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A Sociological Critique of 'Grand Narratives' in the History of Hospice and Palliative Care

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A SOCIOLOGICAL CRITIQUE OF 'GRAND NARRATIVES'
IN THE HISTORY OF HOSPICE AND PALLIATIVE CARE

M. J. CURTIS

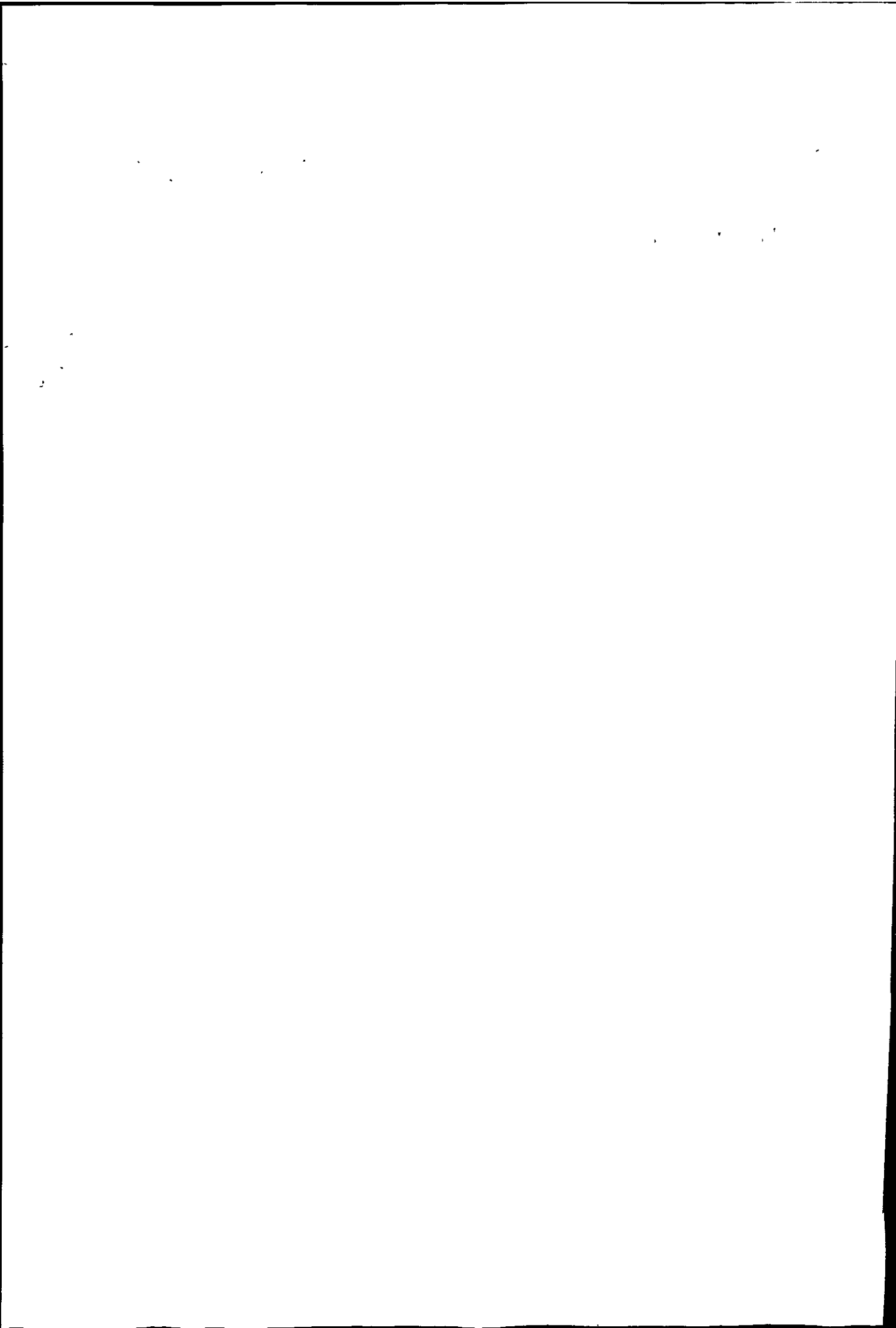
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**A Sociological Critique of 'Grand Narratives' in the History
of Hospice and Palliative Care**

By

Mary Curtis

**A thesis submitted to the University of Plymouth
in partial fulfilment for the degree of**

Doctor of Philosophy

**School of Law and Social Science
Faculty of Social Science and Business**

September 2008

Mary Josephine Curtis

A Sociological Critique of 'Grand Narratives' in the History of Hospice and Palliative Care

Abstract

This thesis is a sociological history and critique of hospice and palliative care: their goals, narratives, and social, clinical and ethical practices. Hospice developed in Britain as a result of and challenge to interventionist biomedicine within hospitals where dying came to be viewed as medical failure. From the mid twentieth century hospice was promoted as a 'philosophy of care' that had at its locus a concept of 'whole' person family care for people who are dying. For the first time patients *and* their relatives became the unit of care. Henceforth, hospice established for itself three major 'goals'; (1) holistic symptom management, (2) acting as a surrogate family for dying persons *and* their relatives in an atmosphere of homeliness where staff (3) worked together in non-hierarchical multidisciplinary teams. The hospice agenda in caring for the dying aimed to 'promote living and even to facilitate personal growth during the dying process' (Moller, 1996:40). This was postulated as the ideal standard in offering humane care to the dying patient and for achieving a 'good death'.

For many years hospice philosophy was practiced in voluntary hospices that were charitable organisations deliberately located outside the National Health Service. An exponential growth in the number of such organisations during the 1970s and 1980s spawned a movement which subsequently led to the creation of a new medical specialty in 1987, that of palliative medicine.

Hospices' 'grand narrative' refers to the dominant 'official' story about their development and about the activities that were or are carried out within them. In addition to offering a new way of looking at hospice history, I used the 'goals' of

hospice as espoused in the 'grand narrative' to guide my observations in two hospices in one British region. I explore how hospice professionals employ methods of control that help both manage the dying process and maintain institutional order. The study took place over a four year period with the aim of determining to what extent the 'grand narrative' matched practice or whether as Lawton (2000) proposed there is a 'gap between rhetoric and reality' of hospice care. This thesis represents a challenge to hospice, a refusal to valorise the story proponents have told and continue to tell about the practices that are carried out under the banner 'hospice' and more recently palliative care / medicine.

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AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other university award without the prior agreement of the Graduate Committee.

This study was self-financed.

Relevant seminars, conferences and other events were regularly attended at which work was presented.

Presentations / Conferences Attended

RCN Nurses Managing Hospice and Specialist Palliative Care Services Annual Conference, 12-14th April 2002, Jersey, Channel Islands
Presented a paper entitled; 'Stormy Waters and Resuscitation Ethics'

St Margaret's Somerset Hospice Fourth Annual Conference: 25th October 2002.
Presented a paper entitled 'Hospice: Public Perception Versus Reality'

Fourth National Stroke Nursing Conference: Stroke Care: Into the Future
1st & 2nd September 2004, Birmingham
Presented a paper entitled: 'Stormy Times for Ethical Decision Making in a Death Denying Culture'

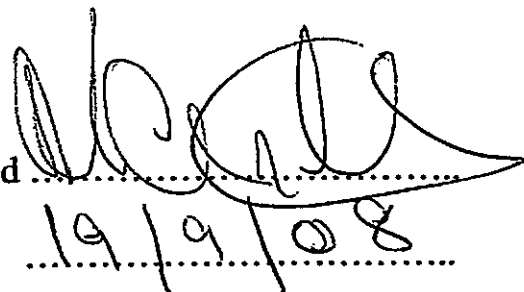
Breast Cancer Study Day, 27th March 2006, Cornwall
Chaired this meeting and facilitated a workshop on Communication.

In addition I organised and ran many conferences and regional events for my employing institution, presenting papers at these.

Word count of main body of thesis – 90,000

Signed

Date

A handwritten signature in black ink is written over a dotted line. Below the signature, the date '19/9/08' is handwritten in black ink over another dotted line.

A Sociological Critique of 'Grand Narratives' in the History of Hospice and Palliative Care

Preface

We use the past to shake confidence in the 'obvious' appearance of medicine today; not in order to sanctify it as has so often happened in histories of medicine (Wright and Treacher, 1982:2).

Introduction to the Thesis

This thesis is a sociological history and critique of hospice and palliative care: their goals, narratives, and social, clinical and ethical practices. The historical period within which hospice emerged and was transformed has been divided into broad categories that I refer to as 'waves' in order to point to shifts in thinking about dying at various historical moments. Having situated hospice in an historical context – 'first wave', the thesis concentrates on twentieth century developments – 'second wave' - as this was a period that witnessed hospice developing into a social movement with specific, highly publicised goals. These then broadened with a new nomenclature – palliative care - into a 'third wave' of developments bringing us up to the present. I have selected a topic that is straddled by many disciplines, and therefore some dialogue between philosophical, scientific and religious insights is inevitable because questions about who and what we are and do cannot be slotted into neat academic categories; and also because questioning seemingly ordinary assumptions and conventions can pave the way for insights into the qualities of human life which are usually taken for granted; these latter are of particular relevance in the thesis.

Hospice emerged in Britain in the nineteenth century in tandem with a newly developing technological approach to medical practice within hospitals.

Hospitals aim to cure, i.e. offer specific medical or surgical treatment for the purpose of repairing the bodily parts of an injured or diseased person. Dying came to be viewed as medical failure and incurable patients were discharged into a social landscape lacking a support network. In contrast, hospice staked a claim for its motivational force as an overriding concern for *care* of dying people. The late 1800s and early 1900s witnessed the development of Britain's first two hospices after which there were no further developments until mid twentieth century. These early hospices, one in Ireland and the other in England, sought to create an environment where both the physical *and* spiritual needs of a dying person assumed equal priority and this focus created conditions that would enable patients to have a 'good death'.

During the 1960s, when medical technological advances were at their height, a second wave of hospice development commenced with the establishment of St Christopher's Hospice, London by Doctor Cicely Saunders, 'as a reaction against over-zealous interventions at the end of life' (Randall and Downie, 2006: vi) and 'an attempt to close the gap between the realities of hospital care of the dying and the realities of patients' needs' (Moller, 1996:39). At this historical juncture hospice was promoted as a *philosophy of care* that had at its locus a concept of 'whole' person *and* family care for people who are dying. This approach involved the addition of a third dimension amenable to care - the psychosocial domain. Henceforth, hospice established for itself three major 'goals'; (1) holistic symptom control, (2) acting as a surrogate family for dying persons *and* their relatives with staff (3) working together in non-hierarchical multidisciplinary teams in an atmosphere of 'homeliness'. The aim was to 'promote living and even to facilitate personal growth during the dying process' (Moller, 1996:40). This was postulated as the ideal standard in offering humane

care to the dying patient and for achieving a 'good death'. For many years hospice philosophy was practiced in voluntary hospices (specially built units) that were charitable organisations deliberately located outside the National Health Service. An exponential growth in the number of such organisations during the 1970s and 1980s spawned a movement which subsequently led to the creation of a new medical specialty in 1987, that of palliative medicine. In the thesis, this latter is referred to as the 'third wave' in hospice development.

Hospices' 'grand narrative' refers to the dominant 'official' story about their development and about the activities that were or are carried out within them. Like all stories certain things are included whilst others are excluded. Foucault, (1991) and I follow him in this, was particularly interested in and referred to the excluded parts of stories as 'subjugated knowledge' – knowledge that had been buried under the official or dominant forms of knowledge that emerge in a social order. From this perspective, official knowledge is not the only explanation of events or things, more a case of some explanations winning over others. I used the 'goals' of hospice as espoused in the 'grand narrative' to guide my observations in two hospices in one locality in order to determine to what extent the 'official' story matched practice or whether as Lawton (2000) proposed there is a 'gap between rhetoric and reality'. Not only was it difficult to translate the goals into practice, it was probably unrealistic and there were many gaps between rhetoric and reality. This led me to explore other matters about hospice practice neglected in the literature, what I call hospices' 'dark shadow' (Bleakley, 1984: 9); for example, the manner in which the ideas of psychiatrist Kubler-Ross' (1969) were used to 'steer' patients through the dying process and the way that metaphor and euphemism were used to describe certain activities. Interestingly, for a movement set against 'over-zealous medical interventions' (Randall and

Downie, 2006); such 'interventions' are now routinely part of end of life care in contemporary society i.e. 'the assessments, questionnaires, counselling, and measurement scales, which have become so typical of the palliative care approach, can also be seen as a kind of harassment at the end of life' (Randall and Downie, 2006: vii) The literature on hospice and palliative care, interview material, records of discussions with practitioners employed in these arenas and extracts from four years of record keeping within two hospices provide the research material for the thesis. Overall, this thesis is a challenge to hospice, a refusal to valorise the story proponents have told and continue to tell about the practices that are carried out under the banner 'hospice' and more recently palliative care / medicine. The following chapters explore hospice philosophy and goals from a number of different perspectives.

Overview of Chapter Content

The first part of this thesis, chapters one and two, provides the background to the study including theoretical and methodological perspectives that informed my approach to and interpretation of the material.

Chapter One sets the context for the thesis and the chapters that follow. As well as setting out the key questions that are addressed in the thesis, it serves as a place to introduce theoretical and methodological perspectives that inform my study of hospice as a 'new discipline' in healthcare practice and which shape the exploration of hospice within the thesis (Armstrong, 1986). Drawing on a broad range of sociological literature, an historical and ethnographic approach to the subject matter is cast through a sceptical lens when exploring hospice as a particular type of care for *dying* people through to observing contemporary practices. In addition I explain how my education practice provided both

pedagogic and research 'instruments' with which to gather and share information and knowledge at local level.

Chapter Two situates hospice in historical context by exploring the conditions that led to its emergence, development and acceptability during the late 1800s through to contemporary times. I use the metaphor 'wave' to delineate one historical period from another. For instance the first hospices to emerge are referred to as 'first wave' hospice, while subsequent developments are referred to as 'second' and 'third wave' hospice. To what problem did hospice purport to be a solution? Despite claims to altruism by proponents of first wave hospice; a 're-reading' (Procacci, 1991: 152) of that literature suggests otherwise. It is possible that the establishment of hospice as a 'special place for dying' (Lofland, 1978) may have provided the means by which some individuals occupying certain social positions were protected from dissection, a practice common in eighteenth century Britain. I try to show something of the contradictions and chance occurrences in the historical period prior to and including the emergence of first wave hospice whilst indicating how certain forms of knowledge become subjugated in official accounts.

I then explore the social conditions surrounding a 'second wave' of developments with the establishment of St Christopher's Hospice, London and the subsequent social movement that emerged. A 'grand narrative' was created within these developments that reinforced a particular perspective about dying in contemporary society; asserting that dying could be a 'fulfilling', 'peaceful' and 'dignified' experience both for the dying person and the people around them, (Saunders, 1965, 1968, 1969, Murphy 1993); even a period of 'growth' the chance of a creative moment' (Saunders 1988); that dying can be symptom and pain free

and that dying people can maintain 'autonomy' and 'control' right up to the moment of death (Du Boulay 1984, Saunders 1960a, 1960b, 1963b, 1965, Stoddard 1978). I subject the 'grand narrative' to a re-reading and treat these claims with scepticism, a scepticism derived from intimate experience of hospice practices at local level over a five year period. As Foucault might say, I 'call them into question' not in order to discredit them but so that others might use my findings to view them differently' (Foucault, 1991).

This brings us to matters relevant to present day practices as I explore the emergence of palliative care which represents a 'third wave' of hospice development leading to the creation of a 'new' medical specialty in 1987 - palliative medicine. Henceforth the terms palliation and hospice became conflated. I explore the social conditions that led to this change speculating what the adoption of the new nomenclature might signify. It has been argued that these changes have directed the hospice mission away from their 'holistic' approach towards the more measurable physical care of the patient (James & Field 1992). Although the shift to palliation did herald changes to the practices carried out in hospices, there is more to the shift than the assumptions made by various commentators or those articulated by hospice proponents might suggest.

I move on in **Chapter Three** to focus on the first of 'second wave' hospice's three goals as espoused in the 'grand narrative - (1) *holistic care*. I examine hospices' commitment to holistic care which is asserted to encompass care in the physical, psychosocial, and spiritual domains (Saunders 1964, West 1993). How is holistic care carried out in practice? After the Second World War there was a deepening interest in the 'inner self', in authenticity, and in personal growth where notions such as 'choice' and 'autonomous individual' became paramount.

Because hospice patients were constructed as 'autonomous' they were envisioned as actively assisting in managing their dying. I examine how and if this occurred in practice. However, because of the kind of people targeted by second wave hospice a gap between rhetoric and reality becomes apparent.

Chapter Four explores the second goal of hospice proponents – (2) *patient and family as the unit of care* – the grand narrative asserts that the partnership of care provided by hospices 'brings relatives into a holistic care agreement with the patients, using a patient-centred and family focused model' (Ashby, 2001). This, it is claimed, provides an 'important base for caring' whereby the patient is declared to remain at the helm fully in control right to the end (Ashby, 2001). Yet, are such claims realistic? They certainly extend the role of the healthcare professional who, up until this point merely had to concern themselves with patients. Might the extended unit of care create ethical dilemmas for practitioners? I explore *how* practitioners incorporate relatives and families into the unit of care and again find reality rather different to espoused ideals.

Chapter Five focuses on goal (3) *non-hierarchical multidisciplinary team working*. Reflecting upon my own role within the team, I explore 'grand narrative' claims that hospice practitioners from a range of professions work in harmonious teams to comfort dying patients and their relatives. Multidisciplinary teamwork is a core component of the ideology and philosophy of second wave hospice and contemporary palliation. This 'differentiates' practitioners from those in the NHS where staff may be too busy to chat and a hierarchy according to professional status exists, or so it is claimed. Yet there is more to this 'ideal' than a first glance might reveal. Hospice does not simply provide an environment for clinical

practice; it also serves as a vehicle for socialisation into certain roles for both patients and professionals and the 'governance' of that 'socialisation'. An 'insider' perspective allows me to explore the range of diversity and heterogeneity that exists with respect to what people say and do and again the gap between rhetoric and reality becomes stunningly clear.

Chapter Six provides a bridge between chapters three, four and five and the remainder of the thesis. It serves as a place to discuss my findings relative to the 'goals' of hospice. These are then mapped onto specific concerns raised in the literature on hospice and palliative care; i.e. hospices losing their original focus and ethos (Biswas, 1993), becoming medicalised, (Ahmedzai, 1993, Biswas, 1993), bureaucratised and routinised (James and Field, 1992) and secularised (Bradshaw, 1996). I then consider a new 'technique' that is being tested at St Christopher's hospice, followed by a synopsis of 'emotional labour' (Hochschild, 1983). Finally I offer a discussion about generalizing from these findings.

In **Chapter seven** I focus on matters that are neglected in the 'grand narrative'. In the 'shade' of the glowing image that second wave hospice fostered, lies its dark side – its 'shadow' – which 'remains inferior, mainly unconscious and unacknowledged' (Bleakley 1984: 9). I explore *how* proponents of second wave hospice created, cultivated and sustained a myth about dying with dignity by aligning themselves with psychological ideas and theories that 'fitted in' with their own ideas i.e. to make dying a creative and positive experience. For example, clinical practices in these hospices were so saturated with the ideas of the psychiatrist Kubler-Ross (1969) that patients were 'steered' through the dying process by staff who took their own actions and the theory that underpinned them

totally for granted. Practitioners utilised Kubler-Ross' ideas as a 'standardised technique' (Chaban, 2000) that 'established a grid of codeability of personal attributes' which was then used to 'chart and judge' human conduct during the dying process (Rose, 1999:135-6) and thus 'contain' an otherwise unruly dying process.

Chapter eight continues the themes of hospices' 'shadow' by turning attention to metaphors and euphemism used by hospice practitioners in the study setting to describe certain activities. Second wave hospice advocates were not only concerned to offer more humane care to dying patients, they were also creating what they perceived was a viable alternative to euthanasia, the proponents of which also cultivated a 'grand narrative' about death with dignity as they sought to make legal the option of assisted death. Yet although both movements do have differences they share many similarities. I show how some patients were propelled through the dying process via the application of pharmaceutical techniques, i.e. medication, when psychological techniques failed or merely to make handling patients easier for staff. These 'disciplinary techniques' rendered patients 'docile' - cut off from families or significant others and therefore 'socially dead' (Foucault, 1991:136, Lawton, 2000). Such disciplining techniques re-constituted patients' identities from 'active' to passive' – from 'subject' to 'object' (Lawton, 2000) making them more manageable thus maintaining hospice's 'grand narrative' and public image as a 'peaceful place to die'.

Chapter nine synthesises the main themes addressed in this thesis. Following a brief review of the subject matter addressed in the study, my perspective is reviewed. I contend that despite focusing on a tiny minority of patients, second

wave hospice became the central space for the creation of new knowledge about the dying process where 'death talk', contrary to the 'grand narrative', can be viewed as a 'disciplining' technique that constituted the identities of dying persons (Loftland 1978) as well as creating a 'norm' to which all dying patients are now expected to conform. Favoured hospice 'norms' and 'disciplinary' techniques rendered patients 'docile', objectified them and deprived them of their personhood. Contrary to the 'grand narrative' one of my arguments in this thesis is that proponents of hospice *did* have a 'preconceived idea' as to what constituted a 'good death'. This latter is merely a romantic myth which was sustained in this local setting by the maintenance of institutional order which also involved keeping staff 'in their place'. As regards 'third wave' hospice, I speculate that contemporary developments are not a 'solution' to anything other than the vastly expensive protection of the interests of a minority. I then go on to speculate about the future, including implications of this study for policy, followed by some concluding thoughts. Recommendations for reform are in appendix one.

Definition of Terms Used Within This Thesis

Euthanasia; derives from a combination of Greek words, "EU" (well) and "Thanatos" (death), meaning 'well death' (BMA, 1988: 3).

Active euthanasia is the purposeful shortening of human life through active or direct assistance, with or without medical help.

Passive euthanasia is the withdrawal or withholding life prolonging measures, a decision not to prolong life or a non-treatment decision; sometimes referred to as *the doctrine of double effect* (Fisher, 1995).

Voluntary euthanasia; a death brought about by an agent at the request of the person who dies (BMA, 1988: 3).

Involuntary euthanasia is the killing of someone who could consent but does not (BMA, 1988: 3).

Nonvoluntary euthanasia is the killing of an individual who has no capacity to understand what is involved (BMA, 1988: 3).

Terminal sedation is a procedure used to relieve patients of symptoms refractory to usual treatment by decreasing the level of consciousness in a patient close to death (Porta Sales, 2001: 97).

Proportional sedation refers to sedation adapted to the needs and requirements to relieve patient's suffering without total loss of consciousness (Porta Sales, 2001: 97).

The rapid, sudden loss of consciousness is described as *sudden* sedation (Porta Sales, 2001: 97).

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Nonvoluntary euthanasia is the killing of an individual who has no capacity to understand what is involved (BMA, 1988: 3).

Terminal sedation is a procedure used to relieve patients of symptoms refractory to usual treatment by decreasing the level of consciousness in a patient close to death (Porta Sales, 2001: 97).

Proportional sedation refers to sedation adapted to the needs and requirements to relieve patient's suffering without total loss of consciousness (Porta Sales, 2001: 97).

The rapid, sudden loss of consciousness is described as *sudden* sedation (Porta Sales, 2001: 97).

Chapter 1

Theoretical and Methodological Perspectives

1.1 Introductory Remarks

This thesis is based on a study of hospice, i.e. literature produced by proponents and practices informed by such literature; in particular literature produced from the mid twentieth century and its impact on contemporary practices. An historical and ethnographic approach to the subject matter is cast through sceptical lens when exploring the historical period that witnessed the emergence of hospice as a particular type of care for *dying* people through to observing contemporary practices. For instance I explore how hospice professionals employ methods of control that help both manage the dying process and maintain institutional order.

Since the mid twentieth century a body of literature about hospices developed that reinforces a particular perspective about dying in contemporary society i.e. that dying and death can be 'positive' experiences and that it is possible to 'die with dignity' fully 'in control until the end' (e.g. Abel, 1986; Corr and Corr 1983; DuBois, 1980; Du Boulay, 1984; Munley, 1983; Parkes, 1978; Saunders, 1965, 1966, 1967, 1968, 1969; Twycross, 1983, 1984, 1986). This, following Foucault (1991), I call hospices' 'grand narrative'; it is a story about how and why hospice developed the way it did and what makes care in a hospice different to that undertaken in other healthcare settings. This story is 'grand' in the sense that it is the 'dominant' story about hospice. Narrative in the sense that I use it in this thesis concerns the 'stories' people tell to explain why they work or behave the way they do (Clendenin and Connelly, 2000). Within a few years it became possible to talk about hospice as a social movement – the hospice movement - which was loudly proclaimed and widely publicized regarding its 'philosophy' of care. A central feature of this 'philosophy' was 'holism' –

attention to the mind, body and spirit of patients *and* their relatives. From the late 1970s hospices adopted a new nomenclature called palliative medicine and palliative care to refer to the work they undertook which is now practiced in a range of healthcare settings. My concern is with how hospices' 'philosophy' both pre and post 1970s actually worked in practice in hospice in-patient settings as well as what effect, if any, the shift to 'palliation' had on the way in which care is delivered. The overall aim of this thesis is to ascertain whether there is a mismatch between theory and practice or as Lawton (2000) put it, a 'disparity between rhetoric and reality'.

Nearly twenty years ago Seale was asserting the importance of finding out 'what happens in hospices in order to assess the claims of hospice practitioners to be providing something different from traditional care' (1989: 553). Yet, despite a plethora of specialised writing on the subject of hospice by proponents, much of it is 'self-congratulatory' (Wilkes, 1981) there is little research carried out over a sustained period depicting what actually occurs in hospices. Jennings, in his critique of hospice ethics argued that there was an 'urgent need for a more rigorous analysis of such taken-for-granted tenets as 'the prevention and relief of suffering', 'death with dignity' and 'good death' (Jennings, 1997:2). Lawton observed that when these concepts are critically examined in light of one of the 'most ethically contentious issues of our time' – debate on euthanasia – the modern hospice movement's position becomes 'more problematic than many people would like to assume' (Lawton, 2000:179). While McNamara (2001: 47) notes that 'the norms and rules surrounding a 'good death' also impose a form of social control. More recently, in their critique of palliative care Randall and Downie postulate that 'palliative care does have considerable weaknesses in its philosophy and in its approaches to care' (2006:3) and that the

practice of palliative care has become 'too elaborate, too intrusive, too precious' (2006:5). One of the central arguments of this thesis is that tensions currently manifesting in palliative care stem from inherent contradictions in the philosophy of hospice as it developed during the 1960s; the taken-for-granted assumptions that individuals made about this philosophy along with the powerful stranglehold that hospice gained within the upper echelons of British society. Moreover, 'concerns have been expressed that some hospices have not been able to maintain their initial high ideals and standards of care' (Abel, 1986; Seale, 1989 cited in McNamara, 2001: 49). This thesis will go some way towards addressing gaps in the literature especially regarding the way care is organized and undertaken and how hospices as organizations are managed thus contributing to debates about the future direction of palliative care.

This chapter sets the context for the thesis and the chapters that follow. As well as setting out the key questions that are addressed in the thesis, it serves as a place to introduce theoretical and methodological perspectives that inform my study of hospice as a 'new discipline' in healthcare practice and which shape the exploration of hospice within the thesis (Armstrong, 1986). To date, no one has undertaken a systematic critique of hospice from the 'inside' over a prolonged period, from the perspective of a salaried employee who was also a researcher. I am using the term 'critique in the sense that I question matters that seem to be taken-for-granted by hospice advocates so that, like Randal and Downie (2006: vii) I can 'establish the strong and weak points' of hospice 'philosophy' as it applies to practice. I treat the claims of hospice advocates with scepticism, a scepticism derived from the 'theoretical perspective' I adopt as well as intimate experience of hospice practices during five years employment. I 'call them into

question' not in order to discredit them but so that others can use my findings to consider how they might be 'viewed differently' (Foucault 1991).

1.2 Historical Periods

'Since the topic of history traces the changing forms of social behaviour and institutions over time' (Layder, 1995: 6) a broad historical and critical approach to the ideas and practices embedded in the discourses of 'hospice' is adopted by exploring their emergence and ongoing development. In order to point to shifts in thinking about dying at various historical moments and to highlight the fluidity of social tendencies I use the metaphor 'wave' within the thesis since waves rise and fall. For instance, ideas about any social phenomenon rise and fall in importance over the course of time. As McNamara observes, 'social movements like hospice and palliative care are subject to the forces of social change and therefore do not necessarily reflect a consistent philosophical and political stance' (2001: 8). 'First wave' hospice refers approximately to the period late eighteenth century to the beginning of the twentieth century when hospice as a *specific institution for the dying* emerged; 'second wave' to developments between early to late twentieth century when 'modern' hospice emerged and 'third wave' from late twentieth century up to the present which witnessed the development and legitimisation of palliative care and specialist palliative care. These 'waves' represent *approximate* indications of the historical junctures at which shifts of emphasis appeared; similarly, each wave does not herald the demise of its predecessor; rather, a change in emphasis is indicated. For example, for proponents of first wave hospice, dying became recognised as a *process*; a process that became *institutionalised* for the first time (Humphreys, 2001: 150). Care was undertaken by religious nursing sisters with minimal medical input. However, concern was

not so much directed at the dying process *per se* but towards appropriate preparation for the afterlife.

In second wave hospice religious discourse whilst remaining important began to recede as lay carers turned their attention to the *process* of dying in the here-and-now for each 'individual'. 'Talking' about dying assumed significance where the aim was to help patients come to terms with the fact of their dying. This period, although situated within a biomedical framework, eschewed 'invasive [medical] technology' (McNamara, 2001: 4) but paradoxically witnessed the development of a swathe of mono professional groups all claiming 'expert' knowledge about dying and death. Whereas in third wave developments the *dying person* begins to recede as focus turns to managing unruly symptoms in patients who are incurable but not necessarily dying. This approach is set within an interventionist biomedical framework that favours using available 'invasive technology' (McNamara, 2001: 4); where 'specialization' becomes a contested territory and the dying process becomes privatised and sequestered.

1.2.1 Aims of the Study

1. Explore how death and dying are constructed in the literature ('grand narrative') of hospice. In particular the philosophy of second wave hospice which contains 'three core ideas upon which hospice ideology is based': (1) commitment to holistic care, (2) non-hierarchical multidisciplinary teams and (3) a definition of care which includes the patient and family as the unit of care, in other words, the goals of hospice (Field and Johnson, 1993). I scrutinise these goals at local level exploring how they are transformed into practice.

2. Use the key issues highlighted in the literature and the questions they raise to guide observations in a local setting; e.g. examining tensions between claims of

holistic care and the development of professional specialism along with claims that hospices are losing their original focus and becoming medicalised, secularized, bureaucratized and routinised.

3. Compare and contrast macro and micro discourses in order to discover what purpose respective constructions might serve and ascertain whether there is a gap between rhetoric and reality.

