leader of the hospital and community teams and RU leader of the ward and day care teams. Two junior sisters led two teams of E grade registered nurses and health care support workers on the ward ensuring care was coordinated and standards maintained. This involved leading a team of full and part time nurses and support workers, to provide physical, emotional, social and spiritual care and to work with people's families over the 24 hour period. The nurses and health care support orkers worked collaboratively, taking over the responsibility from each other at the end of each shift.

The democratic style of leadership and delegation of responsibilities promoted and supported innovation on the ward. New shift times were trialled and reviewed and a project group involving members of the multidisciplinary team worked together on improving the care of people with breathlessness. Ward leadership was a very active part of daily working practice. The team leaders were answerable to by the staff nurses and health care support workers about the care and interactions that had occurred.

Leading the other teams within the service differed from leading the ward nursing team since this involved leading and managing a team of independent practitioners, each individually accountable for the planning and implementation of personalised care. Leadership of the hospital and community teams was less direct. CS used a facilitative style in trying to support each team member, but also to implement new changes to their working practices. CS, although available to support the team members, and as a motivational source, had her own caseload caring for people in the community and in the hospital, as well as her administrative responsibilities. CS led both by example and by experience, but was directive when called for. She, KL and EG used a combination of top down and bottom up styles to manage change within the organisation, engaging with those likely to be affected by the alterations, listening to concerns and managing uncertainty in a consultative manner rather than a dictatorial manner.

The nurses in both community and hospital teams worked independently assessing specialist palliative care needs of people and their families, offering pharmacological and supportive/emotional advice to health and social care professionals. Managing their own case loads ensured that, at least with the community team, there was continuity in the care provided. The Community Team Nurses were often positioned as central coordinators of care for some people. They played a key role in organising and co-ordinating other services. The part time working hours of the hospital team members meant that continuity was not always possible. However, CS, LN and KL were often called upon by the oncology ward, and some of the other medical and surgical wards, to take a lead in planning and assessing a person's care requirements for discharge home.

Therefore, leadership, in the community and hospital was two fold, team leadership by CS and then individual leadership by the nurses and the consultants working in the two teams in guiding and supporting their oncology, general medical and surgical colleagues in the two locations of the hospital and the community.

The social workers and therapists were also managed by EG, in terms of problem solving service development. Mostly they were left alone to manage their day-to-day work and preparation of developmental planning, such as the next Children's Bereavement Day. The ward doctors and IS, the second consultant, were managed by KL. However, this was a very loose arrangement, since there was rarely anytime in which they were all present. When the consultants were working on the wards at the same time as the staff grade doctors, the seniority of the consultant was always deferred to in terms of decision making, despite the greater degree of continuity provided by HN, the staff grade doctor.

The different levels of leadership worked to create discrete manageable areas within the structure in which pockets of power and accountability were located. The multi-layered levels of leadership in nursing highlighted the predominance of the nurses as the main caregivers, and reflected the culture of nursing based on teamwork rather than individual practice. The discreet layers also revealed a dissipation of power throughout the levels of nursing leadership, in which nurses became the objects of the structural power more so than members of the multidisciplinary team, who worked independently, took more responsibility in their decision making and had less of a hierarchical chain of accountabilities.

The role of the nurse specialist steps away from the traditional nursing position and required a different style of leadership. However, they were more subject to the structural power within and outside of the service than were the social workers and therapists. Historically, the other disciplines have worked as individual practitioners within a discrete team, and this was reflected in how these teams managed themselves on a daily basis within the service.

6.6 Teamwork and Team Identity

Teamwork, like leadership, was an integral to the organisation and process of care. From an organisational perspective each discipline had a sense of its own self-identity, which provided a nucleus of shared experience and knowledge. Disciplinary identity was an important component in defining the roles and norms of each team. It provided a position of security and certainty from which each team member negotiated and shared the blurred practice boundaries with the other disciplines. These blurred practice boundaries were the spaces and skills that overlapped to meet the needs of the person being cared for. Discipline was less important than the member of staff who was present in the moment of care where meeting the person's emotional or informational needs could be undertaken by any member of the team.

Teamwork was structured by location. The global multidisciplinary team of the palliative care service incorporated all members of all the disciplines within the palliative care service. Each team worked independently of and interdependently with each other. This formed the identity of being members of the palliative care service, which provided a collection of shared experiences and knowledges. The shared nature of the Palliative Care Multidisciplinary Team (MDT) facilitated a collaborative focus for the input to and outcomes of the care processes for each person and family being cared for. This was unlike the bringing together of disciplines with very separate identities as loosely working teams in the hospital or community settings. Different disciplinary goals and values had to be negotiated more robustly within the traditional hierarchy and the foci was situational as compared to an ongoing process

6.6.1 Teamwork on the Hospice Ward

In the hospice ward, although the majority of the hands on care was provided by the nurses, this was informed and assisted by the contributed advice, observations and suggestions of the MDT who also sat with, talked and listened to and assessed each persons abilities, situation and needs. Despite being sub divided into two smaller teams to care for a specific group of people and their families, the nurses worked collectively. The MDT met together daily during the morning ward round, held in the doctor's office, to receive updated information about the previous day and night and discuss issues arising and plan for the day. However, often not all team members were present for the discussions and decisions tended to occur between the nurses and the doctor on the ward that day. There was usually a focus on the family, the social situation and how people were coping and managing emotionally as well as on the physical aspect of the person's symptoms and care. However, the presence of the therapists and social workers often led to a widening of focus in discussions offering added perspectives. The timing of the meeting preferenced the working practices of the nurses and doctors rather than the contributions of the social workers or therapists who did not start work until after the meeting started. This suggested a reduced prioritisation of the need for formal multidisciplinary decision making, which was not necessarily replicated in terms of informal communication and team working as will be discussed later.

6.6.2 Teamwork Within and Across Locations

The community and hospital palliative care teams were also invited members of the community primary care teams and some of the acute hospital teams. The various disciplines that made up the primary care teams and hospital services had differing concepts of care and goals, which had to be negotiated to ensure a cohesive approach achieving the appropriate care. Working across location and philosophical boundaries, as key members within the hospice and the hospital and community services required adaptability and confidence. Teamwork provided a source of security, support and shared understanding, reinforcing the palliative care philosophy within their work, and enabling this to be adapted within the different locations.

Care within the community and hospital was predominantly undertaken by the nurse specialists, but included episodes of care by the consultants and social workers. Each consultant took key responsibility for working with the community team and working with the hospital team. The community team had weekly advisory meetings with IS, the consultant. However, the nurses often sought either of the consultants when more complex symptom control and disease advice was required in between times. Both consultants' advice was also sought when nurses experienced difficulties working with members of the different primary care teams. The social workers became involved at the request of the community team nurses, and so the nature of palliative care multidisciplinary teamwork altered within these domains.

The only full input of the multidisciplinary team occurred during the weekly service meeting, at which the community team very rarely discussed the people in their care, leaving this until their weekly lunchtime meeting with IS and CS. The therapists and social workers did not attend the community meeting. The social workers commenting that it was a poor use of their time since the meetings were too medically focused when they had so much else to do.

DE, the social worker, felt that, although part of the multidisciplinary team, the social workers were further removed from the centre of it:

> *'I think because we're not sort of nursing or medical we are slightly on the edge, and I think that's, in a way inevitable because the main thing people come here for is for health care and we can't give health care, and although, you know, we are part of that wider team, um, I think we're sort of, just probably one step away...' (DE interview: social worker March 2002)*

The social work team, however, were the one team who had the potential to, and on occasions did, see people through the different areas of the service, from the start of the persons involvement with palliative care through to bereavement follow up for family members, just as they did with ST and her daughter. They were, in fact, quite central to offering insightful observations about the people and their families during multidisciplinary meetings and general conversations.

The hospital team received advice predominantly from KL but also IS. The social workers were occasionally involved with people in the hospital, seeing people in out patients or who were about to be discharged. They were the main resource for advice about family situations and children.

KL experienced her role as a team member situated across different teams from her base in the hospice:

> *'the* [hospice] *team here must wonder what I do a lot of the time, but you see I'm regarded as a core member of GI MDT* [Gastro intestinal multidisciplinary meeting] *and likewise, the oncology and gynae meetings and so you dip into other teams as well, which actually see you as quite pivotal and there are particularly certain colleagues in hospital who deal with the majority of the common cancers, but I think I have a key role in helping those , if you like, active intervention clinicians examine what they're doing.' (KL medical director April 2002)*

The importance of the palliative care input into the hospital teams was acknowledged in an interview with RA, a general surgeon and BT, a medical oncologist.

> *'I was here as a Registrar so I think Chaffinch was the first place I ever came across that had a hospice on site and so they see patients on the ward plus or minus transfer to hospice. The hospice was a very continuous process, err, and also the teaching that was provided by the hospice was quite special...and therefore we were actively involved in the management of patients in the hospice which I had never come across before... one of the things that's also very refreshing about palliative care is they don't only just care for the patient, they care for the staff' (RA interview: consultant surgeon February 2002)*

Part of the role of the hospital and community team nurses and consultants was to enable other multidisciplinary teams they worked with, and were part of, to consider what the aims and objectives of their treatment approaches were and to offer alternative perspectives and suggestions for consideration, much like the social workers and therapists within the hospice multidisciplinary team.

Working in the community and hospital required the teams to work within and alongside other disciplinary teams in an overlapping and integrative manner. Often with a clearer distinction of boundaries than was found within the hospice. It required the team members to manage their own working philosophy and expertise. The nurses needed to be adaptable in negotiating a consensual way forward for each person's care, and have the ability to compromise where there was resistance. There was a very strong supportive working relationship with the two oncologists, who met weekly with the community team, and sometimes visited people who were still under their care in the hospice. The hospital team worked almost daily with the oncology team in the hospital wards or clinics.

Teamwork provided both a central focus of culture, identity, expertise and trust within the palliative care service, comprising the different identities, knowledges and skills of the disciplinary teams. The nursing and medical team were seen as central and nurses the key frontline carers. The physiotherapist, occupational therapist and social workers discussed the benefits of them of not having an identifiable medical background. This enabled them to pursue different routes and approaches to identifying problems and meeting people's needs. Being identified as different within the main palliative care team created the space to explore non-medical concerns and other avenues of care. This required reminding the nursing and medical teams about their different roles.

> *'I think one of our overriding aims needs to be that there is continuity in therapy and our communication with the whole team is good enough and their awareness of what we have to offer so that they either flag it up to us or we're there to flag it up ourselves and actually happens at the appropriate moment for the patients, rather than us be perceived, me be perceived as a discharge planner, but we need to get into it at an earlier stage' (ME interview: Therapist October 2001)*

There was at times some privileging of medical and nursing palliative knowledge, despite generally valuing the sharing of knowledge, skills and experiences during discussions in both formal and informal conversations.

6.7 Meetings and Formal Spaces for Exchanging Information

An essential component of the clinical organisation of care was the regular and routine occurrence of formal daily and weekly meetings, which involved all members of the multidisciplinary team. The number and type of formal meetings differed between the three areas of palliative care with the majority occurring on the hospice ward and the least occurring with the hospital team. The basic purpose of the main meetings was to share new and updated information about each person and the families being cared for by the nursing teams and to engage with the thoughts and ideas of the multidisciplinary team.

6.7.1 The Ward Meetings

The majority of formal meetings occurred on the hospice ward where there were a minimum of three nursing hand over meetings a day, one multidisciplinary ward round meeting a day, and on one day each week there would also be the weekly multidisciplinary meeting and a hot topics meeting that was open to all members of the palliative care service and Hospice Trust. The nursing handovers enabled basic routine information, including each person's name, diagnosis, age, family situation and current problems to be passed on to the next shift of nurses, as well as information about a person's ongoing changes. These meetings provided a forum for discussion, for checking out perceptions and experiences about each person and space for planning how the nurses would approach and organise their care for the shift, taking over any left over tasks and responsibilities.

The morning ward round meeting focused on the handing over of information by the nurses to the ward doctor of the day and discussed the current problems and issues of each person. When the therapists and social workers were present they bought an added social and practical dimension to the discussions. The final decisions rested with the doctors although generally there was open discussion and most decisions were arrived at through consensus, unless the decision required was based on purely medical knowledge alone. However, this rarely occurred especially when the lead nurse, team leaders or more experienced staff nurses were present, as they were able to debate different choices of approach and treatment.

The weekly multidisciplinary team meeting was the one meeting at which representatives from all of the clinical areas of care participated, including the volunteer co-ordinator and day care sister. This meeting provided key organisational aspects of care, in terms of a forum for sharing information about the people being cared for on the ward and for decision making in terms of negotiating plans of care, and for naming and sometimes discussing new referrals to the community and hospital teams. Recording the names of people who had died across the services and whether their choice of place of death had been met. This served as a focus of reflection for the team in considering how things could have been done differently and provided information for audit purposes. This discussion also enabled the social workers to ask questions about potential bereavement risk and support needs.

The first part of the meeting reviewed the deaths and bereavements and the new admissions, the second half of the meeting focused on the care and progress of the people on the ward. The meeting prioritised the ward care in terms of a multidisciplinary focus compared to that of the community or hospital teams, and was reflected in comments by members of the community, hospital and social work teams. Attendance at the meeting was also prioritised by the therapists in terms of their work load, and often missed because they had too many people to see or assess prior to discharge, and so their voices and perceptions were missing.

6.7.2 Day Centre Team Meetings

The day centre sister and the activities coordinator met informally each day, and only attended the weekly multidisciplinary meeting, but not any of the other formal meetings. They preferring to go and talk to the therapists, ward and community team nurses directly.

6.7.3 The Community Team Meetings

The community palliative care team had a weekly meeting and one representative of the team joined the weekly multidisciplinary team meeting, with group clinical supervision on a six to eight weekly basis. The purpose of the team meeting was to discuss difficult cases, new referrals and to review the previous week's decisions and events with the consultant, team leader and the team members. In his interview IS the consultant, described his role as a process of *'advising the advisors'* which for him carried a real sense of responsibility. The team leader, CS, and the consultant, IS, shared the facilitation of the meeting, in which team members took turns to present the people they were concerned about and to discuss the possible options and approaches of care. The other nurses offered their advice and suggestions, using a reflective process. The meeting was also used by the consultant and the team leader to get the nurses to further develop their assessment and critical reflective practice skills, and to manage more complex situations in the home with members of the specific primary care teams they worked with.

6.7.3.1 Joint Community and Oncology Meeting

The community team met weekly with the two medical oncologists from the hospital, who came down to the hospice and joined the community team in their office, and had coffee whilst they talked with each nurse about the people they shared the care of. This enabled the oncologists to hear what was happening for the people within their care and their families, medically as well as socially and emotionally. The nurses were also kept up to date with what was happening in terms of treatments, appointments and other information. Both the oncologists and nurses were able to ask questions of each other and, from a nursing perspective, it also offered a learning opportunity about new treatment protocols. There was an easy friendly and respectful feel about the meetings, which fostered the collaborative work between the palliative care services and oncology services.

6.7.4 The Hospital Team Meetings

The hospital palliative care team was represented at the weekly multidisciplinary team meeting in the hospice. CS attended all of the MDT meetings retaining a much wider awareness of the situation from the hospital, community and hospice ward. During conversations with LN said she rarely attended, suggesting they were a waste of her time since she gained little information about anything relating to the people she was caring for, and it was not the forum in which her concerns could be discussed. However, the hospital team were able to contribute information about people currently on the hospice ward from their previous involvement with a particular person and their previous treatments and relevant family issues.

The hospital team did not have any other formal meetings, relying on informal handover meetings between team members on a daily basis. CS and LN worked together for the first three days of the week. They would talk through the list of names written on the white board of people they were caring for and discuss the current situation for each person, listening to and offering advice and insights to one another. At the end of the day, if time permitted, this was repeated. One of the consultants usually popped their head round the office door and asked if they needed any help or advice at the start of the day. Their meetings were invariably broken into by a member of the community team seeking advice from CS. CS and both consultants shared the responsibility for attending the three different weekly hospital based cancer site specific multidisciplinary meetings: The lung MDT, the gastrointestinal MDT and the gynaecology MDT meetings.

6.7.5 Social Work Team

The social workers attended the daily and weekly multidisciplinary meetings on a much less regular basis than the nursing and medical teams. The starting time of the ward round meeting and the part time nature of their working hours, ensured that the social workers always arrived at least fifteen minutes into the morning multidisciplinary ward round. When both social workers were in the office on the same days they would discuss the people they were working with, share information and plan what jobs that had to do.

6.7.6 The Therapy Team

Rarely did the physiotherapist or occupational therapist work together, as their limited hours only covered the mornings of the week, although these were to be increased by the end of the fieldwork. The lack of time and amount of work often meant they did not attend the weekly multidisciplinary meetings on a regular basis. They prioritised their limited time to be spent undertaking therapeutic interventions with people rather than sitting in the meetings. However, they always caught up with the nurses and doctors afterwards.

6.7.7 Multidisciplinary Team Working Without Attending Formal Meetings

Although there was a philosophy based on multidisciplinary working, seen in the daily working and rich and varied sharing of information between the different disciplinary team members, the role of the multidisciplinary team in terms of the daily and weekly multidisciplinary meetings appeared predominantly to be focused towards meeting the needs of the ward, the collection of statistical data and raising the awareness amongst the group about potential new admissions or referrals to different areas of the service. The collected data could also be used by the Hospice Trust for greeting people bringing in donations and for the collection of bereavement details.

The community team attended several team based meetings, perhaps reflecting their longer term case work compared to the work of the ward and hospital team. Attendance of regular meetings was made more difficult by part time working within the community, hospital, social work and therapy teams, where both time and workload was prioritised in favour of attending the multidisciplinary meetings. However, members of these teams could be guaranteed to be told the information subsequently and chose to speak directly about their concerns or plans with the appropriate member of staff afterwards. The true nature and richness of multidisciplinary working was revealed not within the meetings, but in the informal gathering and exchanging of information and dialogue during the time and space away from the meetings. This highlighted the significance and value of responsive teamwork within the service that was outside of a formal bureaucratic structure. Such a formal structure can risk such adaptive teamwork being under valued by regulatory assessments of the service which requires proof of meetings being held in the adherence to minimum standards.

6.7.8 Supervision Meetings

Clinical supervision was available to the nurses in the form of individual or team supervision meetings. The occupational therapist sought supervision from the lead occupational therapist in the hospital and the social workers had infrequent meetings with the clinical psychologist who was associated with the palliative care service. The ward staff nurses and junior sisters had individual clinical supervision sessions with the senior sister who covered the ward and day centre. Although not observed these were apparently reflective and advisory sessions, enabling the nurses to reconsider situations and the management of them.

The community team and hospital team nurses attended a joint six to eight weekly clinical supervision/team meeting led by CS. I was informed that these meetings were used to discuss issues that the team had defined, managing difficult situations and to discuss ongoing changes. It provided a space where team members could talk about their concerns and ongoing problems, but where CS could introduce and discuss potential changes to working practices. The team also had a yearly ‘away day’ in which they met away from the unit to talk about how to take their service forward.

Each individual nurse on the community team also met separately with IS, the consultant, and CS for a case review, in which they went through the whole of their caseload. These meetings took several hours and were held in monthly rotation. I was only able to attend one meeting on the 4th March 2002, there was a process of facilitated reflection led by IS and CS focusing on the decisions taken by the nurse and a drawing out of the nurse's knowledge and planning skills for managing current problems and looking at potential concerns. The meeting also worked as a tool for which the management agenda for slowly changing practice was incorporated, through the challenging and positive reinforcement of different practices.

The hospital team did not have separate supervision or a case load meetings due to the part time nature of each person contributing to the team and because of the short stay of the people in the hospital. Most of the reflective supervision, in fact, occurred daily during the ongoing discussions between CS, LN and with EG, when she worked on the team one day a week. The informal talking through of the people being cared for by the team, was also a time where reflection and consideration of alternative approaches were raised, and where CS often advised LN.

The difference in provision of supervision does raise questions. Do the different types of supervision reflect the different nature of care in the different locations, or do they reflect the value placed on the different team needs? This is difficult to answer as the ward nurses have individual supervision for a team approach which also relies on individual therapeutic relationships and decisions; the community team nurses have team supervision for individual work and the hospital team have informal, ongoing reflective conversations and no formal supervision. The doctors appeared to have no formalised supervision, and the social workers and therapists organised their own with supervisors outside of the service. There is a disparity in the level of supervision available.

6.7.9 Communication Books

Each team, including both consultants and the lead nurse had communication books which were used to write in telephone messages, messages from other multidisciplinary team members about the palliative care service or information about people in their care. Each member of the various teams would read the book to update theirself with the information. The communication book system was well established and was a central point of information about the service. It included news about staff and for letting members of the team know when someone had died. When members of staff had been away on leave or away because of part time hours, the communication book was a source of continuous information over days and weeks, since each entry was dated. The book was also a point at which information about people or families under the care of the community team could be recorded by the person taking the message, and then ticked off as read by the nurse that the message was intended for. The book, therefore, also had a role in marking clearly the route of accountability from the person taking the message and recording it and handing over the information, for this to be acted upon once read by the intended member of staff and confirmed by placing a tick beside the message and possible comment.

The communication books were not used as an auditable system, but were an integral part of the formal structure of passing on information between people. The books were very much relied upon by the community team when the nurses were out of the office, since they did not use an answer machine, and reading the book was one of the first thing the nurses did when entering the office after visits or meetings.

6.7.10 Diaries

On the ward each of the two nursing teams also had a diary in which they recorded additional information about the people in their care, such as appointment times, telephone calls to be made and for any tests to be undertaken or results to be located. The diary provided a means of continuity in the tasks that needed to be completed by the end of the working day, sharing the responsibility between the three shifts and placing the responsibility on the team rather than on any individual. This was often the site of information about a person's care, which was not usually placed into the nursing documentation. The diary was referred to at each hand over meeting and ward round. Individual diaries were used by all other members of the service since their work was often independently undertaken. The diaries had an organisational function. Community and hospital team nurses listed the people they were going to see and tasks they needed to undertake such as complete telephone calls. The community team also had a team diary.

6.8 The Working Rhythms and Routines

The rhythms and routines of the working day and working week were important components of the structure and integral to the process of care for all areas of the service. However, because of the different nature of the work within the different areas the rhythms and routines were noticeably different. People working with the different teams were aware when people could be contacted, or when they would be in the hospice building. The mornings tended to be the busiest times for all areas and aspects of care, and the office hours kept by all areas of the service reflected this. The ward nurses provided round the clock care and the on call rota for the community team and doctors provided an advisory service over night for the people at home or for the ward nurses to obtain symptom control advice and medication alterations respectively.

6.8.1 The Hospice Ward

The rhythm of the ward flowed over day and the night with peaks and troughs of business, noisiness and quietness. The rhythm of the ward was also structured by the routine regularity of the meal, medication and meeting times and had a direct effect on the care provided, who was available at anyone time and the type of care required. More nurses and doctors were available in the morning and early afternoon, when the majority of people being cared for required physical assistance to wash and dress and have help with eating and drinking. The majority of meetings were held in the morning and after lunchtime. Mornings were the busiest and noisiest times of the day and the afternoon quiet as people rested and the staff documented their care in nursing and medical notes.

The afternoons and night times were usually quieter and had less qualified nurses and health care support workers on duty, with reduced access to medical and other senior staff after 5.00 pm. This meant that when there were very sick people on the ward or several people who were dying and had family staying, the rhythm of care changed, although the routines stayed the same. The nurses were often very busy, sometimes unable to take a break as they provided the physical care for people who were incontinent, who were sick, who were unconscious and who needed mouth and eye care as well as preventing sores forming by manually manoeuvring people into different positions whilst concurrently supporting their families and listening to their concerns and offering advice. The qualified nursing staff were involved in trying to resolve increasing symptom control problems, contacting the doctors for further advice and trying to keep people who had become confused and agitated safe.

The teams' determination to offer personalised care was observed in their determination to be responsive to the needs of the people in their care and those of the relatives and friends present. Teamwork and a sense of cohesion enabled taking over aspects of care that had not previously been undertaken because of lack of time and staff. This included the morning staff laying out a person after death, when the night staff had been very busy or when the person died just before the next shift began.

The doctors would arrive around eight thirty and the therapists, and social workers would arrive on the ward just after quarter to nine and would talk to the nurses about the people they were involved with. The abundance of the multidisciplinary team in the morning added to the business and noisiness of this time, as did the number of incoming telephone calls.

6.8.1.1 Volunteers

An essential component to the smooth running and maintenance of the routines was the presence of volunteers, who also worked in short shifts during the day, coming in late morning, mid afternoon and early evening. They assisted in keeping the bedrooms pleasant and tidy with fresh flowers, changed rubbish bags, recorded people's menu choices and took the meals round at lunch time and supper time. They made up trays with pots of tea and cups of coffee as new people arrived and took refreshments to those who had requested them.

The volunteers often paid attention to the little things that helped out the person being cared for or helped out the ward nurses in their daily work. This was seamless and occurred without disrupting the work of the staff nurses who could focus on completing their nursing care and giving out the medications at lunch and super times.

The health care support workers helped with feeding people, helped people taking their medications and tidied up from the mornings work. The volunteers also assisted the smooth running of the care by being able to go up to the main hospital to fetch hospital notes and x-rays when required by the different teams within the service and by going to the hospital pharmacy with drug charts for medications to be ordered for the ward or for someone to take home. HA, who had been a volunteer for over five years, explained how she felt she contributed, which echoed comments from other volunteers interviewed :

> *'...well I think everyone is so appreciative of anything that we do. I mean, um, for example, I mean, you know, if they want anything, you know, it always say 'could you possibly' you know 'would you be so kind as to go and get something' and I've noticed this on, on wards when I've been asked to go and collect something from different wards, you know, that sort of thing, you know, on occasions, or even notes. Staff there are not, not the same as, you know, even down to the ward clerk, they're not, you know, its quite begrudging what they'd, and you feel in their way. Well you never feel in anyone's way here, you know, its, I mean they always say we're part of the team, and, yes, you do feel part of the team'. (HA interview: volunteer February 2002)*

In many respects the volunteers were the oil that kept the cogs working smoothly. HA continued to describe what she had done in the three hours she had been on the ward the day of her interview:

> *'Well, um, sorting out the dishwasher first thing in the morning, um, then I went down to pick up some notes from, um, MRI scanner and dropped a card into X-ray and had to find X-ray, so UB got on with doing the rooms and then when I came back we finished off the rooms together, you know dusting and doing the flowers, this sort of thing, um and then the trays we're all up and got ready for lunch. Um, we had a cup of coffee and then, of course, it was getting, you know, going to ask the patients what they would like for lunch, this sort of thing, you know'. (HA interview: volunteer)*

It was noticeable when the volunteers were not there and the nurses and health care support workers had to give out the meals or go up to the main hospital, which reduced the number of people immediately available for that period of time on the ward.

6.8.2 The Community Team

The rhythm and routine in the community team was extremely different to that of the ward but similar to the hospital team and the social work team. The initial similarities were due to the working practices of the teams being based on regular office hours rather than across the twentyfour hour period found on the ward. However, the community team and occasionally the hospital worked before and after these hours.

The mornings in the community office upstairs were very noisy as several people would be on the telephone, making or receiving calls to the people in their care or to members of the primary care team or for organising services and outpatient appointments. The telephones would begin ringing from eight thirty in the morning but would lessen after eleven when most of the community team nurses had left the office to go out on their visits. There would be a quietness until mid afternoon when the telephones would begin to ring again and the nurses began returning, depending on the distance and number of their visits. After their return the nurses would read the communication book and make follow up telephone calls, passing on information about people they had seen to GPs or district nurses, and arranging services for them, before beginning to write up their notes from their visits. Although different, there was a predictable rhythm to the office when the nurses were in and when they were out, and what they did during those times.

Each nurse in the team had their own routine, planning visits and telephone calls for each day and visits for each week, fitting geographically together to save time and petrol. Each day for each nurse was structured and planned in advance, although this was adapted and reorganised when responding to sudden deterioration of one of the people in their care or for the assessment of a newly referred but very ill person. The number of telephone calls to GPs, district nurses or to arrange and coordinate services and appointments on behalf of the person could not be planned and varied each day according to the workload.

6.8.3 The Hospital Team

The hospital team, from Monday to Wednesday had two nurses and occasionally the presence of one of the consultants. On Thursdays and Fridays the lead nurse helped out if her other commitments allowed. On a Monday morning the communication book was read for messages and telephone contact made with the wards about people who might have died or gone home over the weekend. CS and LN would discuss the people they had to see and loosely plan their day. It was not common for the hospital team to make many telephone calls, instead they tended to walk up into the main hospital earlier in the day before the community team left their offices. The hospital team often gave advice over the telephone having assessed and asked questions about what they were being told rather than visiting. The hospital team was less predictable in terms of having regular times in and out of the office, as they were more responsive to the needs within the hospital and were more easily available to see new referrals or current people in their care by the nature of being contactable by the hospital bleep system.

Monday mornings were busier in terms of receiving new referrals, requesting the teams input and advice for people who had come in over the weekend or whose condition had deteriorated. Friday afternoons like many other Hospital Palliative Care Teams saw an increase in requests for assistance with last minute discharge decisions and requests for assistance setting up community services or provision of symptom control for people who had not previously been under the care of the team for comfort over the weekend.

6.8.4 The Social Work Team

The social workers also had some routine to their working day but little rhythm. Starting off their day in the office, reading the communication book, attending the ward round and then making telephone calls, going to see and talk with people on the ward or going out to see people at home and undertaking bereavement visits. Where they were and what they did depended on the work they had to do each day, although this would be planned as much as possible.

6.8.5 The Therapy Team

Often the therapists would be in the hospice working alone. There was little routine as their daily work was built around the needs of the people on the ward and in the community. Therefore, each working day would be different. However, after arriving the physiotherapist and occupational therapist would go on to the ward and talk with the nurses and the doctors about the people they were going to see and to ask about any changes, before doing what they had to do that day. Sometimes home visits would be made, or telephone calls to community services and equipment arranged and ordered.

6.8.6 Day Centre Team

The day centre was the most structured area of care in the service. The sister and activities coordinator started at 10 o'clock. They met to talk through the morning plans before greeting people arriving from home, and having a drink and a chat with them about general issues or specific concerns that might have been raised. The sister left as people took part in the different daily activates, although the activities coordinator often stayed. Activities stopped for lunch and then people had a chance to chat to one another or sit quietly before going home around half past two in the afternoon. Sometimes the community nurses or social workers would go to the day centre room to talk with the people they were involved with, either to catch up and see how they were or about something specific. There was a routine to the day helped by volunteers, specific to the day centre, who drove people in from home and those who made the morning drinks and helped with lunches and took part in opening up conversations with people. Everything was over and cleared away by three in the afternoon and that corner of the downstairs corridor was quiet once more, and the day centre office empty.

6.9 Summary

The organisation and structures within the palliative care service provided a framework that shaped the way the different components of care, the teams and the locations worked to meet the needs of people. The division of the work into separate teams to cover the different locations of the hospice, the community and the hospital automatically adapted the manner in which palliative care was provided and the different experience and knowledge required to work in these environments. Yet within this organisation core service values were maintained through shared leadership and the fluid nature of the consultants, the social workers and therapists work in between the locations.

The number of formalised meetings placed an importance on the exchange of information; however, due to the need to prioritise working hours not all meetings were multidisciplinary. This raised questions as to the true understanding of multidisciplinary decision making. Boundaries in palliative care teamwork could be shared where there was an overlapping philosophy and valuing of multidisciplinary input. These became clearly demarcated within the hospital and community locations where differing treatment and care philosophies and knowledges were increasingly hierarchical and bounded by the more traditional professional relationships. How was the concept of teamwork defined and operationalised throughout the service and within the community and hospital setting. Teamwork does not necessarily imply cohesion, shared values or shared aims, but a negotiated and sometimes disputed space within which traditional power hierarchies, disciplinary and personal values interact within the dynamic of the negotiation.

The roles of the management committees, shared decision making and strong leadership directed additional funding to foster the appreciation of art and complimentary therapies as integral to the process of care, encompassing the emotional and social aspects of peoples' worlds, as well as having an informed and educated workforce. Collaborative leadership that valued dialogue infused throughout the service to an extent that, despite the formal meetings, much of the multidisciplinary work and exchanging of information occurred in the informal spaces away from the meetings. How these formal and informal organisational structures underpinning values shaped care will be considered in the next chapter.

Chapter 7 The Processes of Care

7.1 Introduction

A number of different processes have been revealed as central in providing and undertaking care. These processes were found to occur within the different public and private spaces within the hospice, peoples' homes and hospital wards. The structural and organisational framework of the service has defined these spaces and influenced how and where the care was undertaken. There were many different processes involved, which could not be revealed by focusing purely on the structures or values of the service. The structure and formal procedures of care could not be seen in isolation from the processes of care or, in fact, the different knowledges that began to be revealed as underpinning care.

The concept of care as a process also suggested that time was an important facet of care. The regular rhythms and routines provided a temporal structure to the day, within which the other processes occurred, informed by past knowledge, experience, and current changes in information. How time was used and experienced within the temporal framework also affected the processes. There was an ongoing dynamic and often complex interaction between these different layers or components of care, which served to constantly inform and influence one another. There were similarities and differences in the processes across the hospice, the community and in the hospital in providing specialist palliative care.

This chapter will focus on the processes of care that were revealed, by presenting detailed examples of the processes and considering them from a range of perspectives. The reader is requested to note that the processes cannot be separated from the discussion of knowledges in Chapter Eight, as each are interdependent upon the other.

7.2 Information Exchange

Information exchange was the dominant centralising process essential in ensuring that all care was personalised, appropriate and responsive. There was an abundance of different ways of exchanging information. Information could be regarded as any detail about a person, situation or service that was passed on to another. It underpinned every aspect of care within the service as a whole, yet occurred in slightly different ways across the different locations. The culture of the service valued the process of dialogue, formal and informal conversation as the central mediating process by which almost every aspect of care was negotiated, relationships built, established, maintained and information exchanged.

The passing on and receipt of information occurred through individual or group interactions, face to face or over the telephone and through documented case notes, formal letters and notes written in the communication books. Information about a person, their condition, their personality, their history, their preferences and beliefs, their family, friends and home lives was retrieved and employed in a range of ways that informed decision making and the care offered by the staff.

The exchange occurred in different ways across the areas of care, and reflected the different ways of working and the different cultures of the environments in which the teams worked. Standard basic information that was sought, offered, and exchanged throughout the service created knowledge and general appreciation about the person, their disease, medical treatment history, family and home situation. Information was sought from and shared with other health professionals outside of the service and with those being cared for including their families. Information obtained from the person and their family was used throughout the service, but predominantly by the community team, who worked in partnership with family members. They often relied on the word of the person being cared for and the family carer during telephone conversations to help inform their advice and suggestions and this was observed in many telephone conversations undertaken in the community office.

The basic information was usually initially acquired by the nurses or doctors verbally and followed up through reading medical notes, referral letters and other hospital documentation. The therapists and social workers tended to retrieve information from the nursing notes. The essential information would then be passed on to members of the multidisciplinary team during each of the nursing handovers, the daily ward round and weekly multidisciplinary meetings on the ward. Each member of the multidisciplinary team would record this information on hand held notes, scraps of paper, in work diaries and in their formal documentation.

Over the time the information about the person increased. It provided a foundation on which the care was based and then adapted over time. It constructed a comprehensive resource from which to draw upon about the person, their family and their social situations. Information exchange was a dynamic interactive process rather than a linear action occurring during formal meetings and informal conversations with staff and those being cared for. The process was organic and hermeneutic, developing and changing as new insights and information were contributed during the day.

7.2.1 Information Exchange: the Ward

The informal process of exchanging information served a more important function than the formal meetings by keeping the information about each person and their condition up to date as things changed throughout the day. The information included formal and informal assessments of the person after carrying out personal care, or from observing the person over time, insights and personal perceptions were discussed enabling a checking out process to be incorporated. The checking out process enabled different members of staff to share and negotiate their perceptions and evaluations. This enabled a more responsive and adaptive approach to care.

The following example, observed and recorded during a morning ward round, reveals how multiple perceptions and pieces of information were exchanged between the staff.

Ward round discussion about GB 21/11/01

Background:

The ward team were discussing the preparation for the discharge home of GB, who had been admitted two weeks previously with complex symptom control problems which involved difficult to control pain and a complex family situation with heightened stress and anxiety levels. GB had been a very prominent community figure, who had always been in control of herself and meeting her own needs. In trying to cope with her cancer and her increasing problems this need for control was, at times, manifested in her and her family's behaviour with staff, demanding responses and access to and controlling the timing of services. The team had worked very closely with the different needs of GB and her family members, each of whom were struggling to cope. The team looked at ways to support them, whilst still aiming to get GB back home.

JC GB is looking forward to home on Friday, she has got a scan before she goes. Her daughters are quite anxious but they are talking about it quite well.

KL I've just got that, I said to ME just updating what happened last week and I said, as a result of the way she was struggling we've not only got to get GB confident about the discharge but we've got to do the same with the daughters. They're very anxious daughters, very understandably anxious, but we've just got to.

JC GB's been very good about it.

KL She's asked to see me again later

RU What is she having scanned?

KL I suspect it's her liver, it's been booked by YE [Oncologist]

JC yes, it might be that she's not allowed to have breakfast

KL What they said with her recurrent disease they've changed her hormone treatment and if there're rapidly developing metastases they'll put her on chemo sooner rather than later.

ME Can I just ask what the pain in her lower legs is, it is inconsistent in her *reports of it, because her reports are that its incredibly painful, she feels it down here* [points down leg]

KL Well when she came in last week what she was basically saying is the pain at her lower back had eased and the electric shock type pain down the posterior aspect of her right leg, and its wide distribution, and what's happened is the passage of time and steroids she's lost the pain in the thigh it still has the lower leg pain, but I think its in her lower back

ME Right

KL That's what I've been comfortable attributing it to unless you're going to rock the boat.

ME well, I'm not.

KL But certainly the electric shock type pain she's comfortable lying in bed and has no pain down her leg at all, it's on sitting and particularly walking. I'm uncomfortable.

RU It still doesn't explain the continuous pain on mobilising

ME Well, she doesn't have to mobilise actually

KL No but on sitting.

ME Because to dangle her leg.

KL But if you had seen her last week, she could only be comfortable in bed, last week there is no way she would have sat on the bed

ME She is very cautious

KL And one of the problems we've got is, she had great huge distress last week, and it was right to keep her in but we've got to be very careful not to have her.

ME I've agreed with them in terms of needs and input first thing in the morning, have tea and toast and get her medication done at about 8 o'clock, and then she can lie in bed and let that take effect and then get up. She's actually capable of dressing herself and I suggest that they put a chair in the bathroom so she can give herself a wash, but we need to look at the whole bathroom problem which was, they're having a problem with that at the moment and I said I would go to their...

KL but she hasn't been there since they changed her shower, the showers been just while she's been in

ME Yes, nobody's actually gone through how to use it and they have all sorts of ideas about what does and doesn't work and so I think I need

KL I think you need to be careful because she'll take as much time as she wants, shes...
ME My plan is to go in and do a quick follow up visit and see how she's settled in and look at the bathroom, show her how to use it and go from there and I've suggested she could come up here for a bath, I have also suggested she uses more than one stick
LD She was adamant on Monday she would not use a stick
ME It's really hard, I think a frame.
KL A Zimmer frame seems sensible, but for her it would have to have bells on it
ME But I said she may well have it even now, I said its not necessary for ever.
KL She's a pragmatic lady; it's a means to an end
ME Well we had that conversation just now and she thought it might work
RU The scan, I think it could be the liver mets, it could be it staging or it could be post radiotherapy
KL I think its staging her liver mets pre any chemo decisions
RU She's got a appointment with YE early.
KL so basically scan, home, and it won't go smoothly
RU No it won't, you're right
KL We have to be terribly realistic about that.

JC: staff nurse, KL: consultant, RU: senior sister, ME: therapist, LD: therapist

There were a number of important processes interacting at the same time in this example, which related to who provided the information, how the different information was revealed and what advice and plans were made available about managing the practicalities of care and managing the anxieties of GB and her daughters.

Through an ongoing conversation the group was immediately made aware of the emotions that surrounded the situation and a future investigation. The consultant picked this up, acknowledged the anxieties and offered advice to the group about how to manage these. The group were, therefore, aware of the consultant's preferences in managing the family anxieties and recommended a consistent approach to the family by all team members.

Clarification was sought about the scan, which enabled the consultant to reveal her awareness to the group about the oncologist's plans about future treatment and her own interpretation about why the scan was an important tool. The interpretation drew upon the consultant's own knowledge and experience of treatment processes. The consultant revealed further information about the nature of the pain experienced by GB and how this had changed with the treatment over time. This was revealed because the therapist had requested further clarification about the pain. Therefore, the consultant's description was shared with the group, as was the occupational therapist's. The descriptions were negotiated as the other team members listened and gained access to both the therapist's and consultant's experiences and assessments of GB.

The knowledge of GB's personality and her coping strategies were used by the consultant and therapist in planning their care and was explored and discussed before loose ends of unconfirmed information were returned to, the reason for the scan and the reminder that the team needed to be realistic about how the discharge would go.

The processes were mediated by social rules about chatting, observed by people taking over and interrupting each other's conversations with additional view points or information. This was rarely seen during formal conversation where everyone waited for the person to finish before speaking, or where there was an obvious hierarchy, in which deference occurred to the more senior speaker. The conversation highlighted the level of trust and safety between the group members for this use and ease of interruption and questioning to occur. There was a natural flow which was not halted or stilted by the interruptions, but was used to facilitate access to information.

The therapist played an important role as a non-medical voice in the group seeking clarification and understanding of GB's pain. Translating the information into a practical plan enabled and facilitated GB to manage her pain and her ability to function and to retain a degree of independence at home with the support of carers and her family. The meeting facilitated the sharing of and valuing of medical and non-medical knowledge, personalised by an appreciation of GB's personality.

The ward round and the multidisciplinary meetings provided a form for multiple perspectives to be explored and negotiated creating an overall level of awareness about the complex aspects of different people's situations. Professional perspectives were negotiated, if not always agreed upon, revealing and valuing the different knowledges informing practice.

7.2.2 Information Exchange: Community Team

The community team worked within a multidisciplinary environment within the hospice, and had access to the knowledge, skills and experience of their colleagues. They required a different approach to managing and exchanging information in the community. The team were invited to provide specialist advice and skills, but had no power or authority to put their recommendations into action. The process of exchanging information was set within an entirely different context. There was a greater reliance on developing and maintaining working relationships and trust using formal processes of dialogue often without face-to-face contact.

In the hospice the community team worked within the informal face-to-face culture of the service. In the community they had to adapt their style. Exchanging information was predominantly carried out over the telephone, although there were times when the nurses met with their community colleagues, as observed on the 22nd January 2002 when PW dropped into the health centre on her patch to talk with a general practitioner and to catch up with the district nurses.

Relationships with some general practitioners and district nurses remained difficult. Problems arose from sharing work boundaries, medical knowledge, expertise, specialist nursing knowledge and skills. The expectations of the traditional disciplinary hierarchies affected the working relationship, especially where nurses offered advice to doctors. In some cases requests for advice were made only to the consultant covering the community, which affected the processes involved in the giving and receiving of information and the type of care offered.

The exchange of information by a member of the community team often required multiple telephone conversations to the different health professionals involved, the person in their care and possibly a family member. The community palliative care nurse was frequently the pivotal point from which information was aggregated, coordinated and distributed. It was undertaken on an individual basis. The nurses could spend several hours on the telephone over the course of a day, which made for a very noisy working environment.

There was very little ad hoc exchange of information because the telephone calls had to be fitted around the visits. The process involved each nurse planning when to make contact and it required knowledge of the working routines of the other health professionals, when they could or could not reach the person by telephone, when to use the fax, leave messages or get the health professional bleeped. Using the telephone was also at times a source of frustration and time loss when the line was engaged, delaying the passage of information.

The issues discussed are highlighted in the following example.

Observation of RT exchanging information about CJ (22/01/02)

Background

CJ was an elderly lady with a difficult pain control problem, who had a GP who was not always open to advice by the Palliative Care Team. CJ often rang RT in tears in the mornings about her pain and her problems. She had been an independent woman who had wanted to remain at home. She had great difficulty moving and caring for herself, despite help from carers and the use of additional equipment. She had been admitted into the hospice previously for symptom control, but since her discharge had been cared for by RT from the Community Palliative Care Team, her GP and Social Services Carers. RT had only worked in the team for four months.

After listening to CJ [on the telephone], *RT rang CJ's GP to explain that their current medication plan wasn't helping, and that CJ was in fact getting 'excruciating'* *pain in her knee. RT explained the nature of the pain that CJ was experiencing, she listened quietly to the GP, then she asked the GP what he thought about increasing the dose of her anti inflammatory medication, and gave her reasons for this advice. RT also explained that CJ had had a Marie Curie Nurse over night to provide support and to assess her pain and care requirements. After the phone call RT spoke with CS to ask for advice because the GP was not willing to increase the medication. RT then explained the situation in more detail to CS, describing the GPs' response, CJs needs, symptoms and wishes. ME the Occupational Therapist then appeared at the office to discuss CJ's situation with RT. ME explained what she had done the day before in assessing and providing equipment, focusing on the electric wheelchair and what her assessment was of CJ using it at home. RT also explained to ME that CJ wanted to be in the hospice where people 'cared for her', and not go into a nursing home. Other team members who were sat in the office also offered advice to RT and suggested she talk with KL, the consultant. So RT spoke with KL who listened to the situation and suggested that RT call CJ back and ask her to call the GP to get him to take responsibility for her symptoms. RT then rang CJ back and explained what the situation was and suggested she call her GP and tell him exactly how she felt, explaining that she was unable to get her medication changed. RT then called CJ's carer to explain what she had asked CJ to do and asked the carer to do the same.*

(CJ cared for at home, RT community palliative care nurse, ME therapist, CS team leader, KL consultant)

Different dynamic interrelated processes occurred during this episode of information exchange, which gave rise to a very different outcome from that previously seen in terms of the discussion about GB between the ward team. In this exchange different rather than shared values and expectations of care were revealed.

RT received the initial information about CJ's current situation emotionally and symptomatically, which began the complex and dynamic process of exchanging and negotiating knowledge and information with members of the community palliative care team, who shared a common set of values and with the general practitioner and social services carer who had different perspectives, values and roles. RT acted as the focal point receiving and distributing information from CJ about her pain and the basic information was relayed and described to a variety of different health professionals starting with the general practitioner over the telephone. Drawing on her symptom control knowledge and knowledge of CJ's disease, she contacted the general practitioner and relayed the information and entered into a negotiation about how best to manage the pain, respecting the doctor's authority and position of power. RT was unsuccessful negotiating a change in CJ's medication. To aid her case for the medication increase she drew upon an 'objective' professional assessment relayed to her by the Marie Curie nurse. The negotiation failed as the general practitioner did not wish to increase the medication. RT also sought information and experienced advice from her manager because she did not feel she could professionally leave CJ in pain.