1.3 Theoretical Perspectives

Anything that is potentially 'problematic or chaotic' is a target for management - a practice which has become increasingly pervasive since the nineteenth century. It is a 'key element of a particular version of the progressive scientific attitude that allows for, or encourages, an increase in the sum total of control that human beings have over the world we live in' (Parker, 2002: 3). In this thesis I borrow from Foucault's insights, especially genealogy, and those of his followers, alongside scholars of different persuasion. The Genealogical Period covers a time when Foucault came to see practices as being more important than theories as he undertook research for *Discipline and Punish and A History of Sexuality Volume I*. Foucault tried to explore, not just the rules behind regimes of practice, but the ways in which they came to be constituted, maintained, reproduced, and also disrupted and resisted hence his term 'power-knowledge'. The genealogist examines social phenomena which are taken for granted by treating them as if they were strange searching for the superficial and unexpected rather than for depth. A perspective which emphasises the 'jolts and surprises of history', the chance occurrences, and traces 'the descent of practices as a series of events' (Foucault cited in Burchell, 1991: 75).

Management, or in Foucauldian terms, 'discipline' and more recently 'government' (Rose, 1999), Dean, 2006) is one of the ways society controls things by making them manageable, i.e. subject to the control of human beings. Dying is a 'social process' (Prior, 1989) that is managed variously depending on the way society is organised at different historical moments; this in turn is dependent on which ideas gain the 'status of truth' (Rose, 1999) i.e. the way in which forms of knowledge and expertise' shape society (Dean, 2006: 71).

In contemporary Britain management of dying is the remit of health professionals. Foucault's work is viewed by some sociologists as useful for exploring the professions in terms of knowledge acquisition and the way such knowledge enables them to 'discipline' the recipients of their knowledge especially in the healthcare arena (Turner, 1995) where 'the formation of the clinical method was bound up with the emergence of the doctor's gaze into the field of signs and symptoms' (Foucault, 2003: 111). Writing in this vein, medicine, noted Fox (1999) 'fabricates' our bodies and 'territorializes' us through various forms of disciplinary expertise, in the name of health and illness. It does this through 'a clinical codification of the inducement to speak. Combining confession with examination, the personal history with the deployment of a set of decipherable signs and symptoms; the interrogation, the exacting questionnaire' (Foucault, 1998: 65) and through medicalization of the effects of the confession' whereby what is revealed by the patient is 'recodified as therapeutic operations' and 'placed under the rule of the normal and the pathological' (Foucault, 1998: 67). In this way notions such as 'individuality' are created through discourses that affect how individuals come to view themselves as well as how health professionals respond to them.

Foucault viewed the professions as a disciplinary mechanism for governing individuals in society by acting at the level of the individual body which he referred to as 'a micro-physics of power' (Foucault, 1998:139). Surveillance, training and the ordering of the body in space and time is a form of discipline much more subtle than the spectacle of punishment it replaced. Those who were interested in making people more manageable or 'disciplining' them developed 'simple technical procedures' that involved gathering individuals in one institution where they could be observed in terms of their similarities and differences (Rose, 1999: 135). Hospice may be viewed as an example of one such institution. Since the techniques of the disciplines have important connections with knowledge, particularly that generated by the human sciences, it becomes possible to interpret the concept 'discipline' in relation to professional power in the way proposed by Goldstein (1984) – i.e. 'discipline' as a set of rules and punishment *and* as a branch of knowledge.

Viewed this way, the exercise of disciplinary power entails information gathering procedures which become the knowledge base of particular professions. The instrument through which professions such as medicine both discipline the population and gather new information is called 'the gaze' (Goldstein, 1984: 184) – 'the eye that knows and decides, the eye that governs' (Foucault, 2003: 108).

The medical gaze was also organised in a new way. First it was no longer the gaze of any observer, but that of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention. It was a gaze that could and should grasp colours, variations, tiny anomalies, always receptive to the deviant. Finally, it was a gaze that was not content to observe what was self-evident; it must make it possible to outline chances and risks; it was calculating (Foucault, 2003: 109).

By being combined and generalised these techniques of the disciplines 'attained a level at which the formation of knowledge and the increase of power regularly reinforce one another in a circular process' (Foucault, 1991:224). The social

practice of the disciplines serves as the basis for the discursive, which is represented as knowledge or science; knowledge in turn legitimates the non-discursive (Goldstein, 1984). In other words, practice informs theory and theory informs practice in a never ending cycle. While sociological claims that knowledge legitimates professional practice and status may be valid (Greenwood, 1957, Jones, 1979, Jolley, 1989) Foucault's contribution alerts us to the constitution of professional knowledge *through* professional practice thus causing us to question notions of a pre-given body of professional knowledge. Foucault's ideas will be put to the test when I explore how palliative medicine as a 'new discipline' (Armstrong, 1986) emerged and developed its knowledge base. Although I return to these points in later chapters, one argument of this thesis is that second wave hospice can be viewed as an 'explicit programme' of governance – a 'common plane of sight' with its own *prescription* concerning management of the 'proper' way to die in contemporary society and in the process established a 'grid of codeability' to 'chart and judge' human conduct during the dying process (Rose, 1999). The knowledge generated then established a 'norm' for 'governing' and 'disciplining' all dying populations under the guise of palliative care (Foucault, 1991: 80, Rose, 1999). It also formed the knowledge base of professionals who would later claim expertise in this area. This kind of approach facilitates a consideration of macro – micro debates in sociology and the way in which field research such as this study might inform such debates.

This gap between research and theory is nowhere more evident than in the division between macro and micro forms of sociology. In this respect, social theorists have suggested that the macro-micro problem is the major problem in sociology. Unfortunately, however, these discussions tend to be of an exclusively theoretical nature (Knorr-Cetina and Cicourel 1981, Alexander et al. 1987) and thus the link with social research has been neglected (Layder, 1995: 7).

In the main my supporting framework draws on key theoretical ideas from sociological literature; for example, e.g. Bauman, 2001; Baudrillard, 1981, 1983, 1988; Bourdieu, 1993, 2004; Bradshaw, 1996; Clark, 1983, 1991, 1993, 1998, 1999; Clark et al, 1990; Clark and Seymour, 1999; Elias, 2000; Gabe et al, 1991; James and Field, 1992; Kearl, 1989; Kellehear, 2007; Lawton, 2000; Layder, 1995; McNamara, 2001; Scambler, 1991; Seale, 1989. For specific topics e.g. 'medicalisation' (Armstrong 1983, 1986, 1987, 1995; Illich, 1976; Lupton, 1995; Turner 1995, 1997); 'the professions' (Collins 1990; Goldstein, 1984; Hugman, 1991; Klegon, 1979; Johnson, 1992, 1993; Larson, 1977; Lupton, 1995; MacDonald, 1995); 'education' (Bleakley, 1996, 1998, 1999, 2000; Freire, 1970, 1993; Giroux et al, 1996; Lankshear et al 1997; Usher et al, 1997); 'governmentality' (Burchell et al, 1991; Dean, 2006; Lupton, 1995; May et al, 1996; McNay 1996; Miller, 1997; Nettleton, 1995; Petersen, 2003; Rose, 1999, 2003; Ransom, 1997; Turner 1995, 1997). Governmentality, as used by these scholars and within the thesis refers to the 'conduct of conduct'. In the case of hospice, the conduct that is governed is the dying process i.e. the manner in which individual patients and their relatives deal with dying is guided by the 'professionals' who work in hospices using their 'expert' knowledge.

1.3.1 Knowledge Communities and Communities of Practice

Since knowledge acquisition is essentially social in character (Lave and Wenger, 1991) this research draws on the notion of knowledge communities which can be defined as 'a group of people often in separate organisations but united by a set of common norms, values and understandings, who help define the knowledge and production trajectories of the sector to which they belong' (Henry and Pinch,

2000: 4). In the hospice movement 'production trajectories' are not economic goods but refer to the production of knowledge about dying and death which is distributed within and outwith hospice and the expertise that derives from this knowledge, producing a thanatological or palliative expert. Alternatively hospices may be viewed as 'communities of practice' where individuals learn how to become practitioners of a specific kind i.e. thanatological or palliative through a process of 'social participation' and interaction (Wenger, 2007) that takes the form of an 'apprenticeship' where learners move from 'peripheral' to full and 'legitimate participation' within a community of knowledge – 'it concerns the process by which newcomers become part of a community of practice' (Lave and Wenger, 1991:29).

1.3.2 Sociology of the Professions

Generally and favourably for this study, research on the professions which emerged in the 1950s has been dominated by studies of what are considered to be the archetypal professions such as medicine and law. Studies of the medical profession are of obvious interest for hospice and palliation where the physician is considered an expert with high status (Lupton, 1995:25). Despite disagreement about what or who counts as a profession, a number of central characteristics are apparent in the literature on the sociology of the professions. These include, a body of knowledge, the monopoly of a work domain, autonomy of work and a service ideal (Goldstein, 1984). Additionally, entry into a profession is regulated through education or training (Hugman, 1991).

Although pronounced academically dead by some authors (Hall, 1983) others argued that the sociology of the professions entered a post-revisionist phase where professional knowledge came under renewed interest (Collins, 1990: 18).

The importance of professional knowledge was not the existence of that body of knowledge *per se*, but *how* it was socially organised – i.e. ‘the academic organisational structure of a profession has a social rather than a technical function’ (Collins, 1990: 18 -19). The importance of academic education is interpreted as fulfilling a primarily social function but ‘education in the classroom does not necessarily enhance professional practice’ (Collins, 1990: 10). Whilst the post-revisionist phase in the sociology of the professions focuses on knowledge, it has little to say about the formation of that knowledge (Goldstein, 1984: 175). Instead sociologists seem to view a professions’ intellectual core as a *given* and place their attention on social processes such as the application of professional knowledge to social needs or the manner in which a profession carves out a prestigious social niche for itself (Goldstein, 1984: 175). Therefore such concepts, although useful, have their limitations in analysing the professionalization of hospice practitioners which explores the role of both knowledge and experts. It is here the work of Wenger (2007) above will prove fruitful for exploring the way ‘modes of belonging become constitutive of our identities by creating bonds or distinctions in which we become invested’ (2007: 191). As I indicated above Foucault’s ideas are also useful as he contributed to the generation of new perspectives on the professions, particularly regarding ‘knowledge’ and the nature of ‘discipline’.

1.3.3 Medicalisation

Medicalisation refers to ‘defining a problem in medical terms, using medical language to describe the problem, adopting a medical framework to describe the problem or using a medical intervention to treat it’ (Conrad, (1992: 211). During the 1970s several authors wrote about the medicalization of society. For example

Illich (1976) analysing contemporary medicine asserted that the medical establishment was becoming 'a major threat to health' by pathologizing normal events so as to 'invent' disease. Other critiques concern biomedical 'efficacy' (McKeowan, 1976) its 'dominance' and 'its illegitimate spheres of influence' (Friedson, 1970). From the 1980s authors were writing about medicalization as a new form of 'surveillance' (Bloor and McIntosh, 1990) that 'fabricated new subjectivities' from the 'health-promoting self' (Glassner, 1989, Lupton, 1995, Petersen and Lupton, 2000) to the 'whole person' (Armstrong, 1986) to the 'dying patient' (Ahmedzai, 1993, Armstrong, 1987, Biswas, 1993, McNamara, 2001). Lupton comments on the growing 'penetrating clinical gaze into the everyday lives of citizens, including their emotional states, the nature of their interpersonal relationships, the management of stress and other 'lifestyle' choices' (1997: 107). Petersen and Lupton (2000: xii) discuss how 'the new public health is at its core a moral enterprise' propagating 'prescriptions about how we should live our lives individually and collectively'.

Of particular relevance for this thesis is the way Armstrong following Foucault, explored the transformation of this 'clinical gaze' in twentieth century Britain through new medical techniques in which 'patient views and the psychosocial spaces between bodies come to the fore' (Williams, 2003: 17). These new techniques gave rise to new areas of inquiry such as doctor-patient relationships, chronic illness, the 'normal' child, dying and bereavement, as well as new forms of medical specialism or expertise such as paediatrics (Armstrong, 1983:113 cited in Williams, 2003: 17), 'the new public health' (Petersen and Lupton, 2000) or as I suggest 'palliative medicine'. However some authors do not applaud such perspectives. For example, Bury (1986) refers to these 'relativizing' currents as the 'abyss of relativism' that paved the way for a variety of

postmodern perspectives on medicine, the body and health (cited in Williams, 2003: 18). Nevertheless, the varied literature about medicalisation is significant for analysing changes that have occurred in the practices of hospice practitioners particularly since the adoption of the nomenclature palliative medicine and palliative care which some commentators argue altered the 'focus' and 'ethos' of hospice care (Biswas, 1993) so that they became 'bureaucratised' and 'routinised' (James and Field, 1992, Wilkes, 1993), 'secularised' (Bradshaw, 1996) and medicalised (Ahmedzai, 1993, Biswas, 1993) all of which come under scrutiny in this thesis. As Corner and Dunlop (1997: 290) observe, 'the trend towards medicalisation within palliative care deserves particular scrutiny since this is central to current debate surrounding the direction of the specialty'.

1.3.4 Critique

Foucault defined 'critique' as 'the art of not being governed much' (cited in Ransom, 1997: 2); Kant (1781) as the means by which to determine the limits of reason, while Rose defines it as a 'certain style of criticism' (1999: x). This latter view is adopted in this thesis whereby criticism involves not passively accepting 'official' accounts, (Rose, 1999) 'received wisdom' (Randall and Downie 2006: 216) or taken-for-granted assumptions, but asking questions about *how* events and practices come to be talked about or practiced in certain ways and what purposes such representations might serve. In this way this thesis is a critique of the history of hospice, seeking to challenge by making what seems 'familiar' - 'strange' (Marshall and Bleakley, 2008: 30) through interrogation, through sceptical questioning and prioritising 'how' questions. What happens when patients are constructed as 'autonomous' and 'in control' of their dying? How might practitioners help patients undergoing rapid bodily deterioration achieve 'growth',

or a 'fulfilling', 'dignified' and 'peaceful death'? (Murphy, 1993; Saunders, 1960a, 1960b, 1963b, 1965, 1988; Du Boulay, 1984; Stoddard, 1978). I explore how the experience and the process of dying were managed by hospice practitioners in particular ways during specific historical moments so as to achieve certain ends.

I 'problematize' and 'call into question' what *seems* to be self-evident in the stories and practices of hospice proponents through a process of 'eventalization' which Foucault described as 'a breach of self-evidence' (Dean, 1999: 27). This means 'making visible an obviousness which imposes itself uniformly on all' (Foucault, 1991: 76). For instance hospice advocates talk about 'good death', something which most people would like if there were any choice in the matter. But what is 'good' about death and *how* might a 'good death' be achieved? This is not to say that hospice is a 'bad' institution or that I view hospice negatively. Far from it, it is to say that the particular form hospice have taken from the nineteenth century to the present are deeply implicated in a variety of social, political and ethical problems which not only remain unacknowledged but also, perhaps, limit our capacity to imagine other forms of organising care for dying persons. We might ask; how was it that during certain historical periods our society developed 'special' institutions for dying patients and later for particular categories of dying and that this was considered valid?

1.3.5 Historical Dimension

Tracing the historical antecedents of the social phenomena that is hospice is considered paramount for our understanding of the manner in which dying and death are managed in contemporary Britain as well as to enhance the 'explanatory power of the framework' employed in this study (Layder, 1995: 174). I am using

history in two ways; first in terms of a sweeping historical time span to explore the emergence and development of hospice as institutions, and secondly in researching 'situated activity' in a particular setting involving 'sequences or episodes of face-to-face interaction taken from the routine day-to-day round of activity' over a sustained period but shorter time span (Layder, 1995: 12). Talking about 'forms of temporality' Giddens (1987) refers to the *durée* of day to day life, the *durée* of the lifespan of the individual and the long *durée* of institutions (Cited in Layder, 1995:13).

Settings and contexts [such as hospice] refer to aspects of society that may 'endure beyond the lives of those individuals whose activities constitute them at any given moment (Giddens, 1987: 145). These institutional features interweave with the activities of day-to-day life and thus each give continuity to the other (Layder, 1995: 13).

Despite operating on 'different time scales' such distinctions serve to 'highlight the difference between social forms that constitute the immediate environment [e.g. hospice] and the wider, more general institutional forms (such as power structures of gender and class) (Layder, 1995: 13). In this way the historical dimension is 'both a supplement and complement to the analysis' presented in this thesis (Layder, 1995: 175).

For example, the much cited introduction to *Discipline and Punish* compares the public torture and execution of a regicide [killer or participator in killing of a king] in 1757 with the precisely timetabled routine of a young offender's institution eighty years later. This genealogy of carceral systems claims to show how 'the body' as the target for penal repression disappeared over a short historical period in the nineteenth century (Foucault, 1991). It was replaced by more subtle 'normalising' techniques of the human sciences heralding a new disciplining of bodies and minds whereby the human subject itself became the object of study in the modernist project assisted by psychiatry and psychology.

Medicine too underwent significant change during the nineteenth century when doctors began to practice at the patient's bedside in order to learn the 'true art of curing' through the application of a 'gaze' (Foucault, 2003: 85).

Medical sociologists utilising Foucauldian ideas have shown how institutions such as hospitals are part of an apparatus of control, discipline and regulation (Lupton, 1995; Nettleton, 1995; Turner, 1995, 1997) but aside from Clark, 1991, 1993, 1998, 1999, 2000; Lawton, 2000, and McNamara, 2001 such analysis of hospice is limited. Because of the emotional and social tensions surrounding dying and death, the aim of the hospital setting is to establish a regular and routine pattern of death for large numbers of patients (Sudnow 1967, Wright 1981 cited in Turner 1995: 125). The social organisation of the dying process gives rise to particular kinds of 'norms' in an attempt to 'avoid disruptive events which would threaten, not only the organisation of the hospital, but the social environment and management of the dying person' (Turner 1995: 125).

How might hospices manage or 'avoid' such 'disruptive events'? I explore the kinds of 'norms' that operate in hospices in one locality demonstrating how they 'govern' i.e. control, regulate and discipline patients and their relatives through certain institutional practices constructed from discourses of psychology, philosophy, religion, science, suffering and human rights. I also attend to the manner in which hospice practitioners are 'governed' in the context of hospice's goal of multidisciplinary team work (chapter seven) since as Dean suggests, 'those who might be thought to exercise authority are subject to the exercise of other forms of authority' (2006: 27-8). I will be 'problematizing' or 'calling into question' 'taken for granted' assumptions and what seems to be self-evident in the stories that hospice proponents have told and continue to tell about themselves and their practices (Dean, 2006: 27). I will be looking for the obvious in the

history and philosophy of hospice (it could be corporate strategy or nursing practices) and 'making it strange' (Marshall and Bleakley, 2008); exploring underlying rules and relations; to demonstrate how things develop over time to become accepted as normal practice. My aim, following Foucault, (1991) is to write about the *practice* of hospice and palliation to show how this way of caring for dying patients 'was capable of being accepted at a certain moment' as a significant component of the healthcare system, 'thus coming to seem an altogether natural, self-evident and indispensable part of it' (Foucault, 1991: 75).

1.4 Key Historical Questions

Historical investigations are 'diagnostic' since to diagnose is to 'discriminate or differentiate' and are thus used not for knowing but for cutting' (Rose, 2003:57-8).

I 'cut' experiences and accounts in such a way as to cause the reader to wonder how hospice came to appear so natural in British society. The questions driving the historical aspect of my study were; how did it become possible to establish 'special' (Lofland, 1978) 'enclosures' (Foucault, 1991) called hospices to cater for dying persons and no other? For what problem was hospice posed as a solution? What social purpose is served by the concept hospice? How did it become possible to say that dying could be a 'fulfilling', 'peaceful' and 'dignified' experience both for the dying person and the people around them, (Murphy, 1993); a period of 'growth' the 'chance of a creative moment' (Saunders, 1988); that dying can be symptom and pain free and that dying people can maintain 'autonomy' and 'control' right up to the moment of death (Du Boulay, 1984; Saunders, 1960a, 1960b, 1963b, 1965; Stoddard, 1978). How did it become possible to enact these 'concepts' and by whom'? 'In what torsions and tensions with other truths, through what contests, struggles, alliances, bribes,

blackmails, promises and threats?' (Rose, 2003:19). I was assisted in this process by borrowing what Rose (1999) refers to as 'dimensions along which analysis is conducted'. For example, *Problematizations*: the emergence of problems in relation to particular concerns. How did 'dying' come to be viewed as a problem? Who has authority to define phenomena as problems; the criteria in relation to which certain persons, things or forms of conduct come to be seen as problematic and the kinds of dividing practices involved e.g. the dying from the living, normality from pathology (Rose, 1999: xi).

Thus my first key question in this study investigates; how and when did certain 'authorities' in British society begin to view dying as a 'problem' to such an extent that special places called hospice were established? (Rose,1999). To answer that question I explored social and cultural conditions that made possible the emergence of hospice in the late 1800s, (chapter two) its re-emergence mid twentieth century (chapter three) through to its contemporary transformation as palliation (chapter four). For temporal reasons i.e. to acquire observable evidence, the thesis concentrates upon twentieth century developments when hospice became a social movement that had specific, highly publicised goals that then broadened into a 'third wave' of developments called palliative medicine and care.

1.5 Conceptualising and Categorising

The study began with speculation or a partial explanation (de Vaus, 2001:263). This provisional explanation proposes that implementation of hospice philosophy is not occurring in uniform manner throughout the hospice movement but is subject to local interpretations that may have a distorting impact on the implementation of the 'goals' of hospice as espoused in the 'grand narrative'. In

addition, the philosophy that emerged during the mid twentieth century was inherently flawed which raises the question as to whether, regardless of local interpretation, it could ever achieve what it claimed. These partial explanations were tested in one region.

Between September 2002 and July 2003 I undertook an extensive literature review exploring the social landscape within which hospice as an institution for dying patients emerged. Simultaneously an analysis of hospice literature was undertaken; e.g. all of Cicely Saunders' published material, national policy documents on hospice and palliative care (from the Hospice Information Service and National Council of Hospices and Specialist Palliative Care Services including their own written material), several editions of *The Oxford Textbook of Palliative Medicine*. These documents were analysed using another of Rose's (1999: xi) 'dimensions' – i.e. '*Explanations*': about care for dying patients, hospice philosophy, biomedical technology, the operative concepts concerning notions such as 'holism', 'good death', 'relief of pain; the kinds of work done by the relations among concepts e.g. delivery of humane care; the language and explanatory systems used e.g. religious, moral, rhetorics, metaphors, analogies; domains of evidence and the criteria for proof or acceptability involved e.g. who has the authority to pronounce these explanations at macro level and how do such explanations 'acquire the status of truth' (Rose, 1999: xi).

My basic categories for observational purposes were provided by the above 'grand narrative' of second wave hospice and the three major goals proponents set for themselves – (1) holistic care, (2) patient and family as the unit of care and (3) non-hierarchical multidisciplinary teams. The questions that informed this aspect of the study were:

1. Were these 'goals' achieved in practice and if so, how?

2. If the goals were not achieved, what barriers prevented their realization?
3. Is there, as Lawton (2000) suggests, a 'disparity' between the rhetoric and reality of hospice care?

The above research questions are underpinned by key themes derived from a review of sociological literature outlined above; for example the conditions surrounding the emergence of hospice within the context of neo-liberal society (Rose, 1999), 'the medicalization of life' and the 'industrialization of death' (Illich, 1976). These in turn are linked to concerns about the role of professional expertise in society (Rose, 1999, Dean, 1999) and the 'commodification' of healthcare where the 'right to be professionally killed became a major issue' (Illich, 1976: 111) as exemplified in contemporary debates about euthanasia and physician assisted suicide.

Once I had sorted my material into the above broad groups, I began to focus on how particular descriptions within the grand narrative served to support specific patient care activities by observing how these goals were translated into practice. To this end I visited the clinical arenas at different times to watch practitioners in action as well as sitting in on ward handovers, case conferences and multidisciplinary team meetings. I was looking for 'gaps' in what was *considered true*, i.e. any mismatch between rhetoric and reality.

In July 2003 I interviewed Dame Cicely Saunders. This helped to clarify my key categories and initial themes derived from the literature as well as question her about some of the statements she had made about her approach to care, her writings and speeches regarding 'modern' hospice. It also provided opportunity to discuss some of my preliminary speculations and discuss changes taking place in the world of hospice in general. We explored tensions between

hospice as she envisioned it and its current form as palliation. I discuss the interview below.

1.6 The Setting

The research was undertaken in two in-patient hospices situated approximately forty miles apart in one region in Britain. To preserve anonymity the hospices have been given pseudonyms and no indication as to geographical location is offered. One hospice 'Carlow' with eight in-patient beds was situated in the grounds of a community hospital. An independent charity run by a religious order it received all its amenities through the hospital; e.g. electricity, gas, water, oxygen.

The other hospice, 'Thurlow' also an independent charity was situated in its own grounds with 21 beds - a mix of four bed bays and single rooms. Inability to 'fill' all beds led to refurbishment and the number of beds reduced to 16. As well as an education and training facility, a range of additional services were offered; day care, lymphoedema clinic, complementary and Diversional therapies and bereavement service. Unlike the smaller unit, this hospice had its own social worker, physiotherapist, occupational therapist, full time chaplain, financial director, volunteer co-ordinator, fundraising department, and a range of supporting administrative staff. A Chief Executive and a board of trustees had overall responsibility.

Following an approach by the nuns whose numbers were diminishing and their convent to be sold; an agreement was reached between the chief executive and trustees of this hospice and the nuns responsible for the smaller unit; Thurlow would manage Carlow for six years, after which, if there were no adverse financial implications for the larger unit, both hospices would formally

amalgamate to form one charity. My post covered both units i.e. I was responsible for staff training at both hospices but at this stage none of the extra services available at Thurlow were offered to patients at Carlow. The hospices did amalgamate in 2006. The patient profile of these hospices were a mix of short term respite and terminal care until 2003 when respite care was abandoned and the hospices began to view themselves as specialist palliative care units. By 2006 most patients were admitted for short term symptom control and a few for terminal care.

1.7 Educational and Researcher Gaze

I consider it important at this stage to insert my 'self' prior to a discussion of methodology since, as Layder notes 'in practice selves cannot easily be separated from the social situations in which they are routinely embedded; (1995: 74). If we take a very broad notion of 'self' as a person's sense of themselves – i.e. identity or identities - and 'perception of the social world as these things are influenced by his or her social experience' (Layder, 1995: 74), this offers some leverage within which to contextualise both my teaching and research practices as aspects of the 'situated activity' I explore in this thesis, i.e. practitioner approaches to care, the kinds of social relationships that exist and the manner in which these hospices are organised. I was employed as Head of Education and Training within this study's setting; a role that conferred some seniority and authority (important in considerations of status differentials between researcher and respondents) but one that gave me total freedom of movement throughout both hospices.

A previous nursing background and later an educational practice teaching senior medics and other professionals in the National Health Service (NHS) provided me with knowledge of, and familiarity with healthcare settings as

well as 'insider' knowledge about how various professionals think about their practice. For example, for several years I was part of a team that taught a Postgraduate Certificate in Education. Individuals attending this programme were required to undergo teaching observations which were undertaken by the tutors who then offered them feedback. I undertook many observations of practitioners teaching within their clinical arena. Like Lawler (1991) this meant I had developed the habit of asking questions that could get at the 'essence' of healthcare practices even those normally 'taken-for-granted' (Lawler, 1991: 6). Therefore my in-depth knowledge of how medical and allied professionals function was invaluable when observing practice in the study setting as well as helping me to develop and foster relationships with clinical staff. In other words my professional 'social experiences' (Layder, 1995) were relevant for the kind of 'self' I assumed as a 'researcher'.

By the time I embarked on my doctoral research in 2002 I had been working at the hospices for one year. During this period, following an unsettling experience that arose in the clinical arena when I had been in post for two months I had started making notes about certain events and discussions. I did this because of potential legal repercussions concerning my own role as regards the kind of systems in place for monitoring staff competence (which I was in the process of developing from scratch owing to an absence of such systems). Although this event is referred to within this thesis my own notations are not used. The point to note is that I had acquired the habit of note taking within my educational role. Unintentionally I had become a participant observer.

A couple of months after I enrolled at the university when talking about my research with the Chief Executive I mentioned that I envisaged interviewing and or recording discussions with various employees at some stage and what did I

need to do about getting formal approval to do this. I suggested submitting a proposal to the board of trustees to gain their approval. I made it quite clear that I would not be recording patient conversations as part of the research nor have I (although I regularly chatted with patients and relatives as a member of the hospice teams). His response which I noted was as follows;

I don't have a problem with that. You're a paid member of staff are you not? You work here so there's no reason why you can't converse with whoever you wish. No need to go the board [of trustees] it's within my gift. I see no reason to object since you'll be writing about hospice. We've been pretty poor at doing research so it will be good for our profile (CEO, 2002).

It was as simple as that because hospices are 'self-governing' and thus free to make their own rules. As time went on although I did discuss my research with various members of staff, what some practitioners did not appreciate (including the CEO) is that I was also noting my observations of them as they interacted with one another and with me. I became a participant observer and it was this aspect of my researcher role that remained covert to most of the employees in these hospices. For example, although I would talk with practitioners about my observations as a basis for our classroom based activities, they took these observations for granted because of my education role and I did not enlighten them to the contrary. Let me be clear, those whose voices appear in this thesis have given their consent for me to use their speech. However, my overall impressions regarding the way in which the hospices were organised and managed (chapter 7) are as much underpinned by my observations and experiences of the way in which the 'atmosphere was distributed and maintained' (Marshall and Bleakley, 2008) as from practitioner comments and descriptions

about life in these hospices. This is relevant to the problem of maintaining 'objectivity' in research which I discuss below (Williams, 2005).

Nevertheless my teaching practice was situated within the arena I was observing and this was bound to have some impact on the kinds of questions I asked or that way that questions were framed. For instance, I was privy to informal conversations in the staff room at one hospice, where apart from myself, none of the doctors or senior members of the team ever went. It was viewed as a place where nurses, allied practitioners, ancillary staff and volunteers could blow off steam and get away from '*that lot*' (Maz) [i.e. management]. (Where names are used they are not the persons' real name). Unaware of this, from the start of my employment I had developed a habit of visiting this room to chat with staff, discuss my plans for educational activities and elicit their views regarding the kind of subjects they would like addressed. I had also erected a notice board in this room detailing up-and-coming educational activities. It was only after a considerable time that someone said to me that staff liked how I didn't *look down my nose* on anyone (Olive). When I enquired as to what they meant I was told '*your office is always open and we can nip down for a chat or if we're upset, you come on the ward and cheer us up, you take an interest in what we say, you fight our corner and you come in here and have a laugh Your predecessor wouldn't speak to anyone. She would walk right past you and not acknowledge your presence and she used to tell tales to management about us*' (Olive). This was not contrived on my part as I am naturally convivial and inclined to work alongside my colleagues tending to ignore hierarchical cliques. It so happened this stood me in good stead when I wanted to interview or record discussions with staff. It was important that they could trust me and I had already established myself as

someone who, despite my seniority, would not *'tell tales to management'* well before I embarked on this study.