The story was repeated to CS, the therapist, who provided updated information about CJ's new equipment, the team and the consultant. The consultant was aware of the problems with the general practitioner and offered advice which required RT to telephone both CJ and her carer to explain about the general practitioner not wishing to review CJ or change her medication. RT had no power and had to pass the responsibility back to CJ requesting that she ring the general practitioner and tell him about her pain, and for the carer to do the same.

The dynamic was complicated by the different values and expectations of all involved about the care provided. The general practitioner responded in a hierarchical manner, possessing the power to stop RT fulfilling her role towards CJ. CJ and her carer expected RT to be able to make a difference and be her advocate. Had RT been in the team longer she would have had a better awareness of working with this General Practitioner and how to best support and advocate for the person she was caring for. The experienced advice of CS and KL was drawn from the process of time, developing skills and practical know how in managing difficult situations.

7.2.3 Information Exchange : Hospital Team

The hospital team shared some similarities with the way information was exchanged and sought in the hospice and by the community team. As was the community team, they were based within the hospice and had access to their multidisciplinary colleagues and drew upon a shared value system. However, their main area of work was within the general hospital setting, working alongside different medical, surgical and nursing teams and predominantly with the oncology team. As an advisory service within the hospital, the team were invited to advise on a person's care within an environment steeped in and informed by traditional disciplinary hierarchies, values and boundaries. Unlike the community team only some of the information exchanged was undertaken over the telephone after being bleeped. The majority of information was exchanged through ad hoc face-to-face contact on the wards with ward staff and some information was gathered and exchanged by reading and writing in the medical notes before and after the palliative care team's assessment had been completed. The lack of one clearly describable vignette is partly due to this ad hoc corridor conversational style, very quick snatched part and full conversations over the notes trolley, in the clinical room or the corridor with doctors or nurses.

No part of the hospital palliative care team work could be undertaken without initially seeking out information and asking questions of the person making the initial referral to the team. The hospital palliative care team rarely saw anyone without having armed themselves with as much information about how that person was diagnosed, what had or had not been done to them, what tests and investigations had been carried out, what the results were and most crucially what had or had not been said to that person and their family, material not always available to the community team. This awareness was very important. The culture of the hospital environment required health professionals to know their information, as this endorsed their credibility in the eyes of the senior doctors and nurses, and credibility was essential.

CS reflected on the adjustments between working in the community and the hospital and explained the events she encounters as part of the processes involved for her in trying to carry out her work:

> *'I thought, it might well be thin curtains, it might well be a busy ward but just switch off to all that's going on around you which took me quite a time, if I'm honest with you because I felt very uncomfortable in my skin and also in a home you feel very secure because you can sort of discuss things intimately, got good relation with the GP once they know what you're like, SHO's* [senior house officers] *they're constantly changing, registrars, consultants, that you are dealing with don't even know who you are, that sort of thing, so very difficult, but you have to get your membership really. You've got to get your membership badge and gradually that came and gradually things became more confident, you have to... its a different scenario. You don't want to tread on anybody's toes. You want to work in a partnership with them but you have to, its like being invited into their homes, the consultant's home, if you like and working very closely with them and putting things - 'may I suggest..., do you consider...' and I think, 'my', and sometimes I think 'just put the things down 'cause I'm very tired'. So I just put them down.' (CS team leader: hospital team April 2002).*

The often very frightened or extremely unwell state of the people being seen required the team to gather information to reduce the effort and energies of the person they were introducing themselves to and assessing. Instead of always asking the person to go over their problems the team members would, if the person was very weak, begin by talking about the details they had attained and watched for confirmation of these facts. Often this was greeted with relief.

On the hospital wards the palliative care nurses and consultant sought the ward sister and the ward doctor to discuss the person before seeing them, and then again after the visit, updating and sharing perspectives, as they did in the hospice. This was clearly observed on the 19th of March 2002 when both CS and KL were talking on the oncology ward about having assessed IA. LN and I arrived and she talked with her team members, each updating one another before talking with the ward staff about a man under her care there. Information would be exchanged verbally during these meetings and then documented in the medical notes. This kept everyone aware of the current plans, aims of treatment and who had said what to whom. Hierarchical values would exclude the involvement of the nurses where a consultant insisted upon a consultant to consultant referral.

7.2.3.1 Power dynamics

The hierarchical power dynamics challenged the advisory and holistic approach for both the community and hospital teams. It affected the ward nurses, junior doctors and district nurses who were unable to formally invite palliative care support or symptom control. In these situations both palliative care teams were open to listening to the situation and offered off the record advice about how to approach or manage each situation or symptom control problem. Advice was offered about medications for junior doctors or district nurses to recommend to their consultants and general practitioners. The palliative care teams resisted the hierarchies of power by working 'off the record', and quietly publicising this to new staff attending teaching and support sessions.

7.2.4 Assessment Process

7.2.4.1 Admission Assessment

The initial assessment undertaken by the ward doctor or consultant, when someone was admitted to the hospice ward, was used to assess and build up a basic yet personalised set of information about each person. The nurses were not part of this assessment meeting because they felt they could rely on the doctors to tell them everything. They completed their documentation with unsung information gathered by the doctors, undertaking their own assessment separately. This was repeated to a greater or lesser extent as different multidisciplinary team members undertook their own specific assessment. Although the initial assessment had a formal purpose, it was often undertaken in a sensitive yet less formal manner, relying on both professional and personal social skills whilst drawing on a range of different knowledges.

The initial assessment required the assessor to ask questions of the person, and sometimes their family, about themselves in terms of the medical history, current problems and about their understanding of their illness as well as undertaking a physical examination of the person. Information was sought about family and social issues and their living arrangements. The process, however, was primarily discursive with the initial questions being asked and questions followed up as they arose. The information was not necessarily gathered in a linear fashion, but emerged during a complex storytelling process.

The art of gaining information was to carefully retrieve the essential comments from the stories, and follow up these when further information was required. This process gave the assessor some insight into the person's experiences, values, life histories and concerns about the future. Sometimes, however, people were too ill or weak to engage in the process. Fewer questions were asked and the information was sought from other sources, such as the family. The process was equally true of the initial assessments undertaken by members of the community and hospital teams. These initial assessments were an important aspect from which trust was developed and relationships established and built upon.

The following observational extract reveals some of the process involved in one initial assessment by the Ward Doctor.

Observation record of HN the ward doctor undertaking the admission assessment of EA, and her husband (17th January 2002)

Background

EA had been under the care of one of the Community Palliative care Team Sisters for several months. That morning she had been visited by CS as EA's Nurse was on leave. EA was suffering from increasing sickness due to her cancer and increasing sleepiness from her medication. After a discussion with EA's GP it was decided she should be admitted that day as there was a bed available, to assess her needs and to try and relieve her symptoms. Her husband bought her in from home.

'HN was very friendly and chatty as she came to see EA, who had just had a pot of tea made for her by the volunteers. She suggested they go into the doctor's office to talk. EA's husband helped wheel EA into the doctors office and began by ensuring both were seated comfortably, and then introduced herself by her first name, and explained that she was one of several doctors they would see, and that IS would be mainly responsible for EA.

HN asked EA what she preferred to be called. HN then asked EA how she was, and she realised that she was feeling very unwell. HN listened and then read through her notes and summarised her medical history – this worked to save EA from going through it all, and managed the time by being quicker, but it also allowed EA and her husband to talk about something as it cropped up. EA then took over the conversation and, with her husband, talked about her chemotherapy. A dialogue was set up between EA and her husband and then HN. This then led HN on to ask EA about how she saw her problems. After EA talked about these, HN picked up on something she had talked about and asked about how their family was, who the members were which in turn opened up a conversation about their daughter and grandchildren, during which both were visibly choked and tearful. They explained that they had talked to them about their 'nanna' being ill. HN acknowledged this and the closeness they had with their grandchildren, and how hard it must be and how important they have been. (HN told me after that she had said this to see where they were with things and what they understood about it.)

HN then asked them to go back to the bed area so she could carry out a physical examination and assessment and, she helped EA get onto the bed and get comfortable. In doing so HN made an observation about EA's pyjamas, which acted as a point of contact and social interaction and they chatted in a friendly way about the niceness of cotton. HN then asked if she could examine her and carefully placed her hands on her abdomen and felt over it, whilst talking to EA. HN then asked to listen to her chest, and I assisted HN support EA sitting up. HN also raised the cot-side so EA also had something to hold onto to give added support. Afterwards HN was very careful to ensure EA's pyjama top was re-buttoned and pulled down properly. HN noticed EA's *ankles were swollen and asked about them, then said she would leave them as they were and she would see tomorrow what they were like after EA had settled down. HN finished by asking if either of them had any further questions to ask'.*

The doctor guided the beginning of the assessment and began with the question that every member of staff throughout the service asked of each other and of the people they were caring for 'how are you? A simple question, which allowed the people to answer any way they wished, and often opened up the primary concerns and main problems troubling the person offering the assessor a place from which to start their assessment, rather than using a formulaic approach. Also because of its simplicity, and everydayness, the use of such a simple question was one which most people were comfortable answering. As the conversation developed EA led its direction and HN asked questions, as key aspects of the information she required arose, such as who was in the family and what they understood about EA's illness.

Even when undertaking the physical examination, the doctor used her other senses and skills, observing swollen ankles but asking about them in a casual manner without causing concern. The process was drawn to a close by returning to the concerns of EA and her husband. The lack of a formulaic approach to gathering information enabled the process to be focused on and responsive to the person's needs and priorities rather than completely directed by the doctors. Any other information would become clear as more members of staff spoke with EA or her family, piecing the picture of the person, their illness and family together by working as a team.

7.2.4.2 The Community Assessment

The majority of the community first assessments were undertaken by the nurses. Visits were arranged by telephone contact where the nurse was able to begin to assess how the person or family were managing before visiting. Some people had met the hospital palliative care team, others were new to the service. Previous contact with hospital team, meant CS or LN would have talked with the community nurses about the person, their situation and needs. Where there was no previous contact the community nurses often call the general practitioner to confirm that they consented for them to visit and to discuss the person's situation. The following example is of the first visit undertaken by DA to WA. Often home visits revealed more than the person's physical and emotional status, as the nurses could never know what the housing would be like they assessed this as well as the person.

Observed first assessment visit of WA at home with DA on the 11th February 2002

Background

WA had been referred to the Community Palliative Care Team by his haematologist, after completing radiotherapy treatment for a lymphoma, which was causing him trouble breathing. He lived on the edge of the patch in his own home with his mother. DA had made contact with WA previously, had spoke to him on the telephone and arranged the visit sometime before, but had not visited because of his daily trips for radiotherapy. He had, however, been referred to DE the Social Worker, who had tried to help him get some financial assistance.

'A woman in her seventies answered the door. DA smiled and introduced herself. The woman said 'hello' that she was WA's mother and that they had been expecting us. We were invited into the sitting room, where WA was sitting by the window.

DA was very pleasant and friendly and spoke in a light lifted tone as she sat on the sofa facing him. This was not an established relationship and was highlighted by the more formal informality used by DA when talking to WA. DA sat facing WA and his mother. DA began by asking how he was feeling in a friendly casual conversational tone. WA said he felt his radiotherapy was making a difference and he thought the break over the weekend had helped this.

WA asked if it had been said in a rhetoric manner, if this was normal with radiotherapy to the lungs. DA confirmed this and asked if he was still taking the Oromorph, which he said he did at night. She asked if he was taking his painkiller *regularly. He said he needed to over the day. DA said that some people leave it until they are in pain before they took their medication and then wait for it to work, and then you are chasing the pain all the time, so its better to take them regularly to get on top of it'*

WA then said he had been give some codeine linctus, but this hadn't agreed with him. DA asked how often he was taking the Oromorph and said he could take this up to 4 hourly and up to double the dose if he needed. WA received this as new news.

DA moved on and asked how his appetite was. Each question was interspersed with some conversation, and so it was more of a information finding and information giving conversation, rather than a list of questions to be asked. WA explained his appetite was ok, his mum added that he was eating less and this developed the conversation between him and his mother about the fact he didn't expend as much energy as when he was working – he said he didn't run up and down the stairs like he used to. DA then asked about his bowels but used the phrase 'how's the other end'. He said he was no longer taking the senna as 'the other stuff' was working.

DA said he was doing well, and she was encouraging and upbeat, and then the conversation turned to work. She asked whether he had heard about the income support. He said he had received the Disabled Living Allowance and Mobility Allowance last week, but the Income Support only sent a cheque for £3. DA was astonished and she asked if he knew why and then added DE would be horrified. He said DE was coming out to see him soon and said he thought he could see why, and explained that it was worked out alongside the weekly amount for the minimum wage and that it could have been sorted out sooner. DA said DE would be upset as she had expected him to get a large sum paid back. WA said perhaps it was related to his National Insurance Payments. He then added that his bank had taken out money for the mortgage without notice from his account and that they were supposed to be in discussion with him about this.

DA actively listened. WA said he couldn't be bothered as his repayments were reducing, but then said exasperatedly how awful this was but that the DLA and

Mobility Allowance would help. DA said that they hoped to get him enough to help out without struggling. WA said again how helpful DE was.

DA then moved the conversation on to ask how the family were and he and his mum talked about how his brothers helped. This opened a conversation about hoping to go to London to an exhibition in a few weeks and that a wheelchair had been ordered by his district nurse but had not yet arrived. DA then said she would be away next week, but she would contact the district nurse to let her know and when she got back, if the chair still hadn't arrived, she would see if they could borrow one. His mother said that that had answered one of her questions. Another brother was helping with the driving and another building an aquarium for him.

Then his mother asked if the radiotherapy could be used to treat other areas of his body which had the lymphoma. DA gently but clearly said that this wasn't curable and that the radiotherapy was to help treat the symptoms, which he was having in his lungs. His mother asked about his spleen and again very gently and clearly DA said that it couldn't because of damaging the organs around the area and that the best treatment was chemotherapy, but this hadn't worked. She then said that his consultant wanted to keep an eye on him and certainly wouldn't give up.

His mother said they hadn't got an appointment to see the consultant. DA said that this was probably due to his having radiotherapy and said that she was sure he would want to see him and then she read from the letter in the notes in which his consultant had asked his colleague for the radiotherapy and any further advice about treatment. WA's mother was pleased to hear this. DA picked up that she was perhaps not entirely ok as she said everyone kept asking for information. DA offered to talk with the brothers.

DA then asked his mother how she was, and she talked about her arthritis and that she wasn't sleeping. DA asked if this was new. She said it was since WA was diagnosed. DA asked if she had been to the GP, and suggested asking for something – she said she was trying a natural remedy and DA was supportive and said it was certainly worth trying. She added that it must be hard for her, and said empathically *'no parent expects to see their child become ill before them'. WA's mother began to cry, and DA got up off the sofa and knelt in front of her holding her hand and knee and as she cried. DA again said this must be hard and let her talk and WA went out of the room. On coming back he made eye contact with me, and wandered about in the room before sitting down. DA spoke some words of comfort then bought WA into the conversation and began to lighten the tone and as this happened there was some laughter as she talked with them focusing on helping WA to live life. She was saying how difficult it is watching the person with the illness*

Somehow DA was there ahead of the questions WA and his mum wanted to ask. DA offered to find things out for them and moved the tone and pace according to what was being talked about. She rounded off as they all do, with asking them if they had any other questions . She then reviewed what she was going to do. She confirmed that DN would be in next week, as they alternated weeks.

During the conversation DA had mentioned the Support Centre in terms of relaxation and reflexology as a way of helping – this was after WA's mum asked about the benefits of complementary therapies. She suggested they both came to the Support Centre to see her and said, ' not that you might ever need to come in, but you can have a look round and see the place'
(Observation notes 11th February 2002)

DA began by introducing herself, using a friendly and down to earth style whilst also polite and respectful. DA was after all a guest in their home. She began by asking a very open question, 'how are you', which allowed WA to talk about what was most prominent in his mind, about how he was feeling rather than being directed by DA's priorities. For WA it was the effects of his radiotherapy making a difference, but that he still had problems with his cough and breathing. Thus DA began by following-up and assessing his main symptoms, offering some information about using his medication and encouraging his management so far. Positive reinforcement was an important aspect of encouraging coping behaviours.

Questions related to his physical condition, his appetite, bowels and observing his ability to move and walk around provided a baseline to monitor changes. To prevent the experience being like an interrogation, the questions were interspersed with conversation, and further small inquiries as DA carefully build up her assessment of his problems and needs.

The holistic focus enabled discussion about his financial problems and that DA had been talking with the social worker who had been trying to arrange his benefits over the previous couple of weeks. This reinforced the team approach, leading on to a conversation about his family support and at which point his mother entered into the conversations, although DA had engaged in eye contact with her throughout to include her. DA was able to identify who was in the family and how they were able to help, just by gently exploring the conversation, without asking any specific questions.

When WA's mother asked about the possibility of more treatment, DA sensitively talked about the incurable nature of WA's disease. She reassured her about the continued contact with his consultant, and read an extract from the consultant's letter to confirm this. What this achieved was to support her comment and to prevent his mother from feeling they had been forgotten.

By focusing on WA's mother, DA was able to provide advice, information and emotional support, especially by verbally acknowledging the mother's pain at the prospective death of her son. DA used her experience at identifying her concerns, and used touch and closeness to provide a degree of emotional support or comfort. DA was able to judge the tempo of the conversations to stop and listen and then to move the conversation on, which is how she bought WA back into the conversation as his mother stopped crying. DA seemed to intuitively know the questions that were on their minds and raised them and addressed them before they were asked. As she moved the conversation out of the painful emotions of the mother, she provided some sense of hope in terms of offering to help by organising and arranging things for them. She took the focus away from the emotions to a point of coping. Then before ending reviewed what they had discussed and what her plan was going to be, therefore, creating some degree of containment and emotional safety, and a sense of something being done to help. She also offered them the opportunity to visit the hospice in terms of using complementary therapies. This was a method the nurses used to introduce people to the hospice, addressing their conceptions about it sometime before it was anticipated the person might need an admission.

Working within a person's home requires a great deal of sensitivity, awareness and astuteness. Being present, in terms of answering questions, being flexible and being able to follow a persons key issues, picking up the information needs and addressing the emotions as they arose, were important since a poorly handled visit could prevent the nurses from being permitted to return.

7.2.4.3 Ongoing Assessments

Information was gathered from a range of different approaches from the verbal, visual, aural and nasal senses. During this aspect of information gathering the dynamic interaction with the different forms of knowledge held by each member of staff alerted them to relevant information worth gathering about each person or situation. This information was either stored until it formed a significant concern, picture or pattern or was shared and exchanged with colleagues during the ad hoc update chatting or during formal meetings and telephone conversations.

Standing looking into a room from a distance enabled the ward team to observe a persons colour, behaviour, their breathing, facial expressions and those of their visitors and to hear how they sounded; whether their breathing was normal, slower, laboured or bubbly, and whether there was any smell coming from the room. In her interview JF, one of the ward doctors, talked about how valuable just noticing such aspects about a person were to assessing their current status and becoming aware of changes in their condition. She commented that noticing changes came from spending time with people enabling the detection of even the smallest of changes, which might be significant.

In the community the frequency and the nature of the information gathered or given often required the nurses to rely on verbal reports and descriptions from the person themselves or from family members, district nurses and general practitioners, until visits took place. Therefore, the nurses, doctors, social workers and therapists develop a finely tuned sense of awareness, picking up on small details and comments in the way the person had spoken, the tone and strength of their voices rather than on the use of visual observations. On the hospital wards the team would talk with the ward sister, staff nurse or doctor looking after the person and explain their observations and what these might indicate.

Shared understanding of a person's changing condition was expressed in the contextualised and relative use of various terms or metaphors. The terms 'not well' and 'I think she is really going down' were always expressed in relative terms specific to that person, so that someone who could be quite well relatively speaking were, in fact, dying. The ongoing gathering and reviewing of information was considered in light of the original assessment and the subsequent developments over time. This was a process that was common throughout the work across the different teams within the palliative care service.

7.2. 5 Chatting

Chatting, was one of the most common aspects of the interactions between members of staff and also commonly occurred between staff and the people being cared for throughout the day, whatever their position or professional role, and across the different teams. Chatting was an informal and friendly component of exchanging information, serving a much wider role in enabling and facilitating all of the other processes of care to occur.

As a social process, chatting was fluid and multifaceted. It enabled exchanges about personal and social information between staff and between the people being cared for to flow smoothly from one to another. The flow of topics varied immensely yet the 'updating' and 'catching up' process was an aspect all members of the ward staff, including the consultants, engaged in, moving seamlessly between personal and professional information in a conversation. Chatting was a proactive component of building and maintaining trust and personal relationships and was a component of accessing and providing individual support, revealed through the openness and willingness of people to listen to personal or professional concerns and to respond to these.

On the ward, chatting between the staff was often care focussed and occurred throughout the shift. The nurses would chat to one another as they emerged from behind the closed doors and would often catch up with one another about what they had done so far and where they were at in terms of the care they had provided and to whom. This often enabled the nurses to be flexible and adapt their plans for the shift and also enabled the team to respond to changing situations.

One of the health care support workers explained about the role of chatting:

> *DF: ' I think it saves a lot of time wasting to be honest, obviously, if I know how far my colleagues got with whatever she's doing then that's freeing up time, extra time for me to be spending with whoever, rather than sort of extra running around finding out what's been done. So its just good to keep up to date and to know what, what's going on in the unit really' (DF Health Care Support Worker January 2002)*

Chatting and updating made the nurses both more efficient and equally more responsive to the changing needs of those being cared for and their families. Chatting was also supportive and enabled team members to be aware of and offer support during difficult situations. Chatting was recognised and valued as a pivotal aspect of communication throughout the ward between the different members of the team and as a vital component of providing care.

> *HN: 'I think most of the multidisciplinary meeting work is done person to person like talking to LD about the man in the next room, or to ME about someone and from the morning meeting. I think RU is very good about passing things on to the other members of the team who haven't been here; but for myself I'm probably not very disciplined but I speak to them* [the nurses] *when things come into my mind. I'll probably go and find them having their coffee and say something. But errr, I think there's lot of interchange but I think its often, um, informed...Its that sort of intimate 'by the way, guess what, look*

> *what I've noticed, can you help with this'. That's what works best with, if we can do like that, and when I first worked here I can remember being embarrassed at being in the coffee room on several occasions, when KL came in and I said 'I hope you don't think I'm always in here' 'cause I always seem to be here'. She said 'no' she said 'I regard this as the most important part of unit because its where a lot of the interchange goes on'. That's perfectly true and its nice to know that's recognised and its okay' (HN Staff Grade Doctor October 2001)*

The informal nature of the exchanges revealed a degree of equality, mutual respect, trust and shared understanding, which increased general awareness, informed observations and decision making throughout the range of care and caring processes.

The process at times was a little like gossiping, but without the negative context or connotations with which this word is usually associated. The aim of sharing and collecting the bits of information was for the good of each person's care. Unlike gossip the information was not necessarily unsubstantiated or unfounded. The service had constructed its own social relational medical approach to care which was employed through a range of processes including information exchange and chatting rather than relying upon a technical-medical model limited in social interaction.

This social process created a space in which small and often symbolic observations about physical signs and changes in a person's condition could be raised along with the feelings and intuitive sensing about situations with the person or the family. Often a combination of the observable and the intuitive could be discussed and was valued within the spaces created by the ad hoc chatting. Through the negotiation of each other's observations and information, new information or explanations would come to light, or a picture or pattern would begin to emerge about a newly developing problem.

However, the lack of private space for staff meant many, although not all, of these conversations were held using lowered voices at the nurses' desk, in the corridor or in the clinical room and could sometimes be overheard by passers by.

The informality of chatting was signified by spatial relationships, team members working in close proximity chatted more often and developed supportive relationships. The ward team chatted socially and about work concerns, as did the social work, community and hospital teams, in the offices upstairs. The therapists, doctors and administration teams chatted with people on the ward and in the upstairs offices, but did not have such close working relationships.

Most of the conversations over the telephone, with additional service providers, required a more formal conversational tone and language. The social relational medical approach to chatting and exchanging information within the services was adapted to fit the predominantly technical rational medical approach with other health and social care providers with subsequently reduced social interaction. Where there were good working relationships the style became less formalised, more socially oriented.

The hospital team used both formal conversation and informal chatting in their interactions on the hospital wards. The different approaches had different purposes. The formal conversations, set within a technical medical approach, were held with senior doctors, consultants, and with staff on the wards that were infrequently visited by the team. The formal conversations were used to present facts, knowledge and advice and to seek information from those with the disciplinary power to make decisions based on the team's advice. Acceptability and credibility was important for the hospital palliative care team, in building the trust of consultants and nursing teams unused to palliative care, or with misconceptions about palliative care. The way the team was presented was a very important aspect of the choice of formal and informal conversational styles.

Informal chatting tended to occur with nurses and with junior doctors, with whom the team had developed good working relationships, predominantly with the oncology and the gynaecology wards' nurses and doctors. The chatting created a space to ponder on observations, experiences and intuitive thoughts about people and to check these out with the team who would be caring for the person. It was also used to enable ward staff to feel comfortable, put them at ease and reduce the power balance, so they could ask questions about issues they were not clear about, such as symptom control or how to work with a particular family. By being friendly and sociable it made the team more approachable, which enabled the team to informally teach the ward staff about the basics of palliative care and also to be supportive. However, when the hospital team wanted to ensure their advice was acted upon or when they were advocating on behalf of a person in their care they changed into the more formal style of conversation as was observed on the 6th March 2002.

The palliative care service used normal social relational processes and an egalitarian way of conversing and chatting in order to reduce hierarchy, build team identity and trust and to create a sense of 'normalness' for those being cared for. The use of chatting had an everydayness to it, which increased the degree of openness and inclusiveness within the service and in the working relationships with the people being cared for. It offered a degree of normality into a highly abnormal situation.

7.2.6 Documentation

Documentation was a central tool for the recording and archiving of initial and ongoing assessments, planning and evaluations of care. Each team recorded notes separately after undertaking particular aspects of care within the ongoing process, recording what had been done and what had been said. The notes were used as a record and repository for the information collected over the day and over time and had a role in defining accountability. However, there was a clear difference between the ward nursing team and the other multidisciplinary teams in what the documents recorded and the implications this had for care.

The therapists always recorded the person's subjective account of their problem, an objective professional assessment of the problem, an overall assessment and a mutually agreed plan, enabling a greater understanding by the therapist of the person's expectations allowing for a plan of care that was shared rather than professionally driven. In some respects this was similar to the medical, hospital and community team notes which usually contained a subjective assessment by the person being cared for about how they felt that day, but were recorded more infrequently because contact was less frequent.

Medical notes were brief and to the point and included a subjective assessment of how the person felt, and the observations of the doctor with a list of the current problems and sometimes a brief explanation of what had been discussed. A plan was set out which incorporated information about potential problems, their possible causes, treatments and plans for the future. Commonly the person's first name was used when describing the assessment of how that person looked and what they said. This personalised the exchange within the notes. This format was repeated by the members of the hospital team, when writing in the hospital notes and their own palliative care records.

The community team focus was equally shared between physical problems, symptom control issues and emotional concerns and family support. Anyone picking up a set of community team notes would be able to read what had happened over a period of time, what had been said to whom and by whom and what each person's concerns, wishes and aims were. This could not be said of the hospice ward's nursing documentation, which was based on an adapted model of the Activities of Daily Living, and had one overarching problem for psychosocial support. Physical care was placed at the heart of the documentation and the apparent focus of the nurses' work.

The personalised approach to assessment and evaluation, drawing upon the subjective account of the person being cared for was rarely evident in the ward nursing care plan documentation in which the problems were defined by the nurses rather than with the person being cared for. It became clear that what was not recorded was as important in the process and knowledge of care as what had been recorded.

The nursing care plan documentation was divided by different problem oriented care plans and evaluation sheets, creating a fragmented collection of information, which did not give an holistic account of either the complexity of the care provided or the creativity and processes involved in meeting each person's differing needs. The personalised care that was observed was not recorded and the rich matrix of information that was exchanged verbally was not revealed clearly or, at times, ever recorded. Undefined information, that which was not considered a problem, was, placed on a separate sheet, which became a repository of unconnected pieces of information. If it was not defined as a problem it was not clearly accounted for.

7.2.6.1 Lack of Documentation of Necessary Information for Care

The preformatted care plans were rarely personalised with particular details specific to each person's care or preferences which would enable a bank nurse to pick up the document and 'know' how to approach a person's care. The reliance on verbally sharing the information and holding it within the general shared awareness of the team increased the risks associated with particular aspects of care for ST.

ST was a woman with advanced breast cancer who had fractures of her neck vertebrae, her collar bone, her shoulder and femur, requiring precise and careful actions by an informed team of at least three nurses to move her without causing further damage or pain. No instructions were recorded about how to move ST and there was no problem identified in her care plan for her immobility. The nurses 'knew' ST well and despite an obvious sense of emotional caring for her, the decision making and the planning behind the care was not revealed in the documentation, although discussed during meetings. ST had a care plan for pain, bowel care, urinary problems, sleeping problems and psychosocial support for relatives. The reliance on the verbal exchange of information placed the high quality of care and ST's safety in danger. DF, a health care support worker, explained she was involved in trying to move ST in bed with a colleague.

> *DF '...Maybe it should have been more structured and maybe each time there should have been three people Each time she was moved and I know on a late that can be made really difficult but it could of been done...Part of me just thinks that there should have been maybe a hard and fast rule that if I'd know when you, you know, when you need to move her, you just ring for a third person to come. You know, not to be there all the time but particularly on moving her up the bed. So, I felt absolutely awful' (DF Health Care Support Worker January 2002)*

There were no formally written guidelines, no descriptions. The lack of continuity contributed to the less than ideal manoeuvre. The knowledge about safe handling was not made concrete, and had implications for all forms of care for everyone. The comparison across the nursing notes revealed the same patterns. Dependence on fluidity and the responsivity of information and knowledge sharing by the team personalised care at one level, however, by not stabilising and concretising specific care knowledge. This also increased the risk of poor and dangerous care when core team members and knowledge holders were not present. Specific knowledge was not accounted for, challenging and preventing personalised care.

The nursing discharge forms were purely problem orientated, brief, and rarely personalised. This completely masked the complex dynamics involved in providing and engaging in different aspects of care, revealing physical care being valued as important for the nursing focus, rather then the holistic.

7.3 Supportive Care

Support was a central component of the process of care and consists of a combination of knowledge, actions, attitudes and manners that were not always easy to identify or for people to describe. The nurses and the other members of the multidisciplinary team used the word 'support' and talked in terms of the concept of feeling supported or supporting others. The people being cared for did not use this word at all, but described actions, attitudes and mannerisms that made them feel cared for and helped them in a variety of ways. By combining the interviews with the observations of episodes of care with people in the hospice, in their homes and in the hospital it was possible to develop a greater understanding of the components of support and how integral these were to the process of care.

The concept and the components of support appeared both in terms of the process of providing care for the people throughout the different areas of the service and also as an aspect of teamwork, supporting and caring for one another. The analysis was, therefore, divided between the process of support for the people being cared for and the process of support for the staff. The important aspects of supporting others was developed through building and maintaining relationships, working with emotions and coordinating and organising the services and being person centred and family focused. The key components of these aspects of support are built upon the actions of talking and listening and of a personal and organisational value system, which respected and valued the other person, regardless of who they were.

7.3.1 Building and Maintaining Relationships with People Being Cared For

7.3.1.1 Use and Presentation of the Self

The introduction to the members of staff and to the palliative care service is an important step in building and developing new relationships with people who are referred to in the different areas of the palliative care service. Initial impressions were seen as important in developing and gaining trust. During a conversation with LN on the 11th March 2002 she described part of her role in terms of 'public relations' because of this aspect .

The development of the relationships varied in the different locations of care. When a new person was referred to the care of the community team or social workers, the relationship commenced with the first telephone call by the nurses to arrange a time to visit the person in their home, or with staff in a nursing home. DC, one of the community sisters explained how she approached these initial meetings by trying to be relaxed with people and gently finding out a little about them.

> *DC 'I've sort of told them about me first and what I do and where I fit in, 'cause anyway I think they need to know why they're telling this stranger that's walked into their house so I actually tell them about me and then I say, 'I'll tell you about me and then you can tell me about you' type of thing and I think that seems to work quite well 'cause then they seem to be quite happy to open up and I normally say something like 'what's been happening to you?' to find out what their views of what's been happening to them as regards their*

> *illness are and sometimes it works really well and if their good historians and if they sort of move on from one subject to the next without me so much changing a subject and do what I need to do and sometimes it's a bit of a muddle which is fine but it just depends, you know, how their thought process work really... what they're expecting as well. '(DC interview: Community Team February 2002)*

By trying to put someone at their ease, this sometimes enabled people to talk about what mattered to them and what was on their mind, and to clarify their perceptions about the palliative care service. The use of reciprocity, in sharing information as a way of building trust, was used to facilitate the process, which is something more akin to building a friendship rather than a professional relationship. Trying to get to know someone a little, what is important to them, as well as finding out information about their condition and their needs, enabled the nurses to initially begin to develop a picture of how to work with the person, what language to use and areas of general interest to talk about. Another important component to the process of building and maintaining a working relationship with people was how the nurses managed the presentation of themselves and adapted their personalities over the course of their involvement with each person and their family.

> *DC 'I certainly adapt how I am with different types of people, yes I do, because I think in order for there to be a rapport or for them to feel comfortable, certainly I don't know at first, I do change how I am with people and depending on what their mood is or who they are to some extent, and yet I don't like to feel that I'm false in any way but I just, I do, you know the language I use at different, is different with different types of people certainly and how much detail they want obviously is different. '(DC interview: Community Team February 2002)*

This process is helped when the nurses like and get on well with the person, but it is often harder when they do not get on or like the person very much, and yet they must provide professionally equitable care, advice and respect. It is recognised, within the service, that the development of the interpersonal relationship is central to providing good community palliative care and being able to continue to enter peoples' homes. It was also acknowledged that, where there is difficulty in establishing or maintaining a relationship, it might be necessary to offer the person the opportunity to have a different member of the team. Although for most services, this is difficult. CS as team leader would take on this responsibility if it occurred. In her opinion it was preferable for the person being cared for to

> *'feel comfortable and to be able to relate to somebody' (CS interview April 2002).*

CS also spoke of how some peoples' anger and distress at the dying of their loved ones could precipitate difficult relationships:

> *CS 'Now, when I went back to do the bereavement follow up, she had somebody valuing the house and so said it was inconvenient for me to call and I could have said well 'shucks lady' but I didn't, I went back. I thought I've got to, for my own salvation want to go. We offered her a different palliative care sister which she turned down, um, 'cause, you know, ... and I said 'I don't think I did the best for you, that I could have done' and she looked at me and turned round to me and she said 'No', she said 'I just used you as my bat 'cause I knew I could be so bloody horrible to him, 'cause I felt so awful about everything and you just used to take it and never criticise or said a word.' (CS interview : Hospital and Community Team Leader 2002)*

However, for most of the time, members of the multidisciplinary team developed and built trusting working relationships, by using themselves, their social skills, disciplinary skills and knowledge with people in their own homes. This was valued by the people being cared for, who would refer to the nurses, and also the consultants they had met, as being 'natural' and 'friendly' with them, and this was highlighted in the interview with CA and his wife.

W *... yea and of course, because you can talk to her* [community palliative care nurse] *more openly than you would sort of talk to your GP and talk to her about other things like when you see the doctor, its a case of going in and telling them what's wrong and that, you can't discuss anything in that hospital, what's sort of wrong with yer*

CA *with RT you can. Or, I find I can. So, that is, she shows you that she, that gives us the impression she, she sort of comes over that she really cares for you in way she talks, the way she behaves, her whole general attitude*

W *there's more of a friend there*

CA *more of a friend...* [later talking about KL the Consultant] *...she was natural here. She didn't have that air about her that oh I'm the doctor I know best attitude'*

(Interview with CA, who had cancer and his wife WA, cared for by the Community Team January 2002)

Rather than putting on a performance, the nurses felt they were drawing on different facets of themselves to facilitate the developing relationship and, in observing them, this use of the self was corroborated during the observations during January/ February 2002. In the hospital, however, the nurses spoke openly of presenting themselves in different ways and consciously thinking about this in terms of a performance, not just for the person who had been referred to their care, but also for the surrounding people on the ward. Often the palliative care nurses or consultants would arrive unexpectedly at an unarranged time in the day, and begin with what was just another face.

EG, the lead nurse commented that everything she did in the hospital was a form of performance, even when talking behind the curtains, because there was no privacy in a hospital ward, and people could hear what was being said, despite the curtains being drawn. She explained that sometimes the people in the beds surrounding the person she was going to see appeared tense and concerned before she pulled the curtains to talk to the person about their illness and the problems they were facing. She noticed that when she had finished talking to that person those in the beds close by often appeared more relaxed, as if what she had said had also made a difference to them and their perception of their neighbour's situation.

This is the performance, using oneself in a busy environment, which offers little or no access to privacy. The palliative care nurses and consultants managed the difficult subjects of diagnosis, symptom control, dying, and the emotional distress of the person with the awareness that they could be heard. The way the team introduced itself, talked with and learnt about that person affected how they were perceived by those in the beds close by. This was unlike the usually private situation in a person's home, where no one else could hear or see what was being discussed or taking place. The performance in the hospital setting was valued as important in terms of challenging perceptions, making palliative care more acceptable and trying to remove some of the fear and stigma associated with it. Performativity in developing trust and working relationships were also aspects of the community team's work. How the team introduced and presented itself and explained palliative care to people newly referred to them, or new members of community staff, affected whether their care would be accepted or not. Performativity was essential in breaking down misconceptions and concerns about palliative care, enabling care to occur at an organisational level and face-to-face.

In the Hospice ward, the people being admitted were usually 'known' to the members of the hospital team or community team, but had yet to experience the ward situation and develop relationships with the ward staff and members of the multidisciplinary team. The work across the different locations of care and the ease at which the nurses and doctors could talk about the person and their family's needs enabled this to be used as an aspect of developing trust. Not having to entirely start from scratch was helpful, and a degree of familiarity was useful in referring to the nurse and doctor who had been involved with the person prior to admission, reinforcing the notion of shared awareness. Sometimes the community palliative care nurse or hospital palliative care nurse would come on to the ward to say 'hello'. This helped to reinforced the fact that the members of the service worked together and that a person had not been abandoned by someone in whom they may have developed a great deal of trust.

There were slightly different approaches used by the different disciplinary members in developing and building trust and developing working relationships. The nurses often tried to find a point of common ground to talk about, be that children, television programmes, the persons hobbies or interests, even the Royal Family. Sometimes trying to build rapport did not happen easily and yet finding the right subject to chat about could entirely change how the person being cared for responded in the future. CD, one of the staff nurses, during her interview talked about this and how she had been finding it difficult to build a rapport with one woman until she made a comment about the Queen Mother, after which they talked for some time This appeared to be the thing that made the difference and after which both she and the woman were able to begin talking about other things of importance and eventually her illness.

Humour was also an important part of managing and developing relationships with the people being cared for and was shared across the disciplines. Humour could help disperse stress, tension and difficult situations, and was a great equaliser between people. Laughter was often heard coming from the bathrooms, as people chatted whilst having their baths, and from the staff room and offices. Observing YA on the 12th September 2001 having an assisted bath, it was YA who told the jokes and continued to do so during her stay on the ward.

For ME, the therapist, developing trust and building a working relationship with the person being cared for was an essential component of the care process since the acceptance of advice and help at home on discharge depended upon it.

> *'when you begin to build up the trust and its only then that I feel that, having gone through that process and assessed and pulled strands together that you're in a position of them trusting you sufficiently, um, for your advice and provision of what the format takes to hold any weight really, um, and you've got to earn that and it takes time for that therapeutic relationship to be established'(ME interview: Therapist November 2001)*

There was a less obvious degree of performance on the hospice ward, since the nurses would have had to be performing all shift long and act differently with each person. Instead they presented a continuous work persona, but still adapted this to the different emotions and sensitivities of the person they were working with or caring for, rather than changing how they presented themselves each time. HK and JS both commented in their interviews that the work persona occurred when putting on their uniforms at the start of the shift. The use of two teams of nurses also changed the reliance on one person having to manage and maintain the working relationship with the person being cared for, as in the community team. The team offered a range of people and personalities for the person to talk to and develop closer links with. The details and concerns expressed with one member of staff would then be shared between the staff as they exchanged information throughout the day.

7.3.1.2 Building and Maintaining Relationships with Multidisciplinary Team Members

The development and maintenance of working relationships between staff members was perpetuated by the focus on teamwork. Within each discrete team, the members relied on one another for advice and assistance and chatted about social and personal concerns as well as work issues. The arrival of a new member of nursing staff to the service involved a period of time spent on the hospice ward before joining with the community team. This was designed to begin the development of links and working relationships between that person and the members of the multidisciplinary team, to understand how the ward worked and what it was like. The person learnt the culture of the service and became immersed into it, becoming accustomed to the implicit and explicit rules of everyday interactions.

The culture of chatting and close teamwork required team members to get to know one another, who had what experience, what knowledge, how each other reacted, who had what strengths and what weaknesses. It was only over time that the work friendships developed, extending for some outside of the working environment. Trust, respect and openness were important components of building and maintaining working relationships between the different members of staff across the service, and was clearly visible during the many episodes of chatting between members of the different disciplines. Throughout the service 'getting to know someone' appeared to be important for the staff. It was an aspect of the culture that personalised working relationships between members of staff reflecting to a degree those between the staff and the people being cared for. What this suggested was a culture that valued people for who they were rather than what they were.

One of the staff nurses talked about how the social aspect of developing working relationships had an important role to play in creating and maintaining the cohesive supportive nature within the ward team, and how this created a much more relaxed working environment:

> *VB 'I think we're a very supportive cohesive team. We choose to see each other socially, we have nights out now and then, I think that's very telling, otherwise we wouldn't do it if it was just for the sake of work, we do it because we enjoy each others company but I think that is also very good for bringing us closer together and that's very important in this situation that we get on well together, because although nothing is said, that again, you know, intuition, if it will tell the patients, they often comment on how relaxed and secure they feel and if we didn't have these relationships between us, we weren't comfortable in each other's company and worked well together, then, I don't think that would be quite the same. And I think, you know, things like the OT and Physio, ... as you would expect we're not working with them every day but we get on well together' (VB interview: Ward Staff Nurse November 2001)*

The relaxed and supportive working environment was seen as both important in creating the feel of the ward and contributed to the sense of safety and security for the people being cared for. This was also commented upon in interviews with some of the people being cared for there.

ST had been admitted to the ward on several occasions for different episodes of care, had observed the ward and the interactions of the staff.

> *ST 'The nurses here in the palliative care they like the work they're doing. You can see that by the way they do it. They enjoy it. They enjoy each others company as well as the patients.' (ST interview: person cared for on the ward October 2001)*

The friendly chatting held by staff at shift handovers and during coffee and lunch breaks about home life, social events as well as work issues was picked up on by ST. The relaxed style of interaction was then repeated with the people being cared for who were able to engage in social chitchat.

Away from the ward, the community, hospital and social work teams had developed supportive relationships, which provided the opportunity to talk about emotionally heavy days or difficult situations with colleagues who appreciated the pressures and similar circumstances they worked in. The nurses and the social workers would wander in to each other's offices to talk about a person and then go on to talk about the situations on their mind. The shared awareness of situations and their contexts was important in developing mutual understanding between the different areas of care, the different pressures and the politics the different team members experienced.

7.3.2 Organising and Coordinating Practical Support

Much of the work of the community palliative care team and of the social workers was the organising and coordinating of care and services for people at home. This was part of the process of care in terms of supporting people to continue to manage physically at home as well as emotionally.

Organising and coordinating services was very much valued by people at home as an integral part of being cared for by their community palliative care nurses. Identifying the needs of each person and activating access to the resources and services enabled people to stay living at home for longer, even dying at home, and also helped maintain some sense of normality. This was appreciated because people felt overwhelmed by coping with their illness and trying to adapt to their changing abilities. The help received setting up services, organising disabled parking permits, getting attendance allowance forms filled out and talking to the doctors about their symptoms on their behalf enabled the person and their family to focus on coping with their problems and managing each day, as commented on by

> *EA : and then as I say DC's done so much for us, its unbelievable. She got us a, the, um, the thing for the car, um filled out all my forms for me, straight away,*
> *HA : Free tax, care money and all sorts*
> *EA: everything*
> *H: Yea, she's been a real help she has*
> *(Interview with EA and her husband at home January 2002)*

During his interview CA described RT his community palliative care nurse as:

' 'my intermediate between me and my doctor' (CA: January 2002).

However, during an observed visit at home to KU, he said that DC was:

'the only one who guides a path through the different opinions' (KU: January 2002)

He felt his consultants communicate between themselves and that DC was the only one who bought it all together and helped move things forward.

Assessment and experience were components of being able to consider the needs of each individual and to think ahead about what might be needed. Acting as an advocate was important in talking with consultant and hospital appointments systems on behalf of people who did not have the energy or the confidence to do this themselves. The nurses or social workers then informed the other health professionals involved and the person about what they had done. The social workers often spent time on the telephone trying to chase up benefits for people in financial need. The following extract from the observations undertaken with the social workers revealed the process of coordinating the information and tracking down information required to help get the correct financial benefits for a man being cared for at home.

> *'DE then makes a telephone call to the benefits agency to chase up the benefits for someone; She makes another to ask for information about benefits for industrial disease, as she has previously had trouble getting through. They*

gave her another number which she then rings to talk to the person about the correct benefits. She then received a telephone call back from the benefits agency with further information about their visit and the letter they would send to the person on whose behalf she was ringing. After this DE then rang that person and explained what she had been told on the telephone, she then asked the person how they were, and listened to what they had to say. She then suggested they give her another call if they didn't get the letter from the benefits agency with the date for the visit. After this DE recorded the telephone conversations in the person's social work file.' (Observations 26th March 2002)

Working collaboratively with other health professionals and social services agencies was an important aspect of providing practical support for people to manage at home. The type of support was also offered by the hospice ward team and the hospital team when arranging discharge home and assessing the needs that person or family had for equipment and services.

Advocating for the discharge home to enable that person to die, often required a great deal of organising and coordination of transport, equipment such as beds or special mattresses, nursing and medical services. This was one of the most time consuming aspects of the hospital team's work. Often there was only a narrow window in which the person was able to tolerate the journey home. The hospital team nurses assisted the ward nurses to organise transport and contact the district nurses and liase with the community palliative care team and general practitioner about the person's needs, as was observed on the 5th March 2002 when LN spent three hours trying to arrange the discharge of a woman who wished to die at home. LN had to negotiate with the doctors to allow the woman's discharge then, at length, with the ward clerk and ambulance control to get an ambulance to take her home that day. Often the hospital team nurses worked for the person but against the hospital culture where medical consent for someone to go home had to be sought, and where there were fine timelines within which to act for that person to die where they wished. LN talked about how frustrating trying to arrange suitable transport had been while trying to balance the different priorities of the ward and transport services with the needs of the woman who was dying, answering her bleep and arranging a double pro-pad mattress so the woman and her husband could still sleep together.

The different cultures and aims of care required that the hospital palliative care team nurses took on these roles, as their priorities were different from the needs of the nurses with a ward full of other people requiring their care and focus.

7.4 Emotional Care

Working with emotions was part of the everyday interactions between the staff and the people being cared for throughout the palliative care services. The emotional aspect of support and care was dynamically related to building and maintaining relationships and the concept of emotional knowledge. Working with people's emotions was the aspect of support most difficult to define by members of the multidisciplinary team, and was seen more in terms of talking and listening to people. However, it was also observable in the actions of the palliative care staff. Talking and listening were important components in the process of care.

7.4.1 Talking and Listening

The emotional focus of many of the interactions came from asking simple open questions about what people were thinking about and then sitting quietly and listening whilst they talked, often whilst undertaking physical care on the ward. Prioritising time to listen to people's concerns was valued by everyone throughout the service. One of the junior sisters observed:

> *'Really, its been interesting to see how people, when they first come into this environment they feel they need to talk. The patients talking about things, they need to talk about and actually just by listening is probably all you need to do. In a lot of instances and then things come up, but, um, its allowing that environment, or allowing that to happen in the first place, really.'(HK interview: Hospice Ward Junior Sister October 2001).*

Listening was very much part of the care process, perhaps more than talking at times. On the hospice ward the value placed on listening, when a person needed to talk, was reflected in the way the other nurses took up the remainder of their colleague's work to enable her to stay with that person.

> *'I mean I know there's lots of technical stuff we do but, and I think we try to give them time in a time when they feel they've got no time, I think perhaps, even in the way that we try to make out that we're not busy and if we are busy its just so important to give them a feeling that yes we've got all the time in the world to stand and listen to them because just at this moment that's when they need to talk, because time is so precious to them. You couldn't necessarily say 'Ill come back tomorrow and talk it through', or they might not even be up to talking about that type of difficult stuff tomorrow, whereas perhaps just at this moment they can talk about it, you know'(JS interview: Ward Staff Nurse March 2002)*

Listening was prioritised as an aspect of emotional work and emotional care, because it was recognised that the people in the ward, at home or in the hospital who were dying might not have another opportunity to talk about what was on their minds, and that putting it off might be detrimental to their emotional wellbeing. This was equally true of putting time aside for family members who also often needed to talk about things with the nurses and sought them out,

> *'Such as when I talked to that boy about his family situation, last week and the next week he came calling and he said 'thanks for the chat last night, it really helped' and he did the talking for about three quarters of an hour. I put in a very odd comment here and there and didn't feel I'd been helpful at all. I hadn't been able to say anything during the chat, but he obviously found it helpful' (VB interview: ward staff nurse November 2001)*

This openness and prioritising of time was recognised and appreciated by the people being cared for in the hospice and in the community. GB was in the hospice, but had also been cared for by the community team.

> *'... you can talk to people who know how you're feeling. I've got a wonderful family but they can't possibly know anything about nursing and the reasons why I'm acting sometimes the way I am, and things like that, and I think its a lot of understanding. I'm also very aware of the amount of time the doctors spend with you, which is great really. I mean they don't come, when I've been in hospital before doctors come along, stood at the side of the bed, said 'how are you, yes good morning' and walk away. The doctors here don't. They sit down. They have your chart open and they discuss with you how you are and really make you feel as though you're the important one they're not the important one'(GB interview: cared for on the hospice ward November 2001).*

In the community and the hospital settings the main focus of the care provided by the team was by talking and listening, which enabled assessment of symptoms, emotional well being and facilitated coping. The team members allocated set time for each person and were not involved in providing physical or bodily care. On the ward there was a strong focus on the giving of physical and bodily care by the nurses, which was often the time that talking and listening occurred. The similarity was that this was time allocated by the nurses or the members of the multidisciplinary team specifically to that person, which made it a safer time to talk about concerns and fears without the member of staff rushing off to someone else. This did not deny the important talking that emerged from light-hearted conversations at other times during the day. Despite the differences between the areas of palliative care, working with emotions was common to all, and occurred by entering into conversations and actively listening to people's concerns and responding to these.

7.4.2 Managing Distress

Working with people's distress required flexibility and adaptability by the staff as to how they managed their interactions, which then enabled the person to talk about what was important to them as concerns arose during an episode of care over several meetings, or over several days. Exploring the coping mechanisms that helped in the past and considering what the person could do now to prepare for the time ahead or their impending death were important aspects of working with distress. It required a degree of personal courage from team members to meet and respond to the emotional pain and anguish experienced by the person or their family.

An example of the process of working with a woman in distress came from EG, the lead nurse, working with the hospital team. The following piece of reflective narrative reveals how working with emotions is a process often mediated by time and teamwork, and one which is informed by skills drawing on a range of different knowledges. EG also considered she used herself as the tool, adapting her manner and her approach.

EG discussing the process of emotional work through reflection about an incident of care she had been involved with

'I went to see a lady on behalf of CS, who they'd been battling with symptoms, it was a few months back now but sort of within the last year, and it was the classic situation that none of the tried and tested pills were working and I thought early, you know, you immediately get the, sort of, warning signals. And I remember looking through the notes, going straight to the family tree page, not looking at any of the written notes and then, sort of, feeling guilty because I thought maybe I'm making assumptions here, but then I though 'no' because I've never met this lady, its just what I'm picking up here. And she just had this ongoing terrible pain and the staff, CS and LN, I think had both seen her and had felt drained...

I went to see this lady and whether rightly or wrongly, I mean I feel it went well and I think it did, and I think this is an example where sometimes we very much like open to the patient 'what do you want to ask' and I tend to be not a challenging person, but I actually I stuck to my guns and explored with her, yet she'd say 'oh, nurse, nurse the pains terrible, I need another pain killer' and I basically talked round where this pain was coming from and we talked about the emotional aspects of her illness and she talked very, well I mean, it didn't take that long actually 'cause I had to go in and say *to her 'now, let's see what we can do about that; I have got to leave by...' I was quite directive which was quite an unusual approach for me, or, you know, I've been directive before but not in that, quite that way with patients, and it was a very focused conversation and cut a sort of longish story short, the patient, um, I acknowledged her pain, I acknowledged her physical pain and she'd only recently had a painkiller and I said 'I don't think you have given it time to work, so let's talk through a few issues around there and you know, if we find it hasn't worked, well we'll look at something else to give you', so I didn't ignore what she was saying, because otherwise she might of thought I was just not believing her pain, but I talked to her about pain comes in different forms and you can't separate sort of physical pain, from what people, you might be thinking about the illness at the moment. And that's sort of how we got into it and she talked at length about something that wasn't a deep dark secret as such, we picked up on issues within her family and previous illness. Um, but she really, I, you know, I feel I came at the right time, you know others had built on that and I think that's where the team approach comes in. You can't just walk into a situation, it's a drip by drip effect.*

I think it can be very demoralising for someone whose done the drip, drip effect and then someone comes in at the right time, like me and the truth comes out so to speak, or something you can work with. That's what came out for me. That there was something you could work with, even though it wasn't, um, tangible. Um, and having said that, you know, I just listened really. It was like a, sort of, um, you know, verbal diarrhoea. All this stuff came out and her whole body changed. Err, the way she was holding herself, the body language, and we came out with a plan, and in fact she was transferred to the hospice, because she was terminally ill, and there had been problems up on the wards because many times psychological issues are incredibly time consuming and on a busy general ward they're very difficult to handle; but she did have symptomatic problems as well so it was decided that she'd come to the hospice, and, I know it sounds terribly twee to say that she died a very peaceful death. It was like she got a load out...

I suppose having the courage to go in there and almost say 'no, I'm not going to give you another painkiller' without making it seem like 'no you're not' and then having *the courage to sit and listen, because there was quite a silence after I'd done my patter, and then I think I said something like, 'so tell me how it is for you at the moment' and then it just came. And just letting her talk and talk and talk, um, but, you know, drawing some things together so we had an action plan. It was a very sort of simple action plan and realistic expectations, something to do with that, um, and seeing someone who's able to shed a burden. It was still there, it was still there, nothing had changed, but everything had changed. She had got control back over her life and of her dying. She was still frightened, and you know, work to be done there, but she was no longer diverted by it, she was able to concentrate on the job in hand for her.(EG lead nurse interview April 2002)*

The emotional work involved in caring for people in distress requires using and drawing on both the personal and professional aspects of the self and the information exchanged between the team members. It also uses the range of different skills and knowledge of symptom control from a perspective wider than just the physical causes and controls, working with people by incorporating awareness of the range of concerns and issues most people have at the team member's disposal. The aim was often to explore what was behind a person's physical and emotional expression of pain, and to find a way to deal with it, enabling the person to focus on their needs and wishes. By putting some boundaries on the time that EG could dedicate to the woman she aimed to create an emotionally safe space. By acknowledging the woman's pain, EG was able to open up the opportunity for her to talk through the issues causing her pain, yet kept the space safe.

Courage, strength and knowing oneself on a personal and professional level was required to work with emotional pain and distress because it takes insight and strength to explore a person's pain, carefully challenging and listening whilst remaining with their distress. As EG acknowledged, this is often a process that occurs over time, and is gradually built upon. It is only when the person is ready to talk, about their fears, that they will talk and that the skills to facilitate this come from the experience and maturity of the palliative care team member.

It is this intangible aspect of emotional care that is the most difficult aspect of palliative care to explain, teach, and to explore and measure in terms of evidenced based practice. However, it is one of the most significant and substantive aspects of the work carried out by both the hospital and community palliative care teams. Experience and maturity were important components in learning to work with people in extreme distress. There was a need for those working in palliative care to have an inner toughness, as EG puts it in her interview, to be able to support and care for someone who is dying and remain with them even when they are 'kicking *and screaming and you can't make it better'* whilst being able to stay in control of the situation. Losing control of an emotionally charged situation can create an emotionally unsafe space, which can, in turn, lead to the person loosing control emotionally and preventing any further work by the team. The two most senior nurses EG and CS, both saw this a skill developed with experience.

> ' *You're not going to alter the course of dying but I think that, by being aside, listening and suggesting and working with families, I think that that awful sheer hell for them we can pluck things out, at least their out of that hell hole ...Remember you've got a soul to survive with, you know, and I'd take that on and that only comes from a of lot years' experience you can't do that when you're new into this job. It takes a lot of experience'. (CS team leader Community and Hospital Teams April 2002)*

Emotional safety was important, and so the palliative care staff had to be able to create this and then contain the emotional situation for as long as was needed, and be able to draw the threads and emotions together so that they could also leave the person retaining a degree of control over themselves. Observing the community and hospital team nurses, safety and containment was developed from the way the team member talked, friendly, but calm and by the tone of the voice and the language they used. Also how closely they sat to the person. For some people this involved sitting closely to them on their bed and using touch, holding the person's hand or stroking their forehead. For others it was sitting a couple of feet away and by how they developed the conversation, discussing safer issues and chatting first before guiding the conversation to the emotional pain.

7.4.3 Anger

Anger was another very strong emotion that the different team members had to work with on the wards and in people's homes. Managing physical outbursts, such as kicking doors as well as verbal assaults. Listening to the concerns and issues and verifying what had been said were important aspects of managing situations, as well as staying with the person or with the family. Both social workers and the team leader of the hospital and community team recounted difficult meetings where they had found themselves in people's homes and were the focus for their anger.

> *'...actually, it was really awful, it was really awful, 'cause I was sitting in this room, there was the boy, who sat right in the corner and hid his face completely under his baseball cap, um. The eldest daughter, who was actually the one who managed to carry things for the family through, um. The two youngest daughters with very, um strong personalities, very angry, you know, understandably saying that their mum had died and now their dad was dying, um, still quite young, and dad was there and they had a lot of stick for dad, and I wasn't quite sure what that was about, really, and I'd say it was one of the hardest situations I've been in...and they'd got somebody* [herself] *and they were directing all their questions, well their anger really' (DE interview: Social Worker March 2002)*

Often anger arose through misunderstanding and fear. Listening to why the family or person was angry, validating their feelings and exploring what they had experienced previously and what information needs they had, was often one way of managing anger. Staying with the family, or returning to visit was also valued as important, acknowledging the ongoing needs, whilst appreciating the multiple factors involved in the expressed emotions.

Emotion work required a level of experience and a degree of pragmatism. Not everything could be solved or made better. Working with intense emotions took its toll at a personal level and required that staff also took care of themselves which may offer some insight into the high level of support for the community team nurses from their team leader, consultants and social workers. As independent workers, they were alone in people's homes, working daily with people's emotions, distress, anger and uncertainty as well as managing the symptoms by using themselves, their experience and knowledge to manage and facilitate some degree of coping so that people could stay at home if they chose. The ward team had one another to share with as each person from each discipline has some awareness of the situations. The hospital team could at times share with the hospital ward staff and doctors, and with one another, although they too are similarly dependent upon their own skills and experiences.

7.4.4 Managing Uncertainty

Managing uncertainty involves openness on behalf of the palliative care team members to answering questions, looking ahead at possibilities and remaining consistent. Listening to the concerns and enabling people to look at ways of managing their anxieties was one part of working with uncertainty. Responding to concerns and giving information, when possible, helped people to manage their uncertainty, which was seen in the many telephone calls and conversations taken by the community team from people at home and when the team was organising assistance or services and trying to re-arrange appointments for people. Trusting relationships were seen as important by the people being cared for by the service who felt the hospice provided them with security because they could call for advice at anytime , as BA, described in her interview.

A calming, unhurried and unflustered tone was used by the nurses when talking with someone who was anxious on the telephone in an attempt to calm the situation and anxiety of the person they were talking to. The nurses listened and acquired the information they needed to offer advice, as was observed on several occasions during December 2002. On the hospice and hospital wards the team members sat with the person and listened, using similar warm, calm and unhurried tones of voice and expressions, offering information and advice where available. Part of the art of working with uncertainty used by the nurses and social workers was to get people to focus on their families or the relationships that were constant and gave them a sense of who they were. Linking into the core beliefs and interests of people was an effective way of enabling people to use their own strengths.

7.5 Personalised and Individualised Care

Personalised care was central to the process of care that was carried out throughout each area of the palliative care service. It was influenced by how the care was structured and combines the processes of exchanging information, support and emotional care by 'getting to know' the person being cared for and through the development of a trusting relationship with them. Listening to their concerns and wishes, and responding in order to meet their needs in a way that is specific to them and their family.

7.5.1 Caring for the Essence of the Person

Paying attention to the essence and humanity of each person was considered an important component of the care provided by staff throughout the different areas of the service. It involved recognising and taking account of the beliefs, values and selfhood of each person as best as possible. The knowledge or awareness about each person was constructed out of the multiple conversations and chats held between staff and the person being cared for and their family members. This information was exchanged during the many meetings and informal conversations held by staff about the person being cared for. This was also observed in the time spent by different team members as they sat and talked with the people and their families, exploring who and what was important to them, what they enjoyed and what they disliked.

This was broader than gathering and sharing knowledge about the person's illness and their previous or current treatments. The different team members sought to learn about each person in a manner that was not just about collecting medical facts, but was about actively understanding and appreciating some of the aspects of what made the person who they were, their history, personality and their values and beliefs. This awareness was shared between the staff to ensure everyone had some understanding or appreciation of who that person was and what was important for them. Listening to people's stories was an important aspect of gaining some insight about each person. For some people this involved exploring the person's faith and their spiritual world, for others this involved talking about what gave that person meaning or what challenged their understanding of their place in the world. At other times it involved recognising and responding to a person's sense of humour.

Searching for an understanding of the 'essence' of each person, was important for the staff because it enabled them to consider how they would approach difficult symptom control, emotional, social or existential problems, in terms of what would be best suited to each person, as they did when considering how best to help NO. She had been described as a 'determined lady' who, although very breathless, exhausted and almost immobile, wanted to remain entirely in control. She wanted to sit out of bed everyday, even though the oedema in her legs and tumour size growth in her abdomen made this very difficult for her. Until finally on the evening of 14th October 2001 she asked for help because she could not manage anymore and she accepted a therapeutic increase to the medication for her breathing in her syringe driver, which she had previously been reluctant to have. The reference to the subjective expressions and individual personalities was observed during all of the ward meetings and in discussions held by the community palliative care team with people in the hospice or on the telephone.

During assessment visits by the community and hospital palliative care teams the nurses and doctors not only asked about how each person was feeling and assessed their needs, they would also ask about how members of their family or friends were and how they were managing or coping. Often they would ask about something specifically important or relevant to that person. When RT visited BA on the 25th January 2002 she asked how her son's weekend visit had gone and talked about trying to arrange a week away at for her at a special hotel run for people with cancer since BA had not been out of her home for a long time.

Shared memories were also part of caring for the essence and humanity of the person, since a degree of closeness developed over time between the palliative care team and many of the people being cared for. This was because at times it involved sharing something of each other's humanity, an intimacy and at times giving something of the self by the palliative care professional in the interaction. On the 12th February 2002 DC visited EA at home, who was now very weak and beginning to die. Despite the sadness between EA and her husband, there was a warm shared humour and appreciation when DC was exploring how they were sleeping with the new double pressure relieving mattress on their bed. EA joked about her husband stumbling at night when getting out of bed instead of her. All three shared warm knowing eye contact. This had followed a painful conversation about EA's situation and preceded a later conversation in which DC was able to begin talking with HA downstairs about EA's impending death and listening to how he could not believe in a God who caused suffering.

Several of the people who were cared for on the hospice ward and at home talked about how much being treated as an individual made them feel cared for in comparison to how they were treated in other areas of the National Health Service, especially in the hospital where the care had become depersonalised.

> *ST* '[about the hospital]. *They've so many patients to look after and their list of what they have to, its not the same as sort of having palliative care where you're , an individual, you're not a stranger; you're an individual that they know because they've been dealing with you for some time'(ST interview: cared for on the ward)*

> *EA 'You feel as though you're being cared for yourself, don't you other than being like a number, being like a conveyer belt* [in the hospital]*' (EA interview: cared for at home)*

This echoed CS's own observations of the hospital from working in the hospital palliative care team. For other people, the recognition of their individual subjective humanity was what they experienced of the care they received in the hospice

> *YA 'I think to be treated, um, as an individual person, um, to be called Y, to, um, to be talked to, to be chatted to, to ask how you are, um, anything you*

> *need, um, are you sure, can I do this for you, um, all that goes on automatically' (YA interview: cared for on the ward)*

> *GB 'I think they show me respect and they show that I'm a human being and, um, they listen to what I've got to say'*

> *SS ' Well, its the way, its the way they speak to you. I mean, they treat you like a human being... I feel comfortable and I think that's, if you're not well and you know that something's going to happen that its important to be able to feel comfortable and at ease with people...I just thought it would be, well, a hospital, like any hospital I didn't think there would be the personal care that you get here.' (SS interview: cared for on the ward)*

Acceptance of and working with each person's personality and belief system was revealed in how the person was talked about at the hand over and ward round meetings, and how the physical care was adapted to suit each person, although on some rare occasions the staff found their efforts were resisted, or they found that a person's personality was difficult to work with at times, as was the case with HI and CL during October and November 2001.

Even in death the importance of seeing someone very much as the person and the personality the team had come to know were important. There was a general feeling on the ward that the care of the person was very much continued after death, with the washing of each person's body and laying them out. MJ talked about TT, who was very much a character on the ward, who had a good sense of humour and had his own way of doing things.

> *MJ' when I went into him and he died and, I just felt the humour was still there, and giving him his wash again, you know, and just going over what we sort of said yesterday and how he didn't call me MJ, he called me S and when I was sort of washing him and that and we were turning him, then I could imagine him saying 'oh S for goodness sake' (laughs remembering the incident) you know, how he would have spoken to me 'now stop messing me about' as he would have done. You know 'that's enough' and that was just,*

> *sort of, like he was still here, you know and he still needed to be washed, and when we'd finished sort of seeing to him what we'd, UC was with me, and we both looked at him and said 'doesn't he look peaceful', and it was so nice to see him look like that after all he'd been through... When people just come through the door and then in a couple of hours they die, you don't know that person, but you still do very sort of personal things for them its more difficult in some ways you don't know their likes and dislikes and probably they haven't even had chance to speak to you either, they're probably unconscious you know, when you go into them. It is a person, you know, its not just a body' (MJ interview : ward health care support worker)*

Compared to the observations of social withdrawal by staff caring for those at the end of life in previous studies (Lawton 2000), the staff in the hospice still valued and appreciated the uniqueness of the people they had cared for. Pride was taken in respecting the way each person had been and what they preferred to wear was chosen for them to be dressed in unless the family provided other clothing. Undertaking such care for people who were not so well known or understood was found to be more ritualistic rather than personal, and contradicted their philosophical approach to the continuing care of the whole person.

7.5.2 Care of the Body

Looking after and physically tending to a person's body was one of the most personalised and intimate aspects of care. This predominantly occurred in the hospice ward, and for a handful of people attending the day centre who were given a bath. The hospital and community teams did not undertake any bodily care, although they assessed physical symptoms by observing, feeling and moving peoples bodies and occasionally by setting up syringe drivers. The main focus of the work on the hospice ward, however, was to provide physical bodily care as well as assessing and managing other symptom control issues and personal needs.

Working with people's bodies was not just undertaken by nurses but also by doctors, who felt, percussed, manipulated, listened to and observed different parts of bodies to aid diagnoses and manage different symptoms. The physiotherapist observed people's movements, used exercises to improve function, manipulated people's limbs and percussed their chests to facilitate better breathing. The occupational therapist observed and recommended different ways for people to move and position their bodies and use equipment to manage everyday living so they could retain some degree of independence. These different aspects of bodily care were informed by a variety of different knowledges about each person, their problems and their needs.

The bodily care provided by the nurses was often very intimate, requiring a lot of observation and touch, which was carried out generally with sensitivity and always with the person's consent when conscious, and consent of the family when unconscious. During observations on the morning of the 12th November 2001, ST became more muddled, although she was not entirely confused. Mid way through her wash she stated firmly that she did not want it to continue. The nurses tried to negotiate completing the wash and the changing of the sheets but ST remained defiant and so the nurses stopped and respected this. As they withdrew they discussed her changing mental state and how they would monitor this. Her condition continued to be evaluated and the nurses returned later when she was less muddled and she then consented to having her wash completed.

GB, a very proud woman, commented in her interview that the way the nurses cared and maintained her dignity had saved her from feeling embarrassed about the loss of one of her breasts.

FG, speaking in her interview, said it was a relief to have someone to help her, having had to struggle at home unable to do things by herself because she was so weak and ill.

For SS the experience had changed her perception of being cared for, of being helped:

> *'I'd never ever thought I'd be able to tolerate anyone helping me to bath so to me that was the height of indignities but it's the way they do it. They are so professional with it, you know, you just, you don't feel, don't feel embarrassed*

> *or awkward at all and its a wonder feeling really.' (SS interview: cared for on the ward October 2001)*

This intimacy was almost an unspoken and accepted practical aspect of being cared for on the ward. The practical bodily care and the physical bodily care carried out every day by the nurses was often used as a route to assess a person's functional ability, to get to know their usual colour, expressions and to develop a relationship from which the nurses could explore other concerns that the person had and also to get to know them a little more.

Two nurses or health care support workers would usually wash someone who required help with most things. This occurred either in their bed, if they were very weak or dying or, if a little stronger, they would take the person to the bathroom using the hoist for a warm bath. People were asked each morning if they wanted a wash or a bath. However, if someone did not want either they were left to sleep , although the offer was repeated later in the morning. It was not uncommon for people to have a wash later in the day, or occasionally a bath. Washing someone required teamwork, preparation and coordination, to ensure all of the bedding and towels were ready, and that the person was also ready in themself. Depending on the person, they would either be engaged in a conversation, if they were able and wished to participate, or just spoken to gently as the nurses and health care support workers moved the person to wash their front and back, explaining what they were doing. Occasionally the nurses would talk between themselves, excluding the person from the conversation.

Bodily care required the nurses to wash the personal areas of a person's body if they were unable to do this for themselves, and this was carried out with a degree of matter of factness. Often catheters had to be inserted to enable urine to be passed or suppositories inserted into the bowel to relieve constipation. The nurses would talk through what they had to do, how this might feel and always explained what was to happen just before it occurred.

The following example offers some insight into the process of washing and caring for NO when she was dying :

> *HK fetched new sheets, and pillowcases and towels. We went in to NO's room and I asked if she minded me helping. She said this would be ok. I went to the side of the bed by the window as HK placed herself on the right hand side of NO. HK spoke to NO about what she wanted washing and how she wanted this to happen. NO remained very sleepy and allowed HK to wash her. After HK washed and rinsed NO I dried the part of her body had been cleaned. We took it in turn to wash each side of her body and limbs. NO remained dozing, although HK talked with her throughout and explained what she was going to do next.*
>
> *I think both HK and I felt a little awkward, and both of us also chatted together as well as to NO. Having washed NO's front I carefully placed my arms and hands around NO's shoulders and hips, explaining what I was doing and pulled her towards me so that she was off her bottom and HK could look at her back and bottom to observe any breakdown in her skin and then wash both. This was difficult for NO as her breathing was more difficult lying down. HK placed a half rolled sheet in under her back so that we could change the sheet along with a sliding sheet. When we rolled NO back HK then rolled her towards herself and I pulled the clean sheet through and removed the old one. We quickly rolled NO back and then we moved her up the bed using the sliding sheet.*
>
> *HK then went to put clean dressings on her legs which had small breaks on them from being so swollen with lymph fluid which leaked out. NO wanted to sit out but HK suggested she try and stay in bed for a little while longer as she was unable to move easily and also needed to have her bottom protected on the air mattress. NO said she would try, and then slept again (Observation notes 19th October 2001)*

On some occasions during the morning people were left whilst the nurse went to check on other people, sometimes getting caught by colleagues or to dispense medications. During an observation of care on the 26th October 2001 KM left ST with just a towel over her. Although ST was sleepy, (I was sat by her bed) we were unaware of how long KM would be. I felt awkward for ST and covered her with a blanket as she dozed. Usually one nurse or support worker would remain, but occasionally the person was left alone.

Where the person was known to the nurses and a rapport had been built up, the nurse would talk about something related to the person's life, or would have a conversation about issues in the news or on television as well as prepare the person for the intervention. Often there would be a long conversation held between the person being cared for and the nurses, sometimes humorous, sometimes serious. During observations on the 26th October 2001 ST was having a catheter inserted as she could no longer walk, and KM continued the conversation they had been having during her wash about what KM had done at the weekend, interrupting it to let ST know what she was going to do next with the catheter. It created a surreal paradoxical degree of distraction as well as normalising the whole procedure, which, in fact, was very intimate and very different from the care previously described given to NO, who was too sleepy to engage in a conversation.

Attention to detail ensured the day clothes and night clothes for each person were chosen with their agreement, or chosen with that person's preferences and needs in mind if they were too ill to comment. The moving of people was guided by the Health and Safety Regulations and required cooperative teamwork and knowledge of safe handling. In the same way that washing someone required touching of the body, so did moving someone. What was also required was calm confident leadership of the movement and trust from the person being moved. The nurses would explain and check that the person was to do as they were asked, before leading the action. Where the person suffered from pain, often pain-killing medication would be administered and allowed to work before the person was moved, to ensure it was carried out with as much comfort as possible.

Bodily care also involved dressing wounds where the skin had broken down and had become sore and where fungating tumours had broken through the skin and continued growing. Managing the smell and excretions of fungating tumours required the nurses to manage their own reactions to the often awful sight of decaying flesh and the smell of rotting flesh, whilst acknowledging how this can affect the person with the wound.

Managing such wounds required knowledge about the disease and the dressings. It also required some creativity, as the wounds were never the shape of the dressing or in an easy place to fit. CD, one of the staff nurses talked about the care she had previously given to one woman, where she and her colleagues had been creative in personalising how to manage and change the dressings but still ensure that the important aspects of the woman's personality and appearance were attended to:

> *' She had a massive fungating breast tumour. Um and we used to do a dressing which was just awful and we'd got very good at doing the dressing. It looked horrible and it was extremely painful for her and we used to give her oromorph to start and then we discovered that a gin and tonic was just as good. Just talking to this lady, she was very special, very special, she was such a character. We'd have a gin and tonic in one hand and we'd have all the dressings stuck in the other. We'd do the dressing and we'd do it well, the dressing as well, but in between that, you know, she'd have the gin and tonic and swear whenever you got a nasty bit, but we used to have such a laugh doing this lady, and when I look back, I mean, it was absolutely horrific. It was a horrific dressing, but we would have such a laugh, and such a joke and she'd have her gin and it would be about 11 o'clock in the morning and there she was with her gin and tonic and the dressing trolley, and dressing this wound, slushing it out, cleaning off and... You just think to yourself, you know, there must be nobody else on the face of the earth that when its done, and there we are with a gin and tonic and that was always good, you know, always made me feel good that we'd got this up together and made her look, she was a lady that like to look just so, in her silk pyjamas and make up, her hair'(CD interview: ward staff nurse)*

How the physical bodily acts of care were carried out for people whilst treating them as individuals was important. It gave CD a sense of satisfaction in that she and her colleagues had personalised how they did this dreadful dressing and had been able to ensure that the important aspects of the woman's appearance and body image were also addressed.

Coping with unpleasant smells and not revealing how disgusting these could be was important for the nurses in maintaining the person's dignity, and the person's own embarrassment. Every effort was made to ensure people were not incontinent because of weakness and inability to move or get up, bells were responded to immediately. The use of catheters was a last resort, and always negotiated with the person. However, the observation of smells was an important aspect of recognising changes to the person's condition and wellbeing, as were changes in continence. Development of vomiting and observations of what the vomit contained was an important assessment tool. This was an important aspect of ST's care as her condition changed and she began to vomit faecal matter on the 12th November 2001. This lead to the team considering how best to manage this, in terms of her constipation, her reluctance and inability at times to take her medication by mouth and her comfort in terms of giving suppositories, and rolling her over when she had multiple fractures all over her body.

7.5.3 Symptom Control

The control and management of physical symptoms was the main priority for the admission of most people into the care of the service. Admission requests and referrals for the hospital and community palliative care teams were predominantly made for the control of symptoms and secondly for psychosocial support. Symptom control is an extremely personalised aspect of care, since what works for one person is not necessarily guaranteed to work for another.

Many symptoms could be exacerbated by anxiety, fear and stress and, therefore, it was rare that the management of physically presenting symptoms was without recourse to the emotional and social state and previous experiences of the person. At every meeting the symptoms took priority after handing over the standard information about a person, and were often discussed before addressing the emotional aspects of concern for the majority of people. Symptom assessment, control and management were entirely dependent on knowledge and experience. The doctors were the principle holders of such knowledge and experience, although this was shared with the more experienced and senior nurses, who debated the person's present situation and the benefits and disadvantages of different medication choices and approaches.

The majority of decisions made about controlling symptoms were made during the morning ward rounds after information about each person's symptoms over the previous twenty-four hours had been exchanged and the perceptions of the group negotiated. Suggestions were recommended by the more experienced nurses, and either agreed upon by the doctor or negotiated with the doctor's recommendation. The staff nurses with less experience tended to listen and take the advice of the staff grade doctors or consultants. Once a plan was agree upon, the decisions were discussed with the person being cared for before the changes were implemented. The following example shows an aspect of a negotiation between the assessment of the person and the suggestions at a ward meeting:

> *'RU started by saying her [HI's] last drip bag was in situ, HN said she was surprised it was still up, and said IS hadn't tried to put an IVI up. RB then said that HI was still stiff, very sleepy, and very demanding, especially when family came in. She also went on to say that since the reduction in the diamorphine and the Nozinan in the syringe driver she was now complaining of more discomfort. HN then asked if HI was getting out of bed at all. RU said that HI had a catheter in, she was declining food but sucking sponges as she was 'quite dry', that she looked ghastly when in room 3, but that the 'girls' [the nurses] felt she had picked up. HN said something I didn't quite catch, but then RB added that HI had a pv* [vaginal] *discharge which was worse than last week. There was some discussion over the medication which they had tried to change previously and having tried to reduced the analgesia this led HN to say 'what are we achieving if she's got discomfort?' RU then suggested possibly trying Voltarol pr* [rectally], *and HN said yes, she's still very stiff' (Observations 1st October 2001).*

HN assessed what HI was and was not able to do and agreed with RU after they discussed the different pieces of information about HI's current state of illness and abilities. RU was able to recommend trying a new medication to HN, for her symptoms. Controlling the uncomfortable symptoms was seen by everyone, during their interviews, as one of the most important aspects of palliative care, and this often came first in interviews when staff members were asked what they understood about the care in palliative care.

Negotiating medication changes was indicative of the respectful approach to people by the team members. As ST began to become increasingly uncomfortable and her pain became less well controlled, changes were always discussed with her, and her opinion sought on what she wanted. When the doctors recommended changes they would discuss these with the person and never make the changes without that person's consent, unless they were too ill to give it. Changes were openly discussed with family members, especially where there were concerns over increased sleepiness or muddledness, which was not related to the medication but to the disease process, as occurred on the 13th November 2001 between HN and ST's daughter

The hospital and community palliative care team nurses developed a wider range of knowledge and experience of symptom control assessment skills and knowledge than most of the staff nurses on the ward. Part of their role was specifically to assess people's symptoms and make recommendations to the hospital doctors and general practitioners about what medications to use. When the nurses were unsure they would ask either of the palliative care consultants or their team leader for advice. Often recommendations would need to be negotiated with the person being cared for and with the doctors who had the responsibility for prescribing the recommended medication. Knowing how the medications worked was important in talking about these with people who were concerned about their side effects, or the stigma attached to medication such as morphine.

When symptoms became problematic at home the community nurses often admitted people into the hospice or hospital, as beds were not guaranteed in the hospice. In the hospital the palliative care team often faced a lack of appreciation of the importance of regular medication and access to 'prn' or 'as required' medication for pain control, controlling sickness and breathlessness. Often misconceptions and fears of the general hospital staff about giving certain medications, such as morphine and sedatives, meant that some people did not get the medication that had been requested by the team. In the community sometimes the general practitioners did not wish to prescribe the medication and even if they did so it could take several days for the prescription to be collected and the new medications to be started by the person.

The hospice provided the environment where symptoms could be better controlled, stabilised and monitored with the provision of regular medication and the flexibility to make immediate changes, as required. This enabled an increased responsiveness, which was often required with a person's changing condition. Working together and considering the wider picture was always at the centre of considering how best to manage a person's symptoms. Although the majority of symptoms had a physical presentation, this would be explored by staff in the light of a broader understanding of that person's reaction to previous treatments and current concerns. The hospice ward provided an environment where this could be achieved in a supportive way.

7.5.3.1 Medical Interventions

Being part of the general hospital, gave the hospice team greater access to investigative procedures such as x-rays, ultrasound and MRI scans, and also to the analysis of blood tests. On several occasions people were admitted for blood transfusions because they were weak and breathless due to disease related anaemia. Others such as ST and WY had intravenous drug treatment for high calcium levels. Both ST and GB had a dose of chemotherapy whilst at the hospice for their symptoms, which perhaps may have been more difficult if the hospice was not attached to the hospital. This integrated aspect of the hospice within the hospital also enabled procedures, such as ultrasound guided ascitic taps, to be undertaken to relieve the pressure of fluid collected within peoples' abdomens. KL, the medical director did raised her own concerns and echoed those of other members of staff in her interview when she said:

> ' *I'm terribly aware as a palliative care service attached to a DGH* [district general hospital] *we can get an MRI and its that balance I hope we end up... when we get our new staff grade in, I want to be much tougher on our investigations because I think we're lapsing into 'it's easy to do'...and I wouldn't do anything unless I thought it would change my management, and*

> *too often patients go up for abdo xrays to see if they are constipated, and they haven't actually had a pr, and that makes me cross and my worry is I'm going to get too interventionist, that's what, that's what to me would be bad, if you don't know when to use the interventions appropriately. You're bound to get it wrong sometimes but hope not too often...That's what haunts, that's what when I go home feeling it's bad when I think I should have not intervened and should have let nature go.' (KL interview: medical director April 2002)*

7.5.4 Care of the Person Dying and Their Family Before and After Death

When people were dying the ward team cared for both the person and their family members. The nurses were the key care members of staff providing the physical care to the dying person and the emotional care to the dying person and the family. The doctors would acknowledge in their conversations with people about how ill they were and ascertain where they would like to die. This was also an important aspect for the nurses in the community and hospital palliative care teams in trying to ensure this wish was respected. Choice of place of death was always recorded in the bereavement folder. This was not always achieved because some people were admitted into the hospital just before they died, when they had wanted to be at home. Or people died in a nursing home having wanted to be at home or in the hospice. People often died in hospital because there were no beds in the hospice.

When someone was dying on the ward the conversations about the person during the ward meetings focused on how the person was, how their symptoms were and how the family were coping, and what else they as a team could do.

In one of the final conversations with ST, HN, the ward doctor, spoke with her, in part, to find out whether she was comfortable but also to acknowledge her current situation:

> *HN went in and said hello and that it was her there and that I was with her. HN walked around to the window side of the room and leant forward towards*

> *ST, so there was about 10-12 inches between their faces. ST had her eyes half closed. HN asked her how she felt and ST mumbled and this was very difficult to hear and understand. HN said to ST, looking at her and holding her position, that it must be hard for her at the moment and over the last couple of weeks. ST said something in reply, but again this was very unclear because she was unable to talk more clearly, but the one thing we did hear was 'its all for nothing'*
>
> *HN reflected this back after a few moments pause and asked her 'what do you mean?' ST was quiet and HN allowed a few moments to go past once more, and then she said to ST that she was glad ST had been here for the last couple of weeks as it had given her daughter, her start as a health care support worker, and that now she had been able to pop in and out at the end of the day to see her mum. I noticed ST move her hand to her head and HN asked her if her head was sore, ST said 'no'. HN then told ST that she had spoken with her daughter yesterday, and that she was enjoying her work, but that she still needed her mum. ST remained quiet as HN told her these things, not moving. HN then said that she thought that this hasn't been for nothing as her daughter still needed her mum and that with ST here she could still see her each day.' (Observations 13th November 2001)*

The nurses or health care support workers would sit with a person who was dying whilst their relatives took a break, or sat with someone who had no relatives,

> *'And some of them, a couple of the nurses, when we've been, come out, well they've actually gone and sat with him and holding his hand talking to him, umm they've asked us about him, about what kind of person he is. And I just think they are very very caring, and not only for my father but they've been very helpful to us, supporting us, they understand how hard it is umm, they've left us alone when they've felt they needed to; they've come and comforted us and put their arms around us, the doctors explained certain things we didn't understand' (Interview XF daughter of RF who was dying on the ward October 2001)*

The problem arose for the nurses when there was more than one person dying at a time and more than one family to care for and support. On one occasion, during October 2001, three people were dying overnight when there was only two nurses on duty and, therefore, three families all needing support. One person died early in the night, and the family wanted to stay. The staff nurse had to balance the needs of all the people being cared for and their families, and so requested that the family of the dead person go home in the early hours of the morning.

After death the body of the person was cleaned and dressed and the room left tidy with a dimmed light. Some of the nurses talked about how the room or bed used to be left empty for twenty four hours as a mark of respect but that his was no longer the case and the bed would be filled with someone new within the day. The body of the dead person remained on the ward until the families had gone, or returned to say goodbye. They were then removed by a local undertaker rather than going into the hospital mortuary. Death was not an open event on the ward, and only when people were in a shared room was the removal of the body discussed or the death referred to if someone else knew the person from the day centre.

For the people dying at home, the nurses would speak with the person and the main family carer about their wishes and how these could be met, with support from themselves. Often this meant adapting the home so the person could remain there, moving a bed downstairs or bringing equipment in. Also gently broaching the subject of whether they had made plans about the funeral. Timing was an important aspect of knowing when to talk about dying. Getting the timing wrong could fuel anxieties and defensive coping strategies by preventing people preparing and planning, or even stopping communication altogether. It could stop the process in its tracks, just as death did. However, judging the timing by picking up on issues in conversations, or introducing the subject and getting it right, helped people begin to prepare and plan ahead. Getting the timing right also required working very closely and sharing information with the district nurses and the general practitioner. JL one of the community team nurses commented that :

> *'I think things go well, when people work well as a team very much with the Gps and district nurses so everybody knows, is aware what the patient is*

> *aiming for, or they're hoping for , and that everybody is well informed and the patient is clear, and their choices really... I mean I think we all work quite well as team here to be honest. Again its communication isn't it all the way down the line. It's important we're kept informed about patient decisions but also that we keep other parts of the services informed as well. '(JL interview : community palliative care team)*

In the hospital there might not always be the chance to do this. Sometimes it meant working very quickly over a matter of days, or even less, with the shock of the person finding out that they have cancer and the fact that they are dying, to planning for their deaths. The reality required strength, gentleness and responsiveness to work with the range of emotions that were bought up from absolute rage, tears and profound sadness. CS worked with IA in the hospital who was raging against her diagnosis and her impending death, and had alienated herself from most of the ward nurses and doctors.

> *'IA was lying on her right side, and CS sat on the bed beside her and facing her. I sat at the end of the bed saying I would sit out of her way...CS listened to what IA had to say about the doctors and maintained eye contact and listened quietly and after about ten minutes of talking about what had happened IA became tearful and said that she was scared and that this was happening too fast and that she wasn't 'ready to go yet'.*
>
> *CS held her hand as she listened and IA cried, saying it was 'now real', she then said that there were problems passing her home and estate onto her family. CS continued to listen and stroked her arm and then her head and then IA became quiet and they were quiet together for some time as IA continued to cry and CS gently waited and watched. CS then reflected how tough it was for her, and IA then said that she had not sorted her mother's estate out yet and still had this to do...as the conversation lightened CS talked about the help she might need and that she was thinking about how the social worker needed to ask about the attendance allowance. CS then asked if IA would agree to see the occupational therapist for an assessment and let the social worker arrange some care. There was some laughter as IA made a comment about social*

> *workers, but then CS listened some more as IA talked about her pain. She began to look to have more angst when talking about her pain. CS then asked if she wanted any pain killers, then IA rang her bell and a nurse came along and took the drug chart and bought back her pain killer. CS drew the conversation to a close and said she would go now as she felt she would distress IA more by staying as she was still very tearful. CS said she would come back once the pain killers had had a chance to work. Before leaving she held her hand tight and gave her a kiss on the forehead. (Observations March 18th 2002)*

CS stayed with IA through her angry comments about the care in the hospital, through to her crying and considering her approaching death, and the things she still had yet to sort out that were worrying her. CS looked at some practical help that IA might want to think about, before addressing her pain. After the meeting CS made contact with the hospice local to IA's home and explained the difficult nature of the shock diagnosis and rapidly advancing disease, and how this had affected IA physically as well as emotionally.

This example also reveals how often the emotional aspects of a person's symptoms and distress have to be addressed concurrently with the physical ones, ignoring one or the other will not provide effective management of the symptoms and enable the person to prepare for their time ahead.

7.6 Time

Time was an integral part of the process of care. Time is a multidimensional concept, which becomes regulated and understood by the structures that are put upon it, the shift patterns of the nurses, the meals times and the regularity of weekly meetings. However, the perception of time although guided by these structures had its own dimensionality.

Both EG and CS discussed at length the importance of experience, that is time spent working in palliative care, which enabled members of the multidisciplinary team to work with people's distress and emotions more effectively. Skills and knowledge were developed over a period of time. Also, working with people in distress and working with their emotions was a process that took time and the team often used a 'drip drip' little by little effect to build trust and to slowly open up and work the difficult issues that were causing people so much pain and distress.

The importance of timing was also recognised and valued and commented on in interview by all the nurses and health care support workers working on the ward when carrying out their care. Most people talked about how time was such an important factor for the people they cared for. That listening to someone when they wanted to talk was given priority, because that person might not be able to talk about what was on their minds again, or that this was the moment for them and by denying them this opportunity may mean the person might never say what was on their minds.

> *CD 'I still think we have the time, much, much busier than it was, a bit different than it was, but I still feel we've got the time and you can make the time whereas if you can't get them all washed in the morning, well they don't all want a wash, in the morning, it doesn't matter... suppose I'm one of these people that when I believe that when your time comes, and there is nothing you can do about it, and you're alive until you're not alive, so you have to make the best, you know you have to live each moment. It can only ever be at one moment, so you have to be at that moment and not worry about the next moment, which is easy for me to say, perhaps not if you're dying. Um, so I try, you have to try and make that time as best for them that you possibly can, and I think if you feel like that, or you think like that, perhaps it transmits to them.' (CD interview: hospice staff nurse November 2001)*

The nurses and members of the multidisciplinary team throughout worked 'in the moment' and valued the 'moment' of their care and the time made available to the people and their families. This was part of providing person centred care, responding to the needs as they arose, which were supported and enabled by the complex chatting and updating processes and cohesive teamwork on the ward. The notion of making time was also picked up by the people being cared for on the ward. During their interviews, YA, ST, EA and GB, and in the community, BA and CA, commented on the nurses taking time to sit and listen and to talk with them in an unhurried manner.

7.6.1 Pace and Process

Pacing care was an important facet of the care process, which incorporated a 'watch and wait' or '48 hour rule' approach, where few changes where made for some people coming in to the hospice ward whilst they were observed and assessed to see what a change in environment, the presence of care and assistance and regular medications could make to their condition. Often, when it was unclear about whether a person's condition was changing, letting nature take its course in terms of watching and waiting, whilst maintaining regular nursing and medical input, would identify whether the person was going to pull through a crisis or not. Time was important because the process of the body's responses had to be allowed to occur.

Pacing in terms of speed of action was also important, and reacting to an acute event was as important as watching and waiting. In her interview, HN, talked about time in terms of needing to act with speed on behalf of a man recently admitted to the hospice ward. This gentleman's condition had changed rapidly in only three weeks, indicative of rapid disease progression. Her awareness of this fact meant she needed to work very quickly to sort this man out and get him 'emergency' treatment, to improve his condition and symptoms. She talked about how information availability was time related since she had quick access to his medical notes. However, the GP had received the information, as the man's hospital appointment three weeks earlier would have alerted him to the cause of the problem.

Time in terms of disease management was an important factor for KL when considering whether people newly referred to the service had been offered other helpful palliative treatments or had been referred to an oncologists for review. On occasions this would be helpful in managing disease progression and some symptoms developing from this, which was observed in the ward round discussion on the 7th September 2001 when KK was first admitted, and KL noticed he appeared not to have been offered chemotherapy which might help him palliatively.

7.6.2 Temporality

Time was also an important component of marking one's stay, as NO briefly talked about during her interview. She could not remember the date, but knew she had been in the ward for three weeks. When I explained the date, she said it was her daughter's birthday in the week and that someone had send the card off for her. The interview was poignant in itself in that, although only ten minutes long, it felt like half an hour because NO had to stop every few words to get enough breath to speak and take a sip of her tea, but determined she wanted to 'be of help' despite my own unsureness of continuing and rechecking with her before commencing. She died only a few days afterwards, and yet in her very short interview the temporality of time and existence was revealed. NO's experiences of losing track of time whilst on the ward, decades of being a mother and still remembering it was her daughter's birthday, the date she was born and then my feelings of taking up her precious time alive, in an interview that felt like it had lasted three times longer than it had, made the whole notion of time during those moments a surreal and metaphysical experience. All the dimensions of time were being experienced all in one moment

In the community, time did not present itself as a topic discussed by the staff during their initial interviews, but this was mentioned by EA and her husband, CA and his wife, BA and DB's husband when they were interviewed at home in terms of having time to talk with the community team nurses. They said they always felt unable to talk with their general practitioners or district nurses because they perceived them to be too busy. During a follow up discussion with the community team nurses, they commented that time was important for them in building up trust and a relationship with the person being cared for, and as an aspect of how long they were then involved with this relationship.