Why then did I choose to observe covertly considering the ethical implications it entails? – (which are dealt with below). I did so primarily because of the way power operated in these hospices. Certainly I could have put up notices or distributed memos informing staff about my research but once the reader views discussions about organisational hierarchy in chapter seven it will become apparent why I choose not to do so. An example in the meantime will suffice; some staff in these hospices viewed my educative role (and me) as threatening because when practitioners attended my programmes they returned to practice in questioning mode and that was viewed as intolerable because it meant that staff would no longer 'know their place' i.e. a pattern of organisational behaviour had been established and become entrenched that was more in keeping with 1950s sensibilities than the 21st century and I was viewed as disturbing that pattern.

Despite gathering a great deal of data over the years, the material used in this thesis derived from and is situated within my educational practice as much as from my researcher practice. My status as researcher enabled me to apply 'new knowledge' to my teaching practice (Fish and Coles, 1998:55). For example, one of the stated goals of hospice is to offer patients and their families 'holistic care' i.e. attention equally to mind, body and spirit (the subject matter of chapter 5). Yet my observations of clinical practice did not bear this out so I set up seminars and workshops to enable practitioners to explore this goal. My research informed this teaching activity which can be viewed as 'a form of enquiry beginning to be known as insider practitioner research which is essentially educational, whose concern is with practical enquiry' (Fish and Coles, 1998: 56). These workshops and many others ran regularly throughout the period of my employment in order

to educate new staff (and the wider healthcare community) about the hospice approach to care as well as to provide existing staff with a forum within which to safely reflect upon their practice. Likewise with the other goals of hospice, practitioners attended my teaching sessions as a way of reflecting upon and improving their individual practice. This was my 'salaried' role in the hospices; to establish and organize appropriate induction programmes, learning and training opportunities for all staff and not just those in the clinical arena but there was overlap between my 'self' as educationalist and my 'self' as researcher. However I did not plunder information elicited from practitioners but returned it to them in light of the latest theories and research in such a way that it would have practical relevance. In similar vein, the findings of this study will be disseminated to members of the hospice movement.

To some extent then, the generation of material used in this thesis was a collegiate activity in that this material was used to develop new programmes and to focus on topics of relevance to practitioners in the study setting. For instance, when considering hospice philosophy practitioners talked about how the team functioned and how this impacted on the way they delivered care; discussions that inform chapters 5, 6, and 7 – the goals of hospice. Likewise, particular contradictions and tensions that emerged from these discussions became the basis for chapters eight and nine. Although one is using people's talk to explore issues, the 'research' concern is not so much about what is said as to the discourses which *shape* such talk. This gives us scope to identify what it is permissible to say, what different people say; from what points of view, and in order to obtain what kind of results (Foucault 1998: 27).

1.8 Development of Method

This is a qualitative study employing a mix of approaches to data collection e.g. documentary analysis, informal interviews and discussions and observations so as to build as full a picture of two hospices in one regional location as possible (de Vaus, 2001; 230) thus offering a deeper understanding of social phenomena than might be achieved by quantitative approaches (Silverman, 2000: 8). The main aim of this study was to explore the interpretation and implementation of hospice's 'grand narrative', in particular, its guiding philosophy, within two hospices in one region. This narrative is situated in and draws upon certain discourses of which liberalism, individualism, holism and humanism are examples. Discourse then, is a domain of language use unified by common assumptions thus providing a 'gaze' with which to view the world; e.g. we may speak of an educational gaze, medical gaze, therapeutic gaze, legal gaze and so forth. Proponents of hospice have a gaze 'holism' - from which they construct their 'grand narrative', the basis of and for regulation. Discourse analysis focuses on the language used in social texts, both written and spoken, i.e. interview material, group discussions, hospice literature, policy documents. Attention is given to the structure and organisation of discourse with concern for the possible consequences of the use of particular versions or constructions in the text. Because of this, context is seen to be important. The aim of discourse analysis is to examine the construction and meanings of phenomena in society that are available and drawn on by people as they make sense of various aspects of their lives. Our concern is at the level of shared meanings, and conceptualisations available and used by participants to inform their practice. Since discourses are conceptualised as culturally and historically embedded and socially communicated, the arguments of opinion leaders are made possible by the pre-existing pool of discursive resources which they draw upon to represent

themselves and their ideas. In this way, discourse analysis moves the unit of analysis away from the individual (Cassell and Symon, 1995, Potter and Wetherell) to macro level forms of social organisation.

Published research by leading lights within the hospice movement provided documentary resource material e.g. Saunders (1958 to 2003) Baines (1983), Du Boulay (1984), DuBois (1980), Doyle (1987, 1992, 1993, 1997, 2004, 2005, 2006), Summers and Teller (1981), Twycross (1979, 1983, 1984, 1986), Twycross and Lack (1984, 1990) along with a range of others. Literature by other researchers e.g. Armstrong (1983, 1983b, 1986, 1987, 1995), Clark (1991, 1993, 1994, 1995, 1997a, 1997b), May (1992a, 1992b, 1995), provided an enlightening source of sociological ideas while Jennings (1997), McNamara (2001), Webb (2005), but especially Lawton (2000) helped to direct my attention to specific clinical issues. For organisational matters I found Field and Johnson's (1993) ideas invaluable branching out to read a range of texts on management and organisational matters.

By exploring the kinds of narratives and discourses that proponents of hospice and palliative care use or draw upon when talking about themselves as service providers of a certain kind, and comparing these with local observations and narratives I am able to offer contemporary illustrations of how day-to-day hospice practices are constructed at a micro level, and the difficulties that practitioners encountered in attempts to realise goals postulated at macro level. Insights from the former led me to shine a spotlight on novel aspects of hospice neglected in the literature— its 'shadow' or dark side (the subject matter of chapters 8 and 9). This entailed pursuing themes that arose during the course of this study – e.g. use of metaphor and euphemism to describe certain practices along with the implementation of ideals derived from the work of the psychiatrist

Elizabeth Kubler-Ross that were so completely taken-for-granted by their users, they *seemed* perfectly normal but which, if utilised in any other healthcare setting would be considered unethical and perhaps, unlawful. In addition I have drawn upon an eclectic range of research or anthropological material to compliment and supplement the observations and interpretations I have made as a participant in these local settings. The thesis is based on an interpretive approach to, and critique of, the history of hospice - interpretive in the sense that following Wolcott (2001:82) 'my interpretations are just that: 'interpretations' – subject to further interpretation. This means I will be using long extracts from the local context of my research to enable the reader to make some interpretations of their own.

Questioning what other people regarded as 'natural' was the starting point of my inquiry. If I was going to pursue doctoral research from the theoretical and methodological perspectives that interested me, I needed to be a participant and an observer in a 'natural setting' documenting what the subjects of my research took for granted about one or more aspects of their world. I had an incredible opportunity to use my employment virtually unnoticed to 'get my hands dirty with real research' (Geertz, 2000). I had a unique opportunity to maintain a diary while working as an educationalist in a hospice and to use the data gathered to write a sociological analysis of hospice based on how the rank and file actually think about and perform their work.

1.9 Participant Observation

Participant observation is 'an essentially qualitative style of research originally rooted in the work of anthropologists and particularly associated with the Chicago school of sociology' (Robson, 1995: 190). One version of this kind of approach is called ethnography whereby the researcher goes to be amongst the people they

wish to study, immersing themselves in the culture so as to understand how the people lived. In this sense I was immersed in hospices culture for a number of years. Participant observation 'permits a lack of artificiality which is all too rare with other techniques' and is therefore a useful technique to employ when studying cultural context (Robson, 1995: 191). One of the advantages of observation in the way in which it has been used in this study is that it can 'usefully complement information obtained by virtually any other technique' (Robson, 1995: 191). Observation allowed me to view events that might not be identified in interviews because either the interviewer or interviewee takes them for granted; for example in ward handovers, case conferences and multidisciplinary meetings I was able to observe the manner in which patients were spoken to or about, which voices were listened to and which silenced. Information thus derived guided specific dialogues and informal discussions with practitioners pertinent to this study. These latter in turn helped me to validate and refine what I observed and formulate further questions.

A major advantage of observation as a technique is its directness. You do not ask people about their views, feelings and attitudes, you watch what they do and listen to what they say. This in turn enables the collection of first-hand data that are uncontaminated by factors standing between the investigator and the object of the research (Nachmias and Nachmias, 1994: 199).

As Montaigne noted four centuries ago 'saying is one thing; doing is another' (cited in Robson, 1995:191). I observed how practitioners 'did things', following this up by asking them to explain what they did. For instance, I watched how nurses performed care of dying patients, observing their interactions with patients and one another and the procedures involved. I then ran seminars where I encouraged them to talk about what they meant by 'holistic care' and what this entailed in practice. They were asked to give examples of and tell stories about tenets such as 'good death', patients in control, relieving suffering, dying with

acceptance. These responses became the basis for the kinds of questions I later asked individual practitioners. In this way observation was complimented by interviewing techniques. The focus of interest is on *how* the 'activities and interactions of a setting give meaning to certain behaviours or beliefs (Bogdewic, 1999: 48).

I did not have to 'adopt' an insider perspective I *was* an 'insider' a 'full member' of the team in these hospices (Robson, 1995). I attended ward rounds, case conferences and other meetings where patients' care and management was discussed. I attended meetings with management, fundraisers, shops staff, kitchen and domestic staff, volunteers, heads of department, trustees. Informal conversations with staff were a useful source of information that could be pursued in informal interviews or seminars. It was my employment (not my researcher status) that enabled me to *experience* how these hospices created and fostered a particular 'atmosphere' and how this was 'distributed, maintained, resisted and felt collaboratively' (Marshall and Bleakley, 2008: 33) thus helping me to attempt to understand 'what happens' (Seale, 1989) in the hospices in this region. Within a year I had two roles, one as educationalist the other as researcher. I was a 'complete participant' (Gold, 1958: 219) which meant I was able to use my experience and knowledge to identify and explain emerging concepts from data in an ongoing process.

However, I had to balance these two roles simultaneously; an educationalist who *shared* information and encouraged staff to reflect on their practice and a researcher who *obtained* information - acting as - a 'social interaction device for securing information' with a 'set of behaviours in which an observer's self is involved' (Gold, 1958: 218). This tight balancing act meant that I had to develop a 'heightened sense of self-awareness, and 'introspective attitude'

that memo writing aside, necessitated 'cooling-off periods' away from the field so as not to compromise or 'violate' the data (Gold, 1958: 220). This involved time when I could quite literally be 'myself' and reflect on my 'field' behaviour dispassionately. Collegiate and 'congenial' interaction with my supervisors, university and other colleagues was crucial to this process (Gold, 1958: 220).

I undertook 'field excursions' in the sense that I took every opportunity to attend educational events, conferences and meetings in hospices in other regions and at national level, presenting papers at some of these. I undertook collegiate activity with educationalists in other regions and had regular meetings with some of these as well as visiting numerous hospices. I too organized conferences, regional and local events all of which provided opportunities to interact with many professionals within the hospice movement and other palliative care settings within the NHS. The aim was to build up a detailed picture of life in my employing hospices by collecting from a wide range of constitutional elements.

I was learning the 'culture' of hospice through both 'living it' and 'watching it' (Cook, 1997). Data were collected in the form of field notes and although these were transferred to larger notebooks daily, they were not always typed up immediately. My educative role allowed me to move in and out of the field to collect data, analyse it and then return to collect further data in the sense that Strauss and Corbin (1998) advocated i.e. using different sources for comparison (e.g. the 'grand narrative', memos, employees' talk, teaching activity, observations, hospice literature).

Nevertheless participant observation does have disadvantages, for example, apart from being 'time consuming' the extent to which the observer

affects the environment within which they are observing has practical and ethical implications (Robson, 1995).

It is commonly claimed that this can be overcome – for example, by seeking to ensure that the observed are unaware of being observed, at one extreme; or by them being so accustomed to the presence of the observer that they carry on as if she were not there, at the other extreme (Robson, 1995: 191).

I had not entered the study setting with a ‘deliberate and planned intention to deceive’ nor ‘seek to become a full member of the group’ (Robson, 1995: 196) since I was already a ‘full member’ of the group when I embarked on the study. What altered was the way I undertook observations i.e. they became more systematic so as to provide a ‘supplementary’ tool for framing questions while responses to these questions were ‘validated and compared with actual behaviour through observation’ (Nachmias and Nachmias, 1994: 200). My employment meant that I did not have to postpone note-taking until ‘safely alone thus heightening the danger of seriously incomplete and selectively biased accounts’, nor face the risk that my ‘true purpose would be discovered’ (Robson, 1996: 196). For me it was a matter of operating at different levels of ‘self’. I support the view that ‘the known observer can, by his or her presence, disturb the natural environment which causes a change in normal behaviour’ and ‘consequently the researcher can record unreliable data’ (Field and Morse 1989: 79 cited in Lawler, 1991:12). Bearing in mind my education role bestowed a level of seniority and because of the way hierarchy worked in these settings, it would have been very threatening to junior members of staff to be told that I was systematically observing them. No amount of reassurance would have convinced them I was not acting as a spy for management while some staff already perceived me as a threat to the way power circulated in these organisations. Had I been overt about my

observations I have no doubt that I would have produced totally different findings to those presented in this thesis.

In some ways I could be described as a 'marginal participant' which Robson describes as 'a largely passive, though completely accepted participant' (1995: 198) in that my role was unique in these hospices, I did not have to participate in clinical activity i.e. hands-on care or other practices that I observed and wrote about but could legitimately wander about taking notes wherever I happened to be. I discuss ethical implications of my research approach below.

Because I was an employee, the purpose of my presence in these hospices, in other hospices and at gatherings for hospice and palliative care professionals was never questioned; why would it? To them I was a 'native' (Schwartz and Jacobs, 1979) but I never really 'went native' (Robson, 1995) because I did not develop any attachment to the ideology within which hospice practice is fashioned. I never experienced problems faced by other researchers 'in the field' concerning how to 'gain access', obtain 'cover' or become part of the environment e.g. Lawler (1991), Lawton (2000), McNamara, (2001).

Transcending the immediate context of one's understanding of the world to persist with the task of trying to analyze and theorize the apparently mundane features of social life are key aspects of a social scientist's work. I worked from the basic premises that whilst going about my normal work I should observe and record as much as possible of the seemingly routine and insignificant. Initially data would be gathered about as many colleagues and in as many contexts as possible, e.g. the work of allied health professionals, duration of ward handovers, who spoke in meetings, who was ignored, how volunteer activity was distributed, the activities of administrative, domestic, fundraising and maintenance staff, the behaviour of management personnel, the activities of the board of trustees. This was

'naturalistic research in real and uncontrived circumstances' (Lawler, 1991:14). I then chose to focus on neglected and taken for granted areas at the level of the 'little and mundane' (Rose, 1999: 11) to which I had open access and or which were easily observable.

For instance, although I do not include any patient accounts, in my role as educator it was relatively easy to determine if and how patients are 'listened to, are 'given control' and 'involved in decision making' in light of hospices' grand narrative' and 'goals' by attending ward meetings, shift 'handovers', multidisciplinary team meetings, case conferences and so forth. This meant I was able (whilst legitimately taking notes) to observe and attend to decisions made by individuals who actually deliver hands-on care to patients, a factor which, as demonstrated by Bogdan et al (1974) can be crucial to the success or failure of any health care programme. These observations concerning the 'conduct of conduct' have a 'diagnostic rather than a descriptive role' (Rose, 2003:19).

They seek an open and critical relation to strategies for governing, attentive to their presuppositions, their assumptions, their exclusions, their naiveties and their knaveries, their regimes of vision and their spots of blindness (Rose, 2003:19).

The power of such an approach is not only that it 'opens a space for critical thought' but 'sticks to the surface' in order to attend to the way problems are defined or explanations given for example (Rose, 2003: 19). In other words I am exploring, describing and analysing but not attempting to construct 'theory'.

1.10 Data Analysis

Field notes can be written into a notepad during a brief moment but they are better recorded systematically over a long period of time. I had a small pocket notebook which I kept on me at all times and which also served as my reflective diary

(renewed as it became full), in addition to several A4 hardback notebooks which I kept locked up at home. My approach was thus, I would write copious amounts on A4 paper and in my notebook during the course of the day, which I would then transfer to a hardback notebook each evening. I never failed to record the date on whatever medium was being used. I had to ensure that the data I collected were valid and reliable.

Data analysis was an ongoing process, i.e. 'analysis of the data occurs at the same time as data collection and influences further data collection' and are open to modification (McNamara, 2001: 140). For example I constantly noted themes and made focused observations relevant to the aims of this study which I then cross referenced in my field notes and diary. All data has ultimately been transformed into text. Interviews, discussions and conversations that were recorded have been transcribed, participant observation notes were transcribed and policy documents are also text. I used the 'editing' approach to analyse texts (Addison, 1999). The Latin use of 'edit' derived from the verbs 'edere' and 'educio' meaning to give forth and or educate. Addison notes that editing in its higher form 'can be thought of as an organising style of analysis that helps to bring forth greater understanding or meaning from text or data' (1999:146). This involves firstly, coding transcripts using 'in vivo' codes which refer to any words or phrases that stand out as potentially significant for understanding the phenomenon being studied (Addison, 1999: 154). For example, notions such as 'autonomy', 'control', 'suffering', 'spirituality', 'denial', 'good death', 'talking', 'listening' 'little things', 'steering', 'teasing out' were relevant in the context of 'holistic care' and in the context of 'patients and families' as well as words or phrases concerning problems, values, class, disposition, compliant, anger, demanding, sedate, behaving, and accepting were significant, while the use of

metaphor or euphemism became significant for staff descriptions of attempts to achieve a 'good death' for patients.

Secondly, transcripts were coded using a reflexive process where the researcher highlights what they felt to be significant, 'on what I thought their practices meant and were connected to, on what I did not understand, on how I thought my presence influenced their practices (Addison, 1999: 154). Reflexive codes were used to analyse reflexive memos (as part of the exercise to be self critical) as well as transcripts derived from audio recorded material. Following coding, transcript extracts were put onto index cards. The next stage of analysis could then begin. I searched the cards for emerging themes and patterns drawing on my baseline categories followed by further searches for patterns that coincided with the dimensions derived from Rose's (1999) work on governmentality. Once the cards were organised into themes I used flip charts to draw these together diagrammatically. A structure for the findings of my thesis then developed out of these analytical themes. Despite being cumbersome this system of using index cards meant I was able to remain in control of and close to the analysis process (Meadows and Dodendorf, 1999: 195).

1.11 Verbal Data

My role as educator provided me with very many opportunities to engage my colleagues in discussions about concepts such as 'good death', 'death with dignity', 'prevention and relief of suffering' (Jennings, 1997), physician assisted suicide' and many others. These explanations were of great use in the research because they link with the 'goals' of hospice as postulated within the 'grand narrative'. It became possible to compare these with the *actual* behaviour of colleagues in these hospices. In addition I had a micro cassette recorder that I used

overtly to record teaching sessions and specific research related discussions with practitioners as well as the interview with Saunders. For this I used ninety minute cassettes that I transcribed verbatim. These hospices employed approximately two hundred employees, a larger number of volunteers as well as staff who worked in the hospices charity shops. I had conversations with and undertook training with all of these people at one time or another. However, I confine myself to material specifically relevant to the key questions addressed in this thesis. This means that a total of forty six practitioner 'voices' will be heard in subsequent chapters. Interestingly, many of these practitioners no longer work in the hospices for reasons that will become clear as the reader moves through the thesis.

1.12 Checking the Evidence

I undertook one informal focused interview in 2003 with a key 'authoritative' figure (Rose, 1999) - the espoused leader of second wave hospice, Dame Cicely Saunders. It comprised broad areas of questioning around the 'goals' of hospice and other topic areas relevant to this study. This interview was audio recorded and fully transcribed with permission. The interview is viewed as a form of social interaction; a means of exploring the varied ways of making sense, and the interviewer's contribution is taken to be important. Both interviewer and interviewee are seen as constructively drawing on a range of resources which are of interest in the subsequent analysis, (Cassell and Symon, 1995, Layder, 1995, Potter and Wetherell, 1987). The purpose of this interview was to clarify and probe certain aspects of the 'grand narrative' derived from my analysis of the literature outlined above, initial observations, speculations and practitioner accounts. Within the thesis I interweave Saunders' responses and comments where they are pertinent to the subject matter being discussed. While interviews

are useful in allowing the researcher to examine significant matters, there are certain limitations in terms of the material gathered. For example, participants may offer a limited version of accounts in an interview setting. Consideration regarding the nature of the interaction between the interviewer and interviewee including power inequalities in the relationship are relevant here as in any interviewing context. Appearance, age, speech and gender may also influence responses (Nachmias and Nachmias, 1992).

In-depth interviews allow people to construct their own accounts of their experiences (de Vaus, 2001). Unlike MacDowell I did not perceive myself as being in the position of 'supplicant, requesting time and expertise from the powerful with little to offer in return' (1992: 213), partly because Saunders was very easy to chat to and partly because as an educationalist I was quite comfortable asking questions and challenging Saunders on her views. However, that is not to say that I was unaware that my respondent had her own views which she was keen to get across. I agree with MacDowell's observation that interviewing is a game where both interviewer and respondent are playing to different sets of rules and constructing a particular version of themselves for the purpose of the interview (1992: 214). Nevertheless, this interview was considered a useful means of gaining insight concerning *how* an opinion leader makes sense of their arguments within their constructions of death and dying as well as a means of checking whether the material I gathered from local practitioners resonated with any of Saunders' ideas or experiences.

1.13 Values and Generalization

Although qualitative research has become popular in the field of health, it is not without its critics. It has often been accused of anecdotalism and therefore

researchers need to demonstrate that their account is based on a critical investigation of all of their data (Silverman, 2000: 176). Using the concept 'moderatum generalization' Payne and Williams argue that 'qualitative research methods can produce an intermediate type of limited generalization' that 'resemble the modest, pragmatic generalizations drawn from personal experience which, by bringing a semblance of order and consistency to social interaction, make everyday life possible' (2005: 296). If we view hospices as communities of practice (Wenger, 2007) or 'knowledge communities' (Henry and Pinch, 2000, Lave and Wenger, 1991) it is possible to make theoretical generalisations if we ask what the practices in a specific locality can tell us about hospices in general (Payne and Williams, 2005) or about adopting a particular perspective (de Vaus, 2001: 237).

Research should be designed in such a way that moderatum generalizations are consciously produced. Nor do such generalizations offer a 'soft option' to solving the problems of generalization: whereas everyday lifeworld generalizations need not be wholly accurate or carefully set in an evidential context, sociological research should aim at constructing externally valid and unambiguous generalizations, even when these take a moderated form (Payne and Williams, 2005: 297).

Authors such as Stake (1994) argue that generalisations should not be the primary purpose of this local approach; rather the local should be valued for its own uniqueness and particularity. Whilst bearing Stake's proposition in mind, the data used in this thesis will be used to develop 'moderatum' theoretical 'generalisations' (Payne and Williams, 2005). Thus we should not, as qualitative researchers dismiss notions of Generalisability too quickly. I agree with Baxter and Eyles' argument;

If qualitative research is to be used to initiate policy or improve the human condition then its findings – as stories – must resonate with others in wider society' (1997: 180).

Throughout the course of my five year employment at these hospices I ran scores of workshops and educational events during which I talked with hundreds, if not thousands of health care professionals, not least of which were individuals employed in the study setting. Participants at these events worked in various settings including hospices. Although I confine myself to practitioner accounts that derive from the study setting, my broader experience suggests that the views expressed in this study will have resonance for *all* the voices that I heard over the years. For instance, in chapters seven and eight my critique is underpinned by a myriad of 'invisible' voices as well as those expressed by practitioners in the study's locality. Therefore, although this study was conducted in one regional location in Britain it is anticipated that the observations and analyses developed will 'resonate' with many others (Baxter and Eyles, 1997) and have broader application, contributing for example, to the ongoing general debate about hospices in terms of 'policy and resource allocation' (Randal and Downie, 2006: 194), 'changing models of hospice care' (Clarke, 1993: 5) as well as to debates about euthanasia and physician assisted suicide.

Such generalizations are 'moderate' in 'scope – 'they are not attempts to produce sweeping sociological statements that hold good over long periods of time, or across ranges of cultures and second they are 'moderately held' i.e. they offer a view that is 'open to change' which is 'important because it leads such generalizations to have a hypothetical character; they are testable propositions that might be confirmed or refuted through further evidence' (Payne and Williams, 2005: 297). This requires that the researcher uses a 'broad range of evidence' (Payne and Williams, 2005: 303). To this end the research upon which this thesis is based employs document and textual analysis (e.g. statements, papers, reports, books written by prominent hospice advocates along with recorded information

that is transcribed and transferred to text); one in-depth interview with a key 'authoritative' figure – recorded and transcribed verbatim; participant observation, recorded informal conversations, dialogues, discussions, and derivatives of educational activity. By employing a range of methods a clear picture can be built up, allowing analysis of component parts as well as the surrounding context (de Vaus, 2001:231). Multiple methods have been used not for the purpose of 'triangulation' (Silverman, 2000:17) but to elicit as full an understanding as possible of the hospices in this locality and thus facilitate making 'moderatum generalizations' (Payne and Williams 2005: 296).

An important aspect of qualitative research is to be reflexive about the process. This involves recognizing the position of the researcher, rejecting the view that we can research 'the ideal viewpoint and with the steady gaze of the notionally external observer' (Schatz and Walker, 1995:15). However, although I brought my own set of values and perceptions to the study which need to be acknowledged in the research process this is not to say that 'objectivity as a value' was not worth striving for (Williams, 2005).

Value freedom is indeed impossible, but a version of objectivity that begins from values and is therefore situated within particular social contexts is possible. The key premise of my argument is that all investigative disciplines are rooted in social values, but one of these values must be that of objectivity for investigation to be possible. If natural and social science are desirable and possible enterprises, then objectivity must also be desirable and possible (Williams, 2005: 99).

Once I embarked on this study I endeavoured to remain a 'disinterested observer' (Williams, 2005: 99). Although I cannot claim 'value neutrality' i.e. to say that my own values have not entered into the research, I have, following Williams, attempted to 'embrace objectivity as a value'; a position he calls 'situated objectivity' (2005: 117). Once I had embarked on my doctoral programme, sociological research underpinned my role inhabitation and I worked hard to

maintain a dispassionate stance to my observations. I was a researcher with a unique opportunity to gather data in an unusual setting and did not want anything cluttering my reporting of what are essentially 'sociological' observations and findings.

My own biases derived from what I perceived to be a disparity between the 'grand narrative' and micro practices as well as disparities between what practitioners said they did and what I observed them doing in practice. Had there not been any disparities, there would have been a completely different thesis. As Wolcott (2001: 360) observes 'there is no such thing as pure description . . . without some preconceived idea of what is to be described, there can be no description'. Therefore, the ability to be reflexive is crucial. This is a technique through which researchers turn the focus back on themselves to evaluate their influence on the findings and interpretations. I maintained a diary and reflective memos written throughout my observation period and following particular discussions with practitioners. I also had 'cooling off' periods (Gold, 1958) as noted above. In addition I took time writing up the research findings which helped create distance between my 'self' and the research setting so as to remain a 'disinterested observer' (Williams, 2008).

1.14 Ethical Considerations

Permission was requested and granted to audio record all discussions/interviews that are used in this thesis. This process was 'overt' and all participants whose voice appears in this thesis have given their 'reasonably informed consent' (Nachmias and Nachmias, 1994: 81) for the material to be used and disseminated. I use the term 'reasonably' in the sense that I offered a 'fair explanation of the procedure and its purpose' telling respondents about their 'right to withdraw'

from the study (Nachmias and Nachmias, 1994: 82). Rather than adopt long winded research jargon I simply said:

'I want to learn about hospice from your experience. I would like to record our conversation so that we are free to talk and not be interrupted by my note-taking and so that I can transcribe what we discuss accurately. I will write an account about your experiences which you will see once I have completed my study. However, if you would like a copy of this transcript in the meantime, you are welcome to see it. Please be assured you will remain anonymous. Your real name will not be used because you will be given a pseudonym. If you decide at any time that you don't want me to use this material you have the right to withdraw your consent. Just so you know I keep the cassettes safely locked in a cabinet in my home'.

Throughout the thesis, all material derived from informal conversations, dialogues, discussions or teaching activity that uses hospice practitioner's words is in *italics*. Except in the case of my interview with Cicely Saunders who was allocated the letter S., all informants have been given pseudonyms, while the letter R. has been assigned to the researcher at all times whose contributions are in normal text.

Several participants did receive transcripts of our recorded discussions particularly those who made contentious remarks. This was important as it gave those individuals an opportunity to 'withdraw consent and to discontinue participation' in the study (Nachmias and Nachmias, 1994: 82). This collegiality was also an important aspect of this study as it enabled me to follow up particular lines of discussion with certain practitioners so as to develop certain themes. The content of one particular classroom based workshop with six participants where the concept of 'holistic care' was explored is used predominantly in chapters three, five and six. This was audio recorded, transcribed and utilised to develop other workshops – a practice I had developed for small group activity over many years prior to my employment at the hospices. However, because of the manner in which these hospices were changing focus and following my interview with

Saunders I sought participant's permission retrospectively to use this material specifically for this study. I did this by giving each participant the transcripts I had produced from the workshop and by providing them with time and opportunity to refuse permission for the material to be used in the thesis. (Two participants had already left the hospices but I had their contact details). Again avoiding jargon respondents were told:

Remember that workshop I ran earlier this year when we explored the way holistic care works in practice? You all gave me permission to record our discussions which I transcribed and used to develop other workshops. Well my interview with Saunders last month made me have another look at the matters we discussed in that workshop and I would like to use the material for my research and later publication. Would you have any objections to this? I give you my assurance that you will remain anonymous. You will all be given pseudonyms. The reason I am giving you the transcripts is to remind you about each individual contribution which I would like you to take some time to consider. If you have said anything that you would prefer me not to use, or you feel I have been inaccurate please highlight this area and we can talk about it when we meet up.

One month later I met with each participants in a neutral environment e.g. restaurant and, in the case of the two individuals no longer employed at the hospices, at their home, to discuss potential implications of my use of this material. Having assured each individual that they would remain anonymous and be given pseudonyms and that where they referred to someone's name or made other identifying remarks, these would be omitted, all workshop participants gave their consent for the material to be used. They also agreed to participate in other discussions with me (at a later date) which were recorded and transcribed and used variously within the thesis. To reiterate, throughout the thesis where names are used, it is not the person's real name, and italics are always used for any remarks or comments by informants. Material or words that have been omitted are denoted thus (. . .). I add [] to contextualise a comment or to make the meaning clear. Words that have been emphasised by informants are underlined.

Nevertheless, I do think there are multiple meanings of any one situation, and therefore aware that the various responses I elicited from 'informants' did not necessarily give me direct access to their *actual* experience since I believe they were actively constructing their own 'narratives' at any one time (Silverman, 2006) which I tried to bear in mind when analysing field data since as Burke noted 'A way of seeing is always a way of not seeing' (1935:70). In addition, some respondents in this study reflect on and discuss aspects of their practice that occurred in the past which, due to 'distortions in memory may significantly contaminate the data', thus highlighting the importance of observing behaviour as it occurs (Nachmias and Nachmias, 1994: 199).

1.15 Ethics and Covert Research

The ethical researcher is educated about ethical guidelines, carefully examines moral alternatives, exercises judgement in each situation, and accepts responsibility for his choice (Diener and Crandall 1978 cited in Nachmias and Nachmias, 1994: 78)

The fact that I was undertaking research was not hidden from employees in these hospices. What was concealed because I felt it would contaminate the data was that fact that I was covertly observing their behaviour. However, I did not use 'deception to gain access to observations that the researcher would otherwise have been denied' (Nachmias and Nachmias, 1994: 77) since as I noted above, I had free reign to move about these hospices and therefore could not help but observe things. I was not exposing participants to 'substantial risks' or request that they 'forfeit personal rights' and thus did not consider that I needed to seek written 'informed consent' to undertake my observations (Nachmias and Nachmias, 1994: 79). Nor were staff the 'primary units of observation and analysis' *per se* since my interest was concentrated on how the grand narrative was translated into practice

not in pointing out which individual did what. My observations served as a means of getting at explanations about how practitioners 'practiced' hospice philosophy. Nevertheless, some individuals who came under my research 'gaze' were not properly aware of the nature of my research; 'had not agreed to participate in the study and thus had not exercised fully informed consent' (Nachmias and Nachmias, 1994: 77). To justify this, borrowing from Reynolds (1979) if, there were full information, there would be no reason to conduct the research – research is only of value when there is ambiguity about a phenomenon (cited in Nachmias and Nachmias, 1994: 81) and as noted earlier above there have been concerns that some hospices were unable to maintain the 'high ideals and standards' espoused in the grand narrative (Abel, 1986, Seale, 1989).

Let me be clear that ethical decision-making is not a dispassionate pursuit or an objective enterprise and it would have been no surprise if I was caught between what I thought *ought to be* the case and what *was* the case. After weighing the options I decided to carry on taking notes and thus begin covert fieldwork. This seemed the only realistic option if one were to explore *what happens* in hospice as opposed to what proponents or practitioners want us to think happens (Seale, 1989). However, having made the decision in principle to conduct covert observations, I had to face its practical implications. My primary concerns were a mixture of acute attention to fieldwork and a handling of discomfort about the way some of my colleagues behaved. Other research methods do not present these risks of participant observation. Unlike experimental, questionnaire and other more controlled research methods, covert research is equivocal; those who are being researched control the situation as much as, if not more than, the researcher; and in this setting 'control' was a significant factor. When the subject of the research is a health service provider

definition of limits of ethical tolerance is significant. Codes of ethics such as those adopted by the professional associations for social scientists, deal with predictable and planned research, conditions that are not present in fieldwork.

Any participant observer, overt or covert, intervenes in the research situation. The point is to know how and its consequences. Covert research is stressful and this has to be managed to the researcher's advantage. I tried to use my situation to heighten my awareness regarding what was happening around me, especially when stressful incidents occurred. I endeavoured to sustain as systematic an approach to the collection of data as I could manage. Certainly incidents occurred that affected me personally but my interest was focused on the mundane aspects of hospice life. Situations that might inspire sensational headlines did occur but I took seriously Williams proposition that 'objectivity pursued as a methodological value will use the best known means possible to seek the truth about the properties of the objects of interest' (2005: 111). The argument that all individuals have a 'right to privacy', i.e. freedom from observation, investigation and subsequent publication based on an investigation is persuasive but needs qualification when applied to any individual or organisation offering the public a service.

The freedom of the individual to pick and choose for himself the time and circumstances under which, and most importantly the extent to which, his attitudes, beliefs, behaviour, and opinions are to be shared with or withheld from others (Nachmias and Nachmias, 1994: 83).

In the case of hospice, all previous research has been overt. This might explain the neglect in the literature of discussions about *actual* organisational culture in hospices as opposed to the 'idealisations' that commentators want us to 'imagine' is the case (Rose, 1999) especially regarding the ethical tensions that arise in

clinical practice. As Jennings, in his critique of the ethics of hospice and palliative care, argues:

We can no longer regard the movement's commitments as 'self-evident, noncontroversial, and in need of little explicit analysis and examination. On the contrary, there is an urgent need for a more rigorous analysis of such taken-for-granted tenets as the 'prevention and relief of suffering', 'death with dignity', and the 'good death' (Jennings, 1997: 2).

But how is this to be achieved? In my view, an effective research strategy had to penetrate hospice's protective shield since when things are 'taken-for-granted' they seem perfectly natural to the people who do them or think them. I consider that my education practice provided excellent opportunity to explore, question and analyse the tenets to which Jennings refers and to use that role to observe 'what happens' in hospice. Indeed I doubt that I could have obtained such quality data had I chosen other research methods. Although my approach may not be what Jennings had in mind perhaps my observations will provide the impetus for others to develop some of the themes identified in this thesis.

Moreover, hospices are 'public' buildings; in other healthcare settings staff are accountable for the way they operate and there are systems in place for monitoring practice; systems that were absent when I joined these hospices.

The proliferation of hospices has been in advance of adequate evaluation studies of the services they provide and it may be that the 'movement' has been able to build around itself an aura of high quality provision which has yet to be demonstrated empirically (Clark, 1993:4).

That situation had not altered significantly when I commenced this study. Doyle (1997) a palliative care consultant, gave a scathing address at a conference addressing the Future of Hospice and Palliative Care where he made the following comment: 'When I travel around so much I perceive so much self-satisfaction, so much smugness, so much complacency that is, I think, dangerous'. For me there was no conflict between the 'right to research and to acquire knowledge' and the

right of individual research participants to self-determination, privacy and dignity' since the latter are providing a public service and thus constrained by laws that apply to all members of society (Nachmias and Nachmias, 1994: 79). If too much weight is given to 'right to privacy' this gives practitioners (caring for vulnerable patients) free reign to behave as they please and in some cases, as will be shown in this thesis to behave unethically.

Researchers have the obligation to weigh carefully the potential benefits or contributions of a proposed project against the costs to individual participants. Such costs may include affronts to dignity, anxiety, embarrassment, loss of trust in social relations, loss of autonomy and self-determination, and lowered self esteem. The benefits of a study are potential advances in theoretical or applied knowledge, gains to the research participant (including monetary compensation), satisfaction in making a contribution to science, and better understanding of the research phenomena (Nachmias and Nachmias, 1994: 78).

I did not impose a 'limit to freedom' on any participant in this study (Robson, 1995). Nevertheless the matter of 'secrecy' in covert research and its associated ethical implications are abhorrent to some researchers. Field and Morse (1985) view covert research as 'indefensible' while others take the view that;

There are very serious, perhaps damning, ethical problems in *all* covert research if the presumed immorality of deception is the overriding concern. Deception is no less present in public and open setting research than in preplanned, 'deep cover' research in closed settings. On the other hand, if other concerns are also important (for example, lack of harm to those researched, of the theoretical importance of a setting which can never be studied openly), then we can find no more justification for abolishing *all* deep cover research, preplanned or not, than for abolishing secret research in public settings (Loftland and Loftland, 1984: 23).

The case for covert research is strengthened by the position the hospice movement has assumed in our society. Compared to the size of the NHS the hospice movement is small but very powerful. Most hospices are charitable organisations operating outside the NHS relying on the financial support of a public that view them as 'havens of peace' staffed by 'angels' (Ahmedzai, 1994: 121). In recent years well placed hospice proponents have been making increasing financial

demands on the NHS, requesting government to divert more funds to hospice. But are such demands warranted? Could the activities undertaken by hospices be performed elsewhere within mainstream settings? Are they? Writing about the benefits (or otherwise) and cost effectiveness of the hospice approach Randall and Downie (2006) refer to the 'lack' and in some instances the 'absence' of research undertaken by hospice and palliative care proponents speculating that;

This work may not have been undertaken because a considerable proportion of the funding for specialist palliative care services (more than 50 per cent) actually comes from charitable sources, not public funding. Where palliative care services are not funded either by the taxation or insurance, the benefit derived from resources may be less closely scrutinized. Charitable trusts are able to use their funds in whatever way they consider best (Randall and Downie, 2006: 89).

Yet, however independent they might seem, or perceive themselves to be, hospices are constrained by the rule of law, a constitutional restriction on their right to privacy but one they endeavour to neutralize by maintaining a protective organisational culture. When institutions are overprotective, their members restrict their right to privacy; it is crucial they are researched. The covert researcher of hospice works within a powerful and influential organisation that begs revelation of its public and private face by first hand observation.

As Whyte (1943) put it in his classic study of gangs in a Chicago slum; I also had to learn that the fieldworker cannot afford to think only of learning to live with others in the field, he has to continue living with himself. Covert research and the ethical questions it raises create conditions of stress within which the sociologist has to 'live with himself', or, in my case, herself. For me, there were tensions that stemmed from working with people who seemed to lack values regarding management or clinical practice. So what, you might say, the world is a nasty place? Yes, but I had to take some responsibility for the manner in which these people worked since my role concerned their 'fitness to practice'. I retreated

from difficult situations sometimes because I had been 'marginalized' by management and at others when I perceived I had no control. For instance, there were times when I was prevented from sanctioning a practitioner whose conduct exceeded the bounds of acceptability. Which should have priority – the comfort of the researcher or the longer term gains of research? I decided to sit out the discomfort, record the data, wait to publish an analysis and then try to influence reform. Certain individuals with whom I worked cannot escape moral responsibility for their acts or omissions; neither can I. Writing about hospice, however, making my data available, and other means of engaging in attempts to change policy will hopefully provide a continuing context for working through the difficult moral issues posed by my research and my personal responsibility for the covert stance of my observations.

A more important concern for me once I'd left the hospices, was to protect the people about whom I would write. Some informants made extremely contentious comments about sedation practices at these hospices. How should this information be handled? Were they being naïve or unprofessional? (Cant and Sharma, 1998: 244). My aim was to guard against undeserved harm being caused to them and some practical steps were taken to this end. This brings us to a serious matter that I had to consider - the potential possibility that certain 'judicial or legislative' authorities might 'subpoena' information (Nachmias and Nachmias, 1994: 86) acquired during this study particularly as it pertains to 'sedation practices' discussed in chapter eight. The purpose of including this information was not to create a witch-hunt of any particular individual(s) but to prompt more realistic debate about a topic proponents of hospice have placed 'off-limits' i.e. euthanasia and physician assisted suicide (Caplan, 1997: 17). Firstly, safeguards from harm; – (A) whenever I refer to my hospice research, all place and

identifying names have been changed in the interest of anonymity. For maximum protection the data has been anonymised beyond the level of the region so that individual respondents cannot be traced; (B) secondly, steps have been taken to ensure the security of the data by separating 'identifying information from the research data' (Nachmias and Nachmias, 1994: 86) e.g. the codes that link certain data to particular individuals have been separated and stored in different safe places; (C) thirdly, I have used 'crude report categories' within the thesis to protect individuals within the teams whose numbers are small, e.g. social worker, therapists such as occupational, Diversional, complementary or physiotherapist maintenance person, secretary, chaplain, (Nachmias and Nachmias, 1994: 87). Therefore, aside from using terms such as nurse, healthcare assistant or doctor, all other employees are referred to by generic terms such as allied health professional or ancillary worker rather than specific occupation. When the findings of the study are disseminated I will take further steps to thwart any 'ability to match certain information with the identity of research participants' (Nachmias and Nachmias, 1994: 85) and thus 'protect them from those who read such narratives to discover who's who and who did what to whom, thriving on and filling their own emptiness through others' secrets' (Nafishi, 2003: author's note in *Reading Lolita in Tehran*) by excluding certain information from publications (Nachmias and Nachmias, 1994: 85). (D) fourthly, when preparing this thesis for submission and future publication I took into consideration the fact that medical records are destroyed after eight years and thus records about the events that are discussed in chapter eight are now non-existent. Nevertheless, in the final analysis I am prepared to follow in the footsteps of Russel Ogden (who undertook research on AIDS and assisted suicide in Canada in 1994) who was found 'in contempt of court for refusing to breach an undertaking of confidentiality to his research

subjects, who in law, would be guilty of murder, or aiding and abetting a suicide' (Voluntary Euthanasia Society Newsletter, 1996: 16). The court later ruled that social science researchers have a qualified privilege to maintain confidentiality on the basis that such research constitutes a significant contribution to society, a privilege I am prepared to assert. A different risk to the sociological community also had to be considered: it might be said that sociologists cannot be trusted! This is a risk I have been prepared to take and will defend rigorously. The final research account will be published as well as presented in a form that is accessible to hospice practitioners through contacts made at regional and national level and a database of contacts which has been maintained throughout the study.

1.16 Conclusion

This thesis is an historical study with the 'grand narrative' of hospice as its focus. It is a way of using history to understand present practices; a perspective that attempts to bring certain questions into view. The main focus is on second and third wave developments where my basic categories for observational purposes were provided by the 'grand narrative' of 'modern' hospice i.e. the three goals of hospice. Quite simply, do they or do they not *happen* in practice? If they do occur in practice, how and in what way does this manifest? If the goals are not achievable in practice; what are the obstacles to their realisation? I am looking for 'gaps' in what was *considered* true – i.e. for any mismatch between theory and practice or 'rhetoric and reality' (Lawton, 2000). To that end, observation of practitioners in action along with dialogues with those same practitioners whose job it was to translate the 'grand narrative' into practice enabled me to determine whether the 'goals' were achievable within these hospices. My education practice provided both pedagogic and research 'instruments' with which to gather

information at micro level in order to highlight patterns of regularity or difference between the grand narrative and practice.

By describing and analysing what my colleagues took-for-granted in this thesis I am able to demonstrate they accepted an 'imagined' (Rose, 1999) view of hospice work, a contestable version of 'reality' laced with the potential for illegality and error. This is not argued from the evidence of one or two dramatic incidents but a myriad of views coloured by my wider experiences within this arena and observations of the routine and commonplace. Social science, so conceived, blows a whistle on the safety of the taken-for-granted structures and contours of the hospice world. The appearance of hospice work is not its reality, and portrayals of this world by leaders, proponents and writers will be shown to be error, at the level of practice for these particular hospices and at macro level in terms of hospice's ideology. This research, carried out from the inside, penetrated the surface appearance of the world of hospice to reveal a rather different reality. If academic curiosity was a driving force for my research, that curiosity was tempered by moral concern to weigh up hospice practice and, in the longer term, to change it.

I have deliberately chosen to take a particular viewpoint that does not valorise hospice. A view, absent from the vast literature on hospice with a few exceptions, e.g. Clark, (1997b,1999), Lawton (2000), (McNamara 2001) and the more recent critique of the philosophy of palliative care by Randall and Downie (2006). This thesis then is a challenge to hospice, a refusal of the story proponents have told and continue to tell about their activities. What I am doing is exploring what has been 'taken for granted' in the history of hospice and subjecting it to a kind of scrutiny which is absent in the literature on hospice.

In this chapter I have attempted to be clear, coherent and transparent as regards the methodological and theoretical perspectives that inform my approach to this study and I have justified and outlined my approach. I have indicated the qualitative methods to be used, drawing attention to their strengths and weaknesses. I have also highlighted peculiarities of this study such as the adoption of a covert approach to observation and outlined the various steps involved in data collection. Additionally, I addressed ethical issues and the position of the researcher. I have provided information about the theoretical framework of analysis which incorporates sociological literature deriving from perspectives such as governmentality, knowledge communities, professionalization and medicalisation as well as practical details of the methods of analysis. Having explained the research design and theoretical perspectives utilised, the next chapter will present the first element of textual data analysis. Chapter two explores the historical landscape where dying came to be viewed as a problem in British society with hospice presented as a solution to that problem.

Chapter 2

Hospice in a Historical Context

It is culture, not nature, that draws the line between defilement and purity, clean and filthy, those crucial boundaries disgust is called on to police (Miller, 1997: 21).

2.1 Introduction

My first key question in this study investigated 'How and when did certain 'authorities' in British society begin to view dying as a 'problem' to such an extent that a special place called hospice was established? (Rose, 2003:20). To answer that question I explored the social landscape that led to its emergence in the late 1800s, a period I call 'first wave'. I then move on to explore how a 'second wave' of developments following World War Two led to hospice becoming a social movement within which a 'grand narrative' was created about the 'proper' way to provide care for dying patients. Adopting the nomenclature 'palliative care' by hospice proponents in the late 1970s prompted a 'third wave' of developments that led to the creation of a new medical sub-specialty – 'palliative medicine' – and over time a shift away from dying towards a concern with symptom management becomes evident. The chapter concludes with a synopsis of developments between the nineteenth century and the present.

2.2 Population Health

From the late seventeenth century political and mercantilist goals underscored the widespread belief that a nation's population was its most valuable natural resource in need of protection: 'This notion prompted initiatives to enhance the productivity of citizens and health played a crucial role in this quest. Workers had to be protected from disease or injury since these conditions represented direct

losses to community well-being and wealth' (Risse, 1999: 236). Much like today, 'preventing sickness through traditional dietary and behavioural means' (Rather, 1968, Niebyl, 1971) lay at the base of a comprehensive programme that stressed 'environmental hygiene and proper lifestyle' (Coleman, 1974).

The concern with population health coincided with the expansion of clinical medicine. Within the new Enlightenment framework the task of bringing illness prevention and medical therapy to the masses represented a dramatic break with previous less optimistic views of the human capacity to tame diseases. It also represented a 'significant expansion' of the role previously assigned to medical practitioners. Society would henceforth become 'increasingly medicalised' especially in light of deteriorating health conditions brought on by population growth and urbanization (Risse, 1999:237). The underlying premise was that sickness could be controlled, removed, and even prevented by the conscious and deliberate application of enlightened views concerning health and disease. By the eighteenth century:

A reductionist medicine emerged in parallel with early capitalism because people were constructed as machines in the production process which had to be repaired (Armstrong, 1986: 34).

Hospitals became living laboratories providing the 'necessary human tools for advances in clinical medicine and pathological anatomy' with institutional cross-infection and persistent high mortality (Risse, 1999: 330). In the 'controlled' ward environment's many people 'alive and dead were selected for systematic study, classification and dissection' (Risse, 1999: 330). As a 'strategy' (Rose, 1999) to 'achieve greater diagnostic certainty and improve professional identity' these investigations relied on the discomfort of *poor* hospital patients whose privacy could be violated in the quest for new knowledge' (Risse, 1999: 330) and treated

as 'no more than clinical research material' (Richardson, 1988: 50). Foucault alerts us to the morality of using poor patients in this way:

By what right can one transform into an object of clinical observation a patient whose poverty has compelled him to seek assistance at the hospital? He had asked for help of which he was the absolute subject, insofar as it had been conceived specifically for him; he was now required to be the object of a gaze, indeed, a relative object, since what was being deciphered in him was seen as contributing to a better knowledge of others (Foucault, 1989:101).

Hospitals became the central space for the creation of new medical knowledge through the application of the medical 'gaze' (Foucault, 2003: 83) 'the source of medical certainty and professional authority' where the human body 'was reduced to a collection of organ systems and tissues in constant flux' (Risse, 1999: 331). These practices serve as a reminder of the manner in which 'professional' knowledge is constructed i.e. that a profession's 'knowledge base' is not a 'pre-given' to be taken for granted (MacDonald, 1995: 160). The 'techniques' used by professions such as medicine are intertwined with knowledge in such a way that the exercise of power is also an information-gathering procedure (Rose, 1999). For example, physicians kept 'extensive notes on each clinical case' and 'in separate columns listed dates, signs and symptoms, pulse and appetite, bodily discharges, food and drink recommendations and drug prescriptions' (Risse, 1999: 251).

The establishment of teaching hospitals in the late eighteenth century can be viewed as a 'pivotal point for conceptualising the body' (Lupton, 1995:23) as we came to understand it in contemporary society – an 'anatomical-clinical synthesis' that became both the 'hallmark and the shortcoming of modern medicine' (Risse, 1999: 331) as it displaced the role of the patient narrative in preference for the professional's own. 'What hitherto had been lacking, the very practice of the art, the observation of patients in their beds' was to become the

new medicine' (Foucault, 2003: 83). This represented a 'shift in medical epistemology from theoretical concerns and hypothetical reasoning to expanded empirical bedside observation' (Risse, 1999: 252).

As the Victorian age dawned in Britain, medical research became a popular field of study. Significant innovations in the research and treatment of disease were seemingly achieved, but ironically disease remained rampant. Doctors depended on their successes to gain funding for further research, and while trying to confer the gift of immortality nothing was more embarrassing than a hospital full of dying patients. Consequently, 'workhouses were crowded with the chronically ill, dying and disabled and, to the relief of this new breed of professionals, it kept them - out of sight - out of mind' (Manning, 1984:40, Risse, 1999).

2.3 Social Danger

The concept of the workhouse, or 'house of industry', had been devised to discourage people from seeking assistance and enormous stigma was attached to them. However, the 'measured dispensing of relief was a useful technique of control, in that 'hand-outs should have strings attached notably that to accept relief should mean loss of liberty' (Porter 1990:131) - in other words, enter the workhouse, described by Jeremy Bentham as 'a mill to grind rogues honest, and idle men industrious' (cited in Porter, 1991: 131). Assisting the poor is a means of 'government', i.e. steering conduct, 'a potent way of containing the most difficult section of the population and improving all other sections' (Marbeau, 1847 cited by Procacci 1991: 151). Confinement in a workhouse offered a 'new solution' for managing problematic social issues caused by transformations in social structures. It was 'new' in the sense that 'for the first time purely negative measures of

exclusion were replaced by a measure of confinement; the unemployed person was no longer driven away or punished; he was taken in charge, at the expense of the nation but at the cost of his individual liberty' (Foucault 1991:130).

'Their main "success" was custodial – they shunted paupers out of sight' (Porter, 1991: 131). They have been described as 'a rubbish tip including the very young and aged, the chronic sick and infirm, rogues, vagrants and village simpletons. Many were unemployed because of 'trade slumps' and the death rate was extremely high (Porter 1991, Richardson 1988). Although the problems of poverty 'were entirely different in cause and extent' the English system of workhouses was implemented in Ireland in the latter part of 1838 following the Nicholls report (O'Connor, 1995: 60).

2.4 Divine Providence or Chance?

In 1834, the Sisters of Charity established and ran a *hospital* in Dublin - St Vincent's - so that 'the poor could access what the rich could purchase for themselves' (Atkinson, 1925). This was the first Catholic hospital in Ireland, all others being run by Protestants. The 'inspiration' for establishing St Vincent's was to provide a 'refuge' from the 'appalling conditions' endured by 'poor' Catholics as witnessed by the nuns when they undertook domiciliary visits and because Dublin's existing hospital service was 'totally inadequate to the needs of the city'(Atkinson, 1925:146). However, because of developments in medicine, it was not long until those same 'poor' patients were being discharged into a social system lacking a support network. St Vincent's hospital, along with other 'chance' occurrences (Hacking, 1991) created conditions conducive for the emergence of an institution solely for the dying. For example, the winter of 1879 witnessed a typhoid outbreak in Dublin. A novice working as a nurse in St

Vincent's contracted it and brought it back to the overcrowded convent where the sisters lived on the outskirts of the city. Simultaneously, weather conditions were extreme and the sewers at the convent froze. This helped to spread the disease, resulting in the infection of sixteen nuns and although none died it concentrated the mother superior's mind that the sisters needed larger premises in which to live (Butler, 1981: 125). Shortly afterwards the nuns did move, leaving an empty building which was subsequently transformed to create a hospice for the dying. The role of 'chance' is often overlooked in historical accounts and the above events would have been regarded by the nuns as 'divine providence' i.e. God's will, but as Hacking asserted 'I am interested in the growth of the possibility that real chance exists and is part of the underlying structure of our world (1991:187). If not for the weather conditions, combined with typhoid, at this historical juncture hospice might not have emerged in the form we have come to recognise at all.

2.5 First Wave: Hospice for the Dying Emerges

In 1879 'Our Lady's Hospice for the Dying' officially opened. Although a hospice had been established by the same order of nuns in Australia in 1834, this is the first time the word hospice was linked directly with the word dying in this part of the world and was intended to mean - a resting place in the journey of life before the final stage of passing into eternity (Atkinson, 1925).

It is not a hospital, for no one comes here expecting to be cured, nor is it a home for incurables, as the patients do not look forward to spending years in the place. It is simply a "hospice" where those who are received who have very soon to die, and who know not where to lay their weary heads, where patients are surrounded by religious consolations (cited by Goldin (1981: 390) from 1893 text by O'Carrigan, 1977).

We can surmise from this that the 'identities' of patients were constructed within a religious discourse, i.e. death is not a terminus – patients were journeying to another life beyond this earthly one in 'a haven of peace and rest where they can prepare for the last voyage' (O'Donnell, 1981: 30). Like their ancestor the infirmary, hospice enabled the nuns to 'reclaim the souls' of the dying whilst attending to their bodily needs (Risse, 1999: 237).

The nineteenth-century hospice ushered in an era of recognition of dying as a *process* and the *institutionalisation* of that process (Humphreys, 2001:150). Newspaper reports hailed the opening of the hospice as 'a unique charity' and 'one previously unknown in these islands, or indeed in the neighbouring continent' (Butler, 1981).

It is truly a work of the noblest charity . . . Solitary, miserable, uncared-for death beds are too common even in this Christian land, and yet all who ever seriously think of death, cherish in their hearts this one hope, that in their last hours they may rest in an atmosphere of religious peace (The Freeman's Journal, Dublin, December 10th 1879).

2.6 The Fabrication of Dying as a Problem

The patients usually came from poor tenement houses where in noisy, crowded, disagreeable surroundings there was no peace or quiet to prepare for death (Hospice Report, 1882 cited in Butler, 1981:130).

This 'official' quote provides us with a clue about the construction of a 'problem' during a particular historical period and the articulation of that problem as a focus for some form of remedial action. The 'explanatory' language used helps the reader to 'visualise' who is to be helped – or 'governed' (Dean 1999: 30) - as well as implying that individuals who could not prepare for death were having 'bad deaths'. Hospice as a distinct institution represented a new 'solution' to the predicament of dying at this historical moment.

The development of hospice might be viewed as a 'dividing practice' separating the living from the dying, corpses being particularly offensive to both sight and smell. At that time corpses were feared and blamed for the spread of disease and 'excrement, mud, ooze, and corpses provoked panic'.

This anxiety, flowing from the peak of the social pyramid, sharpened intolerance to stench. It fell to the sense of smell to destroy the confused issue of the putrid, to detect miasma in order to exorcise the malodorous threat (Corbin, 1994:230).

Such miasma would not have been difficult to detect in and around Dublin tenements in the latter part of the 1800s as the following quote aptly indicates:

The lanes and streets are filled with filth in Ringsend and Irishtown; there are no sewers; no attention is paid to the ventilation of houses, and the poor are obliged to buy even the water which they drink; it is often of the worst description, and tends to promote disease as much by its scarcity as by its quality. The poor have no bed clothes; we have often seen them expire on dirty straw, and are frequently obliged to furnish them with covering before we can approach to administer to their wants (Aikenhead, 1833 cited in Atkinson, 1925:134-5).

Is it possible that the establishment of hospice represented a means of 'gathering up' of offensive material from public spaces, to shield the eyes and sensibilities of those most likely to be offended by such sights and smells? – the then growing middle classes. Any attempt to reduce the number of these visible 'eyesores' from the streets would most likely have been applauded by those whose developing sensibilities might be offended (Rugg, 1999).

What can be observed is simply that "delicacy" or rather, the threshold of repugnance – was advancing. In conjunction with a quite specific social situation, the structure of feelings and affects was first transformed in the upper class, and the structure of society as a whole permitted this changed affect-standard to spread slowly (Elias, 2000: 98).

Since the sisters targeted 'the poor' as recipients of their benevolence, might it be possible that the establishment of hospice enabled the nuns to clear 'dirt' off the Dublin streets just as their ancestors did with vagrants in the 1700s? This is

speculation since the claims made in 'official' accounts are contradictory and merit further probing. The point to note is that only certain kinds of dying were visible on display at this historical juncture those who were poor; and this visibility was only evident to those who ventured among them. The middle classes could afford to have home visits from a doctor so their dying was more private.

2.7 Techniques of Judgement

Apart from 'enclosing' and separating dying patients from others in a 'special place' (Lofland, 1978), what 'techniques of judgement' (Rose, 1999) were used to determine who should be admitted to this institution called hospice?

While the workmen were still busy at the house, and long before the date fixed for its opening, the sisters were asked to admit two very deserving patients, a young medical student, aged twenty-four, and an elderly lady who had been a governess for years. Both were in the last stages of consumption, and both reduced to extreme poverty (Atkinson, 1925: 435).

So not the poor from 'tenements', since some people were *more* deserving than others – indeed, 'very deserving'. A new discourse about the 'poor' had arisen separating those perceived as 'deserving' - the 'industrious' or those amenable to 'moral' teaching - from those perceived as 'undeserving' e.g. forced to rely on the Poor Law for economic and medical assistance, which included those who were chronically ill or incurable. Victorian Britain developed 'distinct class-bound death cultures' which 'can be traced to the early 1830s' (Richardson, 1988:262) and society developed strong ideas pertaining to the respectability or otherwise of individuals. Elias (2000) alerts us to the 'civilizing' social psyche that was developing in an historical period within which, to be civilized meant, along with being polite and good mannered, being clean, decent and hygienic in personal habits, traits which the poor certainly did not display since the nuns were 'obliged

to furnish people with covering' before they could attend to them (Aikenhead, 1833 cited in Atkinson, 1925:134-5).

From its inception first wave hospice defined itself by the people it *excluded* offering us a flavour of the mindset of the time. Unlike their ancestors in the 1700s, incurables who might be classed as 'shocking to the sight' were *kept out* in favour of those whose disease remained invisible *within* the boundaries of the body 'out of consideration' for 'others' (Atkinson, 1925).

The only qualification for admission is that a patient should be suffering from some incurable disease and that his or her expectation of life should be of short duration. It is not customary, except on rare occasions, to admit those suffering from infectious diseases, mental disorders, chronic paralysis, and some forms of external cancer. These restrictions have been imposed out of consideration for the patients already in the wards of the Hospice and because of lack of suitable accommodation for their reception (O'Farrell 1945:45).

In other words, the hospice catered for more *manageable* patients. The rooms vacated by the novices were usually reserved for private (fee paying) patients and not for the ordinary, but 'deserving', poor who were placed in large open wards. In this way, space was utilised in a manner that enabled the nuns to keep patients within their field of vision or 'common 'plane of sight' (Rose, 1999). The two 'very deserving' people above were offered 'rooms' because the wards were not ready for habitation. So, as well as criteria for admission there were also criteria for *positioning* within this enclosure. Consider the following descriptions of the building:

With bright sunny wards, trees and birdsong without, an atmosphere of peace within, the dedication of the sisters, the comfort of the patients assured with tastefully curtained beds (Evening Telegraph, Dublin, June 16th 1880)

The delicately tinted walls, the white enamelled bedsteads, the dainty screens, the flowers, which always seem to be there in profusion, all contribute to make the hospice a singularly pleasant and home-like institution (A visitor's comment recorded in the Hospice Annals 1880).

Now contrast these with a description of hospitals of the same period 'Cold, naked, clean, half-workhouse and half-jail (Henley cited in Goldin, 1981: 391). Although not explicit, each of the above descriptions alludes to the privacy accorded patients through the use of 'screens' and 'curtains'. Such privacy in hospitals was unheard of at the time. What might have been happening then? Bearing in mind the social conditions in which the 'poor' were said to live at that time (one third of the population of Dublin's inner city lived in single room accommodation), and the way they were perceived, the 'pleasant and homelike institution' referred to above would have been nothing like the tenement homes the 'poor' inhabited. Screens might be viewed as a 'disciplinary' strategy i.e. space ordered in particular ways to maintain order by separating individuals.