In the hospital, the palliative care team, often had little time to work with people and were not in control of the time that that person remained in hospital, unless they advocated strongly against a decision to send someone home too soon or against keeping someone in who wanted to go home to die. Time was often of the essence working with people dying in hospital, and sometimes the luxury of building a relationship over a period of time was not available. The hospital team worked together over a handful of days, or less, to manage a person's symptoms, arrange for them to go home or to the hospice, as well as opening up the opportunity to talk through their fears, concerns and of the things the person felt they had yet to do.

7.7 Remembering and Reflecting

Remembering people cared for over the years by members of staff throughout the service was an important aspect of reflective working practices, especially where there were current complex situations, which reminded the team members of a previously similar case. This remembered information would be used to offer insights at meetings as to alternative approaches for a current situation. Several members of staff throughout the different areas of the service reflected on current issues through the use of story telling and revealing previous experiences. The story was reinterpreted to relate to the current situation, or as a learning tool to inform practice. CS, EG and KL, often related back to previous experiences and many of the members of staff who had worked in the service for several years had an amazing capacity to remember people and the events that surrounded them.

Remembering was also a important component process of caring for bereaved family members, through the sending of anniversary cards, and responding to meetings with bereaved family members in town or who had popped into the hospice with a donation or for a chat. When staff members were concerned about a person they had spoken with, they alerted the social workers who would get a bereavement support volunteer to call the person to assess how they were, and offer support where it was thought necessary. Where names or circumstances could not be clearly remembered by the person concerned, talking with other members of staff appeared to tap into a collective memory bank, out of which the identity and story would be pieced together.

7.8 Summary

Care is not a singular event, it can be seen as an expression of a series of interacting processes, which are dynamic and alter accordingly to the influences within the processes and influence the structural framework of the service. The key processes identified: information exchange, supportive care, emotional care, personalised and individualised care, symptom control, time, and remembering and reflecting are shared across the different locations of palliative care, but alter and are shaped by different spatial and cultural dynamics. Although guided by the same organisational palliative care philosophy, the teams have developed a range of ways to ensure care was personalised and individualised.

Care processes were dependent on the development and maintenance of trusting relationships, between staff and between the person being cared for and the staff. Choice was pivotal, people being cared for chose what care and care processes they would or would not accept. Staff chose to an extent how they would or would not undertake the processes, which is why no care was the same, and why peoples' experiences differed

The exchange of information was central to the processes of care, because multiple forms of information and knowledge were drawn upon to guide each process. Formal conversations and most importantly the informal chatting provided the central thread between gathering and exchanging information before it was synthesis into 'new' knowledge about a person. The frequent updating of information enabled a flexible responsiveness to care, guiding all other process involved. It was the methods and skills that differed between locations to achieve this. The following chapter will explore the multiple knowledges that were revealed within and were integral to the processes of care.

Chapter 8 : The Knowledges Informing Palliative Care

8.1 Introduction

Analysis has revealed a range of different, yet complementary knowledges observed throughout all aspects of care across the hospice, community and hospital, informing the different interactions, behaviours, conversations, responses and documentation. This chapter aims to identify, name and make explicit the multiple and, often assumed knowledges that underpin and inform the dynamic processes of care identified in chapter seven as central to palliative care. Process and knowledge are inexplicably interdependent in care and palliative care. The processes of care are informed by different knowledges and, different knowledges are acquired by what is learned from the ongoing processes, such as information exchange or reflection. I would suggest that care, informal or professional, cannot occur without drawing upon a range of multiple knowledges, activities and experiences.

In order to illuminate the different knowledges from the data, examples from the fieldwork used in chapter seven will be revisited. This revisitation is purposely undertaken to identify and make explicit the knowledges used within the processes of care but, from the alternative perspective of the process-knowledge/knowledge-process dyad.

The process-knowledge/knowledge-process interrelationship is inherently shaped and informed by personal, professional and organisation values. These values orientate the carer to what knowledges will be drawn upon and prioritised as useful to provide care and inform the process over time. The dynamic interaction between process, knowledge, values, time and the framework of the service creates both the environment for and the spaces of care. It is this complex dynamic interaction, which ultimately influences how each person who is being cared for perceives their experience. This chapter therefore requires the reader to recognise the interrelationship between chapters five, six, seven and eight as dynamic and interactive rather than linear and stepwise as they inform and shape knowledge central to care.

The definitions of information as 'facts or knowledge provided or learned,' and knowledge as 'Information or skills gained through experience or education, the sum of what is known, awareness gained by experience of a fact or situation' (Paperback Oxford English Dictionary 2002) reveals the complex interrelatedness of information and knowledge and, both are developed through the synthesis of facts, what ever the 'facts' maybe. For the purpose of this chapter these definitions will be used to create some level of distinction.

The processes of information gathering and exchange are to providing appropriate humanitarian, essence focused, personalised care. The information drawn from observations, evidence, perceptions and impressions were synthesised individually and collaboratively by team and also family members to recognise and highlight changing patterns and to develop different knowledges about each person, their disease and situation. This in turn was used further to inform the care provided by the teams. The process of knowledge use, synthesis and development was itself a hermeneutic dialectical process. Knowledge of the past, including propositional and experiential knowledge, informed the knowledge of the present; propositional, practical, tacit and intuitive knowledge, through the processes of interpretation and reflection. Thus, creating knowledge informing present and future care actions and processes (Guba and Lincoln 1989). Knowledge was neither singular nor static within the service. It was multidimensional, dynamic and evolutionary.

Knowledge has traditionally differentiated each discipline and created professional specialisms. What was apparent was a sharing and overlapping of different knowledges used by the multidisciplinary teams. The different knowledges and the knowledge held by family members and those being cared for, were drawn upon to inform and shape the care provided. The right information and knowledge created a very strong base from which to build support and maintain the ongoing processes.

8.2 Socio-political Knowledge

From the analysis of the political and organisational context and structure shaping care across the different locations of the service, it was clear that some members of staff required different degrees of socio-political knowledge to undertake their work. The leaders of the service used their knowledge of the NHS and regulatory frameworks such as the Cancer Services Quality Assurance assessments (CSQA) and the Commission for Health Improvement (CHI) requirements to complete and present the service documentation to meet the new standardised and regulatory criteria, and prevent the imposition of sanctions. In doing so they were able to present their documentation and service in a positive light, and reap the rewards of being praised for good practice, and as a negotiating tool for increased funding for increased palliative medicine input.

The shared leadership between KL and EG, enabled both to attend important Hospital Cancer Network and Primary Care Trust Meetings to represent the service as well as their own professional disciplines. Both KL and EG talked during their interviews, and throughout the period of the study, about their involvement with the cancer and palliative care networks and how they were responding to Department of Health directives. They represented the service and its needs, influenced future resource and funding allocations and the development of palliative care services locally and across the region. This ensured both the visibility and voice of the palliative care nursing profile as well as that of palliative medicine.

KL was involved in several hospital committees, including the Resuscitation Committee, to ensure the palliative care service had its voice heard and could influence the development of new strategies and working practices. This was the case with the hospitals written response to the BMA guidelines on resuscitation and the development of communication teaching for doctors.

8.2.1 Knowing How to Play the Power Game

Astute use of socio-political knowledge was important where structural power was limited. Both KL and EG acknowledged they had to play the traditional power games at times by using KL's position as medical director in situations where only a medical voice or position would be heard and valued. Awareness of the changes within the Community Primary Care Trusts enabled KL to negotiate the position of the service as one of the main providers of palliative care. Negotiating funding and budget management with the NHS accountant revealed a degree of business acumen and political awareness, especially when KL and EG fought to have their NHS budget reduced by only 0.5% instead of 1.0%, because of the monies provided by the Charitable Trust.

The community team and hospital teams had to be politically astute, using their knowledge of the different personalities and the ways of working of the various consultants, general practitioners, ward sisters and district nurses to inform their approach to providing care to a particular person. Both teams worked across organisational and disciplinary boundaries and had developed an awareness and understanding of how to approach and work alongside health and social care teams with different aims and value systems, since they were advisory services without any statutory powers. Particular diplomatic negotiation techniques were learnt and employed by the hospital and community team nurses and consultants. This played to the power of the hospital doctor, consultant or general practitioner to grant the requested alterations in medication and changes in care. CS describes the approach:

> *'its like being invited into their homes, the consultant's home, if you like and working very closely with them and putting things - 'may I suggest, would you consider' (CS interview: Hospital and Community Team Leader April 2002)*

Reinforcing and acknowledging the traditional power and position of the Doctors in the hospital and community was one method of having the team's advice heard and acted upon. Direct requests were rarely used, even by the palliative care consultants unless there was a good mutually trusting relationship. The sisters and staff nurses on the hospital wards or in the community were used by the teams to reinforce their recommendations, since they were working with the doctors on a daily basis and usually had a closer working relationship them. The hospital ward or community nurses were able to remind the doctors over the course of the day about palliative care requests and recommendations. Some consultants and general practitioners were happy, however, to hand all decision making power to the palliative care team. This too was not what the team aimed at, preferring a partnership approach that was managed in an equally diplomatic manner.

The community team were able to develop longer term working relationships with general practitioners and district nurses and learnt to adapt to different peoples' mannerisms, working values and particular pressures. For the hospital team, however, work with a predominantly changing work force, apart from the ward sisters and consultants, required developing new working relationships every six months with the more junior doctors drawing on the 'know how' of building and developing effective working relationships.

As LN explained, on some wards, such as the elderly care wards the hospital team were less frequently invited in, so when they were approached the team presented themselves in a professional and helpful manner. Often as a method of building up trust they offered to assist in gathering additional information about particular disease management and helped with the creation of resource files. LN had done this for one ward in gathering together information on motor neurone disease, and photocopying the resource file held at the hospice. Sometimes only KL or IS were asked for their opinion by certain consultants, and had to undertake the ongoing assessments alone. Observing IS, it was clear he approached both the consultant and the nurses on the wards with respect, diplomatically offering his suggestions and using positive reinforcement of actions that he had undertaken that had been beneficial to the person being cared for. Although this went against the multidisciplinary team philosophy, sometimes playing into the traditional hospital hierarchies enabled the consultants to develop the trust of consultant colleagues who otherwise had the power to block their involvement altogether. KL was very clear about her political responsibilities in carefully guiding colleagues in the hospital. By using the system, the palliative care service would work it to its own advantage over time.

When KL gave the lunchtime teaching sessions with CS and LN to the new house officers, she explained that the team could be contacted and would be happy talk with the junior doctors if they were having trouble persuading their consultants to involve palliative care, or where they were not sure what to prescribe for particular symptom control problems. By directly supporting the new doctors and advising on managing particular issues off the record, a degree of palliative care was still made available to some people who would not otherwise get it. This was a supportive form of resistance to the hierarchical ownership and power culture within the hospital setting, which prevented appropriate palliative care from being given. By supporting junior doctors and developing good working relationships with them, they were hopefully more likely to continue to involve palliative care as they progressed through their careers.

Socio-political knowledge was also important at a local level, in terms of working within the palliative care services and across the different locations. Knowledge of the different services and their different ways of working were important in knowing how to mediate between them when disputes occurred. Although less political or hierarchical than the hospital or community, a 'them' and 'us' perception was sometimes expressed by some of the ward nurses and the community team. CS, RU and EG had to mediate between the teams to resolve ongoing concerns such as discharge planning. CS also had to mediate between some members of the community team and LN in the hospital team about their knowledge of the hospital team role, and their lack of power to control when people were discharged and whether their symptom control advice would be acted upon. The lack of awareness of the potential consequences of the day centre bringing in a voluntary student counsellor was highlighted by both of the social workers and the medical director, because of their different knowledge and insight. The concept that the personal is political informed this local level political knowledge, which was used to manage the service and retain a sense of cohesion and focus.

8.3 Knowing How To Access Resources

Knowing how to access resources was crucial throughout the service to provide appropriate care. Each member of the team was a resource to be drawn upon However, there were many times where additional services, advice and assistance were required. The social workers had knowledge about accessing financial support. Knowing how to acquire monies from the Benefits Agency, and from voluntary agencies and completing the Attendance Allowance and Disability Living Allowance forms was important in enabling people at home to pay increased heating bills and cover lost income due to sickness. Knowing how and where to locate furniture and helping with re-housing were also aspects of the knowledge held by the social workers. Before DA had been able to undertake her initial assessment of WA at home, DE had become involved in trying to arrange financial support for him after he had to stop work. Knowing how to chase up delayed benefits was another aspect of the social worker's role, which could be drawn upon by other multidisciplinary teams, since they liaised with the Benefits Agency. The social workers were key players. They also coordinated the organisation of care services for people when being discharged home from the ward, unless the person needed intensive home support and was within six weeks of dying, then this was carried out by a special Intensive Home Support Team. The therapists had the knowledge to assess a person's functional ability for the ordering of certain equipment and appropriate help.

Knowing who to contact and how to present the needs of someone at home, was an aspect of the community team work. They often made telephone calls to out-patient departments, consultant secretaries and radiotherapy departments on behalf of the person in their care, since they knew how to get round the system and could be more assertive. This helped in altering appointment times and accessing investigations faster. Arranging help and mediating between services was an aspect of care very much valued by people at home. Knowing which chemists kept supplies of controlled drugs that could be accessed out of regular office hours was important in managing changing conditions of people dying at home. Knowing about the supply of syringe drivers ensured that a person in need of one, in the community or hospital, did not have to wait.

Knowing who to contact about what issues, came with time and experience, as was observed when RT joined the community team in September 2001, and had to learn about the out of hours chemists and who to contact for organising equipment and services. This organisation and resource knowledge was important in facilitating people to stay at home, have their symptoms monitored and investigated and providing person centred care.

The doctors and consultants were resources of knowledge and experience called upon through the day by the ward, community and hospital teams for symptom control advice and advice about particularly difficult situations. The hospital team had built up an extensive network across the hospital, which could be called upon for advice and assistance. They knew about available equipment and potential community resources, which could be discussed in planning a discharge home. They had good working relationships with the Intensive Home Support Team, who could set up care for a person at home and who was likely to die within a couple of weeks. The hospital and community team were also able to arrange Marie Curie night nurses to help care for people at home over night.

The palliative care service was able to use its position within the general hospital to access clinical colleagues, diagnostic and pathology services. The doctors and consultants, guided by their medical knowledge, would request a consultant colleague's advice, arrange for a diagnostic procedure, such as an ultrasound, and have an invasive symptom control procedure, such as an ascitic tap, undertaken within twenty four hours. Good working relationships and astute political knowledge of the hospital meant that some of the diagnostic and clinical departments could be persuaded to fit in people from the palliative care service sooner rather than have them wait.

8.4 Knowing the Person

8.4.1 Constructing the Person Being Cared For

With an organisational philosophy that valued individualised care there was an active engagement in trying to get to know and develop awareness and understanding about each person cared for by the different teams within and across the service. The collection of basic information about a person created the foundations upon which additional information was added and synthesised. Knowledge and awareness of a person and their family's values, beliefs, understandings and expectations enabled an attempt to better understand and meet that person's needs and gain some insight into the essence of who they were. Knowing how to develop, build and maintain a relationship with the person and their family was crucial. By chatting informally during episodes of care and at other points in time specific knowledge of and about the person was gained.

Knowledge about each person was developed and constructed over time, using the different information shared between team members during formal meetings and informal conversations in the corridor.

> *' in the morning handovers, there's everybody's involvement and I think 'cause the family may have said something to one person but something different to another or, filled in the story a bit more somewhere along, you can get the whole picture and each person can do their bit. Actually I think it doesn't matter who you are really, I mean, when I first came here we had a wonderful cleaner and she often got told as many things as all of us did' (IW interview : WardStaff Nurse March 2002)*

Getting to know a person took time, and required the collection and assimilation of often abstract bits of information and insights about the person. The fragments of information and the different insights were shared between the team members in a way that enabled them to construct both a collective and an individual picture of that person, and to reconceptualise and reconstruct their understanding of the person as more information was elicited. This enabled the teams to respond more particularly to each person's specific needs, and to recognise small but significant changes in them. There had to be a willingness, on behalf the person being cared, for to enter into a dialogue with staff and talk about themselves. Having an understanding and knowledge of the person, their values, personality, and their history was used in considering possible choices and decisions about a person's care, in controlling their symptoms and how best to support a discharge home. A synthesis of biomedical, practical, experiential and intuitive knowledges, with the development and use of specific knowledge related to each individual, was required to personalise the care.

As ST explained in her interview, being 'known' was important, since the teams specific knowledge of her improved her experience of care and having her symptoms managed. She was also aware that time was an important factor in developing knowledge about a person and being able to personalising their care :

> *' I mean, you can give care to a certain extent, but unless they know you, know what your pain is, what your circumstances are and how you react to treatment and meal times and what you like to eat, um, unless they know you there's only a slight care there but still enough to make you feel comfortable as you get to know them, you know in my case, I've been here a long time. I've been in and out so many times trying to adjust the drugs but for someone coming in that, God forbid says they've only got about a week to live, they'll get to know them partly. The palliative care is still there, you can see it, you know its there, but, unfortunately, they don't get to know the individual person, the longer you come the more they know you. It is, yea, because I mean they know when I'm in a bad mood and they know when I'm sort of in a jolly mood. Usually I'm up and shouting and causing havoc. I'm not this time, um, and today is the first time that any of the nurses have seen me cry (ST cared for on the Hospice Ward at the time of interview October 2001)*

Understanding and knowing what a person's normal behaviour and reactions were assists in providing more responsive care when changes occur. During a conversation on the 10th October 2001 the Occupational Therapist described ST as coping better emotionally this time and being *'more serene'*, but added that this episode in her illness had bought her up short. Initially when ST became very drowsy possibilities were raised as to potential causes to the change in her mood and her ability to engage with the nurses. The change was initially discussed during the nurses' handover meeting:

> *'ST, was described by KM as 'sleepy' and 'vacant' and 'not right'. KM raised the question as to whether she had cerebral metastases, and the nurses talked about this as a possible cause for her increasing drowsiness. (Afternoon handover observations October 14th 2001)'*

The lack of clarity as to 'not right' meant what was not usual for ST. It was relative to her current physical and mental state, context specific, in that she had multiple problems and was very unwell. This 'vacant' episode was new for her and might not necessarily have raised concerns elsewhere where she was not known so well. The team had got to know ST's personality traits, her values and preferences from having cared for her previously and also her usual patterns of sleep and interaction. They knew her disease state and the potential problems that might arise from it. They drew on knowledge of other biomedical causes of confusion and drowsiness, undertaking basic tests before developing a picture that was indicative of a urine infection, rather than high calcium levels or disease progression. The urine infection was treated, and ST became lucid and quick witted once more, although her general condition continued to decline.

Knowing a persons and respecting their values, decisions and wishes was also revealed in the response to and the discussion about NO, who had, until the point of the following example, refused to have more medication to help make her more comfortable because she feared being too sleepy. On the 1st October 2001 during the ward round meeting, NO was described by RB as a *'very frightened lady'* who was *'on the ball'* and who wanted to *'be with it'* but got very tired by seeing visitors. HN had added that IS had described her as having chronic anxiety, and HN felt she sat and ruminated over her problems. Over the following fortnight HK had cared for NO and had spent time talking with her and listening to what her colleagues had said about her. They had provided physical and emotional care for her since admission, during which time she had increasing difficulty breathing and moving because of the cancer in her abdomen.

> *'HK went to answer NO's buzzer, and came back to get some medication for her, and then said to KM who was by the desk that when they were talking had NO said she wanted to go now,* [to die] *and couldn't take much more …HK said she thought that she wanted to be more sleepy now, and said she thought they should try tonight to do this. I said she seemed unable to relax and HK said yes, it wasn't her breathing, but she had been fighting it. HK added that NO had had a death phobia since her 20's, and felt that now she was asking for help. HK then went to sit with NO whilst she had her tablets and because she was so frightened (Observation notes 14th October 2001)'*

HK revealed knowing of NO's fears about dying from previous conversations with her. HK also felt able to interpret NO's comments about being ready to die, because of having got to know her and knew which medication to give her to help with her breathing and her anxiety. HK also knew that NO was frightened and would appreciate company until she fell asleep. I observed KL gently discuss medication changes with NO, which were only instituted with her agreement.

Respecting a person's decisions and values also required ensuring that the rest of the team involved in caring for that person 'knew' the important facts and details about them and their families. The degree of informal chatting, updating and exchange of information within the meetings, between staff on the wards, along with the level of description in the community and hospital team notes, were important factors in ensuring general awareness.

The team members found it difficult to personalise the care for people they were not able to build a relationship with, either because they were unconscious or because of the personality and manner of the person. One such woman was HI. Several nurses and doctors found trying build a working relationship with her difficult, as they could not get on with or get to know her because she did not easily offered information or enter into a reciprocal conversation, and resisted the suggestion that she was depressed.

HI was described as 'childlike' in the presentation of her personality, and in her response to what was for her a slow and awkward dying. This challenged the nurses preconceived perceptions about how she was expected to respond because of her professional background. Only one nurse found it easy to relate to her because she had previously worked with children and knew how best to approach a frighten and dependent child, adapting this to HI. Several members of the multidisciplinary team struggled at times without knowledge of how to work with the dependant child within HI. It was recognised, acknowledged and recorded that HI was in emotional and spiritual distress, and assistance from the Psychologist was sought after a suggestion by one of the staff nurses to ensure her needs were better met.

The lack of skills in relating to HI, could be seen to affect the attempts to manage her pain and symptoms. During the ward round meetings it was as if her neediness caused some form of resistance in the staff as they tried to reduce her analgesia, because it was felt her pain was not entirely due to her physical condition. Although they were aware of her anxiety and distress, this added to the problems they had working with her personality. In her medical notes it was recorded:

> *'Difficult patient to help – always has a ' but' ready when a line of managing a symptom is suggested. We shall have to work with her to achieve some compromises' (entry in medical notes by HN 1st September 2001)*

It was clear that knowing and using social norms and rituals for getting to know people, required a degree of reciprocity to guide the development of 'therapeutic' relationships. However, knowing how to use these for creating a relationship for care giving and care receiving introduced normalising and disciplinary processes. These effectively saw some people not being able to engage or be engaged with as much as the others and this did bother some of the staff.

> *' inevitably there might be one patient that comes across, like HI, that you're not terribly keen on and you're, sort of doing the care, and, in fairness, you probably aren't giving the same sort of affection that you would to somebody like, say AK, or N, um, but I always hope that I do give exactly the same care.*

> *I mean, how they would perceive it from their angle, I don't know. Um, it's a difficult one, isn't it, really' (ER Health Care Support Worker November 2001)*

The disciplinary practices associated with the normalising processes of care were revealed in the difficulties experienced by staff with HI and with a staff nurse who was not liked by many of the nursing team because of her mannerisms and less sensitive communication skills which were frowned upon by more experienced nurses. HI's care was delegated to this junior, inexperienced and poorly skilled staff nurse, RB. Both were indirectly disciplined for not fitting into the expected norms of palliative care. However, this made for an unlikely alliance between the two. I had been observing RB and helped to wash HI with her. RB left the bathroom and HI began to talk:

> *'RB went out to see how her other patients were doing, which really wasn't the plan of observing care, when in fact I ended up being the one giving HI her wash. It did however give us some time to talk... She then made a comment about being naturally sad and not depressed, as the doctors thought she was. She said she felt she knew what the difference was and that she was naturally sad rather than clinically depressed. She then complimented RB for giving her a hug when she gets upset, saying some of the others don't.' (Observation notes 2nd October 2001)*

HI felt she was not being listened to and her perception was not heard. She was also acutely aware that the care she needed and appreciated was not available to her by some of the nurses on the ward. HK, one of the ward sisters, suggested team nursing helped when a member of staff found it difficult to relate to and work with a particular person, so that the person's needs could be shared between the team and be better met. However, this was different in the community where team members worked independently working at building and maintaining trust without a team to share the care with knowing when a problem existed they would have to offer the person a different Nurse from the team. In the hospital continuity was more far more flexible.

8.4.2 Contextual Knowledge: Knowing the Life World of the Person

Awareness and insight into the social world of the person being cared for, offered some understanding of the influences behind how the person responded to their illness, and how the care could be approached. Contextual knowledge was gained when undertaking the initial assessment and by asking about family and friendship networks. This was formalised in the drawing of a family tree and used to develop further questions and knowledge about the person's relationships, support networks and significant past events such as family deaths.

The awareness of where the significant and close relationships were was an important part of assessing what emotional and practical support was available. Knowledge of deaths in the family alerted the team to previously bad experiences, fears and ability to cope. Knowledge of problems in a family enabled the team to manage different situations on behalf of the person. So when BG was on the ward and requested that no information was to be given to his wife and family about his condition, the team respected this and explained this to his family. During the ward round on the 30th October 2001, the team discussed the visit by ST's sons and how they had ensured the men were supported and had enough opportunities to talk with their mother, even though they were no longer on talking terms with their sister and her boyfriend. Being aware of the family dynamics enabled the teams to be sensitive to potential problems and support the person more effectively.

Contextual information was also collected from a variety of sources and synthesised at a personal and team level. Negotiation occurred between different knowledges available to the different palliative care teams. When KK was admitted to the hospice he had previously been cared for by one of the community nurses, who found she could never talk to him with out his wife being present, and felt she was unable to get the whole picture. However, in a conversation during a ward round it was revealed that KK had explained that, although his wife was physically dependant on him he was emotionally dependant on her, stating clearly that he did not like to talk about things without his wife being present. The different knowledges of the couple's relationship were negotiated to a point of consensus led by the consultant confirming that the team should respect the way of relating that was normal for KK and his wife. The knowledge about KK's wife was passed on to the other nurses, and the therapists so that they all became aware of the situation.

Contextual information about the home was important when planning discharges, so that the person or the family member could manage to the best of their abilities. The information was vital for the social workers so they could inform social services and for the occupational therapist and physiotherapist so they could ensure people were able to function to the best of their abilities with the appropriate equipment made available to support them. LK described during a long conversation on the 29th October 2001, how when her husband KK was discharged home, his bed was put into the living room where he had his sporting trophies around him and he over looked the garden. His wife could sit there with him and there was room for a commode since he was not able to walk the distance to the toilet. When he returned for a second time to the ward, he was dying. The team all knew him and his wife and their situation and were thus more able to meet both their needs.

The community team had first hand knowledge of people's homes and were able to observe and assess how each person functioned within it. It was also likely they would meet with family, friends, neighbours and carers when visiting. Photographs in the rooms were used as conversation points, which could provide additional information about family links and particular occasions. This direct contextual knowledge gave the team an important insight, which they drew upon when advising people about the practicalities of managing at home.

8.5 Knowledge From The Person Being Cared For

The knowledge held by the person being cared for about themselves, and that of their family members or carers, was often drawn upon to form an assessment and to guide future planning. Working in partnership with people required that their knowledge of themselves be listened to and valued. There were at times differing views, between the professional knowledge and opinion and the person's opinion of what they needed and what they felt their problems were. HI commented that her opinion was not always accepted which compared to how ST's knowledge of herself was trusted. It was said on several occasions by RU, KL and EG that ST would know when she was ready to go home, unlike HI who the team felt had wanted to stay until she died.

The daily work of the community team relied on trusting the knowledge and perceptions of the person and family at home. Often the nurses spoke with people over the telephone, and had to trust what they were being told either by the person who was ill or their family carer. The nurses had developed their assessment and intuitive senses to pick up changes in a person's voice and how they were talking about something. Working within people's homes meant that the Nurses had to work in partnership and work with that person's specific knowledge and skills, adapting their own advice to accommodate a person's particular needs or routines. This negotiation was not always easy.

At times professional knowledge was placed before the knowledge the person held about themselves. Reliance on biomedical and technical knowledge would be used to justify particular decisions, such as discharging a person to a Nursing Home because they were not dying, despite the persons requests.

8.5.1 Knowing One Another

Knowing colleagues personalities, values and skills was an important aspect of team building and working together. Nurses in the community team and the ward talked about how they approached KL and IS differently when they wanted something done or prescribed. IS worked much more slowly and took longer to reach a decision, was less trusting of the experienced nurses' request about a particular medication, where as KL was faster, trusted the experience of the nurses and often suggested a back up plan. Using their knowledge of how they worked ensured the requests for assistance or advice were tailored to that particular person's character. This was also a consideration for HN, the ward doctor who said in her interview:

> *'I think I play them differently. I've known KL for a long time and because she's been a consultant for longer and she's known me for longer I have a lot*

> *of clinical freedom with her patients and up till recently I've had it with all the patients and with the second consultant, he's newer. He's not been a doctor as long as I have and he's not been in palliative care as long as I have actually so I'm just aware that, from his point of view, isn't altogether comfortable, but I think with, what I've felt, we can get along quite well, but I do treat, I do play it differently with IS and his need to be updated. He likes to be involved and there are decisions that I'm capable of making that I defer if I know he's been around and we discuss it and that's fine ...IS takes a much slower, more measured speed with his patients. KL's a different character, she's more, sort of vivacious and quick, so I think that reflects in the way she feels, and I'm not suggesting she shoots them all out of hospital at all but there's just a difference of speed and, but, um, you know that's fine.' (HN interview: Ward Doctor October 2001)*

Talking about families and life outside of work was one aspect of getting to know someone within the multidisciplinary team. The two nursing teams on the ward held team social evenings outside of the work environment. This knowing of colleagues did not extend to knowing the district nurses or the general practitioners in such an intimate manner, as they did one another, but the nurses got to know how each health professional in the community worked and responded to different situations. This informed the community team as to how best to approach the situations and experiences with the general practitioners or district nurses, having developed an awareness of their attitudes and skills, and how best to approach these when caring for people and their family needs at home.

The hospital palliative care team, shared some personal information between one another and knew one another's strengths and weaknesses. They knew about each other's home lives, to an extent, discussing their families and also shared some personal information on occasions with the oncologists, with whom they had a close working relationship and who talked about their own families. The hospital team did not get to know the different doctors on the hospital wards as well as other members of staff because they changed jobs every six months. What the team did was build a professional working relationship and learn about how the doctors and the nurses managed in difficult situations. Often a ward was 'known' either to be coping or not coping, as the team picked up on the general stress levels and behaviours of the staff rather than the individuals. They would then respond to these changes, offering increased assistance and support to the ward as a whole and to individual staff members where there was a particularly difficult death or family situation.

Much of the time people knew one another's working traits, strengths and weaknesses, leaving the more personal friendships to continue outside of the work environment. However, the development of predominantly friendly working relationships and awareness of team member's skills and abilities were important in creating an environment, which was not only supportive but allowed for open communication and the non threatening sharing of knowledge and experience.

8.6 Emotional Knowledge and Knowing How To Work With Emotions

The processes of building and maintaining relationships, providing emotional and supportive care and managing symptom control was informed by emotional knowledge and knowing how to work with emotions. This knowledge was expressed during team discussions, during informal chatting and in the interactions between members of staff and the people being cared for. A synthesis of propositional and tacit knowledge, taught theories about people and emotions alongside personal and professional experience and intuition, was revealed. The knowledge guided assessments work with different personalities, establishing trust and building new working relationships and maintaining on going ones. This was also revealed in the appreciation of how different people coped with a life threatening illness and facing death. Knowing how to work with fear, distress, anger and other heightened emotions was shared between the team members across the different locations of palliative care.

The more experienced team members had a richer knowledge and set of skills than those who were newly qualified, or who had less experience of palliative care. The social workers also had a different range of knowledge and experience than other team members, because they worked with young families, particularly before death, and with many people during bereavement.

Being able to understand how a person presented their emotional world from their verbal and non-verbal behaviours enabled the team members to consider the best approach to supporting and working with that person to identify and meet their needs. Knowing when to say something or knowing when to sit quietly beside the person was important in ensuring that care was sensitive and appropriate. JS, one of the staff nurses on the hospice ward recalled a woman who was unable to talk about her distress, which had been recognised by the team. In her description of the woman JS revealed knowledge of behaviours and bodily expressions of non-verbal communication that indicated unspoken distress. An awareness of the emotions the woman was experiencing was probably from the shock of her diagnosis, and an understanding of time as a process was an important component of building trust, and sensitive caring:

> *'there was one particular woman on here, can't think of her name now, and she came down* [from the hospital] *and she'd had a very sudden diagnosis, like often happens, and she came down here and she really held us at arms length, and to cope with this awful blow that had happened in her life she curled up in bed and wanted the curtains all drawn tight and that really was shutting everybody out, wanted pillows all round her, wanted to cocoon herself and find some safety, umm and I sort of met her, and it was difficult because, you tried to build a relationship and that that, you know, she was feeling very frightened, and a bit angry, a bit sensitive, um, and quite withdrawn, and over the weeks, you know, you just kept chipping away really and trying to get her to trust you and to talk through things ... and she stayed here right to the end and by the end she was so open and so loving and felt so secure with us all, and it really, was something special I felt, um, even to the last stages just before she died, she was just so different to how she was this frightened woman, who'd arrived, and very withdrawn and angry and to this really quite affectionate lovely woman saying goodbye really' (JS Staff Nurse Hospice Ward: Interview March 2002).*

In Chapter 7 EG describes at length the process of working with a very distressed woman in the hospital. The narrative reveals several different knowledges informing her care for the woman. EG explains:

> *'I remember looking through the notes, going straight to the family tree page, not looking at any of the written notes and then , sort of, feeling guilty because I thought I'm making assumptions here, but then I though 'no' because I've never met this lady, its just what I'm picking up here'*

This suggests she began by using intuitive insight, informed by the information she had heard from talking with CS and LN about the woman. KL used her knowledge of social interaction when commencing the episode of care, then drew upon her biomedical knowledge of medication and of how to develop trust by acknowledging the woman's experiences and offering more help if the pain did not resolve

> *'I acknowledged her physical pain and she'd only recently had a painkiller and I said 'I don't think you have given it time to work, so let's talk through a few issues around there and you know, if we find it hasn't worked, well we'll look at something else to give you'.*

By discussing KL's knowledge of the multiple causes of pain this opened out the discussion from the physical experiences the woman was having and offered some assurances that KL 'knew' what she was talking about

> *'I talked to her about pain comes in different forms and you can't separate sort of physical pain, from what you might be thinking about the illness at the moment. And that's sort of how we got into it and she talked at length about something that wasn't a deep dark secret as such, we picked up on issues within her family and previous illness.'*

This affirmed her initial intuitive insight with relation to the family. However, EG also talked about her knowledge of the interrelationship between process and time;

that being able to explore emotional aspects does not often occur immediately, rather it takes time and involvement

> *'I feel I came at the right time, you know others had built on that and I think that's where the team approach comes in. You can't just walk into a situation, it's a drip by drip effect…there was something you could work with, even though it wasn't, um, tangible'.*

Knowledge of bodily expression and non verbal communication, both essential when working with emotions, were highlighted in reflecting the effect of EG's involvement

> *'All this stuff came out and her whole body changed. Err, the way she was holding herself, the body language… It was still there, it was still there, nothing had changed, but everything had changed. She had got control back over her life and of her dying. She was still frightened, and you know, work to be done there, but she was no longer diverted by it, she was able to concentrate on the job in hand for her.'*

EG's contextual knowledge of the hospital wards, the lack of in experienced staff and time to work with emotional distress and complex symptoms guided her planning

> *'we came out with a plan, and in fact she was transferred to the hospice, because she was terminally ill, and there had been problems up on the wards because many times psychological issues are incredibly time consuming and on a busy general ward they're very difficult to handle; she did have symptomatic problems as well so it was decided that she'd come to the hospice, and, I know it sounds terribly twee to say that she died a very peaceful death. It was like she got a load out'*

Working with people who were angry required drawing upon particular knowledge and skills. People whose expressions of distress manifested themselves as anger towards the staff often alienated them, and lack of knowledge of this response to distress and how to work with it hampered care. Often the hospital or community Teams would have to explain and teach about these processes to other members of staff. In the following episode of care observed on the 18th March 2002 between CS and IA, CS draws upon different knowledge and skills to care for IA. CS uses her knowledge of social spaces, to guide how near to sit, taking up a position that was close, but not touching initially.

> *IA was lying on her right side, and CS sat on the bed facing her. I sat at the end of the bed saying I would sit out of her way. Then IA said she felt disappointed because she didn't realise that she would still have the same ... IA then described an incident at the start of her admission to hospital when the Dr had wanted to put a needle in her arm and she had said no* [she has a needle phobia] *and the Dr had tutted and left. IA said that perhaps she was having a bad day but they got off on the wrong foot and she said she wished she had never moved wards as she knew people there and could see people at the desk. CS listened and maintained eye contact and listened quietly and IA became tearful and said that she was scared and that this was happening too fast and that she isn't ready to go .*

CS skills were to sit quietly and enable IA take the conversation to what was concerning her, adding only the occasional comment, listening to what had made her angry and what was causing her distress. As IA became distressed and tearful, CS knew this was when she could use touch as a means of comfort.

> *CS held her hand as she listened and IA cried, saying it was now real, she then said that there were problems passing her home and estate onto her family. CS continued to listen and stroked her arm and then head and then IA became quiet and they were quiet together for some time as IA continued to cry and CS gently waited and watched.*

The use of touch and knowing that the process of IA being in touch with her sadness and feeling would need time. CS sat quietly watching for non-verbal signs of change in the quiet which they shared, before she spoke acknowledging IAs situation and feelings.

> *CS then reflected how tough it was for her, and IA then said that she had still not sorted her mother's estate out yet and still had this to do. Slowly the conversation picked up and became more chatty to the point IA made a humorous comment about her world of work having people who were sex mad in it, and we all laughed together.*

By being aware of the cues by IA to move the conversation away from the deepest pain by lightening the content and joking, CS changed the direction.

> *CS then moved the conversation onto looking toward getting home, and asked IA if she would consider having a social worker. IA was adamant that she was not in favour of social workers because of a friends previous experiences. CS talked about the help she might need and that she was thinking about how the social worker needed to ask about the attendance allowance. CS then asked if IA would agree to seeing the occupational therapist for an assessment and let the SW arrange some care. There was some laughter as IA made another less than complimentary comment about social workers , but then CS listened some more as IA talked about her pain.*

Knowing what practical assistance IA would require to get her home and who could organise this, CS brought it into conversation. She used her negotiation skills and humour to counter IA's dismissal of social workers, whilst wanting to ensure some professional advice and support. CS, using her observational skills to pick up that IA still had physical pain, asking her about it, acknowledging she required some analgesia and that IA needed some time without being emotionally distressed further.

> *She began to show more angst when talking about her pain. CS then asked if she wanted any pain killers, then IA rang her bell and a nurse came along and took the drug chart and bought back her pain killer. CS drew the conversation to a close and said she would go now as she felt she would distress IA more by staying as she was still very tearful. CS said she would come back once the pain killers had had a chance to work. Before leaving held her hand tight and gave her a kiss on the forehead. Throughout IA had looked pained, and*

> *appeared almost childlike in her posture and had a facial expression of lostness.*

Handled differently, IA may have remained angry and dismissive towards the hospital staff, as she had been all morning. CS knew to stay near, when to listen, how to respond and when to sit quietly and allow IA to cry, and whether to touch her and stroke her hand. CS recognised the anger as a sign of distress, and stayed with it. Practical, experiential and intuitive knowledge gained through the years' of experience of working with people who were distressed provided the insight about how to work with IA, and how not to explore her distress any further, using time as part of the process.

Sharing knowledge and professional experience with colleagues from different disciplinary teams in the Hospital and the Community enabled greater insight into the range of emotional responses that people have when they have been given a shock diagnosis or are facing death. This created an environment in which the palliative care nurses, doctors, social workers and therapists could advise their peers on potentially helpful ways of talking and working with people by using their own knowledge and experiences as an educative process for others.

As both EG and CS explained in their interviews that experience developed over time was an important foundation in learning about people and their emotions, developing confidence and using skills and one's insight in assessing and then pursuing an approach to opening up the routes of communication. EG stated that often courage, as well as knowledge, was called for to stay alongside a person in distress and to explore this, instead of giving medication and walking away.

CS reflected on both her professional experience and her personal experience as a bereaved person. Personal knowledge informs professional knowledge.

> *'I may not be able to change any of the scenarios very long for them, but I'd like to open up for them ways of coping. They might never cope but I like to help them to look at things that they can do in something of preparation for the impending death because, its not going to make it better but there's a lot of*

> *turmoil, as I know to my cost...I do talk a lot but I do listen to what they're saying and to give them the opportunity to cry and be, be sad and to be able to express all the fears and emotions (CS interview: Hospital and Community Team Leader April 2002)*

An important component of palliative care work included drawing and reflecting on one's own previous experiences, skills and knowledge of coping with difficult times. Education courses and observing experienced staff were important. Many of the nurses on the ward did not feel they had enough knowledge, skills or confidence to work with people's emotions, although many made a point of sitting and talking to people during the day and listened to concerns raised during personal care. There was some consensus between staff nurses on the ward that a counsellor would be helpful, and perhaps explained why the student counsellor was welcomed with open arms, filling a perceived skill and knowledge gap by the ward and day centre nurses. All of the nurses and multidisciplinary team valued BD who was a mental health nurse and was able to offer insights from her experience and mental health knowledge. She also often had long 'deep and meaningful' conversations with people during the night, recounting the issues for the team the next day. In her interview HK acknowledged in conversation on the 10th October 2001 that there was huge disparity between the amount of education and training on symptom control compared to working with emotions.

Several nurses in the community team had undertaken different 'communication skills'courses. They were also generally more experienced, having spent longer in nursing and generally longer in palliative care than many of the nurses on the ward. Working independently in people's homes with the person, rather than in a team situation, allowed the nurses to develop plans for emotional care and followed these through consistently. something that was not possible with shift and teamwork on the ward. CS and EG, both very experienced worked in the hospital team, along side LN whose inexperience of working with complex emotional problems was revealed by the allocation of the people on the hospital wards with complex needs to CS.

Knowledge of coping skills, working with families and children were predominantly the remit of the social workers who were quick to ask questions about people's coping styles and abilities and reactions raising possibilities for the team to consider. The observations about what they felt was happening in a particular situation they were hearing about drew, at times, upon tacit knowledge as they talked through how to manage a particular situation and intuitive knowledge informing a rapid assessment of a situation. The social workers had undertaken previous training themselves and taught their knowledge to the bereavement support volunteers. They did not work to any particular model, drawing on a range of approaches and tailoring their methods to individual needs.

Knowing how to work with a person who was dying fell to the nurses and ward doctor. Care of the family before, and immediately after the death, was undertaken by the nurses, who had to assess how best to support the family and friends present. They drew on their previous experience as well as learning from one another. When a relative returned to the ward to collect the death certificate the following day the nurses explained their knowledge of the procedures involved in registering the death and preparing for the funeral. The community team nurses usually made a follow up telephone call or went to visit the person recorded as next of kin or main carer , although this did not occur if there had been previous contact with the family. Sometimes the hospital team would telephone. The knowledge of working with immediately bereaved families was often learnt during the early days as student nurses by observing more senior staff, which became tacit and intuitive over time, developing and adapting as more bereaved people and responses were encountered. Forming a wide experiential knowledge base.

8.7 Experiential Knowledge and Reflective Practice

Knowledge gained from experience was revealed during interviews with members of staff as they reflected on episodes of care and from observing and listening to different team members across the service when they remembered and reflected upon previous situations or on people with unusual symptoms or family situations, remembering and how these were managed. VB reflected on what she had learnt about being with people when they were distressed.

> *'I remember a patient last summer, no it wasn't it was about a year ago she died, and she had been told that she wouldn't walk again and I remember the incredible anger she felt after KL told her, um, and she said you know 'what use am I to anyone. I'm nothing but a burden to my family'. She was distraught, distraught. I felt, I felt it was very difficult to say anything to comfort her, um, and all I could do, which I have realised the value of now is be alongside her in that distress and I think if you can do that is where its very valuable, um, it doesn't make it easy. Its very difficult thing to do because, as nurses, we feel as though we're there to make it better, even though its palliative care and you often feel in a situation like that.'(VB interview: Ward Staff Nurse November 2001)*

One of the striking observations was the degree to which some people cared for in the past were remembered, the detail with which their problems, their personalities and their families were recalled and how this was a shared memory between people who had been there at the time. As with the daily exchanges of information, in which different team members contributed their observations, perceptions and experiences of a person, the memory was also rebuilt and reconstructed between the people in the conversation. Out of this pooled memory were drawn reflected lessons about what had or had not been tried in managing a persons symptoms, or working with a particularly challenging family situation. These would be considered and applied to the current challenging situation or symptoms.

KL, EG and CS all talked about the need for experience in developing skills for working with people who were emotionally and physically distressed. Often this was juxtaposed by comments about the hospital ward nurses' lack of experience and the doctors being unable to tolerate staying with a person without physically doing something.

RT who only moved in to palliative care in September 2001 talked with CS every morning about the decisions she had made the day before and about the people she was planning to see that day. As the winter months went by RT asked less and began to suggest her own approach and listen to CS's opinion. There was a move from learning facts and information to reflection and analysis during my observations between December 2001 and February 2002 . IS and CS drew on the team's experiential and reflective knowledge by asking the nurses to critically analyse their decision making processes for the people in their care within the weekly meetings that I observed. The nurses would then share insights from their own experiences and developed a pool of knowledge from which to draw from over time. It enabled the development of analytic skills for assessing which knowledges to use and developed further thinking in action as well as reflection on action.

The observations of the weekly multidisciplinary meetings revealed them as a place where collective reflection occurred as was clearly demonstrated on the 13th November as discussion surrounded the death of a man at home with an internal defibrillator and whether prior conversations with his wife had been of any benefit in trying to anticipate his death. The team members drew upon current and past experience and a wide range of different knowledges to reflect on each person's situation. Collective memories of previously challenging situations were often used to offer an alternative perspective to a new problem. The knowledge gained through experience and reflection was an important aspect guiding the care processes, knowing when to listen, when to talk and when to act as well as knowing when to pursue an area of discussion. These required both an understanding of the person's needs and of the context within which the situation was taking place.

8.8 Ethical Knowledge

Ethical knowledge in itself was an aspect of care that underpinned many of the daily and hourly decisions and conversations. Ethical knowledge was never discussed in direct terms rather it was tacitly understood through dialogue with consensus occurring throughout the processes of care and conversations during a day. Understanding the use of particular medications from symptom control, and their potential side effects, was an everyday practice in which ethical implications were considered. This was clearly highlighted when the ward team discussed changing medications for NO as her condition began to significantly deteriorate. The extract from the observation of the ward round revealed the team discussion and search for ethical consensus in managing her symptoms. The following examples attempt to reveal just two different aspects in the continuing ongoing process of ethical discussion occurring over time during the following days within and outside of the formal meetings between staff and with NO.