However, it is equally feasible that the 'singularly pleasant and homelike' hospice reflected a particular kind of home inhabited by certain kinds of people, e.g. those who were 'respectable' thus deserving – i.e. the middle classes, who, by this epoch, developed a certain 'delicacy of feeling' (Elias, 2000: 98). Such persons would likely be 'embarrassed' by any lack of privacy which etiquette of the period demanded, e.g. 'that all natural functions should be removed from the view of other people' (Elias, 2000:115). Since the nuns were drawn from the middle classes (they had to pay a dowry to enter the convent in those days) they were able to model their hospice along the lines of their own 'singularly pleasant' homes. It is clear then, that the nuns had a very specific kind of 'poor' person in mind irrespective of claims in 'official accounts'.

Another 'technique of judgement' useful for monitoring 'conduct' was confession. A 'good death' at this historical juncture whether Catholic or some other brand of Christianity meant having time to 'prepare', i.e. spend time in spiritual contemplation so as to achieve 'salvation'. Taking a lead from their

medieval predecessors a practice central to 'preparing for death' for Catholics was that of 'confession' (normal discourse in Catholic Ireland) viewed as a means of achieving forgiveness for earthly transgressions and thus a 'good death' secure in the knowledge of a place in heaven. The last sacraments also included anointing the body with special oils to ward off evil. In Britain the evangelical movement of the nineteenth century revived the Christian ideal of the 'good death' which can be traced back to the medieval tradition of *ars moriendi* – the Christian art of dying well. However, this ideal could only be aspired to by those occupying certain social strata. Contrary to assertions in 'official' accounts that infectious cases were not admitted to the hospice, the majority of patients between 1879 and 1915 suffered from 'consumption', which had 'no pity for blue eyes or golden hair (Butler, 1981: 133) - i.e. TB (70%) - with the rest having other diagnoses including a few cancer patients (Atkinson, 1925, Butler, 1981, Healy, 2004, Humphries, 2000). Since dying from TB was a prolonged process there would have been ample time to 'prepare the soul' for the afterlife.

2.8 Dissection

Yet, a noteworthy factor relevant to our discussions in this thesis remains silent, below the surface or has just not been articulated in 'official' accounts. By this I mean dissecting practices which were rampant at this historical moment. The Sisters of Charity asserted that the hospice was established to cater for the dying poor purely *because* they were poor, yet they prioritised the 'deserving' poor. I remain unconvinced by their claims to altruism especially in light of further indignities which complemented confinement practices during the nineteenth century as cogently illuminated by Richardson (1988). She argued that the Victorian poor did everything they could to avoid the harsh indignity of entering a

workhouse because the Anatomy Act of 1832 branded them as 'social outcasts' to be handed over to anatomists upon death. Unclaimed bodies in hospitals were also handed over.

Communities throughout Britain reflected this concern about dissection in the first half of the nineteenth century with increased vigilance to the security of the corpse in the form of the 'wake' and for the wealthy extra strong coffins and vaults (Richardson 1988). It is against this social landscape that the emergence of hospice must be viewed. Firstly, the sisters' concern for a 'refuge' ('haven') specifically for the *dying* alerts us to things not said. What is a refuge if not a place of shelter from some perceived danger? Perhaps what was perceived as dangerous was not medical technology, nor medicine's lack of interest in those who were incurable, or the 'appalling' living conditions of the poor; perhaps it was *dissection* that the dying needed refuge from. And the ones to be protected were not 'the poor' who lived in 'appalling' conditions but those perceived as 'deserving'.

For the first ten years of his service at St Vincent's, O'Ferrall worked with amazing industry, examining the symptoms of every patient, and studying closely the morbid results in every fatal case, in the convenient pathological theatre which he designed (Atkinson, 1925:155).

Dr O'Ferrall was obviously very keen on dissection since he designed his own 'post mortem ward' a practice the sisters could not have failed to be cognisant of since contrary to the tenets of their religion *they* created the space for his 'pathological theatre' by 'breaking down the stables' (Atkinson, 1925).

If St Vincent's has made strides as a teaching institution, and if it has done its little part in helping to alleviate human suffering in every form, this is mainly due to the zeal, energy and efficiency of the medical staff, whose whole-hearted devotion to the suffering poor lightens considerably the responsibility of the sisters (Atkinson, 1925: 442).

However, the poor 'suffered' at the hands of medics purely because they were viewed as mere 'clinical research material' (Richardson, 1988: 50). According to the sister's 'official' account evoked to justify establishing a hospice, these same poor were thrown onto the streets when they became incurable or were dying. As the anatomist William Hunter proposed, dissection was important as it ensured *not* 'devotion to the suffering poor' but that medical students acquired the 'necessary inhumanity' – i.e. 'a clinical sense of detachment from the human body' (cited in Lock 2002:301). Lock argues that preserving dissected body parts were considered important skills at that time and 'the knowledge of members of religious orders about preserving holy relics would have been valuable in this work' (2002:301). Secondly, is it possible that the nuns or someone at St Vincent's hospital, wittingly or unwittingly were gaining financially from 'poor' dead patients since there were concerns about an 'export trade' in corpses in Ireland from the early 1800s? (Richardson 1988:102).

With these points in mind it is quite possible that first wave hospice developed as a reaction to fear about dissection which was contrary to the tenets of Catholicism. Not only Catholicism, dissection was 'disowned entirely by the [Christian] Church' (Lock, 2002:301). Since the medical profession were reluctant to openly discuss dissection – 'there seem to have been a self-imposed medical silence upon the subject' (Richardson, 1988:97), it would have been very difficult for Catholic nuns to raise concerns considering political tensions between Ireland and England at that time. However, there was room to 'resist' and the form that this resistance took was the establishment of a 'special place' to die - hospice (Lofland, 1978) - where the nuns, not doctors were in control.

Thirdly, since Catholics have particular reverence for the dead body especially in relation to 'resurrection' issues, it is likely that rumours spread

among the lay population about the fate that befell paupers upon their death. For instance, 'the belief that anatomists allowed human remains to be treated as offal was widespread during the late eighteenth and early nineteenth centuries' and a bodysnatching investigation in 1795 had been told that 'human flesh has been converted into a substance like Spermacetti, and candles made of it, and . . . soap has also been made of the same material' (Richardson, 1988:97). Therefore, it is quite feasible that Irish Catholics were so determined that this fate should not befall them that they supported the Dublin hospice knowing no dissection would be carried out there (that we know of) hoping their support would gain them entry at some later time if necessary. Despite their silence on the subject is it any wonder that the nuns in Ireland were keen to establish a 'useful space' for the 'exclusive use of the dying' (Atkinson, 1925) – a 'refuge' where they could safely journey from one world to another in one piece. This speculation is based on an assumption that dissection was not performed on hospice patients.

2.9 Gateway to London

In 1905 the Sisters of Charity established another hospice, St Joseph's in Hackney, to provide for the large Catholic 'poor' population in London.

St Joseph's Hospice, it is said, was the reward of Father Gallwey's thirty years of prayer. It had been the dream of his life to see a Home in London where the poor who were considered ineligible for other hospitals might die in peace, fortified by the consolations of religion. . . . There are no barriers to race or creed in this little outpost of Heaven (Atkinson 1925: 453-4).

Perhaps there were no 'barriers to race or creed' but when it came to the matter of social class, as in Dublin exclusion or 'dividing practices' become evident. The class bias is apparent in the list of subscribers where 'the names of many of the

highest Catholic families in England are to be found' as well as in 'official' accounts as the excerpts below testify (Atkinson, 1925:454).

Father Gallwey, who had intense sympathy for people of gentle birth in reduced circumstances, was gladdened before he died by the knowledge that many a poor wreck of better days had drifted into the hospice to die (Atkinson, 1925:454).

In other words the 'deserving' saved from the indignity of becoming 'tainted' with the title 'undeserving' (Porter, 1990). Despite claims that the Sisters established a hospice in London to cater for poor Catholics in *that* city, the following extract suggests otherwise:

The story of Frank X., a young man of this type, [i.e. of 'gentle birth'] is interesting and edifying. He wrote himself explaining to the Rev. Mother that he was in the last stages of pulmonary tuberculosis, and asking her to admit him to the hospice. The journey from the Western shire, where he lived, to London, was a big undertaking for one in his condition (Atkinson 1925: 454).

Once admitted he was found to be:

A man of culture and refinement, with a genial manner and a fund of kindly humour, he won the hearts of all around him. He was a grand Catholic too and always showed the greatest fortitude under his many trials. He had two brothers' priests who were very devoted to him (Atkinson, 1925:455).

First thing to note, this patient was not a 'poor' Irishman living in London. Second, even if the patient had not possessed the characteristics attributed to him, his 'priestly' connections would have been more than sufficient to secure this patient a bed at the hospice, since this would have enabled the sisters to see him as 'one of us' - i.e. occupying the same 'habitus' (Bourdieu and Waquant, 1991). The quest for 'respectability' continues if only by association: 'Another Irishman aged eighty four, who had been for many years connected with a leading Dublin newspaper . . . (Atkinson 1925:455). In other words this patient and the others above were 'constituted' as respectable and thus 'deserving' of the sister's

ministrations. Just as the residuum that fell into the social sink could, 'by being in it, become it' (Best 1987:150), one could attain respectability by association with it. Perhaps charity is really self-interest masquerading as altruism?

Despite cloaking their endeavours in the rhetoric of altruism it is apparent that religious orders did discriminate against certain categories of people at this historical juncture. Christian charitable endeavours imply a lack of discrimination towards the recipients of their charitable efforts and 'official' accounts of their activities encourage us to 'imagine' this is the case (Rose, 1999). 'Official' accounts, first wave hospices' 'grand narrative', are what Foucault called 'the internal discourse of an institution – the one it employed to address itself, and which circulated among those who made it function' (1978:28). I am not making a judgement as to the rightness or wrongness of the sister's discursive 'tactics', but merely pointing out that they were discursive 'tactics' in light of what it was *possible* to say at a particular historical juncture.

We are downstairs again in St Joseph's Hall, as they name the small central vestibule with glass walls. There is a piano here and an American organ, plenty of chairs, and some of the flowers that are everywhere. Lucky people, who can play and sing, sometimes give a concert to the household. . . . one comes upon the secret of the peace and joy that is the very atmosphere of this house (Atkinson, 1925:457).

It would take a very long stretch of the imagination to associate piano playing and abundance of flowers with life in a tenement building. However, both the Dublin hospice and St Joseph's set a precedent for later developments. Yet the sisters were not much interested in the 'process' of dying *per se* but in what happened to the person *after* death and that meant ensuring that the person arrived on the other side 'whole', duly repentant for earthly misdemeanours by utilising the dying process in specific ways to ensure this.

2.10 Second Wave: Re Emergence

From 1905, there were no further hospice initiatives until the mid 1960s, when St Christopher's Hospice, London was established by Dr Cicely Saunders. This time around, hospice spread rapidly into a 'social movement' - first in the UK, closely followed by America, and finally more widely. Apart from when it is necessary to refer to theorists or social matters elsewhere that have particular resonance, I confine myself to the UK, where I propose there is a 'grand narrative' about hospices espousing certain claims, ideals and practices.

This 'late modern' situation was one where the ideology of 'good death' became intertwined with 'new' fashionable notions concerning individual autonomy, rights, choice, control, community, 'truth telling', 'open awareness', but especially the expression of feelings whereby 'key elements from new technologies for the management of productive subjectivity' became paramount (Rose, 1999:117). These new techniques 'claimed the authority of science, for they were backed by elaborated psychological theories' (Rose 1999: 117). Second wave hospice advocates were the first to utilise these techniques that addressed not only patient's physical symptoms but their personal, social, psychological and spiritual concerns also. Hospices called this new approach 'holistic care'.

Unlike first wave hospice, second wave proponents opened up a space for a new field of healthcare practice by contesting or providing a 'counter narrative' (Petersen, 2003) to others that prevailed about dying in mid twentieth century Britain. This period might also be described as 'emergence' - the 'entry of forces' - the beginnings of a usurping of power. Emergence in this sense 'designates a place of confrontation' (Gordon, 1991). What was being confronted

was the manner in which society and its institutions *managed* the dying process. It was nothing less than a 'grand' attempt to change the healthcare system.

2.11 Attitudes to Dying

By the mid twentieth-century, the subject of death is said to have become taboo (Aries, 1974, Clark 1993, Mellor 1993, Walter 1994), while the site of death was displaced from home to hospital, where 'physicians and hospital teams became the new masters of death, of its moment as well as its circumstances' (Scrambler, 1991: 99). From the 1950s onwards, finding ways to cure disease, forestall death and prolong life became the focus of public and professional expectation.

Within half a century death began to be perceived as the monopoly of the elderly and society's preoccupation with death receded' (Jalland, 1999: 248).

Commentators suggested that institutionalised dying amounts to a 'denial of death' (Aries 1983, Clark 1993, Gorer 1955, Illich 1977, Littlewood, 1993) in the sense that dying becomes hidden away, sanitised and removed from society's view. I agree with Seale (1987) who suggests that Aries may have been mistaken. Aries (1974, 1981) who was most influential in perpetuating this view provided an important analysis but overlooked certain factors such as fluctuating economic and societal structures, demographic shifts and the increasing use of mortality statistics from the nineteenth century onwards, thus making each individual death a public issue. Add to this the huge number of deaths that occurred during World Wars One and Two, which ensured that death retained a high profile. Moreover, Aries (1974) describes institutionalised dying as 'wild savage death', compared to the 'tamed death' of the pre-modern era where people were supposedly in control of their dying. Yet, the 'tamed death' he describes depended on people's position

in the social structure, and, as I indicated above, many people in previous eras endured what could be described as 'savage deaths'.

What is clear is that from the beginning of the 1900s the place of death gradually moved from people's homes to hospitals or other institutions. Contributing factors include eradication of infectious diseases, the establishment of the Welfare State in the 1940, and the National Health Service in 1948 with free medical treatment for all, and a national system of benefits to ensure people would be looked after from 'cradle to grave' (Field and James, 1992). Additionally were changing family structures brought about by divorce, large numbers of women entering the 'paid' workforce and remaining there whether or not they had children, diminishing 'extended families' resulting from demographic shifts with people migrating from their place of birth (Lawton, 2000). The availability of contraception and abortion meant that women could choose not to undertake 'caring' roles. Until the mid-twentieth century, taking care of sick or elderly relatives was the taken-for-granted remit of women. As this pool of unpaid 'domestic labour' dwindled, the elderly and sick had to be cared for in institutions (Sydie, 1987: 105). I have more to say about these points in subsequent chapters in relation to the 'goals' of hospice and in the final chapter when I discuss current end of life policies.

Assertions about advances in cancer treatment and developments in supportive medical measures contributed to the expectation that the inevitability of death could be delayed (Field & James, 1992). For example, improvements in life support systems and precise monitoring in intensive care units meant that people who might otherwise have died could be kept alive with a variety of transplants or artificial mechanical systems.

It was only when hopes of a natural term of life, formally discounted, were increasingly made real in experience, that heroic medicine

acquired its popular basis' and early death became 'adventitious and senseless (Williams, 1990:120).

Life and death had now become 'medicalised' (Walter, 1994) and this was viewed as a negative situation that led to 'bad deaths' (Hart et al, 1998).

2.12 The Social Organisation of Dying

In hospital the dying were all too likely to be perceived as a medical failure and embarrassment, ignored by medical and nursing staff. Nineteenth century doctors knew they couldn't cure most illnesses of any seriousness but were able to use opiates to relieve pain but that by the mid twentieth century the situation had been reversed, with both doctors and public expectations focused on cure, so that the incurable were all but abandoned' (Jupp and Walter 1999: 271).

Yet only certain privileged classes were able to access whatever opiates doctors had at their disposal, and therefore abandoning incurables is not something new to the twentieth century. Corresponding concerns about the poor quality of care of the dying began to emerge (James & Field, 1992) stimulated by the work of people like Gorer (1955, 1965), Feifel (1959), Glaser and Strauss (1965, 1968), Hinton (1967) and Sudnow (1967). Two powerful sociological studies described the social process and the social organisation of dying and death in modern hospitals. Glaser & Strauss' *Awareness of Dying* (1965) in which they introduced 'the dying trajectory' in the context of 'good' or 'appropriate death' whereby the quality of interactions for all concerned were such that the dying person reached a state of 'open awareness' about their forthcoming demise. Sudnow's (1967) *Passing on: the Social Organisation of Dying* revealed the routinization of dying and death highlighting how organisational efficiency had become more important than human dignity. His work described the medical shaping of the management of dying, institutionalisation and suppression whereby the dying person's autonomy was overridden by hospital staff and the organisation of their work.

Add to this Kubler-Ross's highly influential work addressing itself to the *manner* with which people coped with a terminal prognosis, particularly her 'stage-theory' (1969); Dr Cicely Saunders' proclamations that dying could be fulfilling both for the patient and those caring for them (1965), and we have the seeds of possibility for the emergence of 'counter discourses': the 'death awareness movement' in America or 'happy death movement' (Lofland, 1978), and the 'modern' hospice movement in Britain where the ideology of the 'good death' became paramount (Hart et al 1998).

2.13 Conditions of Possibility For Second Wave Developments

Dr Cicely Saunders trained first as a nurse, then as an almoner, and finally as a doctor, during which time she developed a special interest in patients dying from cancer and the relief of pain in terminal illness. In 1948 while working as a medical almoner (today's social worker) in a London hospital, she had a 'brief but intense relationship with a patient who was dying of cancer – a Jewish émigré from Poland' David Tasma - with whom she discussed the possibility of opening a home so that people like him could find peace in their final days. 'She worked out with him the faint outlines of the kind of institution he needed and would never live to see' (Goldin, 1981: 384). He 'famously' left her £500 in his will to 'be a window in your home' (Clark, 2002). Interesting that nowhere in the literature was this considered unethical. It certainly would be today.

Shortly after his death, Saunders went to work as a voluntary nurse at St Luke's Hospital in Bayswater where she spent seven years in a part-time capacity. Initially called '*St Luke's House, Home for the Dying Poor*' a medical project of the West London Mission, established primarily to care for the dying in 1893 by Dr Barratt, a Methodist (Goldin, 1981). When Saunders arrived at St Luke's, staff

were managing patients' pain by providing regular analgesia. In general hospitals at that time, analgesia was usually prescribed to be given six to eight hourly. This meant that once the effect of the drugs wore off patients would be told '*it's not time for your medication*' or '*you will have to wait*', and '*patients would be left screaming in agony*' (Saunders, 2003 interview with the author). Doctors were reluctant to prescribe more liberally because they were afraid this would result in patients becoming addicted. Saunders' experience at St Luke's provided the necessary conditions that enabled her to develop the biomedical aspect of her 'strategy' for a 'modern' hospice. Having qualified in medicine in 1957, Saunders took a research post at St Mary's Hospital, London which led to her working at St Joseph's Hospice in Hackney; part of the catchment area.

The time for active treatment is over when patients are admitted to our wards. The decision that all that can now be given is comfort and care, and that too much activity would merely be a useless disturbance of peace (Saunders 1965:2).

This, suggests Clark (2002: 8), provided Saunders with a 'source of inspiration about how dying people might be cared for elsewhere' *and* a 'testing ground for the development of her own clinical ideas' regarding pain management. Saunders, it is said, was impressed with the 'humane' approach to care offered by the nuns at St Joseph's and the approach to pain relief developed at St Luke's and determined to combine the two.

2.14 Evocation of the Enemy

During the late 1950s, Saunders embarked on a 'decade of preparation' during which she developed her 'strategy' for transforming care of the dying and developing the first 'modern' hospice (Clark, 2002). This involved articulating her

ideas to a wider audience in the form of pamphlets. The extracts below offer a flavour of their content:

It appears to me that many patients feel deserted by their doctors at the end. Ideally the doctor should remain at the centre of a team who work together to relieve where they cannot heal, to keep the patient's own struggle within his compass and to bring hope and consolation to the end (Saunders, 1958:46).

Death is feared, all thoughts of it are avoided and the dying themselves are often left in loneliness. Both in their homes and in hospital, they are emotionally isolated even when surrounded by their families or involved in much therapeutic activity. When we do come near them we tend to look at them with that pity which is not so far removed from contempt (Saunders, 1965:1).

Strong words, but such words would open up a space for a new field of healthcare practice. Between 1958 and 1968, Saunders published 'fifty-six articles, pamphlets, and reviews' (Clark, 1988a). In parallel with the publications Saunders undertook a 'growing schedule of talks, lectures and teaching sessions' (Clark (2002: 8). Lecture tours to the United States took place in 1963, 1965 and 1966, each one leading to wider recognition, whilst at St Joseph's there were regular ward rounds for medical students. The following excerpt from a talk given at St Mary's Hospital, London offer us further clues into her strategy. 'I am fortunate too . . . above all, in being a doctor who isn't in a hurry, so that I have time to know and enjoy my patients', the implication being that this was a luxury (problem?) unavailable to other doctors due to time constraints (Clark, 2002: 8).

I borrowed the phrase 'evocation of the enemy' from Loftland (1978: 88) since I think it aptly captures the way Saunders and her followers developed their tactics of opposition during which process a 'grand narrative' was created. I am not interested in Saunders' 'intentions' *per se* – for instance to make a judgement as to whether she and her followers were right or wrong in their thinking. Rather, taking Rose's (2003) advice, I am 'sticking to the surface' attempting to analyse

arguments, strategies and tactics in their own terms, in terms of the identities and identifications which they themselves construct, objectives they set themselves, the enemies they identified, the alliances they sought, the language and categories they used to describe themselves, the forms of collectivization and division they enacted (Rose, 2003: 56- 57).

Let us ask, how did second wave hospice advocates articulate their ideas about dying and death in such a way that hospice seemed to provide an answer? Firstly, several complaints were made about the way death was managed in British hospitals. To begin with, dying had become hidden in institutions, i.e. hospitals, so that people had become afraid of it; even the topic of death had become 'taboo'. Secondly, within hospitals dying patients were put into side rooms where they were isolated and practically ignored by medical staff (Twycross, 1992). Dying patients were not told they were dying and were offered inadequate pain relief (Saunders, 2003, Twycross, 1992). Indeed, dying patients not only received poor care but some patients 'lacked care in any significant sense having been so heavily drugged they remained unconscious or semi-conscious until death' (Du Boulay, 1985: 1). This latter is interesting considering Saunders's comment to me about patients left 'screaming in agony' above (2003).

The way to reverse this situation was to re-educate people through an 'open confrontation with dying' (Seale, 1989) to inform dying patients of their prognosis so that they were no longer afraid of it (Glaser and Strauss, 1967), to 'return control' to the dying patients and their families (Saunders, 2003). We have assertions that something is 'lacking', that care of the dying is 'bad', indeed 'very bad' because the alternative to care was the use (overuse?) of drugs. This represented a challenge to and critique of mainstream healthcare. A response was needed, something had to be done to correct this state of affairs and Saunders' response was to establish a hospice – St Christopher's, where these shortcomings

would be addressed whilst simultaneously offering humane and compassionate care that dying patients *and* their families deserved.

St Christopher's hospice became the model which, according to the literature inspired other groups around the country to establish their own hospice and within a few years a movement had been formed (Lunt, 1985). 'The movement provided a radical critique of the supposedly impersonal, medicalised, technological management of death occurring in hospitals' (Lawton, 2000: 12). Hospice advocates emphasized *care* rather than cure, *quality* of whatever life was left to the patient as opposed to quantity so that patients were not subjected to aggressive life-sustaining techniques or excessive technological interventions in their final weeks of life (Munley, 1983, DuBois 1980). It is a *seemingly* simple and straightforward story. The 'tactic' or 'strategy' involved setting up oppositions, e.g. overuse of drugs, technology, lack of care and so forth are 'bad', here is an alternative which is 'good'. Lofland refers to this as 'rearrangement activity' which in the British case involved initially the creation of 'a special dying place' – in-patient hospice (1978: 84). I say initially because Lofland suggested two 'rearrangement' activities, the second of which was 'home death' which is of little concern in this thesis where interest centres on in-patient hospices.

However, there is a third 'rearrangement activity' which, although not neglected by Lofland, tends to be ignored or played down in hospice literature, a 'subjugated' discourse, and that is the activity of another 'dying with dignity' social movement who seek legal changes to permit euthanasia or in current parlance physician assisted suicide (PAS). Although I expand on this subject in chapter eight, it is worth noting a few points briefly here. Proponents of hospice are firmly opposed to euthanasia, a concept which derives from a combination of

Greek words, 'EU' (well) and 'Thanatos' (death), meaning 'well death' (BMA, 1988: 3). The Voluntary Euthanasia Society (now Dignity in Dying) established in 1935 by Lord Moynihan, is positioned within discourses of 'rights', 'choice' and 'individualism'. Proponents argue that the law should be changed so that the *right* of individuals to choose *death with dignity* could be allowed (The Last Right, 1995). They argue that hospices' claim to alleviate all pain and suffering is untenable. Unsuccessful attempts to introduce Bills in the House of Lords seeking to promote voluntary euthanasia were made in 1936, 1969, and 1993. In January 1993 the House of Lords established an ad hoc committee to consider the law on euthanasia. More recently the Joffe Bill had several readings between 2003 and 2006 but was defeated by a small margin each time.

2.15 A Single Plane of Sight

In Saunders' view, society should not ignore death; death was to be accepted and prepared for:

The last stages of life should not be seen as defeat, but rather as life's fulfilment. It is not merely a time of negation but rather an opportunity for positive achievement. (. . .) a positive approach to death and dying is to look continually at the patients, not at their need but at their courage, not at their dependence but at their dignity. We have the endless fascination of watching each individual come to terms with his illness in his own way (Saunders, 1965:1).

How might one 'look continually'? Gather patients into one 'special' place (Lofland, 1978) - an 'enclosure' - St Christopher's hospice - the first 'modern' hospice where lessons would be learned and then applied elsewhere by watching with 'endless fascination'.

Not only skill but compassion also. We want to carry out research in the relief of distress such as has not been done anywhere else, so far as I have been able to discover. It is often easier in a specialist setting to go on learning in this way and by building what we think is an ideal unit we hope to be able to help not only our own patients but to raise

standards generally and also to stimulate others to think about these problems (Saunders, 1965:2; pamphlet).

This then, is not just an artfully crafted narrative in response to a carefully constructed need (lack?) but represents what was to set St Christopher's hospice apart from those that preceded it – unlike first wave hospice, where medicine played a minor role, this endeavour straddling religious, medical and biopsychosocial discourses would be combined with *research* and *teaching* which would be put to use not only for the benefit of hospice patients but also 'to raise standards generally' meaning those in the NHS. Therefore, we might anticipate that 'knowledge' derived from, and through, 'observing' patients at St Christopher's would be put to work in the NHS. If in the nineteenth century the dead provided lessons for the living through dissection, in the twentieth century, second wave hospice would provide the necessary 'enclosures' so that dying patients could give up their 'secrets', as well as be enabled to teach the living *how* to die a 'good death'. The 'gaze' henceforth would be 'calculating', i.e. information would be collated and distributed. Patients would be displayed in 4 to 6 bed wards as part of hospices' 'goal' of 'open confrontation with death' (Seale, 1989). Second wave hospice - a different kind of living laboratory than hospitals in the nineteenth century, with display cabinets of dying patients to be watched with 'fascination' within 'a single plane of sight' (Rose 1999: 135).

2.16 Fabricating a Philosophy of Care

Drawing upon pharmaceutical, religious, social, psychological and biomedical discourses, Saunders developed the concept 'total pain' which was to become a central plank of second wave hospice philosophy

Looking at patients with my background I did look at patients as a whole person as part of a family although I didn't see the families

anything like as much there [St Josephs] as I did later here. That's when I produced the idea of total pain in 1964, of physical, emotional, social, family and spiritual search for meaning. I first wrote about total pain in 64 so that was quite a key phrase for the hospice movement (Saunders, 2003 interview with the author).

By treating the 'whole' person rather than just the physical pain hospice proponents claim that the actual pain is often reduced; if a patient feels he is heard and understood the lessening of anxiety leads to a lessening of drug requirements but in any case pain must be dealt with before it occurs, the patient must never have to ask for pills or injections, or wait fearful and ashamed to ask for them (Du Boulay, 1984).

When I arrived at St Joseph's they had virtually no records. They were giving drugs, em patients had to earn their pain relief first. I mean the regular giving was what I picked up as a volunteer at St Luke's and so I was able to introduce the regular giving which was changing from central painful to pain free They [St Josephs' staff] used give the injection an hour before the visitors came. They really did (Saunders 2003 interview with the author).

'Two features become apparent: an orientation to the prevention' as opposed to the alleviation of pain; coupled with a 'thorough understanding of pain relieving drugs' (Clark, 2002: 9). By coincidence or perhaps 'chance' (Hacking, 1999) the pharmaceutical industry was at its most productive developing new drugs to treat a range of physical and psychiatric conditions between the 1950s and 1970s.

The idea of 'curing' was replaced by hospice advocates with that of caring i.e. 'holistic care' thus 'making whole' through a process of healing by paying equal attention to physical, social, psychological and spiritual dimensions. Hospices are committed to providing *holistic* care with the patient *and* their family as the unit of care which is provided by non-hierarchical multidisciplinary teams (Field and Johnson, 1993). These are the goals of second wave hospice.

2.17 Independent Charities

Because Saunders asserted that the changes to care of the dying she proposed would not be possible within the NHS, St Christopher's was founded as an independent, charitable organisation outside it. 'We moved out so that attitudes and knowledge could move back in' (Saunders, 1981: 4). This meant relying on voluntary contributions for capital outlay to build, as well as ongoing running costs. Despite claiming that 'We moved out of the National Health Service with a great deal of interest and support' (Saunders, 1981: 4) it would take many years to erase the bad feeling the earlier comment wrought amongst NHS colleagues, many of whom had become committed to the ideology of social medicine which the NHS represented. During the 1970s and 1980s hospices sprang up throughout the UK, all with charitable status dependent upon voluntary contributions, all offering care to patients with 'terminal malignant disease' i.e. cancer – a few offered three percent of their beds to patients with diseases such as multiple sclerosis, motor neurone disease and later AIDS. Initially most people attracted to the hospice 'ideal', whether as practitioners, sponsors, fundraisers, or volunteers had strong religious convictions and practitioners seemingly viewed their work, not as a job but a 'vocation' or 'calling' (Saunders, 2003).

A central claim of second wave proponents that I view with scepticism is that hospice is a *philosophy*, an attitude or approach to care (Saunders, 1978). This presupposes its transportability into a range of settings. Yet, how did it come about that so many groups throughout the UK considered it necessary to raise large sums of money to establish the many 'bricks and mortar' units that comprise the hospice movement? To what desires in society did it respond? How come 19th century hospice did not spawn a movement? When something is extremely popular there is something in the *Zeitgeist* that makes it seem plausible and

agreeable. If lots of people take something up it is often because it fits in with ideas they already have, i.e. relations of complementarity are established. What ideas did second wave hospice fit with that existed already?