> *JS went back to talking about NO saying 'she seems frightened, and tired of being strong' HN said that yesterday she didn't get the impression her breathing was any worse. And then asked 'if she were in bed more, would we be thinking about putting a catheter in?' there then followed a discussion between RU, JS and HN about what to do for NO, whether she should be sedated, whether she was less well and what else they should do to make her more comfortable RU said 'there will be a right time'. HN said 'I don't know if we have used Diazepam, I wonder if this might be…I just wonder if a bit of Midazolam in the driver…' then wondered aloud if they should exchange the Metoclopramide for Haloperidol. And then she asked, 'is Haloperidol better? Should we consider a change too RU said 'yes' and JS said 'yes'. HN then said that NO had had five days of an antibiotic and said to the team 'shall we stop it?' (there is very good eye contact between HN and everyone else and open body postures) JS said yes, then added that her urine was still concentrated and there was only small amounts. (Observations ward round 15th October)*

On the 19th October, NO was first discussed in the ward round and then KL went to see her about reducing her tablets further and increasing some of her medication in her syringe driver. NO was now very sleepy, and having trouble talking and breathing, and yet remained determined to be in control. The following extracts continue the ethical approach from assessment on the 15th October to concluding discussions on the 19th October.

> *'HK said, 'she's going down' and explained that she couldn't take her tablets, and now couldn't get comfortable in bed. There was some discussion about her deterioration and KL commented that perhaps they*

> *could crush up her tablets to stop the PV bleeding into jam, and that she felt that NO would be unlikely to want to stop all her tablets. She said they would need to negotiate with her' (Ward round discussion 19th October 2001)*

> *KL asked her how she was, and it took a little while for NO to answer. KL stood close, facing NO and trying to make eye contact when NO opened her eyes. KL also held her hand and spoke gently to her, but not in any patronising way. In fact for such a poorly lady, KL continued to try and find out what NO felt and wanted. KL explained her thoughts about cutting down some of NO's tablets as she described how the nurses had explained how difficult they had observed it was for her to take and swallow them. She also raised the issues of giving NO her morphine using a syringe driver and perhaps something to help her relax a little but didn't want to do anything without discussing it. NO agreed in between moments in which it appeared she had drifted off to sleep, only to wake and take a sip of tea.(KL talk with NO after ward round 19th October)*

The team had to balance their knowledge of the sedative effects of increasing NO's morphine in conjunction with adding more Midazolam into her syringe driver, with the need to improve the comfort of her breathing and the discomfort in her swollen abdomen and legs. Such decisions were never undertaken without discussion with the person being cared for first. Clear logical thought about the potential double effect of speeding up death by treating a symptom were needed before undertaking these potentially ethically sensitive decisions.

Increasing drowsiness in ST led to concerned conversations by her daughter with HN about her mother's medications causing the drowsiness. HN explained her conversation with her daughter to the team on the 13th November 2001, that the medication was not the cause of the drowsiness, but her mothers deteriorating condition. Talking through ethical concerns with staff in the hospital and community about the use of particular medications or doses of medications was an important part of the Hospital and Community Teams' roles. Many of the medications used in palliative care were not commonly used in the general wards, although they were more commonly used in the community. There remained a distrust over doses of Morphine and Diamorphine for pain and breathlessness and the use of Midazolam, a respiratory depressant, for breathlessness.

Ethical knowledge was not just used in relation to symptom control, but manifested itself in how the staff used their awareness and knowledge of family situations to manage disputes and discussions. For the team the ethical dilemmas that surrounded whether to recommend a person be discharged to Nursing Home care were fraught. Balancing the needs of the person with the needs of the service challenged the personalised approach to care that most believed in. This was especially true when people had been with the service for some time, but whose needs were not deemed to require specialist palliative care.

Across the service ethical decisions were informed by the principles of beneficence, non-maleficent, justice and autonomy. However, dialogue was the guiding process with a focus on the contextual and relational aspects and consequences of the decisions. Ethical considerations were discussed in a non-hierarchical manner in which the rights and freedoms of the different individuals involved were considered and negotiated most of the time.

When WY became increasingly unsteady whilst on the ward with other symptom control problems it was found he had a metastasis in the cerebellum. It was agreed he would have this treated with radiotherapy at a neighbouring hospital so he could eventually be able to go home. However, after he recovered from the treatment during early December 2001 his wife decided she could not cope with him at home. The early discussions appeared to have failed to consider her perspective and now she was exercising her right not to have her husband home, which was reflected upon By JL his community nurse on the 17th December. The team had to discuss the ethical dilemma they faced. They had treated WY only for him to live the rest of his days in the community hospital because he was too well to stay at the hospice.

Ethical knowledge become tacit as it is drawn upon constantly throughout the day, never referred to in direct terms, but with an assumption of shared knowledge by the team members as they discuss the multiple choices, potential outcomes and dilemmas.

8.9 Tacit and Intuitive Knowledge and Importance of Timing

Timing was an important aspect of managing the safety of intense or emotional interactions and was often informed by a combination of experience, tacit and intuitive knowledges. When asking members of the community and hospital teams, including EG, about how they knew when to pursue or leave a conversation they were not able to clearly explain how they knew or why they often chose a particular approach to take, they 'just knew'. The nurses said that sometimes this was informed by knowing the person previously, having contextual knowledge of the person's situation, having developed these skills over time and developing an intuitive feel about what they were picking up. They also 'knew' that time was crucial if they were to enable a person or family to manage some of their fears or concerns to live the life they had left and make their plans for the future. The amount of time they had available was an important factor, in that if they were half way through or nearing the end of their meeting with the person, they would not be able to manage the emotions and leave someone in a safe space in such short space of time. Timing was a crucial factor. Picking up the signs that a person was ready to talk were not clearly describable ,but this was informed by a tacit knowingness and an intuitive feel about the situation and the person.

Tacit knowledge was an important part of knowing how to care for someone, in terms of how to approach a person, managing a range of problems and symptoms by drawing upon the myriad of different information, knowledge and skills of 'knowing that' and 'knowing how' often in a split second. Many of the different aspects of care were provided by all experienced members of the service without thinking directly about them, whereas newer members of the team, like RT, had to seek information or check out their intended actions with a colleague first and then review them afterwards. When RT asked her about what to do, CS's answers were often immediate. For RT they had to be searched out and understood in a step by step process. This was also the case with KL, who was able to respond immediately to questions for advice about symptom management and offer a backup plan at the same time, often without appearing to pause for thought. But both KL and CS found they had to really think when they were asked to break down the decisions behind their answers into steps, because they simply 'just knew' what to do.

In the documentation of the community and hospital teams, the action plans written gave some indication of the knowledge held about managing the person's care they were involved with. However, on the ward, the nursing notes did not reveal the knowledge and processes involved in caring for a person other than meeting physical needs through predefined set tasks. The nurses on the ward drew on tacit knowledge to talk with and physically care for people. This included washing and helping some dress, giving injections and the setting up and handling of equipment such as syringe drivers. Repetitive tasks were almost done without thought.

The ward sisters and staff nurses, however, were more used to talking through their plan for the day and how they were going to approach giving care than the community nurses. At the start of every shift they sat down with the health care support workers and often talked through the care that was to be given, the main issues for each person and how they felt it should be approached. The coordination of the care of several different people, management of the ward, giving out medications safely and listening to relatives required much of the work to be undertaken at a tacit level, since having to think through the reasoning behind each decision would have taken too much time. Some aspects of the care became automatic, although this did not mean they became depersonalised. The automatic, unconscious, and tacit aspects of the working knowledge of the nurses enabled them to free up their conscious working knowledge to cater for the individual needs of each person or family, whilst managing many other aspects of their work at the same time.

The following conversation between CS and JL in which they review, with hindsight, what occurred after WY had been admitted from home to manage his symptoms. The conversation reveals the intuitive gut feeling that could only now be understood in the knowledge of what had subsequently happened:

> *'CS and JL are chatting in CS office about WY and what RU (Senior Sister on the Hospice Ward) said about WY's wife not wanting to have WY back home. JL expressed concern about WY's situation and decides she is going to see*

> *what WY has to say. On her return JL explained that she had asked him how he was and that he had said he was feeling better and said he was philosophical about things and told JL that it had been decided he would go to a nursing home. JL explained to CS that she had said to WY that it was 'sad'. CS then commented that it was difficult because they didn't know the reason why his wife wouldn't have him; but that it was maybe too much for her. JL then said that maybe she could have had him for Christmas or for a weekend. She then reflected that when she had talked to WY's wife on the phone and when she visited previously and spoken with her; that she was always very matter of fact and down to earth, and that in her eyes you were either alive or dead. There was a pause. Both CS and JL said that the radiotherapy had made things so much better and the aim of it was that he could go home, and now he couldn't. CS then added, 'we always said he'd end up in a nursing home didn't we' but when I asked why they had thought this, CS couldn't put her finger on it, but said both of them had felt this earlier in their care of him.'*
> *(Community Team Observations 17th December 2001)*

Both nurses had sensed early on that this man would not end up being cared for at home some time before he had even developed his metastasis and while he was still managing at home. Now, with hindsight, their early intuition had been proved right. Perhaps only in hindsight do the deciding and contributive factors become clear, but these are not necessarily consciously available at the time when the intuitive comments are made.

The use of gut feelings and intuition was generally accepted across the palliative care service and valued as an alternative and additional insight to be drawn upon. Basic scientific facts and knowledge of disease and the body were considered in conjunction with experiential knowledge of particular situations developed over time. This included tacit knowledge. On several occasions during the fieldwork KL talked in the meetings about her impression of people's conditions and how she felt they were sicker than they appeared to everyone else. This was very evident with TT, a man who was admitted for symptom control, which had improved with alterations in his medication but whose blood tests revealed some problems with his liver. However, plans were being made by the nursing staff and the staff grade doctor for his discharge because of his apparent improvement. However, KL was adamant that his condition would change quickly and that they would not get him home and this was commented on by RU on the 14th November 2001 during the ward round. His condition did change rapidly over two days and he died very quickly. KL was not able to explain to the team why they should not sent him home, and only had his blood results as a general guide. But everyone trusted her judgment, because she had been proved right so many times before.

HN also found it difficult to account for why one woman had deteriorated dramatically to the point that she was dying stating *'theoretically she ought to be better than she is'* in the multidisciplinary meeting on the 13th November 2001. There was a discontinuity for her between the rational scientific facts and the actual reality of the woman dying in front of her. The feeling and the intuitive sense from the team of nurses was that her diagnosis had been such as shock she had literally 'given up' and wanted to die. HN was guided by this, even thought here was no medical 'proof,' and the woman died during the week.

8.10 Biomedical Knowledge and Knowing the Body

Knowledge of the body, its biological make up, anatomical and physiological structure, functioning and response to disease and treatments was important in terms of deciding how best to manage each person's situation, symptoms and making decisions about the future. Different members of the multidisciplinary palliative care team throughout the service had different levels and areas of knowledge about the body and disease processes.

The main holders of knowledge about the body were the doctors, nurses and therapists. However, there were different forms of knowledge within these groups. The main knowers, in terms of the scientific biological make up of the body and its response to disease and to treatments in biochemical terms, were the doctors. However, some of this knowledge was shared by the nurses, but was dependent on their level of experience and education. The nurses had very practical knowledge of the body; what to observe, how to handle the body in its different states of disease, experience of working with symptoms and how to manage the body and its excretions. The physiotherapist had the knowledge of the anatomy and physiology of the body in terms of enabling greater function by the person in terms of their breathing and their ability to walk and the coordination of their movements. The occupational therapist used her anatomical and physiological knowledge in enhancing the functional abilities of people and facilitating their adaptation to how they used their bodies to undertake daily activities such as washing and dressing, and managing safely in the home.

8.10.1 Biomedical Knowledge of the Body

The biomedical, and scientific knowledge of the body informed how and where a disease such as cancer would spread and the type of effects the growing tumour had the potential to cause. The education of doctors is based upon the scientific exploration and evaluation of the body and its diseased parts and how these can be cured or managed. Therefore, the doctors and consultants within the palliative care service had a very broad but also specialist expert knowledge of the physical and chemical changes that occurred and the pharmacology of medications used to control these changes, and to control symptoms.

The ward doctors and consultants drew on this knowledge as they assessed each of the body systems, their functioning and how this affected the performance of the person they were examining, including their mental functioning. The knowledge and the skills, combined with the taught and experiential knowledge of the range of observations; visual, auditory and olfactory. Listening to the sound of a swollen abdomen and using the fingers to tap or percuss it, the doctor could tell if the abdomen was full of fluid, gas or tumour because of the vibration and the sound that resonated. This was an important clinical observation, which was used to informed treatment decisions for both HI and NO.

Being able to piece together a varied combination of signs and symptoms, was vital in diagnosing disease development and knowing what form of treatment would be suitable. This predictive knowledge of the body and of disease processes was an important factor in assessing a person's prognosis and how long they were likely to live. The doctors were often asked whether the person would be likely to die within 4-6 weeks because this enabled access to immediate funding to pay for care at home or in a nursing home. A prognosis of more than six weeks would mean that funding would take time to be arranged and have to be negotiated for access to nursing home beds or paid care at home. Therefore, medical knowledge was integral in shaping the resources for care. Predicting how fast someone would deteriorate, or when someone would die was not easy as IS found, he and the team would often talk about their thoughts and consider the whole picture of the person in an attempt to make a judgement.

Some of the more senior or experienced nurses also had good working knowledge of disease processes, which enabled them to make suggestions and debate the efficacy of different medications for a particular problem. The knowledge of the typical effects of disease on the body also enabled the nurses to be aware and pick up patterns of emerging symptoms or changes as indicative of disease progression, as with ST when she began to suffer from pins and needles in her leg and numbness down the side of her face. Her breast cancer had already spread to her bones, and the nurses discussed whether the changes were indicative of nerve pain, and the development of further bone metastases. These were bought to the meeting with the doctors on the 26th October 2001 and discussed.

The advisory work of the hospital and community team nurses, required the nurses to have a greater depth of knowledge about the different cancers, their typical metastatic spread and the effects of disease progression. They had in-depth knowledge and understanding of the medications used for symptom control and their side effects and of the different types of chemotherapy and radiotherapy treatments the person had. They were able to gain additional knowledge from the oncologists, who acted as educators as well as colleagues during their weekly meetings. This knowledge enabled the nurses to undertake assessments without the presence of a doctor, and to offer advice to non palliative care colleagues in the hospital and community. The specialist knowledge enabled the nurses to alert doctors to potentially reversible developing physical and biochemical problems.

For both the nurses and the doctors, becoming aware of the development of different bodily signs and symptoms was important in quickly identifying changes that needed further attention and treatment. DA explained how her specialist knowledge made her concerned for a gentleman she was caring for who required emergency treatment for potentially reversible effects his disease.

> *'I felt he had spinal cord compression, he had severe low back pain, his mobility was greatly impaired, he was incontinent of urine although, he was still aware of bowel function and I desperately just wanted to get him in to Blackberry hospital. I knew there was no point getting him in here because I knew he would only have to be referred there anyway, umm but I'd needed a doctor to see him, I couldn't instigate his admission and I couldn't get the Gp to actually visit this gentleman. He kept ringing him but he wouldn't actually visit…I could not get across to him the urgency of the whole thing, and it actually took something like five days, from the time I had first seen the gentleman to the time he was actually admitted to hospital, and fortunately, he was very fortunate, he had his radiotherapy, he did have a spinal cord compression, and he did actually recover quite well from it. Obviously he wasn't able to walk without using walking sticks but at least he; initially he was in a wheelchair but at least he did get some mobility back, but I found that very very hard, very hard indeed.'(DA Community Palliative Care Team Sister Interview March 2002)*

For Specialist Nurses, having this degree of knowledge could be both helpful and frustrating, since in the Hospital and Community Teams their advice could be subjected to disciplinary hierarchical power prejudices. However, they were also able to make a big difference by being aware of potential problems and bringing these to the attention of the Consultants and General Practitioners and ensuring these were considered and acted upon as they occurred. As with DA and the man with spinal cord compression, fast action, high dose steroids and radiotherapy would have saved his ability to walk and keep control over his bladder and bowels. DA felt the urgency for radiotherapy was not being taken seriously by the GP, but her knowledge of the signs and symptoms alerted her in time to take action , and save some of his mobility.

8.10.2 Practical Knowledge of the Body

Practical knowledge of the body, how to move and handle someone in pain or someone who was unable to move themselves to get comfortable, was an important part of the nursing knowledge on the. Knowing how to position a person so they were comfortable in a chair or in bed, knowing what side they preferred to lie on, whether their neck was comfortably supported by the pillows and ensuring they were not likely to get sore, were as important as knowing how to wash someone, to clean and dress a wound or insert a catheter.

Much of the focus of the nurses' work on the was undertaking physical care of the person and handling and managing their body, including how to wash and dress those unable to do this for themselves. The nurses learned from one another, and used the experience gained over the years they had spent nursing on the wards. Knowing how to position pillows was an important aspect of ensuring people were comfortable and great attention was paid to getting the pillows right when someone was unconscious or dying. The nurses tried to ensure that the person's neck was comfortable and in a naturally supported position, that the person's back was supported and their knees were protected from developing sores from pressing together. Preventing pressure sores involved knowledge about the effects of pressure on the skin, how long someone could be left in one position, and keeping the skin clean and dry. They also ensured that clothing and bedding retained the person's dignity without adding to the possible development of pressures sore by being creased in ridges under the person and using the right type of pressure relieving mattress.

Washing a person and keeping them clean and dry, if they had leaking wounds or were incontinent of urine or faeces, were important aspects of care carried out during both day and night. Managing the waste and bodily fluids was done sensitively, and with the least amount of fuss, in the knowledge that almost everyone felt embarrassed and often ashamed about this. Assisting people to wash or bathe required the knowledge of how to work the hoist equipment and the jacuzzi bath. Moving someone in and out of the water, whilst keeping them warm, covered and safe was learnt over time, guided by manual handling regulations.

Moving a person in bed was also informed by Health and Safety Regulations as well as by experience. Many of the older nurses had learnt the newer manual handling techniques for moving people, having been originally trained to physically lift people up or across a bed. The use of purposefully designed sliding sheets made the movement of someone in bed smoother and easier. Learning to work together for the safety of the person and nurses was important. KM, one of the ward Sisters guided and taught the other nurses about how to move ST, being careful of her broken neck vertebrae, collar bone, and thigh bone. KM had worked on a Spinal Injuries Unit and was able to use her specialist knowledge to ensure ST would be moved safely and to educate her colleagues. Her knowledge of how to hold ST and roll her on to her side was extremely important in ensuring STs neck was not moved or jolted suddenly as was initially observed on the 2nd October 2001.

The following example reveals some of the knowledge required to make ST more comfortable in bed:

> *'BD stayed by ST's right side and DF went to the window side of her bed. BD stroked ST's hand and DF had a concerned expression on her face. BD asked if she still felt numb and she said 'yes'. I stood back. Between them it took a few minutes to decide what to do, BD decided to ask ST if she wanted to be straightened and moved up the bed. BD then asked me for my assistance to hold her head steady. Her right leg was very painful to move and touch, which meant any moving, had to be thought through carefully. DF suggested using a sliding sheet. I helped carefully move ST's right leg and DF supported her shoulders and hip as we rolled her onto her side as BD put the sliding sheet in. We pushed the sheet under and rolling her gently back tilted her and pulled the sheet through. BD then asked if I could take ST's head, they moved the bed forward so could stand directly behind her and in alignment with her. Throughout this time both BD and DF talked to ST asking how she was feeling as they moved her, explaining what they were going to do next etc. Before we moved her BD asked her if she could tolerate the head of the bed being lowered. The head of the bed was gently lowered I held her neck still although she winced twice as BD and DF pulled her up the bed using the sliding sheet.*

> *We gently tilted her once more to pull out the sliding sheet and make her comfortable then we moved her out on her bed into the Day Room for a cigarette.' (Observations 29th October 2001)*

Gravity was used by tilting the head of the bed downwards to help gently pull ST toward the head of the bed using the sliding sheet, so the whole move was smoother on her body. Her head was physically supported throughout so that there was no risk of further injury. ST was kept informed and aware of what would happen and how they were going to move her step by step, thus maintaining her confidence and reducing the potential of her suddenly grabbing hold of something because she has been caught unawares, as can happen when people are nervous of being moved. There was a range of knowledge relating to holding and moving the body, of how to instruct others and how to maintain the confidence of the person being moved, preventing further injury to the person or the staff.

The practical knowledge of the body, was not just confined to the nurses. The Occupational Therapist found that not being seen to have a medical background enabled her to work with the everyday practicalities of managing people's concerns in managing or using their own bodies to carry out everyday, and often taken for granted activities important to functioning at home, and this often led to conversations about how they would cope emotionally. Trying to manage the everyday aspects of living bought a person's changing conditions sharply into focus. This practical knowledge was different from the biological and practical medical and nursing knowledge of the body. which focused on managing the body in its current situation and responding to immediate changes. Occupational Therapy knowledge about the body assessed the current abilities and planned ahead teaching how to manage with a body that was working differently than perhaps it had been at home. Knowing how to undertake or assist a person who was unable to carryout their own care, was also important. Teaching someone how to manage the practicalities of everyday living at home, if there was some damage for example due to spinal cord compression, was vital if the person was going to succeed in adapting to the changing state of their abilities, whilst maintaining some independence and dignity.

Some practical knowledge of how to manage and cope at home was taught by the Community Team. It became clear that the body was 'known' in different ways by the different disciplines, but that these were complementary. Although the knowledge of the body and how to manage it has been fragmented into component parts, these were bought together and reintegrated through multidisciplinary team working, where the knowledge and insights were shared during the conversations and meetings, although the specific activities remained discipline based. All of the members of staff involved with the person would have developed their own awareness of what the person usually looked like to them, how they interacted, their usual skin colour, their usual sounds and smells, and would bring these to the other members of the team if changes were noticed. The negotiation of the different perceptions of that person's body informed the different understandings of the person's condition. It was the valuing of the different knowledges that enabled the person to be responded to and cared for in an individual manner by the team

8.11 Process Knowledge

Process knowledge is an aspect of experiential knowledge. It is the synthesis of a range of knoweldges: biomedical, emotional, contextual, theoretical, practical, tacit and intuitive knowledge. Process knowledge draws on an understanding and the use of time and timing. When DA assessed WA at home, as captured in Chapter 7, DA drew on a range of knowledges, information and experience to assist her in her assessment and in developing a trusting relationship with him and his mother. The observation of DA's assessment revealed the temporal nature of the process and how DA guided the process through the time she had. She used her social skills. appearing friendly and non-threatening, whilst maintaining a professional approach , using everyday open questions to gauge WA's concerns, rather than by starting from her agenda . DA chose a light friendly tone to begin with, rather than a more serious one, gently steering the conversation, using her knowledge of his disease to answer his questions, before asking her own about his medication.

DA knew from experience that following WA's lead she could follow the flow by asking questions about his physical condition for her own assessment. DA used conventional conversation as a buffer to building trust and a rapport and to prevent the assessment becoming too intense too quickly. Only when she had asked most of the questions she needed from WA did she answer his mothers concerns, letting herself be guided by his mother and, in turn, allowing the intensity to develop as she supported the older woman

> *'DA was supportive and said it was certainly worth trying, then added that it must be hard for her, and said empathically 'no parent expects to see their child become ill before them'. WA's mother began to cry, and DA got up off the sofa and knelt in front of her holding her hand and knee and as she cried. DA again said this must be hard and let her talk and WA went out of the room, on coming back he made eye contact with me, and wandered about in the room before sitting down. DA spoke some words of comfort then bought WA into the conversation and began to lighten the tone and as this happened there was some laughter as she talked with them focusing on helping WA to live the life he has saying how different it is watching the person with the illness (Observations 11th February 2002).*

DA used her knowledge of working with emotions, sadness and grief to respond to his mother. She was able to bring WA back into the conversation in a seamless manner. Her intuitive awareness and experience guided DA to talk about issues before being bought up by either WA or his mother. DA offered to find things out for them and moved the tone and pace according to what was being talked about. She rounded off as they all do with asking them if there was anything else they wanted to ask. She was able to be flexible and return to her own informational needs, and draw these together, leaving WA and his mother with their emotions contained. This preserved a degree of emotional safety so that she could leave and go to see the next person.

Knowing how to create and maintain a safe space and a level of emotional safety was an important aspect developed by the community nurses and the hospital team. It was important to be able to sit with the distress and the pain and then move the interaction on and lighten the intensity by bringing the person to a point at which they could discuss plans to manage the situation and to leave the person at a point of emotional safety or control. Creating a safe space was vital in being able to return again and follow up the issues.

Time and intuition were seen as the essential components of managing these difficult processes by the community nurses. Process knowledge on the ward or in the day centre also included the synthesis of a range of knowledges.

Processed knowledge was also often related to the physical disease processes which were discussed during ward round meeting and handovers, since they were informed by the ongoing observations and assessments of a persons physical condition. Monitoring for slight changes in the colour and consistency of a persons vomit or urine, would fit the picture of different disease processes, as did increasing sleepiness and confusion. All of these were signs and symptoms experienced by ST. KL was often ahead of the thinking in meetings or when she was asked to prescribe certain medications as people's conditions changed, which was why she could offer alternative plans of action in case the first approach did not help. Her knowledge of the process of dying enabled her to anticipate potential problems ahead of time.

8.12 General Awareness : Negotiated Knowledges

General awareness was developed from the different eclectic and integrative and interlinking areas of knowledge used to inform the care provided. General awareness informed the personalisation of care for each individual and family. The more members of staff and people that knew about a person's specific problems or family situation the more likely they were to respond to the particular needs as they arose, with some notion of the contextual knowledge about that person in mind.

General awareness was created and used differently by the hospital and community teams in that the palliative care nurses became the coordinators of sharing information between the different services and health professionals involved, ensuring that as many of the people involved in a persons care were aware of the key issues, concerns and plans. As JL observed during her interview, that things went well when everyone was well informed. General awareness, unlike tacit and intuitive knowledge, was much more tangible and consciously driven. The spreading and sharing of small and large pieces of information, as they were gathered, with other members of the team in the ward, enabled a rapid response to changing situations as they arose. For EG, an overall degree of awareness enabled her to come in and help out at a particular time and have some knowledge of the key issues about the people on the ward, or to be able to sit down with concerned family and friends and have some general appreciation of the situation they were discussing.

General awareness, as contextualised and integrated knowledge, was not confined only to the people being cared for but also to the members of staff. The hospital team kept themselves aware of changes on the hospital wards and of the stress levels on the wards when they had someone with complex symptoms or emotional problems which the ward team were finding difficult. Their awareness of the staff needs prompted increased sensitivity as to how the ward was coping and perhaps increasing the number of visits the team made. They were able to respond and provided more support with the opportunity for staff to debrief afterwards.

General awareness drew on every form of knowledge; it could be seen as meta-knowledge, a broad contextually specific knowledge, which informed an overall understanding of a situation. This increased sensitivity to the collection of further information and knowledge, and the sensitivity to picking physical and emotional changes would be seen as helpful.

8.13 Summary

There was a range of different knowledges that were drawn upon consciously and unconsciously to inform and construct the care that was provided. Sharing and valuing different knowledges created a greater degree of general awareness, as well as contributing to further knowledge formation. Different knowledges were required at different times throughout the different processes of care, and within the different spaces of care. Experiential and tacit knowledge appears subconsciously to inform the everyday working practices and skills of the work which is undertaken whilst the members of staff are managing and coordinating the care of several people and families at one time, be than in the , community or hospital. The unconscious tacit and intuitive knowledge and use of skills, appears to enable rapid assessment and problem solving, including ethical discussion and decision making. These were informed through prior learning of taught information and propositional knowledge and gained by experience. Other knowledge was more deliberatively drawn upon, such as the knowledge of how to access resources and how to manage the power dynamics within the health system.

General awareness appears to be a form of meta-knowledge, in which there is access to an over arching collection and synthesis of implicit and explicit knowledge specific to the people being cared for within the palliative care settings. Different people, conditions and situations appear to stimulate selective context dependent attention to different forms of information and knowledges held within the working memory of the staff. Mental representations and memories were drawn upon during the more complex situations. Previous cases or situations were recalled and reinterpreted in light of the current situation. The knowledges and information were used individually and negotiated communally within team or interpersonal discussions, synthesised and generated further knowledge and memories for future care processes. Decisions and the processes of care were informed by the interaction of these knowledges.

What knowledge out of this synthesis and hermeneutic reformation would be used was guided by the values of the health and social care professionals and people receiving care within the different locations and spaces in which the care occurred. Specific specialist palliative care knowledge was easily dismissed because it was not valued by particular Doctors who were deemed powerful by traditional hierarchies. However, where this power was resisted or where the knowledge was valued, the rich synthesis of knowledges could be used to provide appropriate specialist palliative care.

Chapter 9: A Discussion of the Exploration and Evolution of Constructions of Care Within Palliative Care

> *'For caring to be an ongoing activity, it is necessarily bounded by the activities of daily life because the entire complex of social institutions and structures determine with whom we come into contact on a regular enough basis to establish relationships of care' Joan Tronto (1989)*

9.1 Introduction

This thesis explores and reveals how care within palliative care is currently understood and constructed within an NHS specialist palliative care service. It was initially motivated by observations of changes within palliative care during my experience as a practitioner. The study commenced by analysing the available literature within palliative care and literature from philosophical, sociological, political, nursing and educational perspectives of care theory before commencing an in depth six and a half month ethnographic study within an integrated specialist palliative care service in the UK. The study was undertaken from an epistemological perspective that values the different truths, knowledges, experiences and voices of participants.

A rich and complex pool of data was collected, which drew upon the voices, experiences, understandings and constructions of people working in the service, people being cared for across the service in the hospice, at home and in the hospital, their family and members of healthcare teams associated with the service. Accompanying these voices were very detailed observations of care processes and practices across the hospice, community and hospital including analysis of the supporting documentation, in which care was recorded. In depth analysis of the data, revealed important and interrelated concepts and practices which continually shaped and reshaped the constructions and reconstructions of care, as well as the processes and knowledges of care on a daily basis. This chapter will summarise the findings before discussing their implications in relation to care, palliative care and the new NICE guidelines (NICE 2004).

9.2 Summary of the findings

The analysis of the data has been presented in four separate chapters, although the findings are dynamic, interrelated and multidimensional rather than linear. The cultural and socio-political context of the setting revealed the central importance of values in guiding and shaping the cultural context of an organisation and the way care is provided. The democratic non-hierarchical leadership and management structure valued collaborative working practices based on open dialogue, a network of sociable working relationships across and outside of the service. Provision was made for all voices within the service to be heard and valued within a working culture that valued conversation and dialogue as central to the processes of care and managing change. This enabled the leaders to manage and incorporate the increasing standardisation and regulatory requirements of Government policies, without loosing the organisations focus on holistic and person centred care.

The study revealed how both formal and informal structures and organisations of care provide a framework, which shapes and is reshaped by different values and processes of care over time. Organisational structures and routines shape the daily functioning of the service. The palliative care service multidisciplinary team was constructed by disciplinary and location-based teams within the wider team, held together by shared values, leadership and the fluid movement across the different locations by the lead nurse, consultants, therapists and social workers. Continuity and consistency provided by the network of shared values and specialist knowledge drawn upon and shaping the care, but which was in turn shaped by the structures, organisation and values within the locations.

A significant finding of this research is that the taken for granted and assumed exchanging of information processes have implications for how organisations structure and value all care processes. Also, how multidisciplinary working is defined and undertaken. Valuing the formal meeting as the only place in which to discuss care disenfranchises and dismisses the ongoing processes occurring across the working day and night when information is exchanged, updated and responded to. And, the complexly interactive and dynamic process of care undertaken and informed.

Care is, therefore, not a singular event, but the outcome of complex interrelated and often taken for granted processes at an individual, team and organisational level; across the service and outside of the service, shaped by both time and space. The thesis makes explicit the taken for granted and assumed processes that shape and inform care. It also makes clear that the processes are interdependent upon the ongoing synthesis of different knowledges: professional, personal and experiential of team members, family carers and those who are being cared for.

Information exchange as one example of a process of care that is a set of multiple and complex processes shaped by spatial, temporal and value differences. The exchange of information between palliative care colleagues within the service was shaped by shared values and working practices and required less deferment to traditional hierarchies of knowledge and power. Information was exchanged more quickly and responded to faster ensuring flexible and responsive care compared to exchanges with non palliative care professionals within the community and acute hospital. Chatting was central to the culture of the service and the hospice ward. However, it was not the predominant mode of exchange between the community team and their community colleagues. Information was exchanged using the telephone and fax machine to ensure the sharing of accurate and updated information to GPs and district nurses. A more formal style of exchange and conversation deferred to traditional hierarchical values within the community to ensure ongoing care of the people within their service. In the hospital a combination of chatting and formal conversation was used, adapted to the type of working relationship held with a particular member of staff. Therefore, the processes of assessing social and formal working relationships and using oneself as the tool were required. Chatting reduced hierarchical and power imbalances and was used to build trusting relationships with less senior clinical staff and formal conversation used with senior clinical staff, who were not well known to the team.

The taken for granted processes involved in supportive care, emotional care, personalised care, symptom control, remembering and reflecting were dependent upon assessment and synthesis of contextual information and different knowledges by staff. This was to ensure appropriateness and general awareness amongst all team members. The processes of care are, therefore, shared across the different teams and between the different team members within palliative care, rather than being predominantly discipline specific. Furthermore, these are dependent on good open and trusting working relationships between team members and the people in their care.

The development and maintenance of supportive and trusting working relationships with colleagues and with people being cared for, are as important as the exchange of information. The multiple processes of care can not occur without trust and awareness. The palliative care staff achieved this by drawing upon different facets of their personalities to develop trust. In addition, altering the style of their speech, their language, the topic of conversation or the way they discussed their professional knowledge with other health professionals in the community or hospital. There is more to discussing sensitive issues with someone than simply following a formulaic method. The social-relational clinical model of care shaped the culture of the service. The chatting saw care focused conversations about those being cared for interspersed with conversation about the well being of members of staff. Conversations were supportive and revealed knowledge about what was important to members of staff across the service and the people and families they were caring for.

Personalised and person centred responsive care, however, was dependent upon the valuing and use of multiple knowledges brought by the different members of the team. Procedural, experiential, reflective, tacit, intuitive and local knowledges were valued and drawn upon. I would argue that the sharing of information created a meta-awareness amongst the staff, which was negotiated and synthesised from the explicit and implicit knowledge revealed about and from the people being cared for and shared with all those involved. Thus, enabling a range of different knowledges to be used collectively and separately at any one moment in time, and for a member of staff to be responsive to the changing needs of a person, even though they may not have been directly involved with them.

Reflections and discussion within the multidisciplinary meetings enabled a reinterpretation of situations from alternative perspective, negotiated perceptions and use of previous representations from past experiences informed current concerns. Palliative nursing and symptom control knowledge was particularly unvalued by some GPs and hospital Consultants, who chose to disregard advice, or to only make consultant to consultant referrals, thus potentially narrowing the breadth of care available to people. This chapter will now discuss the implications of these findings for both palliative care for care theory.

9.3 Key discussions emerging from within the thesis

What this wealth of data and findings have revealed is a complex and dynamic interrelationship between how care is constructed, structured and organised. Also how it is informed by multiple and negotiated values and knowledges, that shape multiple processes of care central to palliative care. Care is, therefore, continuously constructed and reconstructed as an adaptive and responsive process mediated through the development of interpersonal and interprofessional relationships.

9.3.1 Palliative Care As a Person Centred Process

It is clear, that care within this service supported and valued an extremely strong focus on person centred responsive care, which was reliant upon good interpersonal and interprofessional working relationships. These were facilitated by flexible and frequent sharing of information and the valuing of different forms of knowledge within each team and across the service. The development of trust and maintenance of sociable rather than hierarchical working relationships enabled different processes of care to occur over time, including emotional, supportive, bodily care and symptom control and shared decision making. The ability to develop trust and maintain social and professional relationships required self knowledge, knowing how to interact with different people and personalities and knowledge of situational context. For the actions to be perceived as caring, by the people being cared for, some form of expression of care was required by the professional carer, be that through conversation or through the way in which particular care processes, such as bodily care was undertaken, managing and being with a persons distress or organising services. Being treated as an individual with dignity and respect through attention to detail was valued by those being cared for.

In this thesis the nurses, social workers and therapists talked about using their knowledge of how to present themselves to different people to build rapport. They were observed using the performative aspect of roles to allay fears of people in near by beds when discussing cancer, or issues around death and dying. They also talked about experiencing an emotional response of companionate care and concern for many of the people they looked after. The lack of an emotional response of a feeling of compassion or empathy caused them some difficulty with people they felt unable to relate to. This supports earlier focus group findings by Aranda and Street (2001, 1999). The use of the self as the facilitative tool of care is central and can not be undervalued, especially where teaching care as technical rational and procedural tasks and competencies is gaining greater momentum. To be able to use oneself requires self knowledge, experience and degree of reflexivity, to be able to adapt and monitor ones progress within the interaction. Knowledge of processes is also important to guide the interaction, such as creating emotional safety during a sensitive or distressing conversation and guiding the conversation to a safe place from which it and the person can be left.

Sharing and learning from experience are important guides for developing self knowledge and experiential knowledge within interpersonal and interprofessional relationships. Working within a culture, that positively values chatting, open reflective discussion and the use of different knowledges facilitates both team and personal reflection, the development of knowledge and support. The use of remembering and reflection enable past experiences to be drawn upon by all forming a collective knowledge bank, to guide complex situations. This is supported by work on different forms of knowledge and learning used in practice including reflective practice (Rolfe

1998, Schon 1983, 1987) the use of experience, (Titchen and Esser 2001, Eraut 1994, Benner 1984), intuition (Benner 1984, Benner and Wruble 1982) and use of local and cosmopolitan knowledge (Harvath et al 1994).

The use of the self to facilitate the processes of providing personalised and responsive care would appear to reflect in part Heidegger's conceptualisation of care as being within the essence of each person. Revealed through the interaction of one person with another and the expression of each person's concerns. The emphasis placed on getting to know the people who were being cared for and what they valued, is central to Heidegger's (1962) notion of care and coming to know and understand the other person. Thus, knowing one another as members of staff within the broad community of the palliative care service as a whole provided a similar approach informing how best to work with ones colleagues. This challenges the notion, however, that caring is only central to nursing as suggested by other nursing theorists (Benner and Wruble 1989, Watson 1988, Benner 1984, Roach 1987, Leininger 1986). Although this study reveals nursing as central to palliative care, it also argues that continuity of care, values and knowledge are also central to other disciplines with the care provided between services by the fluid work across the locations of care by the social workers, occupational and physiotherapist, consultant and lead nurse.

However, the findings also challenge Heidegger's philosophical concept, which suggests care stops at the death of the person. The data reveals that care for a person continues after death, and so does their sense of personhood. This is important in understanding the values of staff carefully and respectfully undertaking care of the dying person and their body once they have died. James's work on the role of emotional labour in providing personalised care in part shares Heidegger's use of self in the care interaction. James does consider the structure of the organisation in defining who undertakes this personalised work(1992, 1989). However, the findings of this study challenge the notion of a patriarchal family as the organising structure of palliative care today, particularly in services in which the staff are predominantly female including the consultants. It develops further her themes of care being equivalent to organisation, physical labour and emotional labour, but sees these as only part of many different care processes in terms of physical care and emotional care. Within this thesis the role of values, care as a series of processes informed by and informing multiple knowledges are identified and made explicit as shaping personalised care and the care work and labour discussed previously by James.

9.3.2 Achieving Flexible and Responsive Care in an Era Of Increasing Standardisation

Flexible and responsive care was achieved through three key components: Multidisciplinary team work, exchanging information and an ethically just focus on care. Palliative care has traditionally developed with a philosophy of multidisciplinary working, although not all teams have been multidisciplinary. Current policy measures require cancer and associated palliative care services to hold regular multidisciplinary meetings, which can be recorded and documented (NICE 2004, DoH 2000b). The process and concept of what multidisciplinary working is in practice remains open to interpretation. One criticism is that meetings can be seen to be a tick box exercise, held because they are required to fulfil predefined criteria.

The use of regular formal meetings were designed to provide the 'public' sanctioned spaces in which the gathered information was bought together and discussed. Findings from this thesis reveal that formalised and structured meetings do not represent the reality of multidisciplinary working within palliative care settings. Also, that the valuing of multidisciplinary practice sanctioned through formal structures subjugates the reality of the rich and taken for granted networking and sharing of information within the informal spaces over the working day. The ward rounds, multidisciplinary meeting and team meetings were consensus driven, a space in which the different voices of staff could be heard. Yet most of the information and knowledge shared, informing the different processes of care occurred within the hidden or unacknowledged private or unsanctioned public spaces of one to one or small group chatting, or telephone conversations.

Multidisciplinary working can and does work very effectively outside of formal spaces. It is this flexibility that enables the ongoing information exchange and updating between the members of the different teams within the palliative care service. The sociable culture and focus on chatting promotes ad hoc exchanges, which enable care to be adapted quickly. Chatting was the central mediating process by which personal and professional information was shared and valued, teamwork developed, maintained and support provided. Chatting was so taken for granted, that staff were unaware of the extremely important role chatting played in sharing and developing working knowledge of each person being cared for. Social relationships are central to the manner in which information is exchanged, which becomes less fluid and reciprocal the more hierarchical the relationship, as was seen in the community and hospital settings. The passing on of information by ad hoc chatting enables the development of general awareness across different team members and alerts them to changes. In addition, it enables increased responsiveness and increases sensitivity to developing and changing patterns in a person's condition. Knowledge held by the individual members of staff and the collective team becomes continually reproduced and transformed through conversation, which shapes the service and the care provided, creating and adaptive process (Stacey 2001, Shaw 2002).

Written 'public' documentation was used to account for and formally draw upon observations and evaluations and outcomes of care. Written case notes are publicly sanctioned records of care, assessment and evaluation. However, they do not always record the complexity and richness of the information or knowledges used to care for each person. The reliance on the formal spaces and informal private spaces for sharing information, ensure care processes remain fluid rather than concretised. This is a dilemma at the centre of care as an evolutionary process. However, it is essential that specific information and knowledge about how to care for a person is written and concretised, to prevent danger and to ensure care remains personalised. As was the case with ST who had multiple fractures and no nursing record as to how to help move her in bed safely for the bank nurses. This raises the dilemma if personalised and local care knowledge is not written it remains hidden, shared only within the informed group. It can not be made concrete or accessed to by those outside of the informal or formal information exchange network. This is an important aspect considering the increasing surveillance and regulation of care through the use of audit measures. If particular care processes and knowledge are not written or described, they do not exist in the public space, and will remain disenfranchised. The lack of recording such information also places a person at risk in a system of health care that can not always rely on continuity of staff and time for narrative expression.

A paradox is created between the fluid construction and reconstruction of care and care knowledge and the need to concretise this knowledge. This reflects in part the dynamic of the vigil and the gift that Fox (1995) writes about, in the use of the concretised knowledge to develop a professional knowledge base, increasing surveillance and the power to control and regulate care. By concretising the knowledges and care processes bank or agency staff can care safely and, in a more personalised manner for people. The written records can make explicit particular care processes, valued enough to be documented and prioritised. However, this also increases the potential vigil of whether the process is undertaken and dsiciplinisation where it is not. The gift is within the non-standardised interpersonal dialogue and the flexibility to alter a process according to the person on the day. Can palliative care resist the increasing regulatory framework set down by the Department of Health? Resistance to the dominant health care values and central drive for effectiveness and efficiency appears to be possible in this study through access to additional and alternative sources of funding. As with the service in this study, partial independence guided by the values of palliative care organisation and leadership enabled greater freedom and flexibility from the NHS and some resistance to it.

Care is, therefore, shaped in part by money. But, it is also shaped by the values within the context. A palliative care service that is democratic and values the voices of its disciplinary team members, the people being care for including their families will be different from a service where the voice and values of one discipline are positioned above all others. From this perspective, whether a service has extra money or not, it is the values of those within and leading the service that shape the focus on care, and whose voice is heard. The money enables the care to be extended and the aesthetics attended to, rather than the values. This is seen clearly when transferring palliative care out into the community and into the hospitals. Working across these locational boundaries requires an adaptation and some compromising of organisational and personal values. The high standards and respectful collaborative multidisciplinary working practices are challenged by traditional hierarchical power dynamics and different value systems within the primary care teams and hospital wards. Community and hospital palliative care is disenfranchised because it has no structural power, and its knowledge base is questioned and often unvalued. The services are predominantly advisory, nurse led, with consultant input, and therefore, at a disadvantage within a powerful hierarchical system (Seymour et al 2002, Clark et al 2002).

Flexible and responsive care was also shaped by a constant ethical approach to care. Traditional ethics are unable to meet the complex needs and dilemmas inherent within palliative care. Dialogue, discussions and decisions within the service drew upon a range of ethical principles and concepts, although none were explicitly referred to. At the centre was relational care (Gilligan 1982 and Noddings 1984), but this was mediated by a dialogical approach (Koehn 1988) to the negotiation of different peoples perspectives, including the person who was being cared for and their family carers. Palliative care staff also had to draw upon professional codes of ethics in conjunction with a level of moral obligation (Noddings 1984). Alos, intentional care (Edwards 2001) to provide equitable care for people with whom they have difficulty developing trust and good working relationships.

Biomedical ethics and the Kantian notions of self determination combined with the care ethics and utilitarianism guide treatment decisions and decisions to discharge people home or into a nursing home. By drawing upon a wider pool of ethical thinking, it is possible for a service to be flexible and person centred whilst balancing the competing needs of people requiring palliative care with the resources available. Arbitrary decisions are prevented by drawing upon ethical frameworks and though a dialogical approach enabling voices to be heard, valued and negotiated. This appeared to provide more humanistic decisions to be taken. However, it is clear that the central values of a service will also shape what aspects of care are valued as more important. If one perspective is given greater value, the process of care can not be deemed as just. An ethically just process of care can only be achieved through dialogue and the negotiation between the competing needs of all parties.

Concerns have been raised by several authors, initially by Field and James (1996) and followed by White (1999) about the increasing dominance of the medical voice in decision making within palliative care over that of the nurses, but their concerns were not found in this study. What was observed was the development of forms of resistance to the traditional power hierarchies. There was a preparedness to compromise for the sake of the person's needs for palliative care by palliative care nurses and consultants. Resistance to the traditional and structural/spatial power hierarchies was seen by encouraging new members of hospital staff, especially the new junior doctors, to make contact with the team, for off the record advice. Support was offered in return for attempting to put symptom control initiatives into action. In the community ways of resistance were revealed by the nurses taking on the role of co-ordinating a person's care and managing the information. In the hospital and community, the teams maintained their value of high standards for their own practice, whilst accepting that care available to the person was less than they would hope and the best they could get considering the resources.