2.18 Harnessing Public Fears

I contend that second wave hospice advocates harnessed a particular public fear in order to promote their cause. Apart from the matters highlighted above, I propose it was *fear* of a particular disease; a disease that broke through all the carefully constructed class barriers in Britain; so feared it was spoken about in whispers, a diagnosis of which carried a death sentence thus undermining the curative claims of the most technologically advanced hospitals. Often people would be diagnosed only to be dead within a few weeks.

‘We, as doctors, are concerned to emphasise that there are few forms of physical distress which cannot be dealt with by good medical and nursing care, that the emotional and spiritual distress of incurable disease requires human understanding and compassion and a readiness to listen and help’ (Saunders 1975). Although Saunders refers to ‘incurable’, she was referring to a *particular* incurable disease, terminal malignant disease, i.e. cancer. The word ‘incurable’ became at this historical juncture a euphemism for ‘cancer’. I further speculate that proponents of second wave hospice, while claiming that general medical services were unable to meet the special needs of the dying, had in mind certain categories of person who would benefit from their ‘compassion’. My reason for postulating this stems from another discourse about hospice, one I became privy during the course of my work with hospices; the matter of social class that I expand upon in later chapters but a few points are worth noting here.

'Glossed over' in the 'grand narrative' is hospices inherent social class bias. Second wave hospices were highly selective in the patients they choose to help (Douglas, 1992, Addington-Hall et al., 1998) while Lawton's research highlights 'the way space was appropriated and used' in the hospice within which her research was conducted. For example, 'side rooms were almost always allocated to middle-class patients' as they offered 'certain luxuries not available to patients in wards', e.g. 'en-suite toilets and bathrooms and remote controlled television sets' (Lawton, 2000: 168-9). I am not saying that people occupying the lower rungs of the social ladder are never admitted to hospices but I do speculate that a tendency to 'favour' patients with certain social characteristics might explain how second wave hospice became a successful social movement since these are the people with the financial wherewithal to support hospices.

The approach of second wave hospice advocates is reminiscent of their ancestors in the 1700s, when the voluntary hospital was a 'private corporation eager to optimize its charitable mission while limiting its financial liabilities' by relying on sponsorship and volunteers paying regular subscriptions (Risse, 1999). However, like many seemingly altruistic acts, such philanthropy had benefits not least of which was the increased social 'status and prestige' acquired by the donor. 'Philanthropy enlisted the ambitious bourgeois in a moral mission a vindication of their own superior moral worth' charity being viewed as 'the most exquisite luxury' (Porter, 1991: 301).

Beneficent gifts will assuage the ills of the poor from which enlightenment will result for the preservation of the rich. Yes, rich benefactors, generous men, this sick man lying in the bed that you have subscribed is now experiencing the disease that will be attacking you ere [sic] long; he will be cured or perish; but in either event, his fate may enlighten your physician and save your life (Foucault, 1977:103).

As Armstrong observed, 'holistic medicine . . . has tended to focus on the relationship of the whole-person to the natural order (without any recognition that what is taken to be the 'natural order' at any one time reflects just as much on the society which so perceives it as on any reality 'out there')' (1986: 28). The 'natural order' within which 'second wave' hospice emerged and constructed its ideology of 'holistic care' was a class divided society, within which 'the old world persists, thank God', i.e. 'traditional values and class distinctions' (Richard Dimpleby cited in Cannadine, 2000:155). The 'old world' being what is known in Britain as 'the establishment' – the upper echelons of society with whom Cicely Saunders had many contacts.

There was a systematic campaign targeted on the major charitable trusts, London's merchants and the upper echelons of the British establishment. I am lobbying peers at the moment, she wrote enthusiastically . . . (Clark, 2002: 10).

This was the 'habitat' within which Saunders was situated – a 'taken-for-granted' 'civilised' world that predisposes those who inhabit it to certain ways of being.

The Americans took Cicely to their hearts. To them she was a classic example of an upper-class English woman – visionary, dignified, enterprising and mildly eccentric (Du Boulay, 1984:225).

I return to these ideas concerning social class at various points throughout the thesis, especially in chapters six and eight.

2.19 Unplanned Proliferation

In the decade between 1977 and 1987 the number of hospices in Britain grew significantly. Yet, I do not want to create an impression that second wave hospice gained unconditional support in the UK. As Doyle put it, there was a;

huge mushrooming in the number of hospice services. . . an increase in hospices, in spite of the Working Party in 1986 saying, 'please, no more hospices', it still metastasised a little bit and like many

metastases it finished off in many places which were not always very desirable. Sometimes within five miles of each other. Oh no, unforgivable' (Doyle, 1997: 3).

Concerns were raised about the possible implications of such rapid and unplanned proliferation by Lunt and Hillier (1981), who found regional imbalance in British provision. The British Standing Medical Advisory Committee recommended in a report in 1980 that there should be no further expansion of hospice in-patient units and made the recommendation that hospices should be evaluated.

In the future every brick we place on top of another brick to help a dying patient will need to be costed against the benefits that money could have funded in terms of community nursing services. . . . The final admission lasts, for the majority, less than two weeks. A quarter of our admissions to St Luke's are dead in three days (Wilkes, 1981:185).

In 1984, a leader in the British Medical Journal recommended that the era of 'well-intentioned amateurism' should be replaced by 'hard-headed professionalism', (pp 1178-1179) and in 1986 the Lancet suggested that 'an academic review of hospice services in Britain is long overdue' (pp1013-1013). Among the reasons for Doyle's comment above was a concern that hospices were not being established in response to *need* and were highly selective about to whom their services were offered. It was a question of equity. Hospices concentrated their efforts and resources on patients with cancer (and continue to do so) leaving what one commentator described as 'an underclass of dying people' (Harris, 1990 cited in Clark, 1993:172). As O'Neil (1989) noted 'within each district general hospital there are elderly people dying with multiple physical and pathological problems who are not usually considered when planning terminal care services' (cited in Clark, 1993:172). This situation remains unchanged. Another group to be excluded were people from black and ethnic minorities leading some commentators to suggest that hospices were ignoring social

differences related to 'age, gender, sexuality, family circumstances, religion and ethnicity' (Clark, 1993:172). Research also indicates that cancer patients in hospices, particularly younger ones, have a 'special status' which is in marked contrast to patients in long stay hospital units or nursing homes (Seale, 1989 cited in Clark, 1993:172). While Douglas (1992; 579) observed 'the hospice movement is too good to be true and too small to be useful'.

Despite these concerns and the fact that second wave hospice has been situated within British culture for forty years, astonishingly, there continues to be a paucity of research regarding 'what happens in hospices' (Seale, 1989). Why is this? Has an assumption been made that the 'grand narrative' represents reality and is therefore beyond question? If so, I do not subscribe to this assumption. A glaring silence of absence is apparent. This thesis attempts to lift the cloak of 'silence and secrecy' that hospice advocates have wrapped round their practices.

However benevolent Saunders' intentions might have been, a central argument of this thesis is that second wave hospice was to become a disciplinary institution *par excellence* - i.e. a 'technology of power' used as an 'instrument for a particular end' e.g. to reinforce an ideology of 'good death' (Foucault, 1991: 215). It may also be viewed as a programme of 'governmentality' where the field of possible action was structured in very specific ways in order to manage the 'conduct' of those who were dying. It is further argued in this thesis that second wave hospice like hospitals in the 1800s, became laboratories for the dying, places where 'a way of teaching and *saying* became a way of learning and *seeing*' (Foucault, 2003:77). Proponents of hospice attempted to harness a 'secret aspect' (Foucault, 1998:138) of human existence - dying; they claimed to have disciplined a particularly troublesome form of dying by framing their assertions

within discursive practices in keeping with cultural conditions of post World War Two British society, i.e. humanism and neo-liberal thought. However, this thesis will show how hospice practitioners disciplined dying by using 'standardized disease centred', *not* person centred techniques. In addition, although they would take many years to propagate, the seeds of destruction were simultaneously planted by these 'techniques of inscription' and the fate of second wave hospice was sealed creating in the process 'conditions of possibility' for third wave developments (Rose, 1999). During this process Saunders' discourse took a U turn.

Anecdotal evidence is replaced increasingly by objective data as the scientific foundations of this branch of medicine are laid. The essentials of good terminal management have been clarified and are now being widely discussed. Advances in this area of treatment (and it is still 'treatment' not some kind of soft option labelled 'care') are now likely to come from the traditional hospital setting as well as from the special units or teams (Saunders, 1988: viii)

This latter quote from the 'grand narrative' alerts us to a shift in language use from earlier commentary where *care* was viewed as paramount to one where it is derided as a 'soft option' (derision is a 'tactic' used by individuals in attempts to replace one discourse with another). Such shifts are brought into sharp relief when we examine the new nomenclature of palliative care, which hospices began to adopt during the latter part of the twentieth century that I now explore.

2.20 Re-framing Attitudes: The Third Wave

If a stable new attitude towards a concept is to emerge, a transformation of meanings must occur, during which, people develop a new conception of the nature of that concept. This happens through a 'series of discursive strategies in which others point out new aspects of the concept, present new interpretations of events, and therefore assist individuals and the public to achieve a new conceptual

organisation of their thought-world' (Oberschall, 1993:201). The process may be viewed as a series of stages during which one social construct comes to replace another.

A source of confusion developed during the 1970s when hospice practitioners began using a new nomenclature - 'palliative care'. To palliate comes from the Latin 'pallium' to 'cloak over' or cover over patients' symptoms, or distress (Twycross 1995). Why did the change in terminology occur and what might it signify? Palliative care was the name given to the hospice approach in the 1970s by Dr Balfour Mount following a period of clinical experience at St Christopher's hospice after which he returned to his homeland and established a service. 'That was the first use of the word 'palliative' as applied to this field, the older word 'hospice' having come to mean custodial, or less than optimal, care in French-speaking Canada (Saunders, 2003 interview with the author). Basically the philosophy and goals of hospice were transferred to a hospital setting. By 'the late 1980s' the terms hospice and palliative became interchangeable (Clark, 2002). This represents the third wave of hospice developments that broadened the scope of their endeavours.

We should be aiming at a provision of palliative care which is more egalitarian and more accessible to everyone in need than is currently the case, even if this means that we cannot provide the resources for a 'Rolls Royce' service for anyone' (Garard, 1996: 94).

The quote offers the reader a sense of unease whereby hospices came to be viewed by some as offering a limited but luxurious service to a tiny minority. At the time, the average bed occupancy in a British hospice was 75%, with throughput in some as low as 14 per bed per annum (Doyle, 1993:16). Because hospices were established outside the NHS this created a distance, quite literally, both spatially and philosophically, between proponents and their colleagues in the

NHS. For instance 'resuscitation' techniques and other life-prolonging techniques, normal practice for those in the NHS were viewed by second wave hospice proponents as merely prolonging dying. Even routinely taking observations of patients pulse, temperature and blood pressure or inserting an intravenous infusion were seen as intrusive. 'So near death were most of our patients that there was little talk of rehabilitation, discharge home, even palliative radiotherapy and chemotherapy. What most struck me then was how many patients came to us in appalling pain and suffering yet still on treatment which even the referring doctors admitted was futile because to stop it would take away hope' (Doyle, 2008). I now trace how second wave hospice transformed its discourses and practices into something 'other' during which process, concepts which helped launch and secure its place in British society became obscured and some subjugated.

2.21 Spreading and Colonising

Palliative care was defined by the World Health Organisation as;

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of Palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable in the course of the illness, in conjunction with anti-cancer treatment (WHO, 1990).

The latter part of the final sentence 'in conjunction with anti-cancer treatment' had unfortunate consequences for the way palliative care services developed leading to a conflation of palliative care with cancer care (which hospices specialised in during the latter stages only) and other confusing matters, e.g. conflating palliation with cure, that are dealt with in the coming chapters.

The WHO definition of palliative care is not dissimilar to second wave

hospices' 'grand narrative' since it was developed out of it. Before long a distinction was being made between generic (general) palliative care and specialist palliative care leading to further confusion. I define the latter presently below. Between 1987 and 1997, there was a 'modest increase in the number of hospices, a bigger increase in the number of Specialist Palliative Care Units', and a vast increase in the number of palliative care teams (Doyle, 1997:3). In 1977 there were four of the latter and by 1997 two hundred and sixty five (Doyle, 1997). This growth can be seen as a response by NHS service providers to recommendation number 10 of the Calman-Hine Report that there is a 'need for a collaborative approach' to providing palliative care and symptom control for patients at all stages of their illnesses. This led to fears about hospice services being swamped by large numbers of referrals and debates about how palliative care was to be provided for all those who might require it; largely confined to hospices who had the most to lose, since they would have to compete for funding with a range of new providers. Although most free-standing hospices remained charities operating in the voluntary sector, the introduction of a 'market' approach in the NHS in the 1990s was to have a significant impact on hospice activity.

April 1991 heralded in what are arguably the most major changes ever to have occurred in the National Health Service; palliative care services, as with all other aspects of health care, are now being provided and purchased against the background of defined service specifications and agreed contracts. Such terminology would just a few years ago have been unheard of or even thought heretical, by carers in this often emotive and public spirited field (Hancock, 1992).

Although funding matters remain unresolved in mid 2008, as a result of lobbying by powerful hospice advocates the Government became more informed and interested in palliative care and every politician is briefed on palliative care (Doyle, 1997). These third wave developments witness a shift from philanthropic,

altruistic, moral and religious discourses to more secular ones concerning professionalization, 'rights' and 'justice' (George and Sykes, 1997:241).

2.22 The Construction of Palliative Medicine

In 1987 the Royal College of Physicians created Palliative Medicine as medical sub-specialty making Britain the first country in the world where palliative medicine physicians were recognised as accredited people on a specialist register. This led to a vast explosion of professional education, first for doctors, later for nurses, followed by allied professions in the ensuing years (Doyle, 1997). Career pathways were constructed to meet the needs of this new group of mono professionals while the Royal College developed specific career pathways for doctors wishing to develop skills in this area. Some hospices in partnership with local universities developed education programmes to assist this process. Since then palliative medicine became an identifiable specialty embracing many disciplines in health care during which time it has been subject to a number of interpretations.

However, unlike other 'specialties', palliative medicine consultants do not have their own patient lists but must rely on referrals from the primary physician making it imperative that good working relationships are fostered and maintained. The years between 1987 and 1997 brought forth thirteen professional associations for people working in palliative and specialist palliative care; the emergence of the European Association for Palliative Care, the National Council for Hospices and Specialist Palliative Care Services, the Journal of Palliative Medicine, Palliative Nursing and the European Journal of Palliative Care. More importantly, why legitimise 'palliation' but not 'care of the dying'? Apart from

the fashion in healthcare for specialisation, this thesis argues that the shift in terminology led to fragmentation of second wave hospices' 'grand narrative'.

2.23 Nothing Special - A Basic Human Right

Hospices gradually moved away from using terms like 'dying' and 'terminal' as evidenced by Saunders when talking about her specialty in the years leading up to the 1987 legitimization of palliative medicine:

Hospice or palliative care aims to help those for whom the acute hospital is not appropriate and for whom the ordinary community services are no longer adequate. It is concerned with the quality of life remaining for them and their families' (Saunders, 1981:4).

It is subtle but the shift is evident, certainly different to how the hospice approach was described a few years earlier:

Some will find it shocking that we should speak of accepting or even preparing for death and will think that both patient and doctor should believe in treatment and fight for life right up to the end' (Saunders, 1973:4).

Moreover, something has been added when Saunders says hospice *or* palliative care. Hospice staked a claim to be offering something different --'special' to *dying* patients - whereas one might reasonably argue there is nothing particularly special about palliative care. As Doyle, a high profile hospice doctor and later palliative consultant (1997) observed, 'palliative care is part of all good care, be it social, clinical, pastoral, and so forth'. He defined palliative care as:

Easing the suffering when we cannot cure, alleviating the pain and the agony, the terrors of the anticipation, the separation, the divided family, the dysfunctional family, the spiritual needs. Palliative care is part of all good care and there is no specialist in it (Doyle, 1997:1).

A dramatic use of language but so important had palliative care become that it became possible to state that 'It is the *right* of every citizen to receive palliative

care when they need it' (National Council for Hospice and Palliative Care, 1996). 'Palliative care – *the care of patients with active, progressive, advanced disease where the prognosis is short and the focus of care is the quality of life* – is a basic human right, not a luxury for the few' (Doyle 2006:1). [Emphasis in original]. Again we have a reference to special treatment of the minority which hospices served. Because of these kinds of 'statements' it became the *responsibility* of every clinician and health care practitioner to provide palliative care leading to even more confusion as services began to expand further. Yet, as Doyle notes, the principles of palliative care:

are not peculiar to the care of the dying but are the integral features of all good clinical care – freedom from pain and the alleviation so far as is possible, of all physical, psychosocial and spiritual suffering; the preservation of dignity; the utmost respect for honesty in all our dealings with these patients and their relatives (Doyle, 2006: viii).

In an attempt to unravel the confusion surrounding palliation, Clark and Seymour (2002: 86) suggest we distinguish between the delivery of palliative care and the philosophy of palliative care. Speaking about the Australian situation, McNamara suggests that palliative care is 'now practised in two different contexts: first as a specialty, by hospice and palliative care services; and second, in a general sense, by health professionals who work in mainstream health care services' (2001: 122). This is similar to Britain, where the 'specialist form' of palliative care tends to be provided by multidisciplinary teams of professionals in the NHS and hospices; whilst the general palliative care, to which Doyle above refers, can be offered in any NHS setting, community or hospital, in nursing homes, and even by social care providers irrespective of disease, but there are implications regarding the 'skills' of practitioners that I address in the final chapter (Field and Addington-Hall, 1999).

2.24 The Mobilisation of Meaning - A 'Specialist' Specialty

Over time, the word 'specialist' was placed before palliative care, giving us another new title – that of Specialist Palliative Care:

Specialist palliative care is the care of people with active, progressive, far-advanced disease for whom the prognosis is limited and for whom the focus of care is the quality of life (Department of Health, 1995).

A close reading of a text requires us to understand not only what is said but also to ask what is not said so careful attention to language is imperative. In the above excerpt another subtle shift in language becomes apparent, and again, not 'incurable' disease the euphemism for cancer, just 'disease'; 'no longer responsive to curative measures' can mean a variety of things to people with different diseases while 'quality of life' (QoL) is in fact a highly subjective and contested concept (Randall and Downie, 2006). At a general level, QoL refers to the ability to perform tasks of daily living, emotional well-being and physical mastery (Hyland 1995). The excerpt above is rather vague and there is certainly no mention of 'dying'. As Doyle (1997) observed, disease activity can be measured: 'Parkinsons or multiple sclerosis progressing, the heart getting weaker, there are features present that were absent some time ago'.

What this definition *does not say* – what remains silent is what may be considered important. It does not mention specific disease nor does it mention prognosis – merely 'for whom the prognosis is short'. Deliberately nebulous – 'what does this mean - days, weeks, or months'? (Doyle, 1997). Clark notes that 'some early hospice writers made the distinction between 'cure' and 'care' but more 'recent' models of palliative care have 'emphasized that the palliative approach also has its place alongside active, curative treatment and at earlier stages of the disease process' (2002:62). This begs the question as to which disease process is being called up in the commentator's mind, because 'active and

curative' are terms most commonly used when referring to cancer treatment having developed in tandem with such treatments, and would not be used when talking about cardiac disease or multiple sclerosis for instance. Definitions remain nebulous and precise definitions are notable for their absence. A more negative note to the creation of palliative care as a sub-specialty is that:

many have come to suspect that providing palliative care requires unique people to do justice to this demanding work, unique skills to do it well, and more time than today's doctors and nurses ever have (Doyle, 2006: viii).

This thesis argues that such notions were deliberately fostered by practitioners in this 'sub-specialty':

So easy is it to phone a palliative care specialist whether working in a hospital, a specialist unit or in the community, and get advice or an admission that some are leaving the palliative care of patients to them. In fact only about 10% of terminally ill patients have problems so rare or so complex that specialist advice is needed. All the others can be cared for by non-specialists if they learn the principles of palliative care, if they develop the right attitude to it, if they are willing to share themselves as well as their therapeutic skills (Doyle, 2006:viii)

Sharing 'self' requires that practitioners engage in 'emotional labour':

Many emotions signal the secret hopes, fears, and expectations with which we actively greet any news, any occurrence. It is this signal function that is impaired when the private management of feeling is socially engineered and transformed into emotional labour for a wage (Hochschild, 1983: x).

I return to this notion later in the thesis as it is relevant to delivering holistic care. Unsurprisingly, as the umbrella organization for the hospice movement, the NCHSPCS defined '*specialist*' palliative care as 'those services with palliative care as their core specialty'- i.e. hospices. If only 10% of 'terminally ill patients' require specialist 'advice' (Doyle, 2006: viii), which does not necessarily equate with 'intervention', this has resource implications for policy makers. For instance hospice care is hugely expensive – to maintain a small hospice with

approximately twelve to sixteen beds costs approximately three million pounds per annum (smaller hospices more).

The assumption is frequently made that hospice care is cheap and that care provided in the voluntary sector is cheaper than care provided by the NHS or private sectors. This is not true. Proper hospice care, because it is so nurse intensive, is a very expensive form of care. Moreover, there is no evidence to suggest that the voluntary sector is overall most cost-effective. Indeed, some voluntary hospices may be far more expensive to operate per bed than an equivalent service in the NHS (Help the Hospices Briefing Paper 1990 cited in Clark, 1993:10).

By 2006, these matters remained unaddressed, leading Randall and Downie (2006) to comment on the 'lack' or 'absence' of research on cost-effectiveness. Another point that tends to be glossed over in current literature is that hospices were deliberately established *outside* mainstream healthcare provision. It seems strange that the NHS contributes towards their maintenance considering that the services hospices claim to provide are now offered in NHS settings. Even if hospices were to manage the total numbers comprising the '10%' of patients requiring 'specialist' 'advice', and there is no 'evidence' to indicate that this *is* the case, the cost of doing so would still be disproportionate (Doyle, 2006). If the DoH provided half the amount of hospices running costs this is still disproportionately large when perhaps finance would best be distributed among the services that provide 90% of the care. How have these developments affected hospices? Some hospices that had medical director, consultants and nurse managers posts as a result of the legitimisation of palliative medicine became specialist palliative care units overnight; others remained as nurse led units offering care of the dying, with a GP popping by every week, and still others were neither one nor the other. Commentators began expressing concern that hospices were losing their 'original focus and ethos' (Biswas, 1993), were becoming 'medicalised' (Ahmedzai 1993, Biswas, 1993), 'bureaucratised and routinised'

(James and Field, 1992), and 'secularised' (Bradshaw, 1996). In addition, apart from conflating terms such as palliative care, supportive care and cancer care which only creates confusion, there is an assumption that palliative 'specialists' have broadened their expertise to encompass a wide variety of other disease states.

But have they?

We have learned a tremendous amount about care of the dying, but mostly limited to the cancer patient who is dying relatively quickly or at least within a rather limited life span. We have selected a certain kind of dying patient to work with. We have not learned a great deal about other dying patients; patients who die more slowly, whose movement from life to death is much more gradual, even while it is just as inexorable (Torrens, 1981:191).

Worryingly, there is little in the literature to indicate that this situation has significantly altered and fifteen years following the legitimisation of palliative medicine questions continued to be raised about 'how well equipped the new speciality is to deal with large numbers of patients with non-cancer diagnoses' (Clark and Seymour, 2002:63). Conflating cancer and palliative care by policy makers has important effects at the level of practice and may not have produced an appropriate model of care. As Field and Addington-Hall observed there are 'significant barriers to extending specialist services to all people who may need palliative care, including the level of skill of specialists, the difficulty in determining who should receive palliative care, the attitudes of the recipients of care and the resource implications' (cited in McNamara, 2001: 123). I return to the above points in the final chapter.

2.25 Discourses of Clinical Governance and Audit

Since the 1990s, most hospices obtain between 'thirty five and fifty percent' of their income from Government. This means they are no longer independent, 'part of the voluntary sector yes, but *not* independent' (Doyle, 1997). Unlike the NHS,

hospice practitioners were free from outside interference for many years. For example, clinical governance is a framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care, by creating an environment in which excellence in clinical care will flourish (Lilley, 2000). Clinical audit involves systematic and critical analysis of the quality of clinical care, including the procedures used for diagnosis, treatment and care, the associated use of resources and the resulting outcomes and quality of life for patients. Clinical audit is a multi-disciplinary activity which uses peer evaluation to demonstrate and improve the quality of patient care (Working for Patients, 1989 cited in Lugon and Secker-Walker, 1999:183). Despite much of the 'official' literature failing to define 'quality', this became a 'new' discourse within which healthcare practices are now constituted. Hospices were situated outside of this discourse, but as proponents increasingly accept funds from government they will be pulled more strongly into such discourse. Therefore, hospices are likely to be subjected to similar organisational problems that prompted their development, since 'changes in evaluation and funding during the 1990s' (Field and Johnson 1993: 213) implies increasing scrutiny of audit (Higginson, 1993), and will challenge the ideological basis of hospice. The days of hospices 'with freedom from external authorities hovering in the background' began rapidly receding (Saunders, 1984).

2.26 The Dying Disappear

Since the 1990s, a debate has been raging out of public earshot about the *nature* and *purpose* of hospice, palliative care and specialist palliative care, leading one commentator to write: 'I am afraid we may be in the process of selling our soul to the very medical model whose excesses have created the needs our specialty sets

out to meet (Kearney, 1992: 41). The 'grand narrative' of second wave hospice encapsulated what a substantial number of followers came to regard as the 'ideal' form of care for patients in the *last phases of incurable disease* - i.e. they were dying (Manning, 1984). Although the discourse of biomedicine did have a role, this was played down in such a way that it *appeared* to have taken a back seat while psychosocial and spiritual discourses of care had primacy, as practitioners focused on facilitating a 'good death'. As this 'grand narrative' began to absorb and enact the concepts 'palliative care' and 'palliative medicine' the transformation to 'third wave' occurred. At first glance it seemed as though little had changed because practitioners still talked about psychosocial and spiritual care and multidisciplinary team activity. However, a 'fissure' soon developed because the discourse of palliation is firmly grounded within biomedicine, concerned not with 'comfort and care' (Manning, 1984), but assessing, diagnosing and treating physical 'symptoms'. Psychosocial and spiritual care are secondary, indeed as Walter (1994) observed, they are 'add-ons'. As 'palliative' practices 'spread' to other settings, biomedical discourse became much more explicit and the dying patient began to recede in importance. By the time I left the hospices within which I carried out this study, the dying had all but disappeared; 'invasive technology' (McNamara, 2001), i.e. 'too much activity' (Saunders, 1965: 2), and its purported 'problems' - to which second wave hospice posed itself as a solution - had regained its prime position 'centre stage'.

2.27 Tensions in Contemporary Medicine

By the 1990s, two thirds of patients who died in Britain did so in places other than their own home. For example by 1995, 14% of individuals died at home; 54% died in hospital, 18% in nursing and residential homes and 4% in hospices (Jupp

and Walter, 1999: 271). In such settings, treatment decisions are shaped by the 'social organisation of dying within the 'norms and practices' which give shape to institutionalised dying' (Turner, 1995: 125). A medical model remains dominant, characterised by the use of techniques that measure, observe, and assess, during which process patients become objectified rather than being viewed as a sentient person. Now, as the reader saw earlier, this is not new, but it is interesting, because the medical approach is currently practised in a social climate that *claims* to offer 'holistic' healthcare, i.e. a biopsychosocial approach – a concept propagated by second wave hospice advocates.

This represents a tension between two trends in contemporary medicine; one deriving from Hippocrates interested in pursuing the rational scientific basis of medicine as described earlier above – a 'reductionist' model that 'ignores the individuality of patients, concentrating instead on what diseases have in common' - 'the tradition which is dominant at the moment' (Randall and Downie, 2006: 7). The other trend stems from 'the cult of Asclepius', 'first mentioned in Homer's *Iliad*' (Risse, 1999: 20) stressing 'healing' – 'to make whole' as a means of coming to terms with 'suffering or death' (Risse, 1999:31). This approach placed great importance on 'faith and emotion in healing' and outcomes of treatment depended upon the person's 'expectations'. Treatment, often in conjunction with the Hippocrates approach, took the form of 'asking questions, offering guidance or advice, always ending with reassurance regarding prognosis' (Risse, 1999: 31). 'Dreams' were considered an important aspect of treatment, i.e. people troubled by illness, anxiety or suffering in whatever form would sleep in one of the temples dedicated to Asclepius where 'dreams functioned either as cures themselves or as agents for these cures' often 'requiring the assistance of temple priests to decipher' (Risse, 1999: 30). The important point to note is that healing was seen

to come from *within* the patient. In British society the Asclepius approach re-emerged from approximately the middle of the twentieth century manifesting as 'holism' in the work of Cicely Saunders and hospice advocates; from the 1970s as the 'holistic health movement' with the 'British Holistic Medical Association being established in 1983' (Armstrong, 1986: 27).

Despite being viewed negatively by followers of 'holism' the emergence of so called 'reductionist' medicine in the eighteenth and nineteenth centuries also brought forth the 'individual' in the sense that we have come to understand it. As Armstrong proposed, 'the objectification of the individual can be seen as the first step in the actual creation of the individual whole person ((1986: 34) and this has important implications for the way in which 'holistic medicine came to be practised because as the 'individual' was constructed so too was the body of knowledge that described it. For example, the 'individual' that emerged in the 18th and 19th centuries was 'a rather passive object' whereas by the mid 20th century they had become 'active' beings with 'minds' to be viewed in their social context – a new source of knowledge and the basis of new 'professional identities' (Armstrong, 1986: 35).

2.27 Conclusion- Nineteenth Century to the Present

The body of literature outlined in this chapter, the ideology embedded within it and the practices which flow from it, I call the 'grand narrative' of hospice. This chapter has introduced the reader to the main matters addressed in this thesis by exploring the social landscape within which hospice emerged and was sustained, where discourses of liberal democracy, religion, humanism, individualism, psychiatry, secularisation and the human sciences have all played a part. Power, in the Foucauldian sense used in this thesis, is not necessarily negative, i.e. working

to repress people, it is also highly productive in that it produces what we are and what we can do, and it produces how we see ourselves and the world (Danaher et al, 2003).

The exercise of power consists in guiding the possibility of conduct and putting in order the possible outcomes. Basically, power is less a confrontation between two adversaries or the linking of one to another than a question of government (Foucault 1986: 221 cited in May 1992: 597).

The emergence of hospice can be seen to have occurred in three waves; first wave focused on the dying *process* and its *institutionalisation* (Humphreys, 2001: 150). It represents the enactment of 'pastoral power' in the sense that Foucault meant i.e. as a quality of the relationship between institutions which rely on surveillance and their subjects' (May 1992: 596). The sisters wanted dying Catholic patients to receive the 'last sacraments' and the only way to ensure this was to keep the dying within their field of vision to make sure they said prayers and undertook penance, first at the hospital and when conditions mitigated against this, in a 'special' space called hospice (Lofland, 1978). Patients' conduct was guided in specific ways to ensure a successful transition from earthly to eternal life 'whole' and duly repentant for earthly transgressions. To a limited extent the 'individualizing gaze' had landed on dying individuals in the sense that the sisters were able to constantly 'monitor' patients' (Foucault, 1977:141).