Conceptually, different theories can be seen to inform this understanding of care. Hekman (1990, 1999) points out, the hierarchies and binaries that have shaped knowledge are inherent within the power dynamics. It can be argued that gender has a significant role in the construction of care, however, the historical structural hierarchy positioning the status of professional knowledge is more significant today. Some consultants and general practitioners would only refer to the consultants, refusing to be advised by the nurses. Gender was not the significant factor rather the lack of statutory power within the NHS. This is both historical, philosophical and spatial.

9.3.3 Care as an evolutionary process shaped by time, space and knowledge

Care is not written about as a process in any of the literature analysed for this thesis, rather the concepts and constructions focus upon singular or related aspects of care. Care should be considered as a combination of different and interrelated processes. It can be considered as an evolutionary process, shaped and reshaped by time, space, people and knowledge. From the previous discussions within this thesis, it has become apparent that the knowledges and processes of care are interactive and dynamic. They are focused within human relationship and shaped by the values, context and organisational structures of a service and the expectations of the people receiving care and associated stakeholders.

It is apparent for palliative care that people, time, space and knowledge have shaped and continue to shape and developed the speciality. It has developed its own knowledge base, and is currently developing its own evidence base, its own set of values and philosophy. Continuing to adapt to the changing context of health care provision and moved into and influenced the different spaces of care available. Palliative care is underpinned by multiple knowledges, and many of these are only revealed through the processes of care, often obscured by the lack of identification by staff about what they know, and how they know it. The lack of insight into the complex interaction between knowledges denies the complexity of the care itself. Knowledge of care, care practices and processes have historically been hidden by their traditionally private and gendered nature. Although gender is an important aspect of the hidden construction of care processes is not the only cause. Structural and power hierarchies have subjugated such knowledge since class and race have also played a part. Therefore, the hidden and subjugated knowledges of care and caring have been passed on in verbal and experiential form, through story telling and personal narratives, rather than being sanctioned by the public world of the observable, objective and rationality recorded. This schism remains dominant within the palliative care and is clearly recognised in the structural organisation of care.

Tronto (2003) has explored the use of spatial metaphor and the compression of space and time regarding care considering the complex notion of time in relation to its multiple dimensionality, and how this informs our understanding of care. Time for her is circular and linear, reflected in the repeating rhythms over the day, week, month and years, and the movement between past, present and future. This was equally observed within this study, in which structure was provided by routine and the regularity of meetings. Time is resistant to control as is the disease process experienced by people receiving palliative care. Tronto's, concern about care and time are that she believes the time and space of care are being compressed, in order to get more from the perceived amount of time available. Future time is being privileged over past time. However, I would argue that in relation to palliative care, present time is prioritised because future time becomes rapidly compressed as a person faces death with a disease that is also resistant to the control of time or aspects of care. Both the future in palliative care is redefined as time is also redefined. Each moment becomes essential for each person and for care, and it is this valuing of the moment in time and the moment of care, that increases the responsiveness and personalisation of care provision. This is in contrast to Tronto's present concern that participative care processes are at risk of having the professional carers' agenda setting the limits to the care offered, to save time. She suggests the time space compression prevent the processes of learning and reflection, and of healing and dying occurring, and asks what does this means for relationships of care. However, from the findings of this study, it is clear the past is also valued by palliative care in terms of learning from reflection and trying to understanding peoples past experiences enabling greater awareness of the present concerns. Knowledge of process is valued, which requires an understanding of time, disease and emotions in motion and enables care to be prioritised across time and space.

Care is informed by multiple personal and structural constructions, knowledges and values, which inform and shape the complex yet contextual processes of care. Constantly evolving knowledge about the person and their situation is constructed through ongoing information exchange and from an integration of past and present experiences of the staff and those being cared for. Multiple knowledges are reflected and drawn upon by the team which enables personalised care within a framework that supports flexibility, adaptability and responsiveness of the care provided.

If Tronto's fears are confirmed, and future care become privileged in palliative care, then the heart of what palliative care values, in terms of its holistic personalised responsive approach to people would be lost. Services would also potentially loose their collective memories and the wealth of experiential knowledge due to the reduction of time for reflection. In many respects palliative care has tried to decompress time and space preferencing present time by focusing on improving quality of life and trying to improve the life left to live.

Some compression of the time and space of care is occurring in palliative care paradoxically at a time when people are living longer with advanced cancer because they can no longer stay in a hospice for extended periods of care as services are needing to preference the present care of increasing numbers of people. Driven by resource constraints, rising levels of need for care, palliative care has adapted to compensate and has moved from one spatial location into another, taking its principles with it. Hence, palliative care is becoming more common in nursing homes and acute hospital settings (Fallon and Dunlop 2002, Froggatt 2001, Prail 2000). Palliative care can resist this compression further by the way structural frameworks shape and protect the care processes within and how these processes are valued.

What is recognised and valued within palliative care is, that time is its own process and must be allowed to occur in its own manner, so that the relationship, so important for care, can be built and maintained, the process of disease, illness and dying understood. This was recognised and valued by both the lead nurse in the importance of time as process in relation to working with peoples fears and emotions, and by the medical director in the use of a 'watch and wait' approach to care, observing whether a persons condition would change without medical intervention, allowing nature to guide the care process.

9.4 Conclusion and implications of the thesis: the complexity within the heart of care

The thesis reveals how care is constructed in palliative care and makes explicit the taken for granted and assumed processes and knowledges, which are essential to personalised responsive care. The thesis extends the knowledge of palliative care by revealing that care is not a singular event or series of disconnected events reliant on professional and procedural knowledge. Rather, it is a series of multiple processes constructed through the dynamic interaction between organisational, professional and personal values, expectations and organisational structures, which are interdependent upon different forms of knowledge. The thesis introduces the concept of complexity as central to care and palliative care. It is clear that palliative care can be considered as complex and adaptive. The complexity is created by the dynamic interplay between the different constructions of care theory, professional disciplinisation, health and social policy, ethical debates, values, knowledges and the revealed processes that shape and reshape care over time and space. Palliative care is therefore evolutionary, changing and adaptive within different environments and over time and space.

The thesis challenges aspects of the NICE guidelines published this year (NICE 2004). Firstly, the guidelines break down the components of supportive and palliative care into discrete sections of recommendations for practice and service structure yet fail to discuss these as interactive rather than independent. Therefore, they are at risk of perpetuating the fragmentation of palliative care into separate component parts. This could potentially perpetuate the divergence between disciplines and disciplinary knowledge rather than focusing and valuing the shared multidimensional interactive processes and the multiple interrelated knowledges bought by different team members into the care processes.

Secondly, the guidelines require the development of further outcome measures, stressing a focus on meeting and recording the guidance in terms of standards to be met and ticked off during an assessment exercise. Care within palliative care will become recorded and measurable events to be undertaken and accounted for. Thus, reflecting the current cancer accreditation process, in which aspects of cancer care and service criteria are measured and recorded as minimum standards for service delivery. However, as the thesis reveals care within palliative care is constructed predominantly through hidden and assumed complex processes, which are complex, interactive and multidimensional. Care is more than a series of events or tasks to be completed. The thesis has made explicit the taken for granted processes, and knowledges informing care which would otherwise remain disenfranchised and revealed them as central to care. Failure to make these explicit places them at risk of being discarded and lost in a hierarchy that values the measurable and observable. Thus, both NICE guidelines and this thesis are at risk of creating a paradox by making explicit particular care processes and procedures, which can be then be taken and routinised, if no guidance is available about the integration of the processes.

The focus on the measurable and the fragmentation of supportive care in to its components parts by the NICE guidelines, with little reflection on the philosophy and values of palliative care or guidance about the reintegration of these components looses the holism central to palliative care. As this thesis makes clear for care to be holistic and person centred the components and processes shaping care have to be acknowledged as interactive, multidimensional and dynamic. For palliative care the whole is far greater than the sum of the parts.

Multidisciplinary teamwork within the NICE guidance is recommended, seen as measurable in terms of regular formal meetings and attendance at meetings by different team members. This does not account for the majority of multidisciplinary team work, where most of the information is exchanged and decisions are made, that is undertaken as an ongoing process outside of the sanctioned meeting times. It also does not recognise the role of hierarchies and values in shaping how a multidisciplinary team functions, who participates, what role they have and how decisions are undertaken. It is clear from the study that multidisciplinary team work is different between locations of care, and that teams differ in the contribution made by different disciplines. Teams are often created out of teams within teams, where values may or may not be shared and where knowledge and power hierarchies can affect their process.

Key component of improving care within the NICE guidance are to improve the coordination of care, communication and continuity between services. This thesis shows how an integrated palliative care service with a shared leadership and core values that respect the voices and knowledge of all involved in providing care can establish good information exchange networks and processes within the services and across the community and acute hospital through the fluid working of key members of staff across the locational boundaries. Adaptation, open supportive working environments and good relationships enable challenges, such as traditional hierarchies outside of the hospice to be overcome or managed. As with the process of emotional care, multiple knowledges and skills from different members of staff create the care that is experienced. It is often the processes over time that enables a person to discuss something distressing to them, rather than a one-off intervention from one person.

The processes and knowledges informing and shaping supportive care, offer insight to what supportive care is and the different expectation of people who are ill and their family carers. Supportive care is dependent upon the development of open working and trusting relationships. It is multidimensional, and incorporates organisation and practical support, something valued by those who are ill, to tired or lack confidence to do this themselves. Co-ordination of care and information seeking by the community and hospital palliative care team nurses was certainly valued by those being cared for, and supports the NICE guidance recommendation of one named person taking this role. The palliative care nurse specialists are instrumental in this role at the end of life and are able to see the bigger, more holistic picture and coordinate services appropriately until the death of the person in their care.

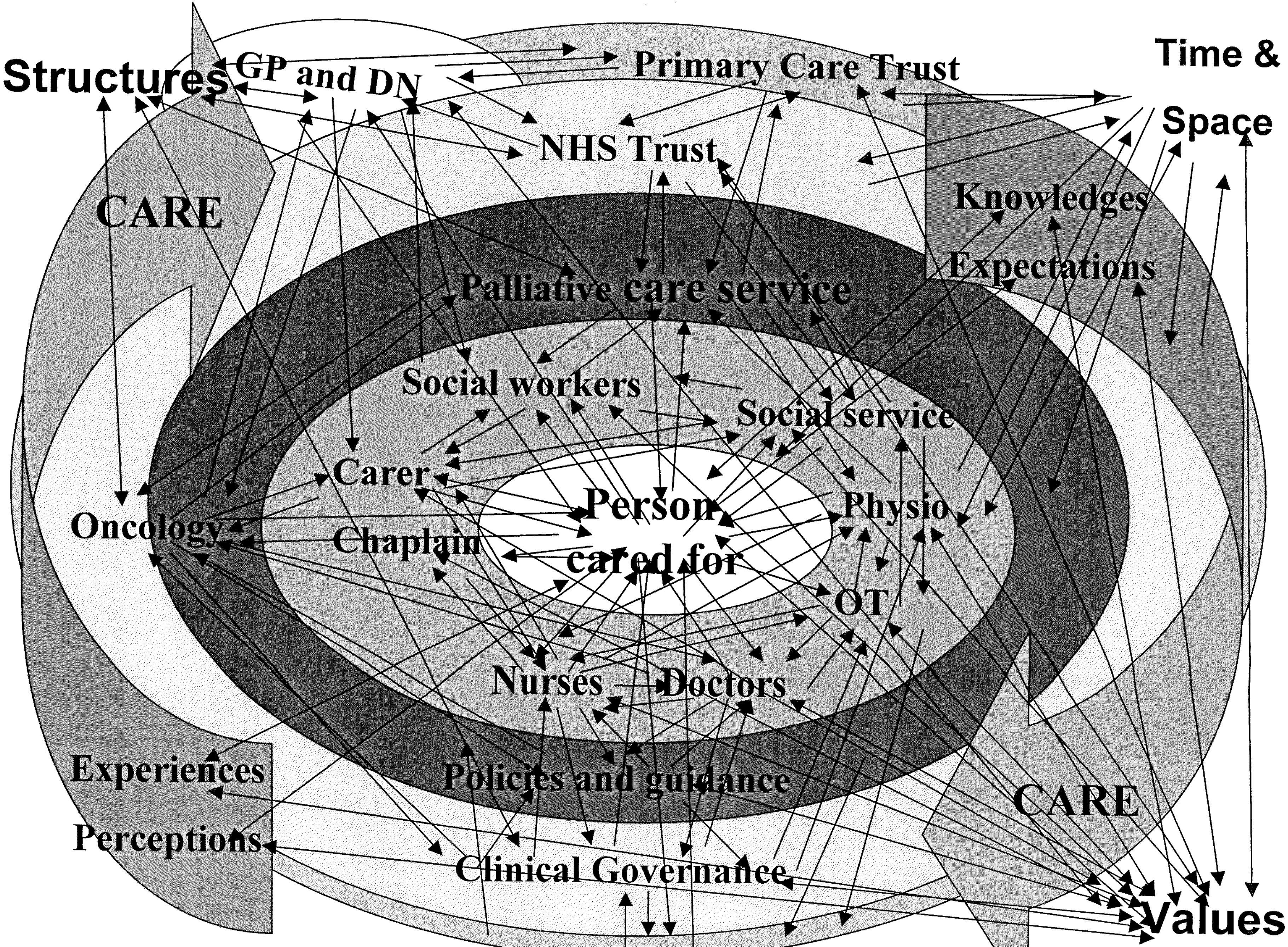
The development and use of the NICE guidelines raises several questions. Is the hierarchy of evidence drawn upon to develop the guidance the most appropriate approach? The quantifiable data and random controlled trials are valued in terms of providing unbiased and objective measurement of care and care outcomes. It has already been discussed in this thesis that this places knowledge and studies about care in a disenfranchised position. Because care is relational and much of the knowledge and undertaking of care is not easily measurable and hidden. However, as it is acknowledged that in part, some observational research has a role to play in capturing certain aspects of care. This study adds to the collection of in depth observational data about service delivery models, an area the NICE guidelines wish to build upon.

Criticism of the guidance is that it is predominantly focused upon living with cancer, with very little focus on end of life care. The guidelines have a present, as well as future focus, making living with cancer and advanced disease better for the person who is ill and their families. In relation to the temporal and spatial aspects of care advanced disease is being decompressed in relation to time by the predominant focus on supportive care as people are living longer with cancer. Care at the end of life and care of the dying however, becomes increasingly compressed; by the lack of space within the guidance document and by being fitted into pathways and potentially standardised whilst living with. The compression of the time and space given to the focus on end of life care is also consistent with the general compression of the space available to those dying with other advanced life threatening diseases and reflects a lack of value about the importance of retaining and improving end of life care for all people who need it. The guidance can be seen to promote and prioritise the time and space of care to the living at the compression of the focus of time and space required for dying. This will, in turn, be reflected in the development of service provision as the guidance becomes the measure for minimum standards.

This thesis raises the question whether palliative care and care can be a just process. Within the processes of care whose needs and voices are listened to? Those values, knowledges and which care processes are predominant will also shape how the NICE guidelines are acted upon. Increasing standardisation is to achieve greater equity across the country is beneficial. However, this risks standardising care and losing an individualised focus if questions are not raised. It is not completely possible to standardise services or care practices because the dynamic interaction between values, organisational structures, processes and knowledges is adaptive and will be different in each organisation. The search for effective service models also fails to account for the influence of local context. The diagram on page 318 is a two dimensional representation of the complex multidimensional dynamic interactions shaping care for each individual. There are multiple interactions between each person and organisation in the course of one day as well as over the time of a persons illness, or the working day and week of a service. All interactions are shaped by the other, and therefore so is care.

Care within palliative care is a complex dynamic process is clear. However, the provision of ethically just care remains reliant upon negotiated relationships and shared dialogue that values the different voices, constructions and knowledges central to providing responsive and personalised care across spatial and temporal boundaries. It is clear that the implementation of the NICE guidelines for supportive and specialist palliative care (2004) will also be shaped by the complexity at the heart of palliative care. The focus on user involvement raises methodological issues for capturing the voices, views and opinions of those who are least well or who are dying. Therefore, palliative care will be shaped by the values of those writing policies, organisational leadership, the people proving the care and the voices of the least ill, unless specific effort is made to capture and value the views of people at the end of life. How this will affect care within the dimensions of time and space in future is as yet unclear.

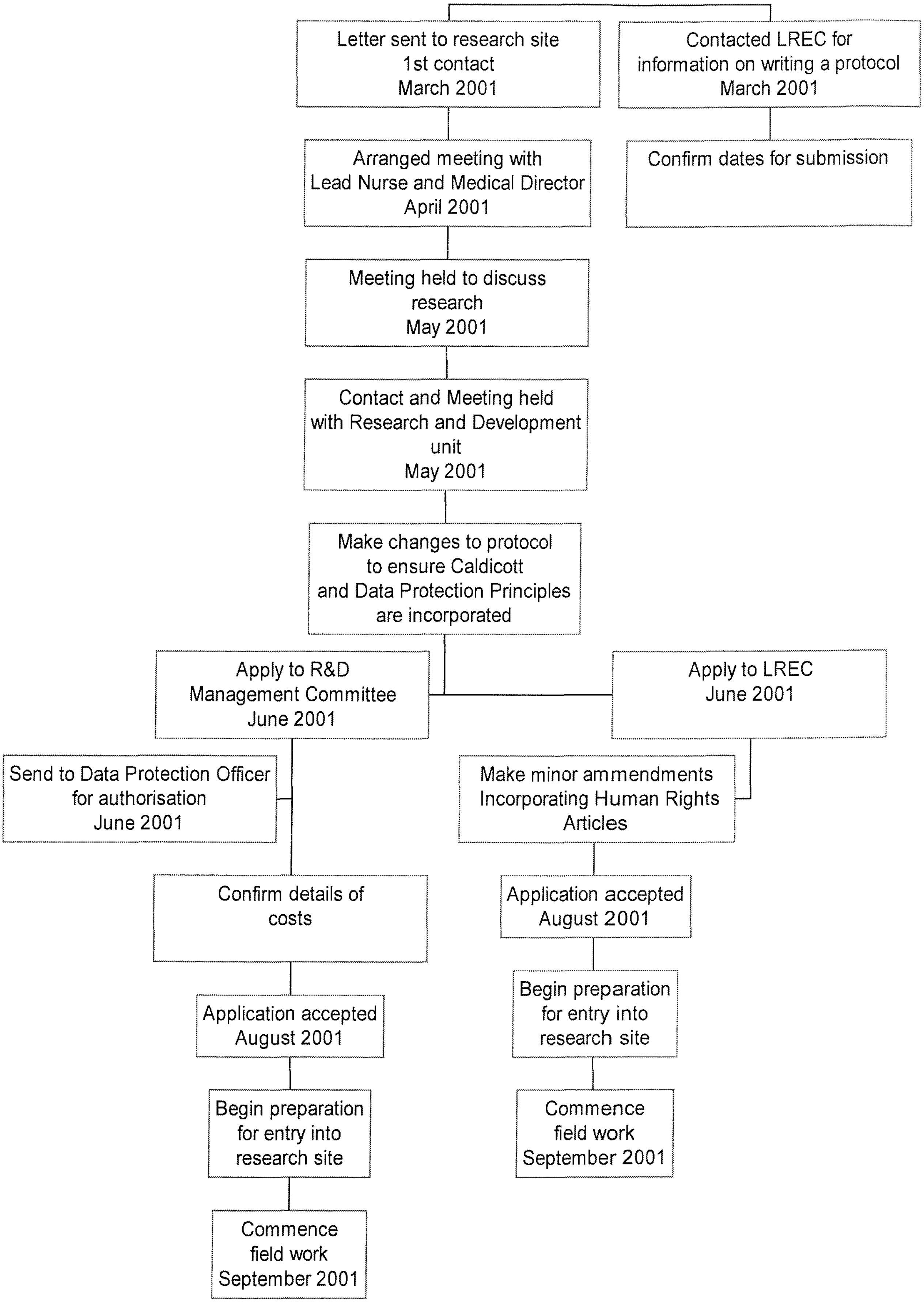
Can care be just process? The data suggests that if there is a respectful balance of voices, knowledges and rights between staff, those being cared for and their family carers at local level it is possible. Whether palliative care can be a just process at a societal level remains in question since the predominant focus on cancer as central to palliative care has become stronger with the increased investment in cancer services at the exclusion of other life threatening illnesses.



The complexity of interactions affecting care processes

Appendix 1: Ethics Approval

Negotiating Access



Appendix 2: Letters

Letter of Authorisation 1

Dear (Member of Staff)

A researcher who has a special interest in palliative care has recently approached us about carrying out a study here in the Chaffinch Palliative Care Service. Her name is Anita Sargeant and she is based at the University of Southampton. The research is about how we care in palliative care. She would like to spend some time watching the way that patients and carers are cared for, how we work, and to interview you about your understanding and experiences of care and care giving in relation to palliative care.

We would like to ask you if you would allow us to give her your name, so that she can contact you and provide you with further information about the research project. Please return the slip at the bottom of this letter to EG, indicating whether you do or do not agree to allow your name to be given.

Yours sincerely

Dr KL	EG
Medical Director - Palliative Care	Lead Nurse - Palliative Care

(please tear off)

I agree / do not agree (please delete as appropriate)

to my name and work details being given to Anita Sargeant, so that she may contact me and provide me with information about her research.

Signed: ....

Name (printed): ....Date: ....

Letter of Authorisation 2

Dear (Patient)

A researcher who has a special interest in palliative care has recently approached me about carrying out a study here in the Chaffinch Palliative Care Service. Her name is Anita Sargeant and she is based at the University of Southampton. The research is about how we care in palliative care. She would like to spend some time watching the way that patients and carers are cared for and to interview you about your understanding and experiences of care in palliative care.

I would like to ask you if you would allow us to give her your name and details, so that she can contact you and provide you with further information about the research project. Please return the slip at the bottom of this letter me, indicating whether you do or do not agree to allow your name to be given. If you do not agree, this will not affect your care in any way.

Yours sincerely

Dr KL
Medical Director - Palliative Care

(please tear off)

Dear KL

I agree / do not agree (please delete as appropriate)

to my name and details being given to Anita Sargeant, so that she may contact me and tell me more about her research.
Signed: .... / verbal consent given (please tick)
Name (printed): .... witnessed by ....Date:
....

Request for authorisation from clinical directors (Chaffinch Hospital/Community NHS Trusts)

Dear [Name]

I am writing to introduce myself and ask if it would be possible for you to release the names of members of your staff who are involved with providing nursing care to palliative care patients [on the wards within the hospital/in the community].

I am a post graduate student based at the University of Southampton undertaking research into how is care constructed, expressed and perceived within palliative care. The research is part of a M.Phil. / Ph.D. I am also a qualified nurse who has worked in a range of palliative care settings in the past.

The research I am proposing involves carrying out observations of the hospice and the care provided by the staff, the hospital palliative care team and the community palliative care team. In-depth interviews will be carried out with the permission and voluntary consent of patients, carers and members of the palliative care staff. Questions will ask about their beliefs, experiences and expectations about care from the service. Documentary analysis is the third component of the research, in which policy documents, leaflets and patients case notes will be studied. The aim of the research is to build a comprehensive picture about how the understanding of care is developed and constructed within the field through the combined influence of actions, beliefs and the written statements of care.

Whilst I hope that the research will not be harmful in any way to those involved, I am very mindful of the possible distress that patients may experience as a result of discussing their care. The research has been carefully designed to minimise any distress to patients or others taking part in the study with attention to issues of consent, how the interviews are conducted, and the availability of support for the patient should he/she become distressed as a result of the research. All participants will be made fully aware that they can withdraw from the research or stop the interview at any point without giving a reason and without any consequences to their care.

In accordance with current data protection rules I can not approach members of your staff to inform them of this research without your permission to authorise the release of names to me. I am keen to ensure [ward managers and nursing staff/district nurses] are provided with information. I would appreciate you assistance with this, as I hope commence the research on the 1st of August 2001.

If you would like further information about this research please do not hesitate in contacting me. I would be happy to come and see you or send you the information you require. You can contact me by phoning xxxxxxxxx or alternatively email me on sargeant@socsci.soton.ac.uk.

Thank you for taking the time to read this.

Yours sincerely

Anita Sargeant. RGN, BA (Hons) PG Dip. Palliative Care
Post Graduate Research Student

LETTER TO GENERAL PRACTITIONER, DISTRICT NURSE, WARD MANAGER OR HOSPITAL CONSULTANT RE: PATIENT INVOLVEMENT

Dear [Name]

Re: [Name and address of patient]

I am writing to introduce myself and to inform you that [Name of patient] has been recruited into a research study based at Chaffinch Palliative Care Service.

I am a post graduate student based at the University of Southampton undertaking research into how is care constructed, expressed and perceived within palliative care. The research is part of a M.Phil. / Ph.D. I am also a qualified nurse who has worked in a range of palliative care settings in the past.

The research I am proposing involves carrying out observations of the hospice and the care provided by the staff, the hospital palliative care team and the community palliative care team. In-depth interviews will be carried out with the permission and voluntary consent of patients, carers and members of the palliative care staff. Questions will ask about their beliefs, experiences and expectations about care from the service. Documentary analysis is the third component of the research, in which policy documents, leaflets and patients case notes will be studied. The aim of the research is to build a comprehensive picture about how the understanding of care is developed and constructed within the field through the combined influence of actions, beliefs and the written statements of care.

Whilst I hope that the research will not be harmful in any way to those involved, I am very mindful of the possible distress that patients may experience as a result of discussing their care. The research has been carefully designed to minimise any distress to patients or others taking part in the study with attention to issues of consent, how the interviews are conducted, and the availability of support for the patient should he/she become distressed as a result of the research. All participants will be made fully aware that they can withdraw from the research or stop the interview at any point without giving a reason and without any consequences to their care.

If you would like further information about this research please do not hesitate in contacting me. I would be happy to come and see you or send you the information you require. You can contact me by phoning xxxxxxxxx or alternatively email me on sargeant@socsci.soton.ac.uk.

Thank you for taking the time to read this.

Yours sincerely

Anita Sargeant. RGN, BA (Hons) PG Dip. Palliative Care
Post Graduate Research Student

LETTER TO CARER : Invitation To Interview

Dear [Name of carer]

I hope you don't mind me writing to you. I have recently been talking to [name] who is cared for by staff from the [Hospice/Hospital Palliative Care Team/Community Palliative Care Team] and he/she thought that you might be willing to talk to me as take part of some research that I am currently undertaking.

I am a research student from the University of Southampton, and I have recently started a research study looking at how we understand what care is and how this is experienced when it is specifically related to palliative care.

I have attached a leaflet to this letter that will give you more information about the research and how you could participate in it.

After you have read the leaflet you would be willing to be interviewed, please either telephone me on xxxxxxxxxx or fill in the form below and send it back to me in the stamp addressed envelope enclosed. If you do not wish not to take part, then please be assured that this decision will not, in any way, affect the care that your relative or friend receives.

I am happy to visit you at home or at a place of your choice, so that we can talk privately and alone. If you would like someone else from your family to join you for the interview that would be alright with me. Please be assured that your participation and everything you say will be treated as confidential.

Thank you very much for taking the time to read this letter and the leaflet.

With best wishes
Yours sincerely

Anita Sargeant
Post Graduate Research Student

To: Anita Sargeant, Post Graduate Research Student,

I---

of ---

--(Address)

Would be willing for you to telephone me on ---
(telephone no.)

or writing to me to arrange an interview as part of your research project.

I understand that my participation is voluntary and that and that I am free to withdraw from the study at any time, without giving any reason and without the care of my [relative/friend] being affected.

Signed ---

Date--

LETTER TO STAFF : Re: Invitation to Participate in the research

Dear [Name]

Re: Understanding 'Care' in Palliative Care

My name is Anita Sargeant and I am a post graduate research student at the University of Southampton and I have a special interest in palliative care. I approached the Chaffinch palliative care service to carry out research about the understanding of care within palliative care, because it is an integrated service offering hospice care, hospital and community support. I would like to invite all members of staff working for the palliative care service to participate in this research and I have been given your name by Dr KL and EG

I will be undertaking research within the hospice; the hospital palliative care team and the community team over the next six months. I have attached a leaflet with this letter that provides more information about the research and its aims.

I am also writing to ask if you would be willing to take part in the research in three ways. Firstly I would like to ask for your permission to observe your care giving, secondly to interview you to discuss your understanding, views and experiences care within palliative care and thirdly to read how you have written about the care you have given to patients in their notes. All observations, interviews and written information are confidential and anonymity is assured. The time and place of the interview can be arranged to suit you. Your participation is entirely voluntary and if you do not wish to be observed, interviewed, or have your written notes read this wish will be respected.

If you would like to be part of this research please complete the form at the end of the information sheet, and return it to me. I will then make contact you to make an appointment, unless I hear that you do not wish to be either observed, interviewed or your notes read. You can contact me or leave a message on xxxxxxxxxxx simply or email me on sargeant@socsci.soton.ac.uk.

Thank you for reading my letter and I look forward to hearing from you

Yours sincerely

Anita Sargeant RGN, BA (Hons) PG Dip. Palliative Care.
Post Graduate Student
University of Southampton

Appendix 3: Information and Consent forms

HOSPICE INFORMATION LEAFLET : Introduction to the research

PROJECT TITLE: **Understanding Care within Palliative Care**

NAME OF RESEARCHER: **Anita Sargeant**

INTRODUCTION

Hello, my name is Anita Sargeant and I would like to thank you for taking the time to read this. The aim of this leaflet is for me to introduce myself to you and to provide you with details about my research project. I would like to invite you to take part in it. However, before you decide whether you wish to take part or not, it is important that you understand why the research is being done and what it will involve. Please take the time to read the following information and discuss it with family, friends or the staff who are caring for you in the hospice. Please ask the me if there is anything that is not clear or if you would like further information. Do take time to decide whether or not you wish to take part.

WHO AM I?

I am a researcher from Southampton University carrying out a study about what care in terms of palliative care means to you, your carer and the palliative care staff providing the service. I have a particular interest in palliative care and the variety of settings, including hospice, hospital and the community that it is carried out.

WHAT IS THE PURPOSE OF THE RESEARCH?

The purpose of this research is to find out how we understand what care means within palliative care and how it is developed through the experiences, expectations and beliefs of patients, carers and health professionals who work in the area.

By understanding how palliative care is being developed, new information may help inform the future development of palliative care services. The research also aims to reveal the unique and often unacknowledged way in which care is carried out. I am especially interested in your experience and views.

WHAT WILL THE RESEARCH INVOLVE?

I am planning to spend about two months in the hospice. During part of this time I will just sit quietly and watch what is going on and other times will be spent taking part in activities and talking to staff, patients, their carers and anyone else involved in the service. Whilst I am watching the daily workings of the hospice, I will also carefully observe the way staff care for some of the patients. In addition to this I will be interviewing some patients about what care to means to them. The third part of the research will involve me collecting information and reading documents related to palliative care, such as policies, procedures and leaflets. This will include with your permission, looking at your medical and nursing notes in order to understand more about the care provided.

If you chose to take part in the research I will be talking to you and watching your care, along with the other patients and staff. You can chose at any time to stop you involvement without needing to give a reason.

HOW DO YOU BECOME INVOLVED?

You will be invited to take part in the study after your admission when you have settled into the hospice. I will talk to you about this but it is up to you to decide whether or not you wish to participate. Your decision will not in anyway affect your care and treatment.

If you choose to take part you will be given this information sheet to keep and you will be asked to return the slip at the bottom of this sheet. If you decide to take you will need to sign a consent form confirming that your participation is entirely voluntary. You are free to withdraw from the research at any time and without giving a reason. Your wishes will be respected at all times.

WHAT ARE THE IMPLICATIONS OF BEING INVOLVED?

If you agree to take part, I will (with your agreement) inform the doctor looking after you in the hospice and your GP, so that they are aware of your involvement in this study.

This research is part of a PhD thesis and will be examined by the examined by the University when it is written up. However, be assured that any information that you give me and that I observe will be completely anonymised and treated as confidential. This is so that your identity will not be linked with anything you say or do. This is important so that those taking part cannot be recognised in any reports, publications or presentations that are written and shared with other professional after the study is complete.

WHERE CAN YOU GET FURTHER INFORMATION?

If you would like additional information speak to the staff in the hospice, or contact me directly. My phone number is xxxxxxxxxxxxx.

Thank you for taking the time to read this and for considering taking a part in the research.

Anita Sargeant
Post Graduate Research Student
University of Southampton

CONSENT FORM FOR HOSPICE : For Observation and Documentary Analysis

TITLE OF PROJECT: **Understanding Care Within Palliative Care**

RESEARCHER: **Anita Sargeant**

Please read the following statements, and if you are in agreement with them tick the box at the end of each statement. I am happy to explain anything if that will help you.

1. I confirm that I have read and understood the Information Sheet entitled [title] and dated [date of sheet] for the above study ☐
2. I confirm that I have had the opportunity to ask questions and find out more about the study ☐
3. I understand that my participation is voluntary and that I can withdraw from the study at any time, without giving any reason and without my medical care or legal rights being affected. ☐
4. I understand that episodes my care may be observed. ☐
5. I am willing to allow access to my nursing and medical records. ☐
6. I agree to the researcher contacting my General Practitioner and Consultant to inform him/her of my involvement in the study ☐
7. I am willing to be approached with regards to being interviewed. I understand that the researcher will provide additional information regarding the interview process and seek additional consent for this aspect of the study ☐
8. I agree to take part in the above study ☐

Signed .... (Name of participant)

Name .... (in block capitals)

Date ....

Signed .... (Researcher)

Date ....

Copy to: Participant with information sheet
Researcher
Medical notes

HOSPITAL INFORMATION LEAFLET : Introduction to the research

PROJECT TITLE: **Understanding Care Within Palliative Care**

NAME OF RESEARCHER: **Anita Sargeant**

INTRODUCTION

Hello, my name is Anita Sargeant and I would like to thank you for taking the time to read this. The aim of this leaflet is for me to introduce myself to you and to provide you with details about my research project. I would like to invite you to take part in it. However, before you decide whether you wish to take part or not, it is important that you understand why the research is being done and what it will involve. Please take the time to read the following information and discuss it with family, friends or the palliative care team staff who are caring for you in the hospital. Please ask me if there is anything that is not clear or if you would like further information. Do take time to decide whether or not you wish to take part.

WHO AM I?

I am a researcher from Southampton University carrying out a study about what care in terms of palliative care means to you, your carer and the palliative care staff providing the service. I have a particular interest in palliative care and the variety of settings, including hospice, hospital and the community that it is carried out.

WHAT IS THE PURPOSE OF THE RESEARCH?

The purpose of this research is to find out how we understand what care means within palliative care and how it is developed through the experiences, expectations and beliefs of patients, carers and health professionals who work in the area.

By understanding how palliative care is being developed, new information may help inform the future development of palliative care services. The research also aims to reveal the unique and often unacknowledged way in which care is carried out. I am especially interested in your experience and views.

WHAT WILL THE RESEARCH INVOLVE?

I am planning to spend about two months in the hospice. During part of this time I will just sit quietly and watch what is going on and other times will be spent taking part in activities and talking to staff, patients, their carers and anyone else involved in the service. Whilst I am watching the daily workings of the team, I will also carefully observe the way staff care for some of the patients who are part of the study. In addition to this I will be interviewing some patients about what care to means to them. The third part of the research will involve me collecting information and reading documents related to palliative care, such as policies, procedures and leaflets. This will include with your permission, looking at your medical and nursing notes in order to understand more about the care provided.

If you chose to take part in the research I will be talking to you and watching your care, along with the other patients and staff. You can chose at any time to stop you involvement without needing to give a reason.

HOW DO YOU BECOME INVOLVED?

You will be invited to take part in the study during your admission when the palliative care team visits you. A member of the team will talk initially to you about this but it is up to you to decide whether or not you wish to participate. Your decision will not in anyway affect your care and treatment whilst you are here in anyway.

If you choose to take part you will be given this information sheet to keep and you will be asked to return the slip at the bottom of this sheet. If you decide to take you will need to sign a consent form confirming that your participation is entirely voluntary. You are free to withdraw from the research at any time and without giving a reason. Your wishes will be respected at all times.

WHAT ARE THE IMPLICATIONS IF YOU BECOME INVOLVED?

If you agree to take part, I will (with your agreement) inform your hospital consultant and the doctor looking after you and also your GP, so that they are aware of your involvement in this study.

This research is part of a PhD thesis and will be examined by the University when it is written up. However, be assured that any information that you give me and that I observe will be completely anonymised and treated as confidential. This is important so that those taking part cannot be recognised in any reports, publications or presentations that are written and shared with other professional after the study is complete.

WHERE CAN YOU GET FURTHER INFORMATION?

If you would like additional information speak to the staff in the hospice, or contact me directly. My phone number is xxxxxxxxxxxxxx.

Thank you for taking the time to read this and for considering taking a part in the research.

Anita Sargeant
Post Graduate Research Student
University of Southampton

CONSENT FORM FOR HOSPITAL : For Observation and Documentary Analysis

TITLE OF PROJECT: **Understanding Care Within Palliative Care**

RESEARCHER: **Anita Sargeant**

Please read the following statements, and if you are in agreement with them tick the box at the end of each statement. I am happy to explain anything if that will help you.

9. I confirm that I have read and understood the Information Sheet entitled [title] and dated [date of sheet] for the above study ☐
10. I confirm that I have had the opportunity to ask questions and find out more about the study ☐
11. I understand that my participation is voluntary and that I can withdraw from the study at any time, without giving any reason and without my medical care or legal rights being affected. ☐
12. I understand that episodes my care may be observed. ☐
13. I am willing to allow access to my nursing and medical records. ☐
14. I agree to the researcher contacting my General Practitioner and Consultant to inform him/her of my involvement in the study ☐
15. I am willing to be approached with regards to being interviewed. I understand that the researcher will provide additional information regarding the interview process and seek additional consent for this aspect of the study ☐
16. I agree to take part in the above study ☐

Signed .... (Name of participant)

Name .... (in block capitals)

Date ....

Signed .... (Researcher)

Date ....

Copy to: Participant with information sheet
Researcher
Medical notes

COMMUNITY INFORMATION LEAFLET : Introduction to the research

PROJECT TITLE: **Understanding Care Within Palliative Care**

NAME OF RESEARCHER: **Anita Sargeant**

INTRODUCTION

Hello, my name is Anita Sargeant and I would like to thank you for taking the time to read this. The aim of this leaflet is for me to introduce myself to you and to provide you with details about my research project. I would like to invite you to take part in it. However, before you decide whether you wish to take part or not, it is important that you understand why the research is being done and what it will involve. Please take the time to read the following information and discuss it with family, friends or the palliative care team who are caring for you at home. Please ask me if there is anything that is not clear or if you would like further information. Do take time to decide whether or not you wish to take part.

WHO AM I?

I am a researcher from Southampton University carrying out a study about what care in terms of palliative care means to you, your carer and the palliative care staff providing the service. I have a particular interest in palliative care and the variety of settings, including hospice, hospital and the community that it is carried out.

WHAT IS THE PURPOSE OF THE RESEARCH?

The purpose of this research is to find out how we understand what care means within palliative care and how it is developed through the experiences, expectations and beliefs of patients, carers and health professionals who work in the area.

By understanding how palliative care is being developed, new information may help inform the future development of palliative care services. The research also aims to reveal the unique and often unacknowledged way in which care is carried out. I am especially interested in your experience and views.

WHAT WILL THE RESEARCH INVOLVE?

I am planning to spend about two months with the Community Palliative Care Team. During part of this time I will just sit quietly and watch what is going on and other times will be spent taking part in activities and talking to staff, patients, their carers and anyone else involved in the service. Whilst I am watching the daily workings of the team, I will also carefully observe the way staff care for some of the patients who are part of the study. In addition to this I will be interviewing some patients about what care to means to them. The third part of the research will involve me collecting information and reading documents related to palliative care, such as policies, procedures and leaflets. This will include with your permission, looking at your medical and nursing notes in order to understand more about the care provided.

If you chose to take part in the research I will be talking to you and watching your care, along with the other patients and staff. You can chose at any time to stop you involvement without needing to give a reason.

HOW DO YOU BECOME INVOLVED?

You will be invited to take part in the study during when you are visited by the community palliative care team. A member of the team will talk initially to you about this but it is up to you to decide whether or not you wish to participate. Your decision will not in anyway affect your care and treatment whilst you are here in anyway.

If you choose to take part you will be given this information sheet to keep and you will be asked to return the slip at the bottom of this sheet. If you decide to take you will need to sign a consent form confirming that your participation is entirely voluntary. You are free to withdraw from the research at any time and without giving a reason. Your wishes will be respected at all times.

WHAT ARE THE IMPLICATIONS IF YOU BECOME INVOLVED?

If you agree to take part, I will (with your agreement) inform your GP, any other doctors looking after you and also your district nurse if you have one, so that they are aware of your involvement in this study.

This research is part of a PhD thesis and will be examined by the University when it is written up. However, be assured that any information that you give me and that I observe will be completely anonymised and treated as confidential. This is important so that those taking part cannot be recognised in any reports, publications or presentations that are written and shared with other professional after the study is complete.

WHERE CAN YOU GET FURTHER INFORMATION?

If you would like additional information speak to the community palliative care, or contact me directly. My phone number is xxxxxxxxxx

Thank you for taking the time to read this and for considering taking a part in the research.

Anita Sargeant
Post Graduate Research Student
University of Southampton

CONSENT FORM FOR COMMUNITY : For Observation and Documentary Analysis

TITLE OF PROJECT: **Understanding Care Within Palliative Care**

RESEARCHER: **Anita Sargeant**

Please read the following statements, and if you are in agreement with them tick the box at the end of each statement. I am happy to explain anything if that will help you.

17. I confirm that I have read and understood the Information Sheet entitled [title] and dated [date of sheet] for the above study ☐
18. I confirm that I have had the opportunity to ask questions and find out more about the study ☐
19. I understand that my participation is voluntary and that I can withdraw from the study at any time, without giving any reason and without my medical care or legal rights being affected. ☐
20. I understand that episodes my care may be observed. ☐
21. I am willing to allow access to my nursing and medical records. ☐
22. I agree to the researcher contacting my General Practitioner and Consultant to inform him/her of my involvement in the study ☐
23. I am willing to be approached with regards to being interviewed. I understand that the researcher will provide additional information regarding the interview process and seek additional consent for this aspect of the study ☐
24. I agree to take part in the above study ☐

Signed .... (Name of participant)

Name .... (in block capitals)

Date ....

Signed .... (Researcher)

Date ....

Copy to: Participant with information sheet
Researcher
Medical notes

HOSPICE INFORMATION LEAFLET : The Interview

TITLE OF PROJECT:	**Understanding Care Within Palliative Care**
RESEARCHER:	**Anita Sargeant**

INTRODUCTION

Hello. As you may remember my name is Anita Sargeant and I am a researcher spending time within the Hospice observing how care is carried out and thought about by the members of the team looking after you. In doing so I am trying to find out what people such as yourself, your carer and the team understand about what care means and what is valued. This will help to piece together a much bigger picture about the development and nature of care in palliative care.

As part of the research, I would like to talk to people like yourself in more detail about your understanding, experiences and expectations about care in this environment. This will help me to understand what care means to you, what you find important and what you value.

WHAT WILL AN INTERVIEW INVOLVE?

The interviews will be quite informal and will take place in private or just occasionally by your bedside. If you are unable to get out of bed, provision will be made to move your bed into a separate room so that you can not be over heard. I will ask you a number of general questions regarding your feelings, experience and expectations about receiving care specifically in terms of palliative care. Our discussions will be tape recorded, however, if you become tired or unwell and do not wish to continue with the interview, you are free to end it at any point.

Sometimes talking about personal beliefs and experiences can bring up a range of emotions for people. If you find this is, you can stop the interview at any point for a break or withdraw completely. It will not affect your care in any way. If you feel you would like to talk about something that came up for you during our discussion you can talk to me or to a member of staff for more support.

WHAT HAPPENS TO THE INFORMATION AFTER THE INTERVIEW?

After the interview the recording of our discussion will be typed up and any names or references to yourself and other people will be removed from the transcript It will be anonymised so that you cannot be recognised from it. Everything you say to me during the interview will be treated as strictly confidential. I may provide you with a summary of the transcript to check and amend if you wish. If you wish to withdraw part or all of what you said you will be able to do so. The tape-recording of the interview will be kept in a locked filing cabinet and destroyed once the study is complete. In the final report some details of what you said may be used, but it will not be possible to identify who you are.

WHAT TO DO IF YOU WANT TO TAKE PART

It is important to know that taking part in an interview is voluntary, and your decision about whether to take part or not will have no effect on your care or treatment. If you decide to take part, you are free to withdraw from the research at any point and without giving a reason. If you would like to take part please let me know. You can do this by asking a member of staff to let me know or by contacting me directly. I can then discuss with you about any other concerns you may have, and arrange a time and a place to interview you. If you are not sure unsure about some of the details of the research or my background I have attached a copy of the initial information sheet called 'Introduction to the Research'.

WHAT DO YOU DO IF YOU DON'T WANT TO TAKE PART

If you do not wish not to be approached about taking part in an interview please tick the box n the slip of paper, so that I know not to bother you. Remember that this will not affect the care you receive in any way.

WHERE CAN YOU GET FURTHER INFORMATION?

If you would like additional information speak to the staff in the hospice, or contact me directly. My phone number is 023 8059 2739.

Thank you for taking the time to read this and for considering taking a part in the research.

Anita Sargeant
Post Graduate Research Student
University of Southampton

CONSENT FORM FOR INTERVIEW OF HOSPICE

TITLE OF PROJECT: **Understanding Care Within Palliative Care**

RESEARCHER: **Anita Sargeant**

Please read the following statements, and if you are in agreement with them initial the box at the end of each statement.

1. I confirm that I have read and understood the Information Sheet entitled [title] and dated [date of sheet] for the above study ☐
2. I confirm that I have had the opportunity to ask questions and find out more about the study ☐
3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason and without my medical care or legal rights being affected. ☐
4. I understand that all the information I give to the researcher will be kept strictly confidential. ☐
5. I give permission for the interview to be tape-recorded for the purposes of research in the knowledge this will be anonymised prior to its use in the written thesis, publications and reports. ☐
6. I agree to take part in the above study ☐

Signed .... (Name of participant)

Name .... (in block capitals)

Date ....

Signed .... (Researcher)

Date ....

Copy to: Participant with information sheet
Researcher
Medical notes

HOSPITAL PATIENT INFORMATION LEAFLET : The Interview

TITLE OF PROJECT: **Understanding Care Within Palliative Care**

RESEARCHER: **Anita Sargeant**

INTRODUCTION

Hello. As you may remember my name is Anita Sargeant and I am a researcher spending time within the Hospital palliative care team observing care is carried out and thought about by the members of the palliative care team who are involved with your care. In doing so I am trying to find out what people such as yourself, your carer and the team understand about what care means and what is valued. This will help to piece together a much bigger picture about the development and nature of care in palliative care.

As part of the research, I would like to talk to people like you in more detail about your understanding, experiences and expectations about care in this environment. This will help me to understand what care means to you, what you find important and what you value.

WHAT WILL AN INTERVIEW INVOLVE?

The interviews will be quite informal and will take place in private or just occasionally by your bedside. If you are unable to get out of bed, provision will be made to move your bed into a separate room so that you can not be over heard. I will ask you a number of general questions regarding your feelings, experience and expectations about receiving care specifically in terms of palliative care. Our discussions will be tape recorded, however, if you become tired or unwell and do not wish to continue with the interview, you are free to end it at any point.

Sometimes talking about personal beliefs and experiences can bring up a range of emotions for people. If you find this is, you can stop the interview at any point for a break or withdraw completely. It will not affect your care in any way. If you feel you would like to talk about something that came up for you during our discussion you can talk to me or to a member of staff for more support.

WHAT HAPPENS TO THE INFORMATION AFTER THE INTERVIEW?

After the interview the recording of our discussion will be typed up and any names or references to yourself and other people will be removed from the transcript It will be anonymised so that you cannot be recognised from it. Everything you say to me during the interview will be treated as strictly confidential. I may provide you with a summary of the transcript to check and amend if you wish. If you wish to withdraw part or all of what you said you will be able to do so. The tape-recording of the interview will be kept in a locked filing cabinet and destroyed once the study is complete. In the final report some details of what you said may be used, but it will not be possible to identify who you are.

WHAT TO DO IF YOU WANT TO TAKE PART

It is important to know that taking part in an interview is voluntary, and your decision about whether to take part or not will have no effect on your care or treatment. If you decide to take part, you are free to withdraw from the research at any point and without giving a reason. If you would like to take part please let me know. You can do this by asking a member of staff to let me know or by contacting me directly. I can then discuss with you about any other concerns you may have, and arrange a time and a place to interview you. If you are not sure unsure about some of the details of the research or my background I have attached a copy of the initial information sheet called 'Introduction to the Research'.

WHAT DO YOU DO IF YOU DON'T WANT TO TAKE PART

If you do not wish not to be approached about taking part in an interview please tick the box n the slip of paper, so that I know not to bother you. Remember that this will not affect the care you receive in any way.

WHERE CAN YOU GET FURTHER INFORMATION?

If you would like additional information speak to the staff in the hospice, or contact me directly. My phone number is 023 8059 2739.

Thank you for taking the time to read this and for considering taking a part in the research.

Anita Sargeant
Post Graduate Research Student
University of Southampton

CONSENT FORM FOR INTERVIEW OF HOSPITAL PATIENTS

TITLE OF PROJECT: **Understanding Care Within Palliative Care**

RESEARCHER: **Anita Sargeant**

Please read the following statements, and if you are in agreement with them initial the box at the end of each statement.

2. I confirm that I have read and understood the Information Sheet entitled [title] and dated [date of sheet] for the above study ☐

7. I confirm that I have had the opportunity to ask questions and find out more about the study ☐

8. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason and without my medical care or legal rights being affected. ☐

9. I understand that all the information I give to the researcher will be kept strictly confidential. ☐

10. I give permission for the interview to be tape-recorded for the purposes of research in the knowledge this will be anonymised prior to its use in the written thesis, publications and reports. ☐

11. I agree to take part in the above study ☐

Signed ………………………………………………………….. (Name of participant)

Name ………………………………………………………….. (in block capitals)

Date …………………………………..

Signed ………………………………………………………….. (Researcher)

Date …………………………………..

Copy to: Participant with information sheet
Researcher
Medical notes

COMMUNITY PATIENT INFORMATION LEAFLET : The Interview

TITLE OF PROJECT:	**Understanding Care Within Palliative Care**
RESEARCHER:	**Anita Sargeant**

INTRODUCTION

Hello. As you may remember my name is Anita Sargeant and I am a researcher spending time within the Community palliative care team observing care is carried out and thought about by the members of the palliative care team who are involved with your care. In doing so I am trying to find out what people such as yourself, your carer and the team understand about what care means and what is valued. This will help to piece together a much bigger picture about the development and nature of care in palliative care.

As part of the research, I would like to talk to people like you in more detail about your understanding, experiences and expectations about care in this environment. This will help me to understand what care means to you, what you find important and what you value.

WHAT WILL AN INTERVIEW INVOLVE?

The interviews will be quite informal and will take place in private or just occasionally by your bedside. If you are unable to get out of bed, provision will be made to move your bed into a separate room so that you can not be over heard. I will ask you a number of general questions regarding your feelings, experience and expectations about receiving care specifically in terms of palliative care. Our discussions will be tape recorded, however, if you become tired or unwell and do not wish to continue with the interview, you are free to end it at any point.

Sometimes talking about personal beliefs and experiences can bring up a range of emotions for people. If you find this is, you can stop the interview at any point for a break or withdraw completely. It will not affect your care in any way. If you feel you would like to talk about something that came up for you during our discussion you can talk to me or to a member of staff for more support.

WHAT HAPPENS TO THE INFORMATION AFTER THE INTERVIEW?

After the interview the recording of our discussion will be typed up and any names or references to yourself and other people will be removed from the transcript It will be anonymised so that you cannot be recognised from it. Everything you say to me during the interview will be treated as strictly confidential. I may provide you with a summary of the transcript to check and amend if you wish. If you wish to withdraw part or all of what you said you will be able to do so. The tape-recording of the interview will be kept in a locked filing cabinet and destroyed once the study is complete. In the final report some details of what you said may be used, but it will not be possible to identify who you are.

WHAT TO DO IF YOU WANT TO TAKE PART

It is important to know that taking part in an interview is voluntary, and your decision about whether to take part or not will have no effect on your care or treatment. If you decide to take part, you are free to withdraw from the research at any point and without giving a reason. If you would like to take part please let me know. You can do this by asking a member of staff to let me know or by contacting me directly. I can then discuss with you about any other concerns you may have, and arrange a time and a place to interview you. If you are not sure unsure about some of the details of the research or my background I have attached a copy of the initial information sheet called 'Introduction to the Research'.

WHAT DO YOU DO IF YOU DON'T WANT TO TAKE PART

If you do not wish not to be approached about taking part in an interview please tick the box n the slip of paper, so that I know not to bother you. Remember that this will not affect the care you receive in any way.

WHERE CAN YOU GET FURTHER INFORMATION?

If you would like additional information speak to the staff in the hospice, or contact me directly. My phone number is 023 8059 2739.

Thank you for taking the time to read this and for considering taking a part in the research.

Anita Sargeant
Post Graduate Research Student
University of Southampton

CONSENT FORM FOR INTERVIEW OF COMMUNITY PATIENTS

TITLE OF PROJECT: **Understanding Care Within Palliative care**

RESEARCHER: **Anita Sargeant**

Please read the following statements, and if you are in agreement with them initial the box at the end of each statement.

3. I confirm that I have read and understood the Information Sheet entitled [title] and dated [date of sheet] for the above study ☐

12. I confirm that I have had the opportunity to ask questions and find out more about the study ☐

13. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason and without my medical care or legal rights being affected. ☐

14. I understand that all the information I give to the researcher will be kept strictly confidential. ☐

15. I give permission for the interview to be tape-recorded for the purposes of research in the knowledge this will be anonymised prior to its use in the written thesis, publications and reports. ☐

16. I agree to take part in the above study ☐

Signed .... (Name of participant)

Name .... (in block capitals)

Date ....

Signed .... (Researcher)

Date ....

Copy to: Participant with information sheet
Researcher
Medical notes

INFORMATION LEAFLET FOR CARERS

PROJECT TITLE: **Understanding Care within Palliative Care**

NAME OF RESEARCHER: **Anita Sargeant**

INTRODUCTION

Hello, my name is Anita Sargeant and I would like to thank you for taking the time to read this. The aim of this leaflet is for me to introduce myself to you and to provide you with details about my research project, and to invite you to take part in it. However, before you decide whether you wish to take part or not, it is important that you understand why the research is being done and what it will involve. Please take the time to read the following information and do discuss it with family or friends. Please also ask me if there is anything that is not clear or if you would like further information. Do take time to decide whether or not you wish to take part.

WHO AM I?

I am a researcher from Southampton University carrying out a study about what care in terms of palliative care means to you, your carer and the palliative care staff providing the service. I have a particular interest in palliative care and the variety of settings, including hospice, hospital and the community that it is carried out.

WHAT IS THE PURPOSE OF THE RESEARCH?

The purpose of this research is to find out how we understand what care means within palliative care and how it is developed through the experiences, expectations and beliefs of patients, carers and health professionals who work in the area.

By understanding how palliative care is being developed, new information may help inform the future development of palliative care services. The research also aims to reveal the unique and often unacknowledged way in which care is carried out. I am especially interested in your experience and views.

WHAT WILL THE RESEARCH INVOLVE?

I am planning to spend about two months with the hospice, the hospital palliative care team and the hospital palliative care teams. During part of this time I will just sit quietly and watch what is going on and other times will be spent taking part in activities and talking to staff, patients, their carers and anyone else involved in the service.

Whilst I am watching the daily workings of the hospice and palliative care teams, I will also carefully observe the way staff care for some of the patients who are part of the study. As well as interviewing some patients I also want to interview some of the carers such as yourself, because you have a unique perspective about care in relation to palliative care and what means to you, your experiences and expectations.
This will help me build more comprehensive picture about the nature and development of care in palliative care. This will eventually inform the future understanding and development of palliative care provision.

WHAT WILL THE INTERVIEWS INVOLVE?

These interviews will be quite informal and will take place in private. I am happy to come and visit you at home or carryout the interview where it is most convenient for you. I will ask you a number of general questions about what care means to you, your experiences of being a carer at home and your expectations about care specifically provided by either the hospice or the palliative care teams and what difference, if any, this makes to you. The conversation will be tape recorded, and will last for time that you can manage. However, if you become tired or no longer wish to continue with the interview, you can stop it at any point. This will in no way affect the care given to the person for whom you are the carer.

Sometimes talking about personal beliefs and experiences can bring up a range of emotions. If this is the case for you, you can talk with me about them or I will have information available about accessing extra support if you feel it is necessary.

WHAT HAPPENS TO THE INFORMATION AFTER THE INTERVIEW?

After the interview the recording of our discussion will be typed up and any names or references to yourself and other people will be removed from the transcript It will be anonymised so that you cannot be recognised from it. Everything you say to me during the interview will be treated as strictly confidential. I may provide you with a summary or copy of the transcript to check and amend if you wish. If you wish to withdraw part or all of what you said you will be able to do so. The tape-recording of the interview will be kept in a locked filing cabinet and destroyed once the study is complete. In the final report some details of what you said may be used, but it will not be possible to identify who you are.

WHAT DO YOU NEED TO DO?

Please remember that taking part in an interview is entirely voluntary, and your decision whether to participate or not will not affect the care and treatment of the person for whom you are the carer. If you decide to take part, you are free to withdraw from the research at any point and without giving a reason.

A letter is attached to this leaflet, which asks you whether you would be willing to be interviewed. If you wish to take part, please complete the form and send it back. I will then contact you to arrange a date and time to meet. Prior to the interview I will ask you to sign a form consenting to be interviewed. If you change your mind between sending back the form and the interview, you simply need to let me know that when I contact you.

WHERE CAN YOU GET FURTHER INFORMATION?

If you would like additional information, talk to a member of staff in the hospice or palliative care team or contact me directly. My phone number is 023 8059 2739.

Anita Sargeant
Post Graduate Research Student
University of Southampton.

CONSENT FORM FOR CARERS : The Interview

TITLE OF PROJECT: **Understanding Care Within Palliative Care**

RESEARCHER: **Anita Sargeant**

Please read the following statements, and if you are in agreement with them initial the box at the end of each statement. I am happy to explain anything you are unclear about if that will help you.

1. I confirm that I have read and understood the Information Sheet entitled [title] and dated [date of sheet] for the above study ☐
2. I confirm that I have had the opportunity to ask questions and find out more about the study ☐
3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason and without my rights and the medical carer legal rights of the person for whom I am the carer being affected. ☐
4. I understand that all the information I give to the researcher will be kept strictly confidential. ☐
5. I give permission for the interview to be tape-recorded for the purposes of research in the knowledge this will be anonymised prior to its use in the written thesis, publications and reports ☐
6. I agree to take part in the above study ☐

Signed .... (Name of participant)

Name .... (in block capitals)

Address ....

....

Date ....

Signed .... (Researcher)
Copy to: Participant with information sheet
Researcher

INFORMATION LEAFLET FOR STAFF : Introduction to the research

PROJECT TITLE: **Understanding Care within Palliative Care**

NAME OF RESEARCHER: **Anita Sargeant**

Hello, my name is Anita and I am a post graduate research student at the University of Southampton, currently registered for an MPhil/ PhD. I have range of experience from working within different palliative care settings. I would just like to thank you for taking the time to read this information about my research.

INTRODUCTION TO THE RESEARCH

The purpose of this research is to find out what you understand about what care means within the field of palliative care and how it is developed through the experiences, expectations and beliefs of patients, carers and yourselves as health professionals who work in the area.

By understanding how the concept of care in palliative care is developed and how the early palliative care philosophy has be adapted for hospital and community palliative care, new information which will inform the future development of palliative care services. The research also aims to reveal the unique and often unacknowledged way in which care is carried out. I am especially interested in your experiences, what care and being caring in your work means to you and also how you express this when with patients or their carers, family and friends. I am also interested in how these activities of care are written about but your self and also by the policy makers.

WHAT WILL THE RESEARCH INVOLVE?

I am planning to spend about two months in the hospice, two months with the hospital palliative care team and two months with the community palliative care team. During part of this time I will just sit quietly and watch what is going on and other times will be spent taking part in activities and talking to members of staff, patients, their carers and anyone else involved in the service. Whilst I am watching the daily workings of the hospice, hospital team or community team I will also carefully observe the way people care for some of the patients who are part of the study. I will be interviewing some patients about what care to means to them, some carers and some members of staff. The third part of the research will involve me collecting information and reading documents related to palliative care, such as policies, procedures and leaflets, including looking at patient notes in order to understand more about the care provided.

OBSERVATION

Throughout the time that I spend with either the hospice, the hospital or community teams I will be observing and listening to all that happens. Whilst in the hospice I will spend some of the time taking part in caring activities as a supernumerary care assistant helping with patient care, but I will not be involved in handling medications, or writing up care notes. At other times I will simply watch what is happening by positioning myself either outside the area of activity or within it. When I am with the hospital and community teams I do not expect to take part in caring activities since these are expected to differ from those of the hospice. Observation will be overt at all times, that is I will not hide my role in observing the care and staff and patients will be informed when this is happening. Where a patient or member of staff does not wish to be observed, I will withdraw from the area. I am likely to spend the majority of my early days observing the service in order to become familiar with it. The periods of observation will become more intermittent as the research progresses, but remain important nonetheless in order to examine issues that arise from other research activities.

INTERVIEWS

Interviews will be carried out with a number of patients, carers and members of staff who have given their consent. These interviews will focus on asking questions about what care means and what experiences and expectations that person has about it. Interviewees will be asked to talk about a memorable incident in which they either felt cared for or an incident in which they felt they were providing care. Interviews are likely to last between 30 minutes and an hour in length, but can be shorter or longer depending on the participant. They will be tape-recorded and transcribed and all interviewees will be given the chance to read a summary of their transcript for amendment if they wish. The other elements of the research will inform the interviews and the issues they raise.

DOCUMENTARY ANALYSIS

Analysis of documents such as operational policies, patient notes, leaflets and job descriptions will be carried out. This will provide information of a factual or historical nature regarding the service and its characteristics. Documentary analysis will take place throughout the period of the research, initially to provide background information and later on as a means of answering questions raised by the content of the interviews.

CONFIDENTIALITY AND ANONYMITY

All observations and information disclosed by participants during the research will be treated as confidential. Written field notes and, tape recordings will be coded. I will also be the only person to transcribe the tapes which will be will be destroyed once the study is complete. All notes and written work associated with the study, including publications and reports will be fully anonymised to prevent the identification of those who have taken part.

PARTICIPATION BY STAFF

I may not be able to interview all members of staff due to time limits and resources. However, I hope to interview as many people as possible in order to understand the diversity of views that may exist. If you would like to be part of this study please contact me, by returning the slip of paper or by contacting me directly by telephone. If I think it helpful to interview you, once you have opted into the study I will contact you either by telephone or by letter and will provide further information at your request. Interviews will not affect your work time, and will be carried out outside of this time. Prior to the interview your written consent will be sought.

FURTHER INFORMATION

If you would like to know more about the research, please contact me by phoning xxxxxxxx or speak to Ms Frances Sheldon, Head of Department and Senior Macmillan Lecturer in Psychosocial Palliative Care, who is a supervisor of the project.

Thank you
Anita Sargeant
Post graduate research student

To: Anita Sargeant, Post Graduate Research Student,

I---

of ---

---(Address)

Would be willing to be part of your research into understanding care within palliative care. (Please tick which aspects of the research you are willing to be part of).

I am willing to be involved in the observation of care being carried out. ☐

I am willing to be interviewed ☐

I am willing to have my written patient notes read ☐

I would be willing for you to telephone me on --
(telephone no.)

or write to me to arrange an interview as part of your research project.

I understand that my participation is voluntary and that and that I am free to withdraw from the study at any time, without giving any reason and without the care of my [relative/friend] being affected.

Signed --------------------------- Date-----------------------

CONSENT FORM FOR STAFF : The interview

TITLE OF PROJECT: **Understanding Care Within Palliative Care**

RESEARCHER: **Anita Sargeant**

Please read the following statements, and if you are in agreement with them initial the box at the end of each statement.

1. I confirm that I have read and understood the Information Sheet entitled [title] and dated [date of sheet] for the above study ☐
2. I confirm that I have had the opportunity to ask questions and find out more about the study ☐
3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason ☐
4. I understand that all the information I give to the researcher will be kept strictly confidential ☐
5. I give permission to be observed and my written notes read. ☐
6. I give permission for the interview to be tape-recorded for the purposes of research in the knowledge this will be anonymised prior to its use in the written thesis, publications and reports ☐
7. I agree to take part in the above study ☐

Signed .... (Name of participant)

Name .... (in block capitals)

Date ....

Signed .... (Researcher)

Date ....

Copy to: Participant with information sheet
Researcher

Appendix 4 Thematic Interview Schedules

THEMATIC INTERVIEW SCHEDULE : Hospice/Community/Hospital Palliative Care Team People

Hello, my name is Anita Sargeant. Thank you for agreeing to be part of this research. You have been invited to take part in an interview which is about exploring your understanding and experience of care in palliative care.

I know you have agreed to take part in this interview, but can I remind you that you can stop for a rest or end the interview when ever you want, without it affecting the care you receive here.

Please feel free to ask me questions if you are unclear about anything. The interview will be tape recorded, but can I assure you that it will remain confidential and I will ensure it will also be made anonymous, so that nothing you say can be traced back to you.

- Before I begin, is there anything you would like to ask me?
- How long have you been under the care of the hospice/community/hospital palliative care team?
- Have you been looked after by either the hospice/community/hospital palliative care team or the hospice?
    - If so, how long?
    - Which team were you looked after by first?
- I am interested in finding out what care and being cared for means to you, would you be able to tell me a little about what you understand by 'care'?
- What does being 'cared for' mean to you?
    - Anything else?
- What makes you feel 'cared for' ?
    - Anything else?
- What make you feel you aren't being cared for?
    - Anything else?
- I wonder if you could describe a time or an incident that made you feel cared for, or a time when you didn't?

- What were your expectations of being cared for by the communit/hospital palliative care team?

  - have your expectations been met?
  - if so how?
  - if not why?

- Can I ask you to tell me if being cared for by the hospice/palliative care teams is different from your experiences in other parts of the health service?

  - if so how?

- Is there anything else you would like to add?

Thank you very much for agreeing to take part in this interview. If there is anything else you want to ask me afterward, then let me know. For some people that I interview I return a type written copy of what has been said to me, or for other a summary of the points that we discussed. Would you like to have a copy or summary of our conversation?

Thank you once again.

THEMATIC INTERVIEW SCHEDULE : Carers

Hello, my name is Anita Sargeant. Thank you for agreeing to be part of this research. This interview is about exploring your understanding and experience of care in palliative care.

I know you have agreed to take part in this interview, but can I remind you that you can stop for a rest or end the interview when ever you want, without it affecting the care you and the person for whom you care for receive.

Please feel free to ask me questions if you are unclear about anything. The interview will be tape recorded, but can I assure you that it will remain confidential and I will ensure it will also be made anonymous, so that nothing you say can be traced back to you.

- Before I begin, is there anything you would like to ask me?
- How long have you been caring for [name of patient]?
- Has [name of patient] looked after by the community palliative care team, hospital palliative care team or the hospice?
    - If so, how long?
    - Which team were you looked after by first?
- I am interested in finding out what care and being cared for means to you, would you be able to tell me a little about what you understand by 'care'?
- What does being 'cared for' mean to you?
    - Anything else?
- What makes you feel 'cared for' ?
    - Anything else?
- What make you feel you aren't being cared for?
    - Anything else?
- What is it like caring for [name of patient]?

- What were your expectations of being cared for by the palliative care service?

    - have your expectations been met?
    - if so how?
    - if not why?

- Can I ask you to tell me if being cared for by the hospice/palliative care teams is different from your experiences in other parts of the health service?

    - if so how?

- I wonder if you could describe a time or an incident that made you felt [name of patient] was well cared for you cared for?
    - Anything else?
- I wonder if you could describe a time or an incident that made you felt [name of patient] was not well cared for you cared for?

    - Anything else?

- Is there anything else you would like to add?

Thank you very much for agreeing to take part in this interview. If there is anything else you want to ask me afterward, then let me know. For some people that I interview I return a type written copy of what has been said to me, or for other a summary of the points that we discussed. Would you like to have a copy or summary of our conversation?

Thank you once again.

THEMATIC INTERVIEW SCHEDULE : Palliative care staff

Hello, my name is Anita Sargeant. Thank you for agreeing to be part of this research. You have been invited to take part in an interview, which is about exploring your understanding and experience of care in palliative care.

I know you have agreed to take part in this interview, can I remind you that you can stop for a break or end the interview whenever you want.

Please feel free to ask me questions if you are unclear about anything. The interview will be tape recorded, but can I assure you that it will remain confidential and I will ensure it will also be made anonymous, so that nothing you say can be traced back to you.

- Before I begin, is there anything you would like to ask me?
- How long have you worked in palliative care?
- Have you worked any other areas of palliative care?

    - if so what areas were these?
    - what did you do?

- I am interested in finding out what care and providing care means to you, personally and professionally. Would you be able to tell what you understand by the term 'care' personally and professionally?

    - Anything else?

- What makes you feel cared for?
- What makes you feel you aren't cared for?
- What do you understand by being caring ?
- What influenced your decision to work in palliative care?

    Anything else?

- I wonder if you could describe an incident where you were caring for a patient, which you felt went well?

    - What did you do?
    - What were your thoughts?
    - What influenced your decisions?

- Can you describe an incident where you were caring for a patient, which you felt didn't go as well as hoped?

    - What did you do?
    - What were you thoughts?
    - What influenced you decisions?

- How do you think providing care within palliative care is different from providing care within other fields of health care?

Thank you very much for agreeing to take part in this interview. If there is anything else you want to ask me afterward, then let me know. For some people that I interview I return a type written copy of what has been said to me, or for other a summary of the points that we discussed. Would you like to have a copy or summary of our conversation?

Thank you once again.

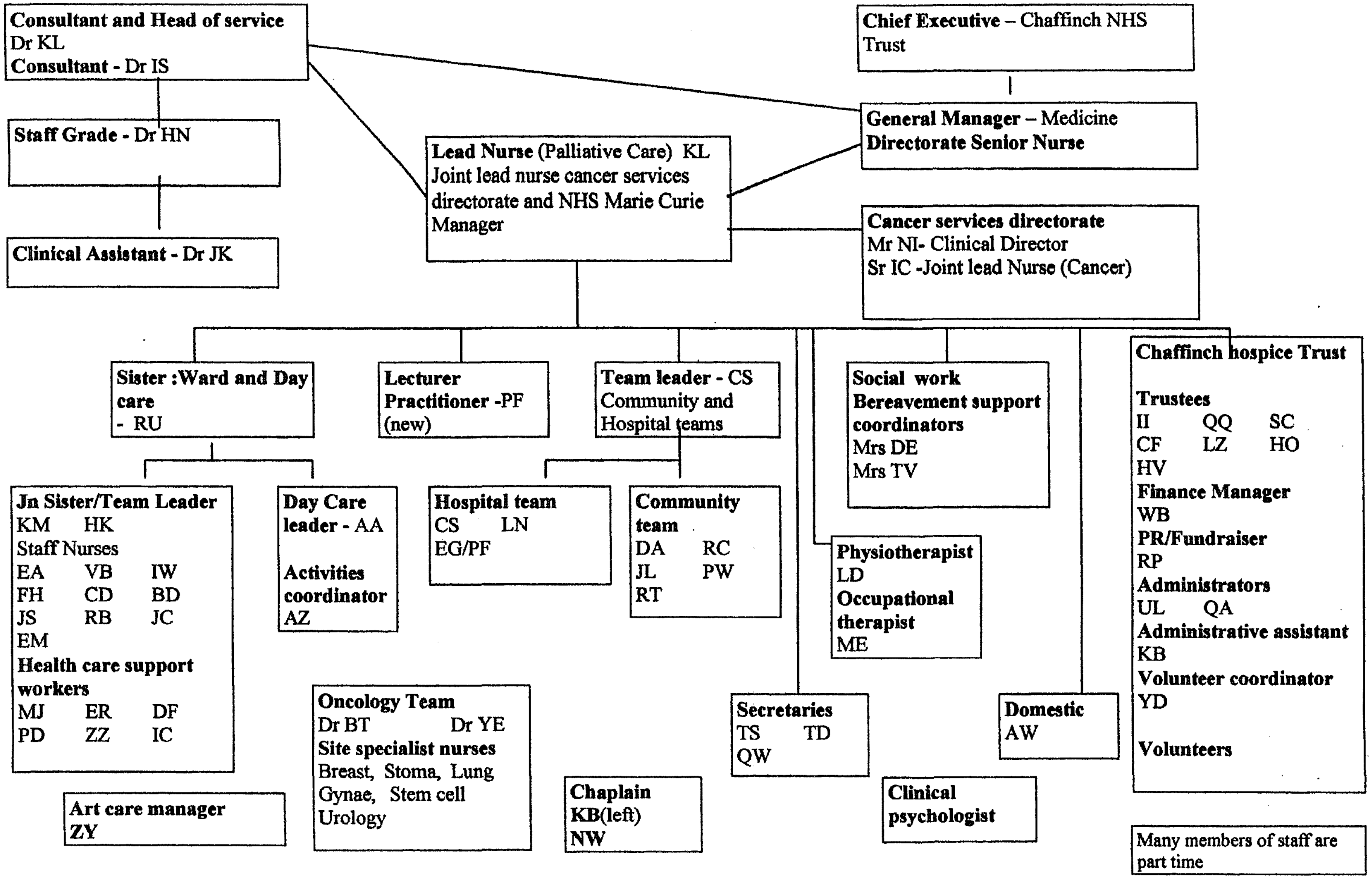
Appendix 5: Participant list and organisational chart

Identity	Role	Location	Gender	Observed	Interviewed
ST	Person cared for in	Hospice	F	Yes	Yes
HI	Person cared for in	Hospice	F	Yes	Yes
NO	Person cared for in	Hospice	F	Yes	Yes
SS	Person cared for in	Hospice	F	Yes	Yes
KK	Person cared for in	Hospice	M	Yes	Yes
JT	Person cared for in	Hospice	M	Yes	No
JT	Person cared for in	Hospice	M	Yes	Yes
RC	Person cared for in	Hospice	F	Yes	No
WY	Person cared for in	Hospice	M	Yes	Yes
AK	Person cared for in	Hospice	F	Yes	No
BR	Person cared for in	Hospital and Hospice	F	Yes	No
YA	Person cared for in	Hospice	F	Yes	Yes
CL	Person cared for in	Hospice	F	Yes	Yes
BE	Person cared for in	Hospice	M	Yes	No
GB	Person cared for in	Hospice	F	Yes	Yes
CJ	Person cared for in	Hospice, Community, Hospital	F	Yes	Yes
TT	Person cared for in	Hospice	M	Yes	Yes
CA	Person cared for in	Community	M	Yes	Yes
EA	Person cared for in	Community and Hospice	F	Yes	Yes
WA	Person cared for in	Community	M	Yes	No
AC	Person cared for in	Community	F	No	Yes
FF	Person cared for in	Community	F	Yes	No
UZ	Person cared for in	Community	M	Yes	No
UA	Person cared for in	Community	F	Yes	No
LV	Person cared for in	Community	F	Yes	No
KU	Person cared for in	Community	M	Yes	No
DB	Person cared for in	Community	F	No	Yes
JA	Person cared for in	Community	M	Yes	No
TA	Person cared for in	Community	M	Yes	Yes
BA	Person cared for in	Community	F	Yes	Yes
HL	Person cared for in	Community	M	Yes	No
VF	Person cared for in	Hospital	M	Yes	Yes
IB	Person cared for in	Hospital	F	No	Yes
VC	Person cared for in	Hospital	M	Yes	No
HA	Relative	Community	M	Yes	Yes
ZB	Relative	Community	M	No	Yes
A	Relative	Community	F	Yes	Yes
YS	Relative	Hospice	F	Yes	Yes
RF	Relative	Hospice	F	Yes	Yes
LK	Relative	Hospice	F	No	Yes
EF	Relative	Hospice	F	No	Yes
EG	Lead Nurse	Hospice	F	Yes	Yes
RU	Sister	Hospice	F	Yes	Yes

Identity	Role	Location	Gender	Observed	Interviewed
KM	Jn Sister	Hospice	F	Yes	Yes
HK	Jn Sister	Hospice	F	Yes	Yes
CD	Staff Nurse	Hospice	F	Yes	Yes
BD	Staff Nurse	Hospice	F	Yes	Yes
VB	Staff Nurse	Hospice	F	Yes	Yes
JC	Staff Nurse	Hospice	F	Yes	Yes
EM	Staff Nurse	Hospice	F	Yes	Yes
JS	Staff Nurse	Hospice	F	Yes	Yes
FH	Staff Nurse	Hospice	F	Yes	Yes
RB	Staff Nurse	Hospice	F	Yes	Yes
DF	Health Care Support Worker	Hospice	F	Yes	Yes
ER	Health Care Support Worker	Hospice	F	Yes	Yes
PD	Health Care Support Worker	Hospice	F	Yes	No
MJ	Health Care Support Worker	Hospice	F	Yes	Yes
NP	Health Care Support Worker	Hospice	F	Yes	Yes
OP	Student Nurse	Hospice	F	Yes	no
RD	Student Nurse	Hospice	F	Yes	No
UC	Student Nurse	Hospice	F	Yes	No
GA	Student Nurse	Hospice	F	Yes	Yes
AA	Jn Sister	Day Care	F	Yes	Yes
AZ	Activities Coordinator	Day Care	F	Yes	Yes
KL	Consultant	Hospice, Community, Hospital	F	Yes	Yes
IS	Consultant	Hospice, Community, Hospital	M	Yes	Yes
HN	Doctor	Hospice	F	Yes	Yes
JK	Doctor	Hospice	F	Yes	Yes
VA	Doctor	Hospice	M	Yes	Yes
CS	Team Leader	Hospital and Community Team	F	Yes	Yes
RT	Sister	Community Team	F	Yes	Yes
JL	Sister	Community Team	F	Yes	Yes
DC	Sister	Community Team	F	Yes	Yes
DA	Sister	Community Team	F	Yes	Yes
PW	Sister	Community Team	F	Yes	Yes
LN	Sister	Hospital Team	F	Yes	Yes
DE	Social Worker	Hospice and Community	F	Yes	Yes
TV	Social Worker	Hospice and Community	F	Yes	Yes
LD	Therapy Team	Hospice and Community	F	Yes	Yes
ME	Therapy Team	Hospice and Community	F	Yes	Yes
YD	Volunteer Coordinator	Hospice	F	Yes	Yes
QW	Administration	Hospice	F	Yes	No
TD	Administration	Hospice	F	Yes	Yes
UL	Administration	Hospice	F	Yes	Yes
QA	Administration	Hospice	F	Yes	Yes
HA	Volunteer	Hospice	F	Yes	Yes
UB	Volunteer	Hospice	F	Yes	Yes
KB	Chaplain	Hospital and Hospice	M	Yes	Yes
RA	Surgeon	Hospital	F	Yes	Yes

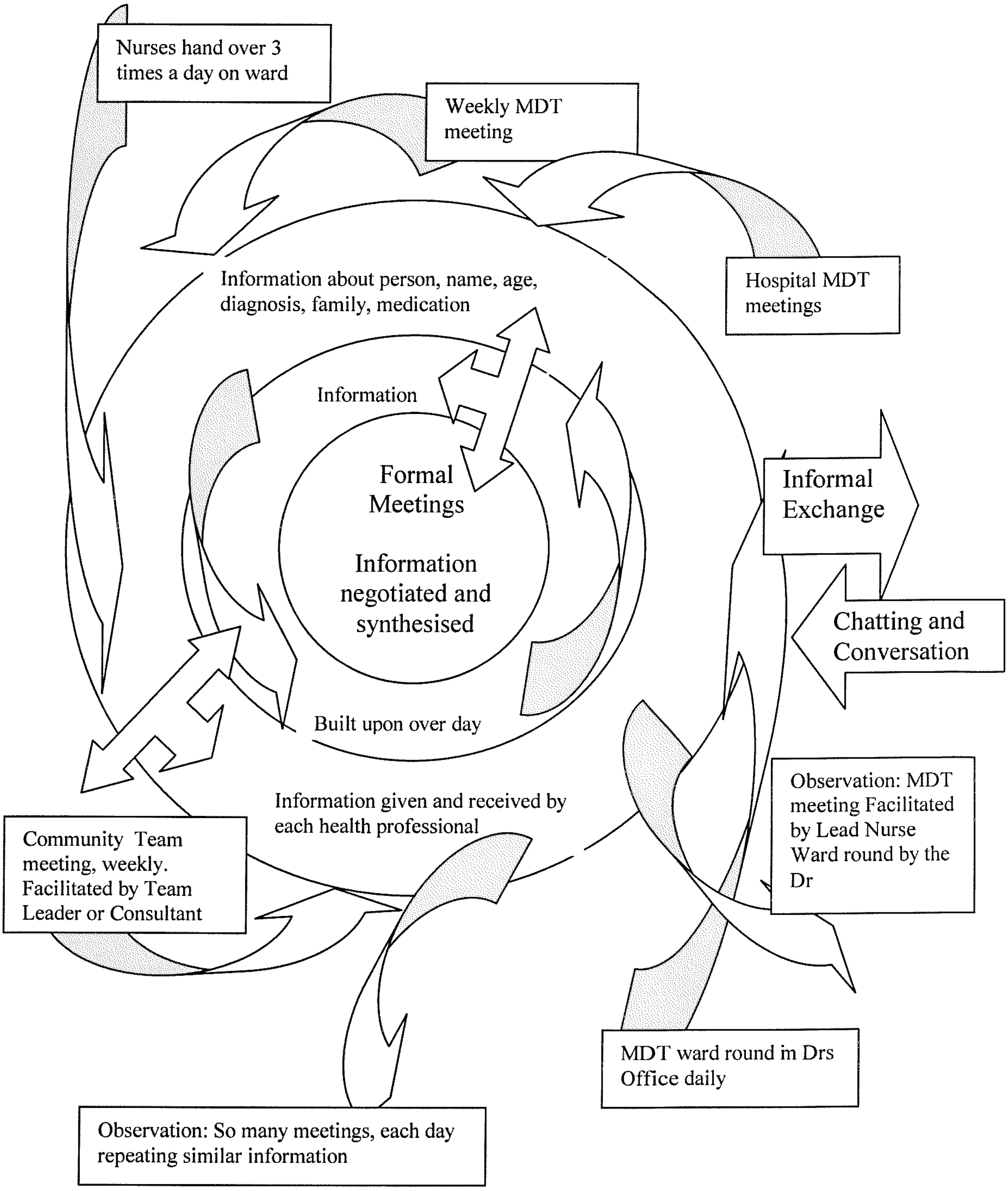
Identity	**Role**	**Location**	**Gender**	**Observed**	**Interviewed**
QZ	Intensive Home Support Service	Community	F	Yes	Yes
BT	Oncologist	Hospital	M	Yes	Yes
YE	Oncologist	Hospital	F	Yes	No
II	Trustee	Hospice	M	Yes	No
QQ	Trustee	Hospice	M	Yes	No
RP	PR/fundraising	Hospice	M	Yes	Yes
WB	Trustee	Hospice	M	Yes	Yes

Chaffinch Palliative Care Services
Organisational chart- position within Chaffinch NHS Trust

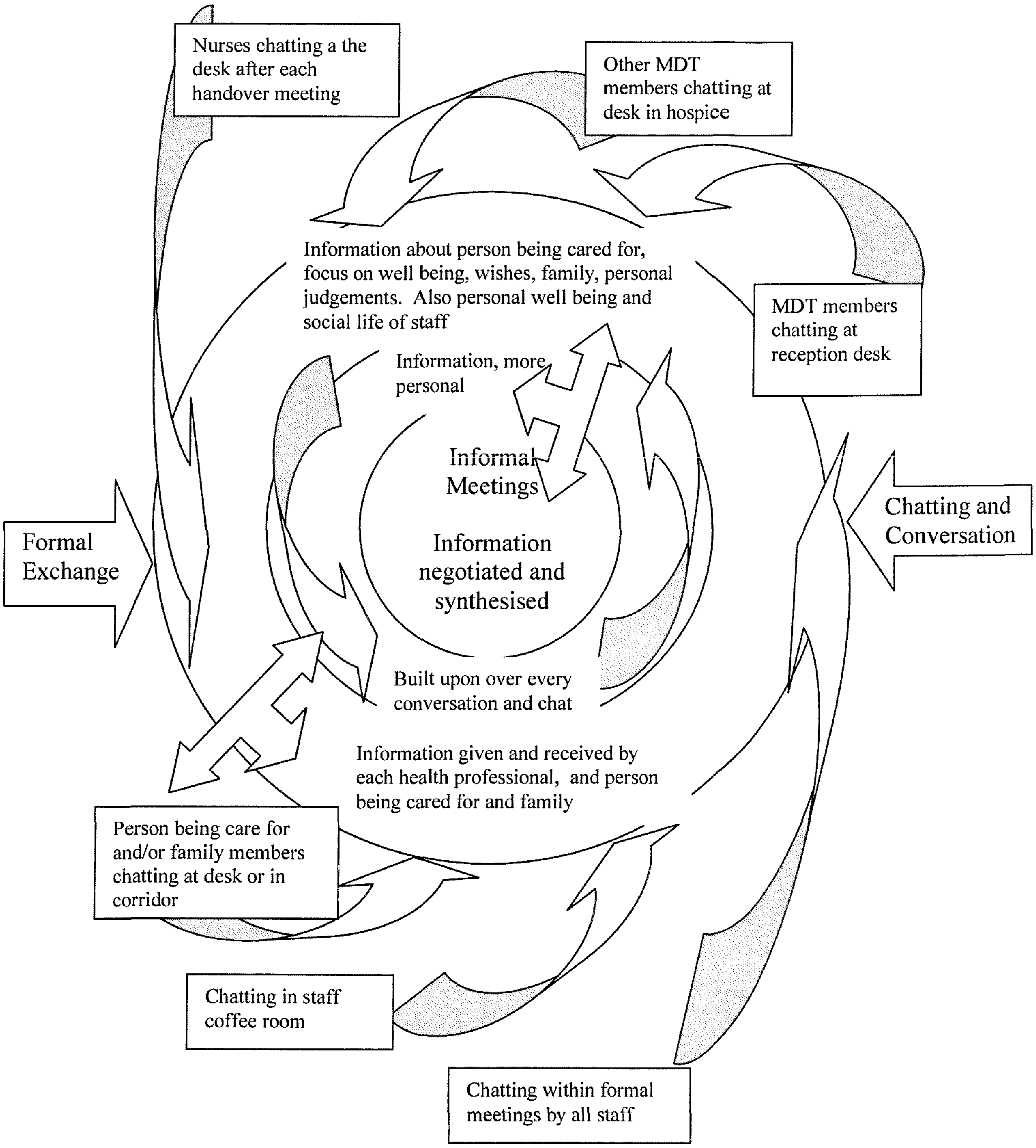


Appendix 6 : Analytical process

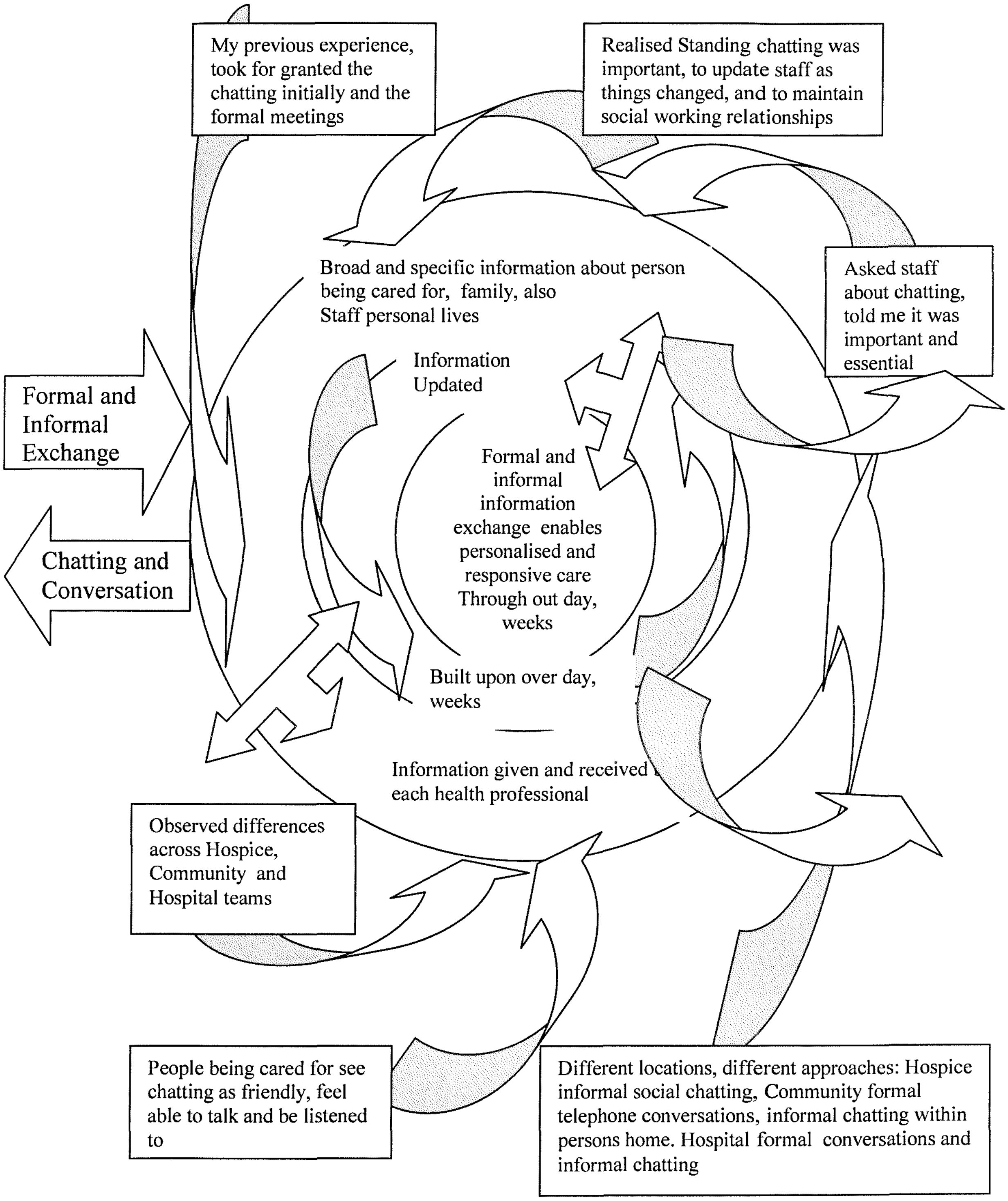
Hermeneutic Analysis of Information Exchange 1



Hermeneutic Analysis of Information Exchange 2



Hermeneutic Analysis of Information Exchange 3



References

Adams R (1998) Social Work Process in Adams R, Dominelli L and Payne M Eds (1998) *Social Work: Themes , Issues and Critical Debates* Ebbw Vale Palgrave

Adams R, Dominelli L and Payne M (2002) *Critical Practice in Social Work* Ebbw Vale Palgrave

Addington-Hall J and Altman D (2000) Which Terminally Ill Cancer Patients in the United Kingdon Receive Care From Community Specialist Palliative Care Nurses? *Journal of Advanced Nursing* vol. 32 no.4 p 799-806

Addington-Hall J, Altman D and McCarthy M (1998) Which Terminally Ill Cancer Patients Receive Hospice In-Patient Care? *Social Science and Medicine* vol.46 no.8 p1011-1016

Addington-Hall J, McCarthy M (1995) Dying From Cancer: Results of a National Population-Based Investigation *Palliative Medicine* vol.9 p 295-305

Ahmedzai S (1993) The Medicalisation of Dying:A doctors View In Clark D (Ed) *The Future for Palliative Care: Issues for Policy and Practice* Buckingham Open University Press

Ajemian I (1993) The Interdisciplinary Team IN Doyle D, Hanks G and MacDonald N Eds (1993) *Oxford Textbook of Palliative Medicine* Oxford Oxford Medical publications

Allmark P (1998) Is caring a Virtue? *Journal of Advanced Nursing* vol 28 no.3 p 466-472

Aranda S (1997) The Nurse as Coach in Care of the Dying *Contemporary Nurse* vol. 6 Issue 3 / 4 p117-122

Aranda S (1998) Palliative Care Principles : Masking the Complexity of Practice In Parker J and Aranda S (1998) *Palliative Care: Explorations and Challenges* London Maclennan and Petty

Aranda S and Street A (1999) Being Authentic and Being a Chameleon: Nurse-Patient Interaction Revisited *Nursing Inquiry* vol. 6 p75-82

Argrys C and Schon D (1978) *Organisational Learning: A Theory in Action Perspective.* Addison Wesley

Armstrong D (1983) The Fabrication of Nurse-Patient Relationships. *Social Science & Medicine.* 17(8):457-60

Armstrong D (2001) The Problem of the Whole Person in Holistic Medicine In Davey B, Gray A and Seale C (Eds) (2001)*Health and Disease: A Reader 3rd Ed* Buckingham Open University Press

Bailey K and Wilkinson S (1998) Patients' Views on Nurses' Communication Skills : A pilot Study *International Journal of Palliative Nursing* vol.4 no.6 p300-305

Banks S (2001) *Ethics and Values in Social Work 2nd Ed* Basingstoke Palgrave

BASW (1996) *The Code of Ethics for Social Work* Birmingham. British Association of Social Workers