Second wave proponents also took as their concern the *dying* process but this time so that patients and relatives might achieve fulfilment in the present, complete unfinished business thus achieving a 'good death' through 'healing', again by keeping patients within a 'common plane of sight' (Rose, 1999). The conduct of dying patients and their relatives was 'policed' and 'guided' by drawing on 'new techniques' derived from psychology. Over time, hospice would become an 'administrative apparatus' where dying could be intensely 'governed';

forced to lead a discursive existence through techniques such as 'confession', first in its religious form and by second wave what Bloor and McIntosh call 'surveillance by proxy' (1990 cited in May 1992), by 'deploying' the 'human sciences' (especially psychiatry and psychology) 'which seek to localise and interpret individual intentions, motives and experiences' (May 1992: 597). While third wave developments witnessed a move *away from dying per se* with the adoption of the new nomenclature 'palliation', to a concern with symptom management.

History is often presented as an orderly sequence of events so I have tried to show something of the contradictions and chance occurrences in the historical period prior to and including the emergence of first and second wave hospice whilst indicating how certain forms of knowledge can become 'subjugated' or buried in 'official' accounts. From 1879 onwards the emergence of hospice represents a practice of segregation, a 'dividing practice' (Rose, 1999) in that for the first time the dying were deliberately 'sequestered', i.e. subjected to connected processes of concealment which set apart the routines of ordinary life from the following phenomena: madness; criminality; sickness and death; sexuality; and nature (Mellor and Schilling, 1993). Perhaps first wave hospice *was* a 'solution' to the 'problem' of 'body integrity' posed by dissection? It may well be that only total sequestration, i.e. a specific institution, would provide a sufficiently protective barrier - a *refuge* - from possible dissection. We know hospital and workhouse patients were preyed upon but what about those in hospices or 'homes for the dying' as they were called in mainland Britain? This might be a fruitful area for research in the future.

The emergence of St Christopher's hospice represents a poignant moment, perhaps even magnificent. Deaths' discursive existence was given a new

lease of life by second wave hospice fuelled by discourses from the human sciences and a cultural climate of liberal democracy. Contrary to the claims of advocates, second wave hospice was not new, nor even particularly different in the sense that dying patients were sequestered in a particular 'enclosure' - they were still *institutionalised*; it did not represent a 'rupture' or 'fissure' marking one epoch from another. Both first and second wave hospice placed the dying 'individual' in a 'common plane of sight' so they form part of the same continuum (Rose, 1999). What was new in second wave were the *techniques* that became available with which to 'establish a grid of codeability of personal attributes' to 'chart and judge' human conduct during the dying process (Rose, 1999:135-6). The 'individualizing gaze' became calculating in that the 'endless fascination of watching patients' (Saunders, 1965:1) would be used to generate information about 'similarities and differences' during the dying process which could be put to work to 'manage' dying in other settings. Dying patients were not only 'made' to talk, they were questioned about their thoughts, inclinations, habits, sensations and opinions. A central argument of this thesis is that patients were made a pure 'object' of medicine and knowledge - shut away in hospice until the end of their life, but also 'one to be made known to the world of learning through a detailed analysis' (Foucault, 1998: 32). These techniques of 'incitement to speak' were carried out at the level of the individual, in individual hospices, but 'judgements' and 'calculations' were made about patient responses that were collated, analysed and shared with others through publications, conferences, teaching sessions and in the process became knowledge which could later be applied in a general way to all people who were dying. (Erroneously I think but I have more to say about this later). Knowledge thus derived then becomes a form of cultural capital - the foundation of professional expertise - with links to and applicability in other

discursive fields, e.g. biomedicine, psychology, counselling, sociology, and policy development - in other words, knowledge derived using certain techniques in one context 'spread' and 'colonise' other areas (Rose 1999). The medical and individualizing 'gaze' in the guise of second wave hospice had now formally and firmly descended on the dying determined to bring forth its 'truth'.

If nineteenth century hospitals were 'living laboratories' where experiments were carried out on the 'poor' hospice, in its twentieth century form would become 'laboratories for the dying' where patients would be 'subjected to' 'techniques' that inscribed identity - i.e. patients would become they way they were described through a process of social conditioning whilst trapped in hospice 'enclosures'. Once hospice practitioners refined these techniques, they would eventually 'reach out' to encompass the whole healthcare field so that rich and poor would be caught up under their 'individualizing gaze'. Henceforth, hospitals were not the only places where disease and death could offer great lessons (Foucault, 2003).

Second wave hospice proponents harnessed psychological techniques in order to manage the dying process in a new way by accessing patient's subjective worlds. I contend that the use of such techniques became a *prescription* for dying in a particular manner with repercussions for those who did not adhere to the prescription appropriately. The idea of 'safe conduct' (Weisman, 1979) became a 'norm' in hospice practice through the application of such techniques and when these failed, pharmaceutical techniques.

When exploring third wave developments I highlighted how, by a subtle shift in language, hospice practitioners (and others) came to view their work as 'palliative' and more recently as 'specialist palliative care'; a move seemingly returning them to the medical fold against which they developed their 'counter

discourse' (Petersen, 2003). However, this does not represent a 'return' at all since they had never left it as I go on to show. Nevertheless, the new nomenclature marked a sea-change in thinking: the ideas and practices developed in second wave in-patient hospices could now, under a new name, be promulgated in a variety of care settings, including the acute hospital itself. Bearing in mind it was possible to become 'tainted' by titles such as 'undeserving' or to attain 'respectability' through association with those considered 'respectable' during the nineteenth century (Porter, 1996:337) is it possible that the palliative approach gained taken-for-granted 'respectability' by association with hospice by virtue of the powerful position the movement established for itself in British society? Is it possible that palliation gained 'respectability' because of its proximity to the discourse of biomedicine, i.e. a 'legitimate' sub-specialty and thus an offspring? Is it possible that proponents of 'second wave' hospice latched onto palliation as a means of 'justifying' its continued existence at a time when commentators became more vocal in their criticism of hospice as indicated above? (Armstrong, 1986: 28).

Although the hospice alternative has become well known and more widely utilized, its 'grand narrative' of supposedly traditional values and mission still remain in need of examination and clarification if it is to be of any use in its new guise as palliative care and specialist palliative care. Instead of embracing hospices' 'grand narrative' uncritically, this chapter has placed a question mark against certain matters to alert the reader to potential discrepancies in accounting practices. These matters will be examined more fully in subsequent chapters as I situate them in the context of local narratives and practices.

The point to remember here is that just because a certain 'scheme' was realised, does not mean that it was inevitable or the only conceivable response.

Foucault (1991) asks us to consider 'What happens'?, not necessarily with a view to determining what is good or bad so much as what might be 'dangerous or double-edged in its effects' (Ransom, 1997). One of my aims in this thesis is to dig into the past which, in the following chapters, means the recent past, 'uncovering battles that gave birth to a world we accept as natural, to make it questionable again, and to make it possible to fight over it once more' (Kaufmann 1969 cited in Ransom, 1997: 5), in other words, to make the 'familiar' - 'strange' (Marshall and Bleakley, 2008).

The espoused 'goals' of second wave hospice are the focus of microscopic scrutiny in the next three chapters as I draw upon information from local contexts to examine how they were translated into practice. Beginning in the next chapter second wave hospices' goal of providing 'holistic care' is explored through local practices and discourses whilst comparing these with the 'grand narrative'. How aligned are the 'rhetorics and the realities' of hospice care? Is there, as Lawton (2000) proposed, a 'disparity' between the two?

Chapter 3

Holistic Care

3.1 Introduction

Hospice strives to be comprehensively effective in every dimension. Concern for the 'whole' person became evident when Saunders proposed that 'mental distress may be perhaps the most intractable pain of all' for which 'listening has to develop into real hearing' (Saunders 1963: 197). This led to development of the concept 'total pain' mentioned earlier which translates as 'holistic care', a central plank in the philosophy of second wave hospice and one of its espoused goals. That is the focus of this chapter – specifically, how is holistic care achieved in practice? My concern is to determine whether there is a gap between espoused goals and their transformation into practice. For example, what did the language of holism 'enable' hospice practitioners to 'imagine and do'? (Rose, 1999: xix).

3.2 The Meaning of Holistic Care – Mini Local Narratives

Often during casual conversations with hospice practitioners I would ask them to tell me what they meant by holistic care. Usually I would get a mini version of the 'grand narrative' as a response i.e. looking after all aspects of the patient and seeing them in their social, psychological and spiritual context. One doctor told me;

For each individual it is different so we have to be guided by the patient whereas in a general setting they would be guided by us. We do a very thorough admission procedure and if I miss anything it's usually picked up by the nurses. We focus our attention completely on each patient, don't rush things and unless the patient doesn't want it we include the family in discussions. Compared to a hospital we're in the slow lane (Dr Rose, 2002).

Another practitioner saw their job as *'totally holistic'* since they spent time *'picking up the pieces'* –

When they come here, they've been through God knows how many treatments and often they're very shaky. Some of them are falling to pieces. All sorts of stuff is going through their mind. I just help them to put it all back together (Sabrina, allied health professional, 2003).

Such responses were to be expected and undoubtedly hospice practitioners perceived themselves as offering holistic care yet my observations of actual practices led me to doubt this. There was nothing to differentiate the practices I witnessed from any other healthcare setting except that ward handover reports seemed to drag on for ages and the pace of institutional life was slower. Wards were managed in routine fashion and were 'task' oriented e.g. early shift nurses would have report and then disperse to wash or help patients to the bathroom and the morning would be spent doing all the tasks that must be completed in any healthcare institution to maintain order. I never once saw a paid member of staff 'just sitting' with a dying patient although occasionally a volunteer was brought in for this purpose.

During many regular workshops I asked hospice practitioners to describe what *they* meant by 'holistic care' and *how* they achieved it in practice. The accounts offered in this chapter derive from one such workshop which I ran at the beginning of 2003. I include this material because the hospices were still operating in 'second wave' hospice mode at that time i.e. caring for *dying* patients. By the end of that year following various changes these hospices began to shift towards a more bureaucratic type of organisation, the pace of institutional life accelerated (albeit slowly) respite care was banned (until that point the hospices took several patients a year for two weeks so carers could have a break), 'resting the bed' – (usually for twenty four hours following a patient's death as a

mark of respect for other patients) – was banished and this was accompanied by practical moves to admit patients solely for symptom management discharging those likely to die either home, to a nursing home or community hospital. Henceforth, these hospices began calling themselves ‘specialist palliative care’ units.

The questions and answers below take place between me and six hospice staff who attended the workshop. All have been given pseudonyms which are in bold text while responses are in italics. I have assigned the letter R. to myself both for my questions and responses or comments which are in normal text. I use ellipses (...) to omit material e.g. where practitioners refer to people’s real names or places. Words that are emphasised are underlined. A pause is indicated by a hyphen e.g. - while [] is used to contextualise material. Sometimes my questions are directed at the group and at other times I pursue the respondent of a particular answer for further explanation. When several participants offer an opinion or explanation to a question, these are grouped together. Responses are compared with the ‘grand narrative’ as well as my own observations of hospice practice in order to ascertain, 1) how ‘holistic care’ is achieved in practice, 2) whether there were any ‘inconvenient facts’ or gaps in transferring the philosophy to practice (Dean, 1999) or 3) disparities between the ‘rhetoric and reality’ of hospice care?’ (Lawton, 2000).

3.3 Physical Dimension - Local Narratives

R. Talk to me about holistic care. What is holistic care and what does it mean in hospice?

Antonia. *Well we try to make the hospice as much like home as possible. One way we do this is not imposing rules or our own values and by taking account of what the patient’s normal life is like. We involve the family or friends in sorting out their routine. Say the patient normally likes a bath in the evening, we don’t tell them you must have a bath at such and such time like they would do in*

hospital, they have a bath in the evening. Or if a wife or husband wants to be involved in the care, we take that into consideration when we do our care planning. That kind of thing

Daryl. *It's about being with and for the patient Being there for them. We don't mind anything at all If they want to have lots of friends in that's OK. Its being their advocate, say if they don't want something or even just want to give up on life and the family keep pushing because they don't want them to die, its acting as a go between. But is also about looking out for the family as well, keeping them in the picture, seeing the whole picture*

Ella. *I agree with (...). I would say it's a system of symptom control that includes all aspects of being, spiritual, mental, emotional and physical. And all the little things really*

R. Talk to me about the little things. What are these little things? Can you elaborate this for me (...)?

Ella. *Its combing their hair they way they like it. It's putting their make up on if they like putting make-up on It was em, well going back to things like em when (...) was there and her husband (...) And I got involved with them quite a lot and it was a little thing to us but a big thing to her was actually, I said to her, do you want, cause he was, I could see he was dying in the next day or so, I said do you want to give him a cuddle? So I put two beds together and they had a cuddle on the bed It's a little thing, you don't have to have skill but it meant a great deal to her. It's organizing a Valentines dinner. It's getting someone in to paint their nails. Its em, that's holistic.*

R. So that's how you see holistic, these little things?

Felicity. *Yes, yes, putting flowers in the room, paintings on the wall, nice bedspreads. It's difficult to explain, it's just the whole thing.*

Claire. *The initial assessment when the patient is admitted is very important because that's when we get information from the family which helps you build up a holistic picture of what the patient's normal life is like.*

Betty. *I see holistic as trying to look after the family or relatives or it could be neighbours as much as I look after the patient. Well, the patient will have certain needs but sometimes we can get sidetracked sorting out all the symptoms and physical stuff the family could get overlooked so I try and remember that we're supposed to be looking after them too*

R. How do you do that?

Betty. *Well, explain things to them, what's happening, what's likely to happen, that sort of thing. I talk to them, draw them out about things that might be worrying them or the patient. Giving them time to ask questions. Telling them where they can have a drink, that they can use the garden; take their relative out if they want. Things like that. Letting them know they can stay the night if they want Just good nursing care really.*

Felicity. *Well yeah I think what we're saying is it's a whole approach to the care of the patient. Doesn't matter what your job is, you could be a domestic or a doctor, it doesn't matter, we're all here for the patient. We give them the feeling that nothing is too much. The way we approach them, not being too busy, or at least pretending not to be too busy when really we're stressed out (laughter).*

R. Is it the way you approach things do you think?

Claire. *Yes, yes, one of the ladies used to have a bone china teacup so we always used to make sure she had the bone china teacup, the one with grey flowers on it and that made a great difference to her because she couldn't manage the bulky cups. So she liked that. It's having their dinner arranged in a particular way on the plate.*

R. Would you ask them that, would you say do you like your dinner arranged in a particular way?

Daryl. *You wouldn't ask them specifically but you would get around that, you would talk around that subject, how they liked their food, how much do you like, what do you like to eat so you would tease it out from them. And you would spend a lot of time talking to the family. OK so what does this person like, what do they like to talk about, what music they like so we could have a conversation with them. What cardigan do they like to put on? If they had buttons come off their cardigan you would sit and sew the buttons on for them. Things like this.*

Felicity. *And you would always go around with your aperitif. I used to say to them you can always have whatever you like to drink whenever you like just let me know.*

R. People would take you up on that?

Daryl. *A few of them would, yea.*

R. What sort of selection of drinks would you offer?

Ella *Well in the early days everything but we got very limited in the last year or so with drinks that we could offer them because there wasn't the funding there to buy it apparently. Em we would have things donated to us and I would say to the family if they would like a glass of sherry or if they want a glass of wine bring it in. If they would like fish and chips, bring it in it's not a problem to us. So whatever they wanted you would get it for them.*

R. Holistic care is about mind, body and spirit and you see these little things as being important to that?

Claire. *It is yes, everything. It working in that way, it's an approach. I say to people it's nothing special, it's the care of everything and you could apply it in any situation. I mean it's the care of the relative, it could be a cat or dog or whatever. Whatever is important to that person? We've had patients bring in their pets. Not so much now though.*

3.4 Discursive Themes

A number of discursive themes can be identified in practitioner accounts relating to family, communication, care, advocacy, choice, healthcare, morality, quality of

life, sexuality, environment and time. Many participants drew upon the discourse of 'choice' to support their explanations of holistic care. Their responses suggest that patients and their families are offered plenty of choice as regards 'personal care and daily routines', 'food and drink preferences', and 'the little things' that make each individual life comfortable and give it 'quality'. This is to be expected and in keeping with 'grand narrative' espousals. As one doctor told me;

Dr Veronica. *The golden goal was time spent with patients regardless of what you did in that time, it was time. Ok, so I always remember the lady who eventually did what was to become Diversional therapy but it was called something else then A good example of this was em we had a chap who was dying, and his favourite jumper was a blue jumper that his wife had knitted him who had passed away some years previously and he was most distressed because there was a big hole in it and em so the Diversional therapy lady and I had a chat about this and, bless her, she quickly went and got some matching wool, got the jumper off him patched it up straight away, put it back on him and he died about two hours later. But that was holistic, she gave him the time. That jumper was for me quite a good example of what the hospice was about.*

R. The little things?

Dr Veronica. *Yes, that's right, the little things.*

However, 'the relationship between occupational rhetoric and 'real' practices is always problematic (May, 1992a: 592) and these views run counter to my experience of the practice arena where I witnessed staff taking control of both patients and their relatives, and where on occasion, patients and their relatives were spoken about in less than complimentary terms; practices I questioned as the reader will see below presently and in the following chapters. The 'grand narrative' postulates that the attention to 'detail' referred to by participants is the essence of 'holistic care' 'just what every nurse would like to give if they had time, and time is essential for nursing of this standard' (Saunders cited in Du Boulay 1984:178). 'Attention to detail' and concern for the 'individual wishes' of patients (Du Boulay, 1984:178) is referred to by practitioners as 'just good nursing care' for which 'one doesn't have to have skill'.

What is interesting in these accounts is that something has changed. For example, participants make reference to how 'in the early days' - pre-meal aperitifs in plentiful supply were offered to patients. At the time of these accounts (2003) this had reduced significantly because of an 'apparent' lack of finance. Hospices began to suffer financial constraints during the 1990s as a result of decreasing 'legacies' and bequests'; a period that witnessed hospices begin making demands for NHS funding so this economising on 'luxuries' may an indicator of such constraints. Participants also talked about patients bringing in their pets which I did observe during my first two years but that too diminished over time. Having 'time' to devote to detail was a 'taken for granted' luxury for hospice staff which was also affected as these hospices shifted from care of the dying to palliation where there is little time for conversation let alone sewing on buttons or patching jumpers.

3.5 Emotional Labour

In second wave hospice communication was paramount in order to access patient and relatives' 'subjective experience' i.e. 'interior' world. *'In our field there is the added pressure of limited time and often urgent demands for reconciliations and farewells. Communication has to be smooth and fast if patient and family strength and peace are to be found'* (Saunders, 2003 interview with the author). This suggests that practitioners must become highly skilled communicators and also assumes that patients and relatives want to engage in meaningful interaction.

R. Talking seems to be important in your approach to patients and relatives. Is talking is the key to holistic care do you think?

Daryl. *Well it is really. How else would we find out about the patient and the family? We have to ask questions. We're very good at that and can usually find out what we need to know by talking nicely, making people feel at ease so that people feel comfortable with us.*

Ella. *Even though some nurses are quiet by nature they still manage to get patients talking. And if one person can't get the patient to open up there is usually someone else who can*

These responses alert us to the 'invisible skills' necessary to access subjective experiences, what Hochschild (1983) called 'emotional labour'; essential for caring holistically – by 'talking nicely' and 'making people feel at ease' the employee's 'emotions' become 'tools' of labour. The employee is expected to display certain emotions or to bring about emotional responses or experience in patients. There is greater emphasis on involvement and empathy (at least rhetorically) on the part of the employee and these dimensions have become part of the service 'product'. However, while there may be a requirement for employees to display 'positive attitudes', behind this display are communication choices and sense making that are culture specific (Marshall and Bleakley, 2008). I discuss emotional labour in chapter six.

3.6 'Stage' Management

It was not apparent to me that I was witnessing anything particularly 'special' or 'holistic' at these hospices. Yes the décor was very nice, the gardens beautiful and well maintained, the food delicious, and everyone seemed friendly and unhurried. However, patients were always assigned ownership of *their* disease. I remember being astonished to hear patients described thus; 'Mr X with *his* lymphoma', 'Mrs Y with *her* breast cancer' (my emphasis). Social aspects received attention in relation to discharges i.e. to the patient's own home, nursing home or community hospital or if a patient or family were seen as problematic. Emotional and psychological aspects however were considered significant especially in relation to Kubler-Ross' 'stage theory' (1969). This was especially evident during my first three years at the hospices after which it diminished greatly.

For proponents of second wave hospice competent symptom control is said to 'open up communication bringing support at a deep level' and that 'nearly all will be helped by a chance to talk of their feelings to a sympathetic listener' (Saunders and Baines, 1983: 44). It is here in the realms of communication that the ideas of Kubler-Ross had particular resonance and influence for second wave hospice's 'grand narrative'. Kubler-Ross proposed that when patients are given a terminal prognosis they proceed through five recognizable stages, **denial** – it cannot be me; **anger** – at anyone and everything; **bargaining** – for a few more days, weeks or years or life; **depression** – resulting from the realization there is nothing the person can do to stave off death; and finally **acceptance** – whereby the person realizes and accepts that their life is coming to an end and if they had 'worked through' the previous stages would enjoy a 'peaceful' or 'good' death, (Kubler-Ross, 1969) also considered important so that relatives might have an unproblematic bereavement.

Those who have had the opportunity to listen constantly to dying people recognize a variety of reactions among them. Kubler-Ross (1970) described these reactions as stages of realization (Saunders and Baines, 1983: 44).

Both the 'grand narrative' and practitioners' accounts tend to be based on an assumption that patients and their families *want* to talk but what happens when they don't or they refuse? This is where 'stage theory' proved particularly valuable. The stage that received most attention in these hospices was 'denial' and this attention usually took the form of an accusation – e.g. '*well we've tried everything and they still refuse to face the fact that they're dying*' (Frances); '*They're in complete denial*'; '*I've spent ages trying to get (...) to open up and its really frustrating because they don't want to accept what is happening*' (Georgia) as though this was a terrible thing for the patient concerned. I subsequently

discovered that 'denial' was one of the greatest and most frequent 'sins' committed by hospice patients leaving staff feeling they hadn't done their job properly or that patients didn't achieve 'closure' or that theirs had been a 'bad death' which would make grieving 'hard for the relatives'. This latter pointing to the *performative* nature of the stages i.e. patients seemingly had to go through them to make bereavement easier for relatives. On the other hand someone might say, *'its great, such a relief, we've really worked on (...), - had a breakthrough, there were lots of tears of course, but that's good, only to be expected, and now they have reached acceptance, everything will be much easier from now on'* (Sabrina) for whom?. And what did it really mean that a patient had reached 'acceptance'? Why was this seen as 'good? I now explore what 'stage theory' 'enabled' hospice practitioners to 'imagine and to do to themselves and to others' (Rose, 1999: xix).

3.7 Psychological Dimension – Local Narratives

The format used above applies here as the discussion is a continuation of the same workshop.

R. I want to return to a concept which (...) mentioned earlier. If you remember, she mentioned 'denial'. Can we talk about this a bit more? Perhaps you could explain to me what is meant by denial?

Felicity. *I dislike that term intensely it's so superficial. People just don't respond the way these people suggest. They just don't and I don't like it. Never have, never will.*

Antonia. *Kubler- Ross, I always used to remember her dabda – depression, anger, bargaining, denial, and acceptance.*

R. Can you tell me some more about dabda?

Antonia. *That's how I learnt it.*

R. Where did you learn it and why?

Antonia. *On my K2 60 my open university course she was the main – she was the person –I thought that was what you had to learn because that was how you*

grieved, how you were bereaved and that's the stages you went through. When I first went into hospice work that was how you grieved basically – that was how you dealt with death and it was – they went from one stage to another. They sometimes jumped back a bit and then went forwards again but you had to go through all these stages to achieve some goal at the end – to actually achieve peace of mind. That is what I was taught. That is what I picked up from the people I was working with, that's what all the books told me, the reading list for the various courses I was doing. Worden was another one. [William Worden (1983) an American Professor of Psychology wrote about Grief Counselling and Therapy].

R. It sounds very neat and tidy. What do you think?

Antonia. *Yes, It all had to be classified in a certain way, given a certain terminology and that's how it was. That's what I believed for several years because I was thinking this is a wonderful world and I know nothing about it. I must learn everything.*

R. How did that pan out in day to day practice? For instance, when you would be doing a handover for a patient and they would be in denial or anger, did you talk about those things, for example, they're at this stage?

Daryl. *Of course, definitely. This was our guide as to whether patients were acting normal or abnormal. It was part of our training when we joined the hospice. New staff always worked with an experienced nurse and they told us about the stages. We were expected to know them off by heart.*

Antonia. *I didn't, I didn't feel that I knew it well enough. It took me years.*

R. But denial was talked about?

Antonia. *Yes it was.*

R. What sort of things would be said?

Ella. *Eh, OK, this person is not accepting at the moment. They're in denial and we need to actually coax them around. We need to help them move on, to move to the next stage so they can achieve a good death or a good bereavement. It was very much oh he's in denial and that was bandied about a lot, he's in denial. You would also get the ones that would say this patient is bargaining now, he's saying 'if I'm really good or do this will they let me live for another three days' or whatever. But the bargaining and the denial was the main thing. Oh and the anger - anger.*

Claire. *I think that we're sometimes guilty of bombarding patients with too much information. I've done counselling courses and the emphasis there is that patients will definitely go through stages which I've never agreed with. We insist on telling people about their diagnosis and then expect them to talk about it with us. I think we sometimes don't realise that some people just don't want to hear. Why should we bombard patients or families with information that they don't want? To my mind it's cruel. Some people do want information but lots of people just don't want to know.*

Ella. *If we question our practice like we're doing now I think we'll find that we don't give patients what they want it's what we tell them they want. We tell them*

what they want. Junior staff weren't allowed to answer patient's questions, we always had to get a senior person or the sister to answer and we learnt from listening to them but we were not encouraged to question their judgement. They knew, we didn't, end of.

Participants then went on to talk about anger which is dealt with in the next chapter.

3.8 Prescription for Dying

Dr Sarah, (. .) *The GP at the time, although I didn't necessarily agree with all his approaches, it was very clear that his association with (. .) hospice was that simply he had a very strong belief in the rights of people who were dying. (. .).*

R. What wouldn't you agree with?

Dr Sarah, *Well he had one couple I very particularly remember, it was an elderly couple, it was the husband who was dying and the GP felt very strongly that they should be talking about how they were feeling about the husband dying but the one problem about this was that they were a couple who had never ever really talked. I mean in some ways making them talk, if you can imagine making in inverted commas had its destructive side as well as constructive, you know, sort of ones. (. .).*

R. Would he have been influenced by the material that was coming from St Christopher's at that time?

Dr. Sarah, *Yes, yes, and that was influenced by Kubler-Ross' five stages and that you had to meet each stage and go through it to reach the Promised Land (laughter).*

R. What do you think about those stages since we're on the subject?

Dr. Sarah, *I think they were probably all right as a theory but there is a total difference if you are trying to put a theory into practice if you follow it slavishly and I don't think originally there was enough recognition that you could exist in all stages simultaneously depending on the weather or something like that. And that you could easily go from stage one to stage three, miss out stage two and then hop back to stage one depending on what was influencing your mood or your family at any one time.*

R. But it was also about encouraging people to talk to complete unfinished business. That was part of that whole theoretical model, wasn't it?

Dr. Sarah, *Yes, but you were imposing that, if you impose that on people who you're trying to get them to go through all the stages in a week, it's never gonna work.*

R. Did it become a prescription in hospices because that's what I was struck by when I went to the hospices and heard people saying 'oh they're in denial', or 'I've worked on them and there has been a lot of tears but its all going to be good

from now on'. I though it seemed arrogant. Is this about managing /containing dying, to make it less messy?

Dr. Sarah, Yes, yes it was prescriptive, but, this might sound quite condescending and I don't mean to – hospice people like the idea of a prescription where patients do this followed by that so it certainly helped them to manage so yes probably, but most of the doctors had a much simpler view of this. It tended to be some of the high powered social workers, nurses and psychologists and counsellors who thought they were the bees knees pushing the stages and the ordinary nurses just did what they were told (. . .) but as to your question about the messiness of it all, well yes I suppose we were trying to contain things because it was em, you know, not very pleasant – cancer is not a nice disease to die of. I must say I find that nurses who work in hospices to be an odd lot, not the brightest if you know what I mean (laughter). Maybe that's why they liked the stages because it meant they didn't have to think [laughter].

3.9 A Reductionist Disease Centred Model Underpins Holism

Even by 2003 Kubler-Ross remained highly influential for these hospice practitioners. Stage theory is based on a 'five stage formula associated with a constellation of symptoms' which Kubler-Ross claimed were predominant in dying patients and their family members. Disease centred models rely upon techniques of assessment and treatment. Assessment determines what symptoms are present and based on that assessment, a diagnosis is made and treatment administered to reduce symptoms (Chaban, 2000). Patients who did not fit hospices' stereotype of people anxious to talk had their reticence labelled as 'denial' and thus viewed as 'pathologically abnormal'. Denial, instead of being pathologised could be a very healthy response or attitude towards dying, or even point of resistance for patients. It may well have been an important 'strategy' that enabled patients to resist incursions into their 'subjective' world if they took the view that these incursions into their personal space were inappropriate. Whatever may be the case it was all too easy to dismiss 'silence' as 'denial' (May, 1992).

3.10 Spiritual Dimension – Local Narratives

There was a tension between spirituality as constituted within a religious discourse and its more recent configuration within secular humanist discourses.

R. (. . .). I notice no one has mentioned the spiritual side of things, why is this?

Claire. *Because when we're talking to patients we find out about their attitudes to religion or spirituality and deal with it that way. We usually get this from them at admission. They might like to have us say prayers with them for example. When we do handover we tell the other staff about their preferences or if they're atheist we let everyone know that. If they're not overly religious, like don't go to church as such but like a little prayer or poem we have special laminated prayer cards with things like that which we can read to them.*

(f) *We used to have prayers in the four bedded bays. We would do prayers at one end and then all troop down and do prayers at the other end.*

R. When you say 'used to' does that mean it doesn't happen any more?

Felicity. *It fizzled out in the last few years since (. . .) left.*

R. OK so what prayers would you say?

Felicity. *Oh we had proper prayer books. We had the books of various prayers and the vicars would come in and do us a very mini, mini service, oh yes, first thing in the morning before you start anything else.*

R. This saying of prayers doesn't occur now. Is that right?

Daryl. *Oh no thankfully. There are still some staff that don't like it though. They think religion is fundamental to hospice care and that it's being eroded.*

R. I've heard that staff used to say prayers around the patient when they died. Is that right? Would all the staff come along?