Beardshaw V and Robinson R (1990) *New for Old? Prospects for nursing in the 1990's*. Kings Fund Institute. London

Beaver K, Luker K and Woods S (1999) The Vies of Terminally Ill People and Lay Carers on Primary Care Services *International Journal of Palliative Nursing* vol. 5 no. 6 p266-274

Benner P (1984) *From Novice to Expert: Excellence and Power in Clinical Nursing.* Menlo Park Addison Wesley

Benner P (1994) Caring as a Way of Knowing In Phillips S And Benner P (Eds) 1994) *The Crisis of Care: Affirming and Restoring Caring Practices in the Helping Professions* Washington Georgetown University Press

Benner P and Tanner C (1987) Clinical Judgement: How Expert Nurses Use Intuition *American Journal of Nursing* vol 87 p23-43

Benner P and Wruble J (1982) Skilled Clinical Knowledge: The Value of Perceptual Awareness *Nurse Educator* vol 6 p11-17

Benner P and Wruble J (1989) *The Primacy of Caring: Stress and Coping in Health and Illness* California Addison Wesley Longman

Bishop A and Scudder J (1985) *Caring, Curing, Coping: Nurse, Physician, Patient Relationships* University of Alabama Press

Biswas B (1993) The Medicalisation of Dying: The Nurses View In Clark D (Ed) *The Future for Palliative Care: Issues for Policy and Practice* Buckingham Open University Press

Botes A (2000) A Comparison Between the Ethics of Justice and the Ethics of Care *Journal of Advanced Nursing* vol. 32 no. 5 p 1071-1075

Brannen J (1988) The study of Sensitive subjects *Sociological Review* vol. 36 552-563

Brechin A, Brown H, Eby M Eds (2000) , *Critical Practice in Health and Social Care* London Sage

Brink Muinen A, Va Dulmen S, Messerli-Rohrback V and Bensing J (2002) Do Gender-dyads have different communication patterns? A comparative study in Western Europe general practices *Patient Education and Counselling* vol. 48 no.3 p253-264

Brkczynska G (1992) Caring – A Dying Art? In Jolley M and Brykczynska G (1992) *Nursing Care: The Challenge to Change* Edward Arnold London

Campbell A (1984) *Moderated Love: A Theology of Professional care* London. SPCK

Carper B (1978) Fundermental Patterns of Knowing in Nursing. Advances in *Nursing Science* vol.1 p13-23

Cartwright A (1991) The Relationship Between General Practitioners, Hospital Consultants and Community Nurses When caring For People in the Last Year of Their Lives *Family Practice* vol. 8 no. 4 p350-355

Charles C, Gafni A and Whelan T (2000) How to improve communication between doctors and patients *BMJ* vol. 320 p1220-1221

Cioffi J (2001) A study of the Use of Past Experiences in Clinical Decision Making in Emergency Situations *International Journal of Nursing Studies* Vol 38 p591-599

Clark D (1991) Contradictions in the Development of New Hospices: A Case Study *Social Science and Medicine* vol. 33. no. 9 p995-1004

Clark D (1993) Wither the Hospices In Clark D (Ed) *The Future for Palliative Care: Issues for Policy and Practice* Buckingham Open University Press

Clark D and Seymour J (1999) *Reflections on Palliative Care* Open University Press Buckingham

Clark D Ed (1993)*The Future of Palliative Care* Buckingham Open University Press

Clark D, Ingleton C Seymour J (2000) Support and Supervision in Palliative Care Research *Palliative Medicine* vol. 14 p441-446

Clark D, Malson H, Small N, Mallet K, Neale B and Heather P (1997) Half Full or Half Empty? The Impact of Health Reforms on Palliative Care Services in The UK . In Clark D, Hockley J and Ahmedzai S (Eds) (1997) *New Themes in Palliative Care* Buckingham Open University Press

Clark D, Neal Band Heather P (1995) Contracting for Palliative Care *Social Science and Medicine* vol. 40 no. 9 p1193-1202

Clark D, Seymour J, Douglas H, Bath P, Beech N, Corner J, Halliday D, Hughes P, Haviland J, Normand C, Marples R, Skilbeck J and Webb T (2002) Clinical Nurse

Specialists in Palliative Care. Part 2. Explaining Diversity in the Organization and Cost Macmillan Nursing Services *Palliative Medicine* vol.16 p375-385

Clarke D Malson H, Small N et al (1997) Half Full or Half Empty? The Impact of Health Reform on Palliative Care Services in the UK. IN Clarke D, Hockley J and Ahmedzai *New Themes in Palliative Care* Buckingham Open University Press

Clarke D, Hockley J and Ahmedzai S (Eds) (1997) *New Themes in Palliative Care* Buckingham Open University Press

Clarke D. Neale B and Heather P (1993) 'Contracting for Palliative Care' *Social Science and Medicine* vol 40. No 9 P1193-1202

Clarke J (1993) *A Crisis in Care? The Challenge to Social Work* Sage London

Clumpus L and Hill A (1999) Exploring the Views of Carers of Cancer Patients in an Inner City Locality *International Journal of Palliative Nursing* vol. 5 no.3 p 116-123

Cooper M C (1991) Principle-oriented Ethics and The Ethic of Care: A Creative Tension *Advanced Nursing Science* vol. 14 no. 2 p 22-32

Corner J (2001) *Between You And Me : Closing The Gap Between People And Healthcare* London The Nuffield Trust

Corner J and Dunlop R (1997) New Approaches to Care Clark D, Hockley J and Ahmedzai S (Eds) (1997) *New Themes in Palliative Care* Buckingham Open University Press

Coyle N (1997) Interdisciplinary Collaboration in Hospital Palliative Care: Chi,era or Goal? *Palliative Medicine* vol. 11 p265-266

Crowe Marie (1998) The Power of The Word: Some Post-Structural Considerations of Qualitative approaches in Nursing Research *Journal of Advanced Nursing* vol 28 no. 2 p339-344

Cumming J from the 1965 2nd Edition. Sheed and Ward Guildford

Davies C (1995) *Gender and the professional predicament in nursing.* Open University Press. Buckingham

Davies C (1995) Competence Versus Care? Gender And Caring Work Revisited *Acta Sociologica* vol.38 p17-31

Davis B and Oberle K (1990) Dimensions of the Supportive Role of the Nurse in Palliative Care *Oncology Nurse Forum* I vol. 17p87-94

De Raeve (1994) Ethical Issues in Palliative Care Research *Palliative Medicine* vol 8 p198-305

Delanty G (1997) *Social Science: Beyond Constructivism and Realism* Open University Press Buckingham

Denzin N (1989) *Interpretative Interactionism* Sage London

Denzin N and Lincoln Y (Eds)(1998) *Strategies of Qualitative Inquiry* Sage London

Department of Health (1995) *A Policy Framework for Commissioning Cancer Services.* A Report by the Expert Medical Advisory Group on Cancer to the Chief Medical Officers of England and Wales. DOH and Welsh office London

Department of Health (1997) *The New NHS: Modern and Dependable.* London. The Stationary Office

Department of Health (1998) *A First Class Service: Quality in the New NHS* Health Service Circular 1998/113

Department of Health (2000a) *The NHS Plan: A Plan For Investment A Plan For Reform.* Cm4818-I London The Stationary Office Ltd

Department of Health (2000b) *The NHS Cancer Plan: A Plan For Investment A Plan For Reform* London The Stationary Office Ltd

Department of Health (2002) *Shifting the Balance of Power* London The Stationary Office Ltd

Department of Health and Social Services (1987) HC (87) 4 (2) London. Department of Health

Department of Health and Social Services (1990) *The NHS and Community Care Act*

Dominelli L and Gollins T (1997) Men, Power and Caring Relationships *The Sociological Review* Oxford.

Donaghy K and Devlin B (2002) An Evaluation of Teamwork Within a Specialist Palliative Care Unit *International Journal of Palliative Nursing* vol 8 no 11 p518-525

Douglas C (1992) For All The Saints *British Medical Journal* vol.304 p 717

Doyle D, Hanks G and MacDonald N Eds (1993) *Oxford Textbook of Palliative Medicine* Oxford Oxford Medical publications

Du Boulay S (1984) *Cicely Saunders: The Founder of the Modern Hospice Movement* London Hodder and Stoughton

Dunlop RJ, Hockley J. (1998) Hospital-based palliative care teams: The hospital-hospice interface. (2nd. Edition) Oxford. Oxford University Press

Dunne J and Jenkins L (1991) Stress And Coping Strategies In Macmillan Nurses University of Stirling for Macmillan Cancer Relief

Dunne K and Sullivan K (2000) Family Experiences of Palliative Care in the Acute Hospital Setting *International Journal of Palliative Nursing* vol. 6 no. 4 p 170-178

Edwards S (2001) *Philosophy of Nursing* Ebbw Vale Palgrave

Ellershaw J (1995) Assessing the Effectiveness of a Hospital Palliative Care Team *Palliative Medicine* vol 9 p 145-152

Ellershaw J (1997) Developing an integrated care pathway for the dying patient *European Journal of Palliative Care* vol.4 no. 6 p203-207

Ellis K (1993) *Squaring the Circle: User Participation in Needs Assessment* Joseph Rowntree Foundation in association with Community Care York

Ellis Carolyn and Bochner Arthur P (2000) Autoethnography, Personal Narrative, Reflexivity. In Denzin Norman K and Lincoln Yvonne S (eds) (2000) *Handbook of Qualitative Research* (2nd Edition) London. Sage

Eraut M (1994) *Developing Professional Knowledge and Competence* London Falmer Press

Erikson Katie (1997) Understanding the World of The Patient, The Suffering Human Being: The New Clinical Paradigm From Nursing to Caring *Advanced Practice*

Eriksson Katie, Lindström Unni (1997) Abduction-A way To Deeper Understanding of The World of Caring *Scandinavian Journal of Caring Sciences* vol.11 no.4 p195-198

Evans J (2002) Cautious Care Givers: Gender Stereotypes and The Sexualisation of Men Nurses's Touch *Journal of Advances Nursing* vol 40 no. 4 p441-448

Fagerström Lisbeth, Eriksson Katie, Engberg Ingegerd Bergbom (1998) The Patient's Perceived Caring Needs as a Message of Suffering *Journal of Advanced Nursing* vol.28 no.5 p978-987

Fallon M and Dunlop R (2002) Palliative Care or is it? *Palliative Medicine* vol 16 p1-3

Fawcett B, Featherstone B, Fook J and Rossiter A (2000) *Practice + Research in Social Work: Postmodern Feminist Perspectives* Routledge London

Field D (1994). Palliative medicine and the medicalization of death. *European Journal of Cancer Care*. vol. 3no. 2 p58-62

Field D (1989) *Nursing the Dying* London Tavistock/Routledge

Field D (2000) *What Do We Mean By Psychosocial* Briefing No.4 London National Council of Hospices and Specialist Palliative Care Services

Field D and Addington-Hall J (1999) Extending Specialist Palliative Care to All? *Social Science and Medicine* vol. 48. p1271-1280

Field D and Copp G (1999) Communication and Awareness About Dying in the 1990's *Palliative Medicine* vol. 13 p459-486

Field D, Douglas C, Jagger C and Dand P (1995) Terminal Illness: Views of patients and their lay carers *Palliative Medicine* vol 9 p45-54

Finch J (1993) 'Its great to have someone to talk to':Ethics and Politics of Interviewing Women In: Hammersly M (1993) *Social Research: Philosophy, Politics and Practice* Sage. London

Finch J (1993) "It's great to have someone to Talk to: Ethics and the Politics of Interviewing Women In Hammersley M Ed (1993) *Social Research: Philosophy, Politics and Practice London Sage Publications*

Fine Michelle (1998) Working the Hyphens: Reinventing Self and Other in Qualitative Research In Denzin Norman and Lincoln Yvonne (eds) (1998) *The Landscape of Qualitative Research* London Sage.

Fine Michelle, Weis Lois, Weseen Susan and Wong Loomun (2000) For Whom? Qualitative Research, Representation and Social Responsibilities. In Denzin Norman K and Lincoln Yvonne S (eds) (2000) *Handbook of Qualitative Research* (2nd Edition) London. Sage

Firth S (2001) *Wider Horisons: Care of the Dying in a Multicultural Society* London National Council of Hospices and Specialist Palliative Care Services

Fish D (1998) *Appreciating Practice in the Caring Professions: Refocusing Professional Development and Practice Research* Oxford Butterworth Heinemann

Flax J (1990) Postmodernism and Gender Relations in Feminist Theory : In Nicholson L (Ed) (1990) *Feminism/Postmodernism* London Routledge

Flax J (1992) Beyond Equality: Gender Justice and Difference In Bock G and James S (eds) (1992) *Beyond Equality and Difference: Citiszenship, feminist Politics and Female Subjectivity* London . Routledge

Fontana A and Frey J (1998) Interviewing: The Art of Science In: Denzin N and

Fook J (2000) Deconstructing and Reconstructing Professional Expertise in Fawcett B, Featherstone B, Fook J and Rossiter A (2000) *Practice and Research in Social Work* London Routledge

Foucault M (1972/ 1989) *The Archaeology of Knowledge* Publishes by London Routledge

Foucault M (1973/1989) *The Birth of the Clinic* Tavistock Publications Limited

Foucault M (1975/1991) *Discipline and Punish: The Birth of the Prison.* Published by Penguin

Foucault M (1977) *The Order of Things* Tavistock Publications ltd

Foucault M (1980) *Power/Knowledge : Selected Interviews and Other Writing 1972-1977* Gorden C (Ed) Hemel Hempstead Harvester Wheatsheaf

Fox N (1995) Post-modern Perspectives on Care: The Vigil and The Gift *Critical Social Policy* vol 15 p 107-125

Fox N (1999) *Beyond Health: Postmodernism and Embodiment* Free Association Books. London

Franks P, Salisbury C, Bosanquet N, Wilkinson E, Kite S, Naysmith A, Higginson I (2000) The Level of Need For Palliative Care: A Systematic Review of The Literature *Palliative Medicine* vol 14 p 93-104

Fredriksson Lennart (1999) Modes of Relating in a Caring Conversation: A Research Synthesis on Presence, Touch and Listening *Journal of Advanced Nursing* vol. 30 no.

Froggatt K (2001) Palliative Care and Nursing Homes: Where Next? *Palliative Medicine* vol. 15 p42-48

Froggatt K (1998) The Place of Metaphor and Language in Exploring Nurses' Emotional Work *Journal of Advanced Nursing* vol. 28 (2) p332-228

Gadamer H-G (1975) *Truth and Method* (2nd Ed) New York Continuum

Gastmans C (2002) A Fundamental Ethical Approach to Nursing: Some Proposals for Ethics Education *Nursing Ethics* vol 9 no. 5 p494-507

Geertz C (1973) *The Interpretation of Cultures: Selected Essays* London Fontana

Gelsthorpe L(1992) Response to Martyn Hammersley's Paper 'On Feminist Methodology' *Sociology* vol26. Pp213-218

George V and Miller S Eds (1995) *Social Policy Towards 2000: Squaring the Welfare Circle.* London Routledge

Gilligan C (1982) *In A Different Voice: Psychological Theory and Women's Development* London Harvard University Press

Glaser B and Strauss A (1965) *Awareness of Dying* Chicago Aldine Publishing Company

GMC (2001) *Guidance for Good Practice* General Medical Council http://www.gmc-uk.org/standards/default.htm

Gott M and Small N (2000) *User involvement in Cancer Care. Exclusion and Empowerment.* Bristol. The Policy Press

Gould C (Ed) (1997) *Gender: Key Concepts in Critical Theory* New Jersey Humanities Press

Graham H (1991) The Concept of Caring in Feminist Research: The Case of Domestic Service *Sociology vol.25 no.1 p61-78*

Graham H (1983) A Labour of Love in Finch J and Groves D (1983) *A Labour of Love: Women, Work and Caring*

Grande G, Addington-Hall J and Todd C (1998) Places of Death and Access to Home Care Services Are Certain Patient Groups At a Disadvantage? *Social Science and Medicine* vol. 47 no. 5 p565-579

Graves Benjamin (1998) Political Discourse – Theories of Colonialism and

Griffiths R (1988) *Community Care: Agenda for Action London* HMSO

Guba E and Lincoln Y (1989) *Fourth Generation Evaluation* Sage London

Habermas J (1974) *Theory and Practice* London Heinemann

Habermas J (1984) *Theory of Communicative Action Volume One: Reason and the Rationalisation of Society* Translated by Thomas McCarthy Boston Beacon Press

Hagell E (1989) Nursing Knowledge: Womens Knowledge. A Sociological Perspective *Journal of Advanced Nursing* vol 14 p226-233

Hammersley (ed) (1993) *Social Research: Philosophy. Politics and Practice* Sage London

Hammersley and Atkinson (1998) Ethnography and Participant Observation In:

Hammersley M (1992) On Feminist Methodology *Sociology*_vol26. Pp187-206

Hammersley M (1992) *Whats Wrong With Ethnography* Routledge London

Hammersley M and Atkinson P (1995) *Ethnography: Principles in Practice* 2nd Ed. Routledge London

Haroon Iqbal H, Field D, Parker H and Iqbal Z (1995)The Absent Minority: Access and use of Palliative Care Services by Black and Minority Ethnic Groups in Leicester. In Richardson A and Wilson-Barnett J Eds(1995) *Nursing Research in Cancer Care* London Scutari

Harvath T, Archbold P, Stweart B, Gadow S, Kirsching J and Miller L (1994) Establishing a Partnership with Family carers: Local and Cosmopolitan Knowledge *Journal of Gerontological Nursing* vol. 20 p29-35

Heath H (1998) Reflection and Patterns of Knowing in Nursing *Journal of Advanced Nursing* vol 27 p1054-1059

Heaven Cathy M , Maguire Peter (1998) The Relationship Between Patients' Concerns and Psychological Distress In A Hospice Setting *Psycho-Oncology* vol.7 p502-507

Heiddeger M (1962) *Being and Time* New York Harper Row

Hekman S (1990) *Gender and Knowledge : Elements of Postmodern Feminism* Cornwall Polity Press

Hekman S (1999) *The Future of Differences : Truth and Method in Feminist Theory* Cornwall Polity Press

Henk ten Have, Clark D (Editor) (2002) *Ethics of Palliative Care: European Perspectives* Buckingham Open University Press

Held V (Ed) (1995) Justice and Care: Essential Readings in Feminist Ethics Oxford Westview Press

Herbig B, Bussing A and Ewert T (2001) The Role of Tacit Knowledge in the Work Context of Nursing *Journal of Advanced Nursing* vol 34 no. 5 p687-695

Higginson I (1997) *Palliative and Terminal Care: Health Care Needs Assessment* Oxford Radcliffe Medical Press

Higginson I, Hearn L (1998) Do Specialist Palliative Care Teams Improve Outcomes For Cancer patients? A Systematic Literature Review *Palliative Medicine* vol. 12 no 5 p317-325

Higgs J and Titchan A (2001) *Practice Knowledge and Expertise in The Health Professions* Oxford Butterworth-Heineman

Higgs J, Titchen A and Neville V (2001) Professional Practice and Knowledge in Higgs J and Titchan A (2001) *Practice Knowledge and Expertise in The Health Professions* Oxford Butterworth-Heineman

Hill A (1998) Multiprofessional Teamwork in Hospital Palliative care Teams *International Journal of Palliative Nursing* vol 4 no.5 p214-221

Hill D and Penso D (1995) Opening Doors: Improving Access to Hospice and Specialist Palliative Care Services by Members of the Black and Ethnic Minority Communities London National Council of Hospices and Specialist Palliative Care Services

Hugman R, Peelo M and Soothill K (1997) *Concepts of Care: Developments in Health and Social Welfare* London. Arnold

Jaggar A (1995) Caring as a Feminist Practice of Moral Reason In Held V (ed) (1995) *Justice and Care: Essential readings in Feminist Ethics* Colorado Westview Press

James N (1989) Emotional Labour: Skill and Work in the Societal Regulation of Feelings *Sociological Review* Vol. 37 p15-42

James N (1992) Care = Organisation + Physical Labour + Emotional Labour *Sociology of Health and Medicine* vol. 14 no 4

James N and Field D (1992) The Routinization of Hospice: Charisma and Bureacratization *Social Science and Medicine* vol. 34 no.12 p1363-1375

James S (1992) The Good-Enough Citizen: Citizenship and Independence In Bock G and James S (1992) *Beyond Equality and Difference* London Routledge

James V (1986) *Care and Work in Nursing the Dying: A Participant Study in a Continuing Care Unit.* Unpublished PhD Thesis Aberdeen University

James V and Field D (1996) Who has The power? Some problems and issues affecting the nursing care of dying patients *European Journal of Cancer Care* vol 5 p 73-80

Jarrett N and Payne S (1999) 'Someone to talk to' and 'Pain control': What People Expect From a Specialist Palliative Care Team *Palliative Medicine* vol. 13 p139-144

Johnston G and Abraham C (2000) Managing Awareness: Negotiating and Coping with A terminal Prognosis *International Journal of Palliative Nursing* vol. 6 no. 10 p485-494

Jones A (1999) 'A Heavy Blessed Experience': A Psychoanalytic Study of Community Macmillan Nurses and Their Roles in Serious Illness and Palliative Care *Journal of Advanced Nursing* vol. 30 no. 6 p1297-1303

Jones L C (1994) The Social Context of Health and Health Work. Macmillan London

Jordan S and Hughes D (1998) Using bioscience knowledge in Nursing: Actions, Interactions and Reactions *Journal of Advanced Nursing* vol 27 p1060-1068

Jupp V and Norris C (1993) Traditions in documentary analysis In Hammersley M (1993) *Social Research: Philosophy, Politics and Practices* Sage London

Kane R, Wales , Bernstein L, Leibowits, Kaplan S (1984) A Random Controlled Trial of Hospice Care Lancet i 890-4

Kearney M (1996) *Mortally Wounded: Stories of Soul Pain, Death and Healing* Cork Marimo

Kearney M (2000) *A Place of Healing: Working with Suffering in Living and Dying* Oxford. Oxford University press

Kennedy C (1998) Ways of Knowing in Palliative Nursing *International Journal of Palliative Nursing* vol 4 no 5 p240-245

Kennedy C (2002) The Work of District Nurses: First Assessment Visits Journal of Advanced Nursing vol 40 no 6 p710-720

Kite K (1999b) Anonymising the Subject: What Are the Implications *Nurse Researcher* vol.6 no.3 p77-84

Kite K. (1999a) Participant Observation, peripheral Observation or Apart-icipant Observation? *Nurse Researcher* 7(1), 44-55

Koch T (1994) Beyond Mesurement: Fourth Generation Evaluation in Nursing *Journal of Advanced Nursing* vol. 20 p1148-1155

Koehn D (1998) *Rethinking Feminist Ethics: Care, Trust and Empathy* London Routledge

Kushe H (1997) *Caring: Nurse, Women And Ethics* Blackwell Publishers Cornwell

Lawler J (1991) *Behind the Screens: Nursing, Somology and the Problem of the Body* London Livingston-Churchill

Lawler J Ed (1997) *The Body in Nursing* Singapore Churchill Livingston

Lawton J (1998) Contemporary Hospice Care: The Sequestration of the Unbounded body and 'Dirty Dying' *Sociology of Health and Medicine* vol. 20 no.2 p121-143

Lee, R.M. (1993) *Doing Research on Sensitive Topics*. London. Sage Publications Ltd

Leininger M (1986) Care Facilitation and Resistance Factors in the Culture of Nursing *Topics in Clinical Nursing* Vl. 8 no.2 p 3

Leininger M (1988) Leiningers Theory of Nursing: Cultural Care Diversity and Universality *Nursing Science Quarterly* vol. 1 p152-160

Leininger M (1997) Transcultural spirituality: a comparative care and health focus. In Roach S (1997) Caring from the heart: the convergence of caring and spirituality

Leininger M (Ed) (1988) *Caring: An Essential Human Need* Detroit Wayne State University Press

Levasseur J and Vance D (1993) Doctors, Nurses and Empathy IN Spiro H, Mccrea Curnen M, Peshel E and St James D (1993) *Empathy and The Practice of Medicine* London Yale University Press

Lincoln Y and Guba E (2000) Paradigmatic Controversies, Contradictions and Emerging Confluences In Denzin N and Lincoln Y Eds (2000) *Handbook of Qualitative Research 2nd Ed* London Sage

Lincoln Y Eds (1998) *Collecting and Interpreting Qualitative Materials* Sage London

Lister R (1997) Citizenship: Towards a Feminist Synthesis *Feminist Review* no 57 Autumn 1997 p28-48

Luker K, Austin L, Caress A , Hallett C (2000) The Importance of Knowing the Patient: Community Nurses Construction of Quality in Providing Palliative Care *Journal of Advanced Nursing* vol 31 p775-782

MacDougall G (1997) Caring – A Masculine Perspective *Journal of Advanced Nursing* vol. 25 p809-813

MacIntyre A (1998) The Nature of Virtues In Sterba J (Ed) (1998) *Ethics: The Big Questions* Oxford Blackwell Publishers

MacLeod R (2000) Learning to Care: A Medical Perspective *Palliative Medicine* vol. 14 p209-216

MacLeod R (2001) On Reflection : Doctors Learning to Care For People Who Are Dying *Social Science and Medicine* vol. 52 p1719-1727

Martin Geoffrey W (1998) Empowerment of Dying Patients: The Strategies and Barriers to Patient Autonomy *Journal of Advanced Nursing* vol.28 no.4 p737-744

May Carl (1995) 'To call it work would somehow demean it': the social construction of talk in the care of terminally ill patients *Journal of Advanced* Nursing vol. 22 p 556-561.

May T (1996) *Social Research: Issues, Methods and Process* Open University Press Buckingham

Mayall B and Oliver S Eds (1999) *Critical issues in social research: Power and Prejudice* Open University Press Buckingham

Mayeroff M (1971) *On Caring* New York Harper and Row Publishers

McLoughlin P (2002) Community Specialist Palliative care: Experiences of Paitent and Carers *International Journal of Palliative Nursing* vol. 8 no 7 p344-353

McNamara B (2001) *Death, Dying and Care* Buckingham Open University Press

McNamara B, Waddell C and Colvin M (1994) The institutionalisation of a good death *Social Science and Medicine* Vol. 39 No. 11 P1501-1508

McNay L (1992) *Foucault and Feminism* Polity Press Cornwall

McQuillan R, Finlay I, Roberts, Branch, Forbes K, Spencer M (1996) The Provision of Hospital Palliative Care in a Teaching Hospital and Subsequent Evaluation of That Service *Palliative Medicine* vol. 10 p231-239

McWilliam C, Burdock J and Wamsley J (1993) The Challenging Experience of Palliative Care Support-Team Nursing *Oncology Nurse Forum* vol. 20 no. 5 p779-785

Menzies E (1967) *The Functioning Of Social Systems as a Defence Against Anxiety* Tavistock Pamphlet No 3. London Tavistock Institute

Miers M (1999) Healthcare Teams in The Communtiy: In Wilkinson G and Miers M Eds (1999) *Power and Nursing Practice* Malaysia Macmillan

Miller Margaret and Douglas Margaret (1998) Presencing: Nurses commitment to Caring for Dying Persons *International Journal of Human Caring* vol. 2 no.3 p24-31

Morris S, Thomas C (2002) The Needs to Know: Informal Carers and Information *European Journal of Cancer Care* vol 11 p183-187

Morrison P and Burnard P (1997) *Caring and Communicating: The interpersonal Relationship in Nursing* (2nd Ed) Hong Kong Macmillan

Morse J (1990) Concepts of caring and Caring as a Concept *Advanced Nursing Science* vol. 13 no. 1 p1-14

Morse Janice M, Bottorff Joan, Anderson Gwen, O'Brien Beverly, Solberg Shirley (1992) Beyong Empathy: Expanding Expressions of *Caring Journal of advanced Nursing* vol.17 p809-821

Mowforth G (1999) Power, Gender and Nursing Work: in Wilkinson G and Miers M Eds (1999) *Power and Nursing Practice* Malaysia Macmillan

National Council of Hospice and Specialist Palliative Care Services (2002a) Palliative Care for non-cancer: developing a national policy *Information Exchange* No 36 September 2002 London

National Council of Hospice and Specialist Palliative Care Services (2002b) *Definitions of Supportive and Palliative Care* Briefing Number 11 London NCHSPCS

National Council of Hospice and Specialist Palliative Care Services (2000) The Palliative Care Survey August 2000 London NCHSPCS

National Council of Hospice and Specialist Palliative Care Services (2000) *Our lives, not our Illness* Briefing No. 6 London NCHSPCS

National Council of Hospice and Specialist Palliative Care Services (1999) *Palliative Care 2000: Commissioning Through Partnership* London NCHSPCS

National Council of Hospice and Specialist Palliative Care Services (1995) *Specialist Palliative Care: a Statement of definitions* London NCHSPCS

National Council of Hospice and Specialist Palliative Care Services (1993) *Needs Assessment for Hospice and Specialist Palliative Care Services: From Philosophy to Contracts Occasional Paper 4.* London NCHSPCS

NCHSPCS (1993) Needs Assessment for Hospice and Specialist Palliative Care Services: from Philosophy to Contracts. Occasional paper 4. National Council for Specialist Palliative Care Services. London

NCHSPCS (1995) Opening Doors: Improving Access to Hospice and specialist palliative Care Services by Members of the Black and Ethnic Minority Communities. Occasional Paper 7. National Council for Hospice and Specialist Palliative Care Services. London

NCHSPCS (1997) Dilemmas and Directions The Future of Specialist Palliative Care. Occasional paper 11. National Council for Hospice and Specialist Palliative Care Services. London

NCHSPCS (1998) Reaching Out: Specialist Palliative Care for Adults with Non-Malignant Diseases. National Council for Hospice and Specialist Palliative Care Services. London

NCHSPCS (1999) *Palliative Care 2000: Commissioning Through Partnership* National Council for Hospice and Specialist Palliative Care services. London

NCHSPCS (2002) Shifting The Balance of Power: What Will The NHS Reforms Mean For Palliative Care? *Briefing no 10* National Council for Hospice and Specialist Palliative Care services. London

NHS Executive (2000) *Manual of Cancer Services Standards* London The Stationary Office Ltd

NICE (2004) *Improving Supportive and Palliative Care for Adults with Cancer Manual* London National Institute for Clinical Excellence

Nias Jennifer (1993) Changing Times, Changing Identities: Grieving for a Lost Self In Burgess R.G. (ed) (1993) *Educational Research and Evaluation: For Policy and Practice*. London. The Falmer Press

Noddings N (1984) *Caring : A Feminist Approach To Ethics And Moral Education* University of California Press Berkley

Oakley A (1999) People's ways of knowing: gender and methodology In Hood S,

Oliviere D (2001) The Social Worker in Palliative Care – The 'Eccentric' Role *Progress in Palliative Care* vol.9 no. 6 p237-240

Oliviere D, Hargreaves R Munroe B (1998) Good Practice in Palliative Care: A Psychosocial Perspective Aldershot Ashgate Arena

Orme J (1997) The Case For Research Into Practice In McKenzie G, Powell J and Usher R Eds (1997) *Understanding Social Research: Perspectives on Methodology and Practice.* The Falmer Press

Orme J (2001) *Gender and Community Care: Social Work and Social Care Perspectives* Basingstoke Palgrave

Orme J (2002) Social Work: Gender, Care and Justice *British Journal of Social Work* vol. 32 p799-814

Paley J (2000) Heidegger and the Ethics of Care *Nursing Philosophy* Vol 1 P64-75

Parker J (1999) Patient of Customer? : Caring Practices in Nursing and The Global Supermarket of Care *Collegian* vol.6 no. 1 p17-23

Parkes C. M (1979) Terminal Care: Evaluation of an inpatient service at St Christopher's Hospice , Part 1. Views of surviving spouses *Post Graduate Medical Journal* vol.55 p517-22

Parkes C.M. and Parkes J (1984) 'Hospice' versus 'Hospital' Care: Re-Evaluation after 10yrs as seen by surviving spouses *Post Graduate Medical Journal* vol.60 p120-124

Parle M, Maguire P, Heaven C (1997) The Development of a Training Model to Improve Health Professionals' Skills, Self-Efficacy and Outcome Expectancies When Communicating With Cancer Patients *Social Science and Medicine* vol. 44 no. 2 p231-240

Pascall G (1997) *Social Policy a New Feminist Analysis* London. Routledge

Patemen C (1992) Equality, Difference, Subordination: The Politics of Motherhood and Women's Citizenship In Bock G and James S (1992) *Beyond Equality and Difference* London Routledge

Paterson Barbara, Crawford Marta, Saydak Marian, Venkatesh Peri, Tschikota Sharon, Aronowitz Teri (1995) How Male Nurses Learn To Care *Journal of Advanced Nursing* vol.22 p600-609

Payne S, Sheldon F, Jarrett N, Large S, Smith P, Davis C, Turner P and George S (2002) Differences in Understanding of Specialist Palliative Care amongst Service Providers and Commissioners in South London *Palliative Medicine* vol. 16 p 395402

Peshkin A (1988) In Search of Subjectivity-One's Own *Educational Research* NO.7 pp17-22

Polanyi M (1967) *The Tacit Dimension* London Routledge and Kegan Paul

Poovy M (1988) Feminism and Deconstruction *Feminist Studies* vol. 14 Spring 1988 p51-65

Porock D, Martin K, Oldham L, Underwood R (1997) Relocation Stress Syndrome: The Case for Palliative Care *Palliative Medicine* vol. 11 p444-450

Potter J and Wetherall M (1994) *Discourse and Social Psychology* London Sage Pubilcations

Prail D (2000) Who are we here for? *Palliative Medicine* vol. 14 p91-91

Radwin L (1996) Knowing the Patient: A Review of Research in an Emerging Concept. *Journal of Advanced Nursing* vol 23 1142-1146

Radwin L (1998) Empirically Generated Attributes of Experience in Nursing. *Journal of Advanced Nursing* vol.27 p590-595

Randall F and Downie R S (1999) *Palliative Care ethics: A companion for all specialities* 2nd Ed. Oxford University Press Oxford

Ray Lynne (1999) Evidence and Outcomes: Agendas, Presuppositions and Power *Journal of Advanced Nursing* vol. 30 no. 5 p1017-1026

Reason P and Rowan J (1981) *Human Inquiry :A Source Book of New Paradigm Research* John Wiley and Sons Chichester

Rees W (1986) Immigrants and the Hospice *Health Trends* vol. 18 p 89-91

Reinharz S (1992) *Feminist Methods in Social Research* Oxford. Oxford University Press

Reynolds William, Scott Brian (2000) Do Nurses and Other Professional Helpers Normally Display Much Empathy? *Journal of Advanced Nursing* vol.31 no.1 p226-234

Richards S (2001) Personal communication Secretary of the Association for Palliative Medicine UK December 23rd 2001

Richardson L (1994) Writing: A Method of Enquiry . In Denzin N and Lincoln Y Eds (1994) Handbook of Qualitative Research London Sage Publications

Rinaldi A and Kearl M (1990) The Hospice Farewell: Ideological Perspectives of its Professional Practitioners *Omega* vol.21 no. 4 p283-300

Roach S (1987) *The Human Act of Caring: A Blueprint for the Health Professions* Canada Canadian Hospital Association

Robbins M (1997) Assessing needs and effectiveness: Is Palliative Care A Special Case? Clark D, Hockley J and Ahmedzai S (Eds) (1997) *New Themes in Palliative Care* Buckingham Open University Press

Robbins M and Frankel S (1995) Palliative Care Services:What needs Assessment? *Palliative Medicine* vol. 9 no. 4 p 287-294

Rolfe G (1998) The Theory-Practice Gap in Nursing: From Research-Based Practice to Practitioner-Based Research *Journal of Advanced Nursing* vol 28 no 3 p672-679

Roper J and Shapira J (2000) *Ethnography in Nursing Research* London Sage Publications

Roter D and Hall J (1998) Why Physician Gender Matters in Shaping the Physician-Patient Relationship *Journal of Women's Health* vol. 7 no. 9 p1093-7

Rumbold B (1998) Implications of Mainstreaming Hospice into Palliative Care Services In Parker J and Aranda S Eds (1998) *Palliative Care: Explorations and Challenges* London Maclennan and Petty

Ruszniewski M and Zivkovic L (1999) Difficulties Faced by Hospital Palliative Care Teams *European Journal of Palliative Care* vol. 6 no. 1 p11-14

Ryle G (1949) *The Concept of Mind* London Hutchinson

Sadala Maria Lúcia Araújo (1999) Taking Care as a Relationship: A Phenomenological View *Advanced Journal of Nursing* vol. 30 no. 4 p 808-817

Salisbury C, Bosanquet N, Wilkinson E, Franks P, Kte S, Lorentzon M and Naysmith A (1999) The Impact of Different Models of Specialist Palliative Care on Patients Quality of Life : A Systematic Review *Palliative Medicine* vol. 13 p3-17

Saunders C (1965) Watch With Me *Nursing Times* Nov 26th 1965

Saunders C (1965/87) I was Sick and You Visited Me *Christian Nurse International* vol.3 no.4 p4-5

Saunders C (1991/2) The Evolution of the Hospices *The History of the Management of Pain: From Early Principles to Present Practice* Parthenon Publishing Group 1988 and Free Inquiry 1991/2 vol. 12 no.1

Saunders C (1993) Introduction – 'History and Challenge' In Saunders C and Sykes N Eds (1993) *The Management of Terminal Malignant Disease* London. Edward Arnold

Saunders C (1993) Some Challenges That Face Us *Palliative Medicine* vol.7 (supplement 1) p77-83

Saunders C (2001) Social Work and Palliative Care – The Early History *British Journal of Social Work I vol. 31 p791-799*

Saunders C and Sykes N Ed (1993) The Management of Terminal Malignant Disease London Edward Arnold

Saunders C, Summers D H and Teller N (Eds) *Hospice: The Living Idea* London. Edward Arnold

Schön D (1983) *The Reflective Practitioner.* Aldershot Ashgate

Schon D (1987) *Educating the Reflective Practitioner* San Francisco Jossey-Bass

Schwandt T (1998) Constructivist, Interpretivist Approaches to Human Inquiry In Denzin N and Lincoln Y Eds (1998) *The Landscape of Qualitative Research: Theories and Issues* London. Sage Publications

Scwartzman H (1993) *Ethnography in Organisations* Qualitative Research Methods Series No. 27 London Sage publications

Seale C (1991a) A Comparison of Hospice and Conventional Care *Social Science and Medicine* vol. 32 p147-52

Seale C (1991b) Communication and Awareness About Death: A Study of A Random Sample of Dying People *Social Science and Medicine* vol. 23 no. 8 p943-953

Seymour J and Clark D (2002) Palliative Care and Geriatric Medicine: Shared concerns, shared challenges *Palliative Medicine* vol. 15 p269-270

Seymour J, Clark D, Hughes P, Bath P, Beech N, Corner J, Douglas, H, Halliday D, Haviland J, Marples R, Normand C, Skilbeck J and Webb T (2002) Clinical Nurse Specilaists in Palliatve Care : Part 3. Issues for the Macmillan Nurse Role *Palliative Medicine* vol. 16 p386-394

Seymour J. (2001) Critical *Moments – Death and Dying in Intensive Care.* Buckingham. Open University Press

Shaw P (2002) *Changing Conversations in Organisations: A Complexity Approach to Change(Complexity and Emergence in Organisations Series)* London Taylor Frances

Sheldon F (2000) Dimensions of the Role of the Social Worker in Palliative Care *Palliative Medicine* vol. 14 p491-8

Sheldon F (2001) Social Work in Palliative Care : Counselling and Communicating *Progress in Palliative Care* vol.9 no. 6 p 242-243

Sheldon F, Turner P and Wee B (2001) The Contribution of Carers to Professional Education in Payne S and Ellis-Hill (2001) *Chronic and Terminal Illness: New Perspective on Caring and Carers* Guildford Oxford University Press

Shotter J and Gergan K (1994) *Texts of Identity* London Sage Publications

Simons H (1996) The Paradox of Case Study *Cambridge Journal of Education* vol.26.no 2. Pp225-240

Skilbeck J, Corner J, Bath P, Beech N, Clark D, Hughes P, Douglas H, Halliday D, Havilard J, Marples R, Normand C, Seymour J Webb T (2002) Clinical Nurse Specialists in Palliative Care . Part 1 A description of the Macmillan nurse Caseload *Palliative Medicine* vol 16 p285-296

Small N (2001) *The Future Vision For Palliative Care* Paper given at the Art of Palliative Care Conference Hosted by the NCHSPCS September 4th London

Snelgrove Sherrill, Hughes David (2000) Interprofessional relations Between Doctors and Nurses: Perspectives From South Wales *Journal of Advanced Nursing* vol.31 no.3 p661-667

Soothill K, Makay L and Webb C (1995) Interprofessional Relations in Health Care London Edward Arnold.

Spender D (1980) Man Made Language Routledge and Kegan Paul

Squires J (1999)*Gender in Political Theory* Cornwall Polity Press

Staden Helene (1998) Alertness To The Needs Of Others: A Study Of The Emotional Labour Of Caring *Journal of Advanced Nursing* vol.27 p147-156

Stacey R (2001) *Complex Responsive Processes in Organisations: Learning and Knowledge Creation (Complexity and Emergence in Organisations Series)* London Taylor Frances

Stake R (1994) Case Studies In Denzin N and Lincoln Y Eds (1994) *Handbook of Qualitative Research* Sage London

Stake R (1994) The Unique Case In Stake R (1995) *The Art of Case Study Research* Sage London

Standing Advisory Medical Committee (1992) *The Principles and Provision of Palliative Care* London HMSO

Stanley L and Wise S (1993*) Breaking Out Again: Feminist Ontology and Epistemology* London Routledge

Sterba J (Ed) (1998) *Ethics: The Big Questions* Oxford Blackwell Publishers

Stewart Hegedus Kathryn (1999) Providers' and Consumers' Perspectives of Nurses' Caring Behaviours *Journal of Advanced Nursing* vol. 30 no. 5 p1090-1096

Sudnow D (1967) *Passing ON: The Social Organisation of Dying* New Jersey Prentice-Hall Press

Symonds A and Kelly A (1998) *The social construction of community care* Macmillan Malaysia

Taylor C and White S (2000) *Practicing Reflexivity in Health and Welfare: Making Knowledge* Buckingham Open University press

Thomas C (1993) De-Constructing Concepts of Care *Sociology* vol. 27 no.4 p649-669

Thomas J (1993) *Doing Critical Ethnography* Qualitative Research Methods Series No. 26 London Sage publications

Thorns A , (2000a) Resuscitation in Palliative acre *International Journal of Palliative Nursing* vol 6 no 6 p264

Thorns A, Sykes N (2000b) Opiod use in the last week of life and implications for end of life decision making *Lancet* 356 vol 9227 p398-9

Titchen A and Ersser S (2001) The Nature of Professional Craft Knowledge in Higgs J and Titchan A (2001) *Practice Knowledge and Expertise in The Health Professions* Oxford Butterworth-Heineman

Tronto J (2003) Times Place *Feminist Theory*, Vol.4, No.2, pp.119-138

Tronto J (1994) *Moral Boundaries:A political Argument for an Ethic of Care London Routledge*

Tronto J (1989) Women and Caring: What Feminists Can Learn About Morality from Caring? In Held V (Ed) (1995) *Justice and care: Essential Readings in Feminist Ethics* Oxford Westview Press

Twycross R (1984) *A Time To Die* London Christian Medical Fellowship Publications

UKCC (1992) *Code of Professional Conduct* London. United Kingdom Central Council for Nursing, Midwifery and Health Visiting

Ungerson C (1983) Why do Women Care? In Finch J and Groves D (1983) *A Labour of Love* London. Routledge and Keegan Paul

Usher P (1997) Challenging the Power of Rationality In: McKenzie G, Powell J and Usher R Eds (1997) *Understanding Social Research: Perspectives on Methodology and Practice. The* Falmer Press

Vachon M (1987) Team Stress in Hospice/Palliative Care *Hospice Journal* vol 3 no 2-3 p75-103

Vachon M (1997) Recent Research into Staff Stress in Palliative Care *European Journal of Palliative Care* vol. 4 no. 3 p99-103

Van Manen M (1977) Linking Ways of Knowing with Ways of Being *Curriculum Inquiry* vol. 6 no. 3 p205-228

Van Manen M (1977) Linking Ways of Knowing with Ways of Being Practical *Curriculum Inquiry* vol6 no 3p205-228 von Dietze E and Orb A (2000) Compassionate Care: A Moral Dimension of Nursing *Nursing Inquiry* vol 7 p 166-174

Von Post I and Eriksson (1999) A Hermeneutic textual analysis of Suffering and Caring in the Peri-operative Context *Journal of Advanced Nursing* vol.30 (4) p983-989

Watson J (1988) *Nursing: Human Science and Human care: A Theory of Nursing.* New York National League of Nursing

Watson J (1999) *Postmodern Nursing and Beyond* London Churchill Livingston

Watson Roger, Deary Ian J, Lea Amanda (1999) L Longitudinal Study into The Perceptions of Caring Among Student Nurses Using Multivariate Analysis of The caring Dimensions Inventory *Journal of Advanced Nursing* vol 30 no 5 p1080-1089

White K (1999) Increased Medicalisation Within Palliative Care *International Journal of Palliative Nursing* Vol5 No 3 p108-109

Wicks D (1998) *Nurses and Doctors at Work : Rethinking Professional Boundaries* Open University Press Buckingham

Wilkes E (1980) Standing Medical Advisory Committee Working Party on Terminal Care

Wilkes E (993) *Introduction* In Clark D Ed (1993) The Future for Palliative Care : Issues of Policy and Practice

Wilkinson G and Miers M (1999) *Power and Nursing Practice* Macmillan. Malaysia

Wilkinson S (1991) Factors Which Influence How Nurses Communicate With Cancer patients *Journal of advanced Nursing*

Wilkinson S, Bailey K, Aldridge J and Roberts A (1999) A Longitudinal Evaluation of a Communication Skills Programme *Palliative Medicine* vol. 13 p 341-348

Willard C (1999) Caring for Paritnets and Relatives: An Appraisal of Palliative Care Philosophy *European Journal of Oncology Nursing* vol 3 no. 1 p38-43

Wolf D Ed (1996) *Feminist Dilemmas in Field Work* Westview Press

Woodward Vivien M (1998) Caring, Patient Autonomy and The Stigma Of Paternalism *Journal of Advanced Nursing* vol.28 no.5 p1046-1052

Woodward Vivien M (1997) Professional Caring: A Contradiction in Terms? *Journal of Advanced Nursing* vol 26 p999-1004

World Health Organisation (1990) *Cancer Pain Relief and Palliative Care Technical Report Services 804* Geneva WHO

Wuest Judith (1997) Illuminating Environmental Influences on Women's Caring *Journal of Advanced Nursing*_ vol.26 p49-58

Young I M (1990) The Ideal of Community and the Politics of Difference In Nicholson L (Ed) (1990) *Feminism/Postmodernism* London Routledge