Felicity. *Yes, we would all gather around that patient. I felt obliged to go the first few times when I first came here because that's what I thought was expected of me. I'm not at all religious in that respect so I stopped going. I would go if the family wanted me there because it was not for me it was for them and I would offer to do prayers over the body if I'd known that family as a religious family and I would do it for them not for me but a lot of people took it as being part of their duty to do that. People would say, 'and how can you not say prayers in the morning, I think it's disgusting' or 'how can you not say a prayer over the body, you know you have to do that'. And I'd say 'well why'?*

R. So until recently the spiritual aspect of holistic care was viewed in the context of religion?

Felicity. *Yes and that used to irk me because it was imposing religion. Now I know hospices started off as a religious setting but they always said that they never imposed on patients. But how can you, if you're standing at the end of*

someone's bed or at the end of a bay where there are four patients in that bay, how can you not impose because they can't get out of that bed and walk away and say I don't want to hear this. But for a long time it was expected by people that came in and that's what happened because they expected it. Because that's what a lot of middle class people expected especially towards that time of their life. They were looking to grab any straw they could and then you know earn smartie points, so yes they would. And you would get quite a lot of the nurses who would – (...) – (...) was lovely, very religious, and (...) would do a start [to a shift] almost like a mini sermon, and (...) would have the Lord's prayer and then (...) would have a blessing afterwards. But the facilities here, people know there's a chapel because we show them around; people want to have prayers, they ask the nurse, because when you actually admit someone they are asked if they are religious, if they go to church three times a day or whatever.

3.11 Theory – Practice Gap

Although I have more to say about these accounts in chapter eight and the final chapter, a couple of observations here seem appropriate. First, until recently, many hospice employees in this locality were 'religious' and those in the clinical arena 'imposed' their views on patients since patients could not escape the daily prayer ritual. In the smaller unit patients were visited daily by a chaplain, vicar or religious sister (sometimes all three). Under new legislation concerning 'protection of vulnerable adults' introduced in Britain in 2001 these practices came to be viewed negatively by 'newly appointed' staff and ceased (although not until 2005 in the smaller unit). This is an interesting development considering the religious roots of both first and second wave hospice; important too in considerations regarding the purpose of 'suffering' for which 'religion' provides a framework in a way that 'spirituality' does not. In this locality there was a distinct shift from 'imposing religion' towards a 'squashing' of religiosity. Anyone espousing religious views or heard talking about 'spirituality' were spoken about disparagingly behind their backs by (new) staff occupying 'new' senior roles.

Whilst our individual understanding of spirituality may vary, within the hospice sector there is a general consensus that it is a fundamental aspect of care. 'The whole care and style of what is usually called the modern hospice movement

is productive of spiritual care' (Lunn, 1984). Practitioners seemed to take the spiritual component of their care for granted and assume others would too. In referring to suffering as an 'aching of soul' practitioners were drawing upon a religious discourse but again there seemed to be confusion about what this actually meant with some participants linking it to the psychological realm. However as the above accounts demonstrate before we can talk of communicating at spiritual levels we have to arrive at some understanding of what this might mean. Whilst it is generally understood that spirituality and religion *may* walk alongside each other, in contemporary society they are perceived to be two different things. The confusion evidenced by practitioners about the *meaning* of concepts integral to 'holistic' clinical practice may well be indicative a gap between theory and practice of hospice care. Again participants refer to various changes taking place in the hospices with religion playing a decreasing role.

3.12 Conclusion - 'Assembling Subjects' Through Discourse

I borrowed the phrase 'assembling subjects' from Rose because it captures the way practitioners 'constituted' patients identities 'through gazes, devices, techniques which extend beyond the limits of the flesh' and which are to be found in 'particular spaces' of which hospice is an example (1999: xx). This chapter has explored how practitioners made the concept 'holistic care' meaningful in their everyday practice during which gaps between 'rhetoric and reality' (Lawton, 2000) became evident. Dressed as 'holistic care' the talk that takes place between practitioners, patients and families from their initial admission through to death has a *purpose* –i.e. maintenance of institutional order, 'good death' and 'good bereavement. Contrary to 'grand narrative' assertions, practitioners in this local setting had been *taught* that patients 'had to go through' Kubler-Ross' (1969)

stages 'to achieve some goal at the end' i.e. 'good death' or to reach '*the Promised Land*' (Dr Sarah). Staff learned in situ in the 'community of practice' that is hospice (Wenger, 2007). The stages became the 'norm' and were used as a 'technique' to 'guide conduct' i.e. 'steering' patients through the dying process; a 'technique' of surveillance - to enable practitioners to decide whether patients were acting normally or abnormally, or whether they were '*in denial*' thus needing to be '*coaxed around*' in order to '*achieve a good death or a good bereavement*' (Ella) in line with the stated aims of the 'grand narrative'. The 'stages' were also used as a technique of 'surveillance' for monitoring learner/practitioner progress e.g. practitioners had to learn the stages by heart thus proving that 'learning' had taken place.

All of these practices I view as disciplining techniques and tactics of 'government'. They are predicated upon the notion that grief either before or after death is expressed through universally recognized emotions which have a 'normal course', a process which, for the benefit of the individual, must be 'worked through' if they are to retain their health or enjoy a healthy death (if such a thing is not a contradiction of terms or even possible). If something blocks the expression of grief, e.g. denial, then that person is deemed to be at risk of becoming 'stuck' and this is viewed negatively because when people become 'stuck' they are labelled pathologically abnormal and definitely on course for a 'bad' death and relatives a 'bad' bereavement. Talking as therapy is designed to help people 'get through the grief process, removing any blockages and either curing or averting any pathology' (Lofland, 1978: 79). Although not all practitioners approved of 'stage theory' or 'bombarding patients with information' which was perceived as 'cruel', this represents an unintended consequence of Glaser and Strauss' (1965) theory of 'awareness contexts'; i.e. perceptions of this

theory by others led to it becoming a vital 'device' to 'enable' the delivery of 'holistic care'; i.e. patients had to have awareness of their predicament if they were to attend 'unfinished business' in order to prepare for and thus 'achieve' a 'good death' (Glaser 1966, Glaser and Strauss, 1965, Seale, 1991, Timmermans 1994). In other words, the theory of 'awareness contexts' provided the instrument through which holistic care might be enacted.

Since meaning is socially circumscribed, I propose that hospice patients and their relatives were socialised into particular ways of understanding their subjective experiences so that perfectly natural feelings became pathologised and medicalised. 'The patient's uncertainties, anxieties and suspicions about, for example, her possible prognosis become explicitly defined in terms of psychosocial problems' (May, 1992a:591). Hospice staff were socialised using Kubler-Ross' work (1969) as a 'technique' that enabled them to search out patient's subjective experience and to constitute these as psychosocial problems to be 'fixed'. I now move on in the next chapter to explore how the hospice 'goal' of 'commitment to the patient's family' is realised.

Chapter 4

Patient and Family as the Unit of Care

I am all for having the family in as workers as far as possible and hope we shall learn more about this when we are working at St Christopher's (Saunders 1965, letter to Anselm Strauss, cited in Clark 2002:95).

4.1 Introduction

The focus on families was considered an important distinction between care at St Christopher's and earlier work at St Joseph's where '*there was a lack of ability to do this adequately*' (Saunders, 1979 cited in Clark 2002:187). Care does not end with death because bereavement support and follow up are also paramount although this is not addressed in this thesis. The focus of this chapter is on hospice's commitment to the ideal that the patient *and* family form one unit of care and its problematization i.e. lay bare what is normally taken for granted. For example, since 'families' are not homogeneous, we must attend to and evaluate the meaning that is given to this concept. Again the concern is to determine whether there is a gap between this goal as espoused in the 'grand narrative' and actual practice. For example, *how* do hospice practitioners go about incorporating the family into the unit of care on a day-to-day basis?

Local practices are further explored through open discussions and dialogue with members of the hospice team where it becomes apparent how the ideal of caring for both patient and family is enacted in the practice setting. The workshop used in the previous chapter continues to inform the direction of this chapter and therefore the format remains unchanged. We again meet Kubler-Ross' 'stage theory' operating as a 'technique' for guiding the behaviour of dying patients *and* their relatives and find that some stages are denied expression (Kubler-Ross, 1969). Comparing responses with 'grand narrative' espousals as

well as my own observations allows me to seek out 'similarities', 'differences', 'gaps' or 'inconvenient facts' as well as introduce the reader to the kinds of 'norms' that operate in these hospice settings and how these 'norms' govern the conduct of patients, their relatives and healthcare professionals, through certain institutional practices constructed from discourses of class, family, the human sciences, autonomy, personhood, human rights and ethics ((Dean 2006: 40).

4.2 Social Context – Families

In 'second wave' hospice the term 'family' was used in its broadest sense to include people who might not be related by blood or marriage.

It refers to those relationships that are significant for the patient and to other networks in which the patient is significant. Thus friends and neighbours may be more important than biological links and a diagnosis of terminal disease will reverberate not only among the biological family but also, for example, amongst the patient's work colleagues, his fellow members of the squash club and his church congregation (Munroe, 1993:175).

To this end hospices were designed to emulate a 'homely atmosphere' (Miller, 1988) where staff acted as a surrogate 'extended' family (Du Boulay, 1984:137).

4.3 Local Narratives – Professionals and Families

Saunders's quote above suggests that persons closest to the patient should be encouraged to take part in the day-to-day care of the patient, as a 'way of experiencing the death and as a way of receiving emotional support' (McNulty and Holderby, 1983: 25). This was not something I witnessed so I asked various practitioners *how* they accomplished this. The responses below are a selection taken from my field notes. To preserve anonymity practitioners have been given pseudonyms.

Well patients more often than not came here to die. I know its changing but that is what hospice was for. It was a place to die. That is the public perception of what hospice is about. Sometimes patients would come in for symptom control and go home again and then come back to die. Relatives were only too happy to leave the caring up to us. Not very many would want to help with washing and all the physical kind of stuff. Just the odd family might offer to help. If we asked relatives if they would like to help, most would say no (Nurse Hilary 2002 - 03).

Families row, resent one another, resent the person who is going to die and leave them and then feel guilty, all sorts of stuff, very fragile. I see myself holding things together for the family, putting all the bits together. It involves quite a lot of counselling to help the families really understand their feelings (Sabrina, allied health practitioner 2003 - 011).

If the families are having problems coming to terms with their relatives dying we usually get (...) [social worker] to sort them out. She can take them off the ward where it's quiet and they can have a good old cry. Some families never accept the person is dying and that can make things very difficult. They hang on to any hope denying anything bad is happening. They are the ones who have a bad bereavement (Lucia, allied health practitioner 2004 - 004).

We do try to accommodate families' wishes. We've even had marriages here in the hospice. One couple had lived together for twenty years and decided to get married. She died three days later. We did all the arrangements, flowers, cake everything. With older people its different, they're much more accepting. Even though we try and encourage them to be involved, they say things like, 'oh no nurse you carry on I'll just get under your feet' or something to that effect (Nurse Charmaine, 2003 - 012).

We used to offer respite care to give families a break but that all stopped this year (Nurse Ella 2003).

We can't presume families want to be involved in the actual care once the patient comes in to the hospice. After all they need a rest too. If we try to push them to be involved they can become resentful. We can make them feel included by discussing things with them, telling them what to expect at each stage of the patient's dying. We can offer them help to get practical support or benefit advice from the social worker. That kind of thing but in my experience you can't force them to continue caring in the way they were doing at home (Dr Rose 2004 - 002).

4.4 Glossing Over

Although I recognize that practitioners may have selectively offered accounts that justified their inability or unwillingness to involve families, they accord with my observations of actual practices and discussions with relatives. The striking thing about these accounts is the general consensus that families, contrary to the 'grand narrative' do *not* want to be involved in the patient's care once they were admitted to the hospices because they are 'grateful to have a bit of a break' or perhaps just fed up with the 'twenty four seven' drudgery. This has implications regarding

current policy initiatives on end-of-life and preferred place of care where the emphasis is on keeping patients in their own home during chronic, incurable and terminal illness. Indeed as one practitioner specifically noted that one of the main reasons for admission is likely to be the family were 'not coping' at home.

What you have to remember is when patients are admitted the families are worn out and just grateful to let us get on with their care. They have been doing everything twenty four seven for God knows how long and so they don't necessarily want to carry on. Actually that's why the patient is often admitted in the first place, because the family can't cope (Danielle, allied health practitioner 2002 - 012).

These accounts are congruent with Neale's observations that hospices make 'blanket references' to 'the family' in a way that 'glosses over the problems experienced by the informal carer, and fails to explore how the problems of patient and carer may be bound up with each other' (Neale, 1993:60). This is rather surprising considering how 'holistic care' has been and continues to be defined. The informal care offered by families (as opposed to paid care in whatever context) is 'usually' undertaken by women especially 'emotional support' despite that 'in principle *all* members' may be involved to greater or lesser extent (Neale, 1993: 53). Informal care is bound up with family obligations particularly stereotypical perceptions of women's caring role in the family especially those pertaining to the invisible skills i.e. 'emotional labour' (Hochschild, 1983) utilised in that role (Syde, 1987, Grimwood and Popplestone, 1993). The literature indicates that spouses 'represent over 50 per cent of carers' because of their co-residence, and because 'ideologically marriage is regarded as the supreme caring relationship' (Neale, 1993). Therefore, in the cultural context of 1965 it might have *seemed* reasonable and 'natural' for Saunders to make a statement about using the family as workers.

I think we tend to get caught up more if the patient is young. Most of our patients tend to be over sixty so when we do get a young person everything seems much

more dramatic especially if there are children. That can be very upsetting for the nurses especially if they see similarities between their own life situation and that of the patient. For example they might have children of similar age (Dr Veronica 2002 - 006).

In the population at large more than 'forty per cent of informal carers are over retirement age' and therefore because the bulk of hospice patients in the study setting tended to be in the older age range these issues may be relevant in explaining why carers were reluctant to be 'involved' (Neale 1993:53, Seale 1990, 1991b, Addington-Hall et al 1991).

4.5 Making Assumptions

One practitioner talks about staff occasionally 'identifying' with patients on the basis of parallels with their own life situation and how staff find certain kinds of dying particularly upsetting e.g. those of young people. This latter is unsurprising bearing in mind that a growing elderly population has an impact on attitudes to dying in contemporary society.

R. So were most of your patients over sixty?

The majority were. The younger ones are the ones who you remember most and therefore seem to be more numerical than they actually were. With the young ones staff got more distressed, they always did, I mean that was very obvious but it weren't the fifty year olds who were more sympathetic with the twenty year olds who were in as patients. The fifty year old were more sympathetic with the fifty year olds so when a fifty year old died it was the staff members who were fifty that were most upset, in fact. Though it wasn't always the rule because the older ones might think of the young one who died as their child but that situation apart it tended to be an age sort of thing. But certainly the younger ones probably had a more active em approach (Dr Veronica).

R. But did families actually get involved in the practicalities of care when their relative became an in-patient?

Not usually, no. Very rarely a wife might say they wanted to do, say help with bathing but for the most part they just let the staff get on with it. They probably saw it a bit of respite (Dr Veronica 2002 - 006).

To die young is viewed as a 'tragedy' whereas older people who are dying are seen as 'having lived out their lives, and no longer deeply involved in the lives of their families or communities' (Mulkey in Clark, 1993:33). However, if families became problematic i.e. did not conform to hospice's 'unwritten rules' and thus exhibited 'problems coming to terms with their relatives dying' not only are they *passed over* to another professional who 'specialises' in this - but they are removed from the ward (for fear of upsetting others?) to somewhere 'quiet' where presumably they can be helped to 'really understand their feelings' so that they may re-enter the ward with their composure intact - a 'disposition' favoured by these hospices (Bourdieu and Waquant, 1992).

The older patient's families don't have too many problems. It's usually younger patients with children; everyone feels sorry for the children and wants to do as much as they can to help. (.) [a situation] where the husband had been under investigation for (.) and (.). None of the staff wanted to have anything to do with him We had social services crawling all over the place. In the end when the woman died they got taken into care. That case left the staff feeling very shaky. Loads of them went off sick (Nurse Tara 2004 - 006).

Two points of note, first an assumption that older people don't experience problems and second, staff were unable to avoid '*putting their values onto other people's lives*'. Regarding the first, why would staff make an assumption that older people were 'more accepting' and thus not experiencing problems? I think it is because these individuals were not in the habit of talking about their problems. They did not fit hospices' stereotype of people keen talk about their 'innermost' feelings so some would have the label 'denial' applied to them; e.g. '*denying anything bad is happening They are the ones who have a bad bereavement*' (Lucia 2004). Alternatively, others would be viewed as 'accepting' since they were not causing any disruption. However, various studies indicate that a high percentage of informal carers experience 'physical, emotional, social and economic burdens' as a result of their activities and responsibilities (Neale

1993:54). When burdens are excessive or long term there is a strong likelihood of this kind of care giving breaking down (Qureshi and Walker, 1989). Social isolation is an important factor in 'tying the carer to the relationship' (Lewis, 1986) and in engendering the feelings of '*guilt and resentment*' (Sabrina) referred to above. Problems are likely to be heightened by anxiety over impending death and bereavement especially given the high levels of dependency exhibited by patients in their last year of life which result in even tighter restrictions for carers (Seale, 1991). Hardly surprising then that carers whose relative was admitted to hospice were 'grateful for a break' or became 'resentful' if hospice staff 'pushed' them to be involved.

Second point, in any setting it's easy to be nice to people we like. The big test for any professional is treating people we don't like or whose behaviour we don't approve of with the same courtesy.

Families come in all shapes and sizes and professionals must avoid judging them against their own internal vision of what behaviour is normal and appropriate in 'the family' (Munroe 1993: 175).

All well and good, but in these hospice practitioners were 'trained' to have certain expectations about what was considered 'normal' in the context of families that coloured their dealings with families. I have more to say about staff 'sicknesses' in chapter five. The 'grand narrative' which helps constitute hospice practices is replete with instructions on 'communication skills' (Lugdon, 1987, 1988, 1989, 1991, 2002, Maguire and Faulkner, 1988) e.g. 'how to 'break bad news' or 'elicit patient concerns'; how to get families reconciled, how to make people feel at home and so forth and although practitioners are unconsciously drawing on this literature, the gap between theory and practice is too great and practitioners have to abandon these 'ideals' and fall in line with what the families seem to want. Or do they?

4.6 Re-visiting the 'stages' – Anger

I now revisit the workshop discussions used in the previous chapter where participants talked about 'holistic care' as it contains commentary relevant to the matters under exploration in this chapter especially regarding 'stage theory' (Kubler-Ross, 1969). The same format is used. My questions and comments are in normal text and by the letter R. Participants have been given pseudonyms which are in bold text and their responses or comments are in italics. Where several responses to a question occur, answers are grouped together. Pauses are designated by a hyphen - . Eclipses (. . .) are used to omit material that might compromise individual or place anonymity and [] to contextualise subject matter. Words or phrases that are emphasized are underlined.

R. (. . .) perhaps you could talk a little more about anger as I would be really interested in your opinions?

Claire. *To me I can understand why they're angry. Dam it they're dying or they're losing a bereaved one. They are allowed to be angry Go with it*

R. Were people allowed to be angry?

Claire. *Not a lot of the time, no. Sometimes, depending on who was looking after them, doctor (...) perfect example of allowing somebody to be angry, wonderful, this young lad is – I don't know if it was his father or mother died, can't remember now, he came back, he went to view the body, going through his bereavement process, he was angry and doctor (. . .) said to him, ok I've got a pillow I'll hold it you hit it. And he did. He felt so much better afterwards because he was allowed to be angry and I think that's really important but I think a lot of the time people aren't allowed. It's this very western notion you've got to keep that stiff upper lip and you've got to behave in a certain prescriptive manner and you're not allowed to scream and shout and get angry and create a fuss cause [whispers] we don't do things like that in the hospice, got to be very serene, very quiet, I remember the hospice used always be very quiet, very peaceful except on a Sunday morning (. . .). But generally it used to be very quiet; it was all hushed tones, [whispers] all very sedate.*

Daryl. *Yes no matter what (. . .) was going on, everyone had to pretend it was all perfectly normal. Of course it wasn't normal, how it could be, but we all took part in the game. We were trained that this is how it is. This is the hospice approach Do it if you're up to it or get out. Full stop. And people did leave.*

Antonia. *I had this morbid interest in death because I wanted to make death – this is being very matriarchal to my patients – being an advocate for my patients –*

I wanted my patients – mine – to die better than I had seen them die. And that's why I came to the hospice because I wanted to learn how to make my patients die better. Not to impose my way on things, to learn how to do it better. But in fact making people go through stages is imposing a way of dying on people. It took me years to realise that.

Claire. Anger, (. .) is right. No one is allowed to be angry in a hospice I don't care what people say. A patient once said to me you're all very nice here but you're like clones a bit too saccharine for my taste so I'm going home. And he was right. That's how it was all sweet and light. We don't deal with and never have dealt very well with people who are angry.

4.7 Class Matters (Classroom Discussion Continued)

R. Right, I get the picture that anger is not acceptable in hospice. Is that a class issue would you say?

Felicity. I would say it's the people who are actually articulate enough to get their relatives into the hospice and the people most likely to do this are usually middle class. Or they know someone working at the hospice. When you get people of lower social class, I hate to call them lower class because I don't like that phrase, but people of lower socio economic group who are less articulate and less likely to know how to behave, I use that word loosely, behave, then they would be judged by the hospice people here. That sounds a terrible thing to say, and it is still going on. You can't impose your standard of living on the person you are nursing but that's what happens. They would say 'oh yes if they don't want to do this they don't have to', well piffle, no chance. 'You will be bed bathed every single day, you'll have your hair washed once a week, and you will do this and you will do that'. Done in a very nice way of course.

R. But surely middle class people don't like being told what to do?

Ella. No they don't. This kind of bossiness was aimed at the lower orders. But again whatever class people were by the time they came to you they put themselves in your hands. But over the last few years patients have become much more empowered and have higher expectations of what hospice will do for them. Because they've been on the internet, they've spoken to doctors, they see what can happen in America and they have higher expectations and they want things done in a certain way and they are less compliant which is a really big, big issue. If you're compliant you get on fine, if you're not compliant sometimes you can have a few problems.

R. In the hospice?

Felicity. Yes. There was a lady who came in and I remember all the scandal that went round, it was dreadful. She came in with a parrot, now it was a laugh when this parrot came in but she was a lady who if I remember correctly was or had been a drug user, disjointed family from a an odd area in (...) and totally non compliant. They would not obey hospice rules in inverted commas. I'm saying rules in inverted commas because we don't let on to have rules and she didn't go down very well at all. Now (...) brought her in and I think he brought her in to kick start everybody because he felt that people were just too comfortable and too

safe with what they were doing and he brought her in just to jiggle everybody up (. . .).

R. I can imagine. I do remember there was a major problem with another family. That chap (. . .), large family with (. . .). Remember them? (. . .) A big fuss was made at the (. . .).

Claire. *Yes I do remember, wrong side of the tracks for most people at the hospice I'm afraid. They were a good example of being the wrong social class. The family were accused of all sorts of things none of which were true. People even made a fuss when the family wanted to eat in the dining room. Other people used it so why shouldn't they? (. . .) all people could do was complain. The fuss made me feel quite ashamed. Here we are saying 'we will treat you as a person, care about your family, make sure you live until you die, blah blah' only to complain if they don't match our expectations. Hypocritical I call it. It was everything I find disgusting about hospice.*

R. Yes, it certainly was quite a contradiction of what hospices say they are about. I thought hospice was supposed to be family oriented and home like. So does the hospice have invisible rules?

Antonia. *Oh yes. As long as you comply it's nice. But don't dare be different. That case is extreme but I've seen what happens to people and I must say I've been shocked by some of the things I've seen because I came to the hospice to learn how to help people to have a decent dying experience which I felt was lacking in nursing home sector. But strangely I think they are better at it now that we ever were. They just don't have the people to shout about it I think.*

R. Would you say middle class people are less comfortable with the unsavoury aspects of cancer compared with other social groups?

Daryl. *Sometimes I would say yes but sometimes I would say that's how the Macmillan steered them.*

R. So Macmillan steered them towards hospice?

Daryl. *I would say so yes. Because if you look at a lot of the Macmillan's they are middle class people, they are articulate and get on with people. Maybe that's why they are drawn to that job. And they say they do things that the patient wants, they work with the patient and a lot of the time they do. But I wonder if sometimes they don't steer patients in a particular way to make it easier, for what they think is going to be easier for the family. Yes, I think you're right, it is because a lot of the time they don't want mess at home, don't want the inconvenience, and they don't want death in their house. It's something we've encouraged though. We have encouraged middle class people to think like that. Hospice especially, we've encouraged that, not having death in the house, oh gosh it's tainted that, death in the house. We can't have that. For working class people it's different because they are much more in tune with death because their life is much more precarious, they live much more on the breadline. They are much better able to cope with things and I do I think they are much more relaxed about bodily functions than the middle classes, for example 'we fart, belch, have sex, we live in small houses with*

thin walls and we all know what everybody else is doing' kind of attitude. Nothing fazes them in that way.

R. There is something very positive about that attitude. What do you think?

Daryl. *Well yes, we tend not to see things like that in a positive way but it actually is when it comes to this fear of death people have.*

Because of the matters that were raised in the above workshop and other comments I was privy to I pursued the social class theme with other practitioners.

4.7.1 Steering in and Shipping Out

R. I've been told that Macmillan steer middle class patients towards hospice. Is that correct?

Bronagh, Macmillan practitioner; *Sometimes it can be right because they are more persuasive at getting what they want but I think we do try and be fair and not biased towards whatever class. We do get all sorts of people admitted but whether they manage to remain in hospice depends on the hospice.*

R. What do you mean by that?

Bronagh. *Well in my experience hospices tend to favour middle class people. After all they are the ones with money and might leave some to the hospice so they are especially nice to them. We find that working class patients tend to get shipped out quickly.*

R. Was there ever a limit on how long patients stayed in?

Dr Veronica. *There was in theory a time limit but no one took a lot of notice.*

R. Now I'm going to ask you something about this, was that related to people's class?

Dr Veronica. *Well certainly if they liked you could stay a bit longer. Yeah, and its funny that because I remember (...) upset some people and it was all related to (. . .) in a funny way. A GP had told (. . .) about this homeless person who lived in the woods but who was ill with cancer and em and he had a dog and (...) used to go to the woods (. . .) to see to him. He did come in for a while but he was dirty and smelly and I don't think the management liked it very much.*

R. What did they do?

Dr Veronica. *He went out again.*

R. Just because he was dirty and smelly?

Dr Veronica. *Yeah but (...) still kept going to see him and that's one of the things I liked about (...).*

R. I've been told that Macmillan steered their patients towards the hospice.

Dr Esmeralda. *Yes, although at that stage we didn't accept referrals directly from Macmillan*

R. Yes, but they could have twisted the GPs arm – they're not coping at home don't forget the middle classes are articulate. What I've been told is that the people who get the beds are the people who are articulate enough to push for a bed

Dr Esmeralda. *No. I think that's true to some extent but I don't think it's where the biggest influence was. The biggest influence was whether the nurses wanted to keep them or not when they got there. I can see your point about that influence about admission but I don't think that was the main part of it all. I think the middle class thing more influenced whether you stayed or not when you'd actually got in*

R. So you had a woman with a parrot who was the wrong side of the tracks?

Dr Esmeralda. *But the doctors liked things like that you see but the nurses couldn't cope and that's what I mean, cause when they got in, if the doctors managed to get in people its when they were in that the other staff had more influence about whether they stayed or not and how fast they were referred to the social worker cause the hospice didn't have one then, for discharge. So the ones the nurses wanted to get rid of were referred to the social worker faster than the ones they liked.*

R. So would you say most of the nurses themselves are middle class or are there quite a few working class?

Dr Esmeralda. *I think they're mostly middle and upper class. A lot of them are married to GPs or attracted in to do good work. The volunteers are very middle and upper class*

R. So they wouldn't like working class?

Dr Esmeralda. *No and the governing body were all upper class (. . .). I know it sounds very defensive about the doctors but I honestly don't think that's where the problems lay. I think they've often tried to blame the doctors. Nurses can be very manipulative.*

4.7.2 Bloody Hard Work

Freda, *Macmillan practitioner; I've worked in a few hospices in different parts of the country and it's amazing how similar they are. I would say they are designed by the middle class for the middle class. Just look at all the paintings and flower*

arrangements never mind the volunteers who do the arranging. They are usually middle class. Probably took classes in flower arranging. Would never see them in a working class home. At least I never have and I've seen more than a few homes. A few prints maybe but that's your lot. Let's face it the majority of patients tend to come from the middle and depending on the area, even the so called upper classes. For example (...) in (...) is crammed with rich and titled patients. Mind you they're bloody hard work

R. In what way are they hard work?

Freda. *Oh they are so demanding, nurse could you just fix my pillow, do this, do that, be a dear and pass me whatever when they are perfectly capable of reaching it themselves. They see the staff as servants at their beck and call. They're afraid of dying. They think money and position can buy them everything and it comes as quite a shock when they discover they can't buy or charm their way out of dying. They also hate the physical deterioration that comes with dying of cancer. I mean I can understand why because they've become so used to grooming themselves in a certain way and dying of cancer is so undignified as well as smelly. That's one of the reasons complimentary therapy took off in hospices. The oils they used help to mask the stink. Hospice suits their psychological make-up because all the nasty stuff is hidden. If you think about the reason most people are admitted to hospice invariably besides pain, which can cover a multitude of things you find 'social reasons - something along the lines of 'not coping at home'.*

4.8 Habitus and Dividing Practices

For Bourdieu, practices are embodied skills represented in the habitus. 'The habitus is a set of dispositions which incline agents to act and react in certain ways. The dispositions generate practices, perceptions and attitudes which are 'regular' without being consciously coordinated or governed by any 'rule' (Thompson, 1991: 12). Bourdieu uses the notion 'habitus' – a 'sense of one's place' to explain how practices come to be at home (no pun intended) with themselves; examining them in relation to their 'field of operation' and highlighting the discursive arena of 'practice fields' thus emphasising the constitutive effects of the language of practice i.e. how people *become* they way they are identified (Bourdieu and Waquant, 1992:120-1). For example, in chapter two I noted how the poor were constituted as 'deserving' or 'undeserving' and how some of the deserving would 'find themselves in the social sink with the residuum where being in it they *become* it' i.e. tainted by association (Porter,

1996). Habitus then is the product of experiences and mundane processes of learning which become embedded and embodied as 'second nature' so that individuals 'know their place'; - i.e. learn how to 'behave' and this involves accepting '*this is how we do it here*' that 'everything should be right and proper'. Therefore dispositions are structured through the conditions in which they are acquired; for example, '*You certainly weren't allowed to answer the phone or speak with relatives. In fact up until a few years ago junior nurses would never dare speak to relatives on the phone We just accepted that was how it was here*' (Nurse Diane, 2005). So tightly 'governed' are these practices that junior staff would never dare to do otherwise because they know their place but don't necessarily see themselves as being governed.

At a more general level people are socialised into certain ways of 'being' in the world depending on one's 'place' in the social strata in such a way that it becomes automatic i.e. refraining from emotional displays in public thus maintaining a 'sedate' disposition. This, Bourdieu defines *tenue* as the sense of 'dignity of conduct and correctness of manners', implying, according to the dictionary, 'a refusal to give way to vulgarity or facility' (2004:206). In hospice, *tenue* would manifest as a 'disposition' that was 'sedate', not given to excess emotivism and 'accepting' (Bourdieu, 2004:206).

4.9 Fostering Particular Dispositions

In this locality 'stage theory' was used as a technique to 'steer' patients and families through dying (and bereavement). However, some stages are denied expression, 'denial' which we met earlier and 'anger' as expressed in the above accounts. The 'habitus' or field of practice that is hospice generates and fosters particular 'dispositions' for both patients, their relatives and practitioners both in

terms of 'social position' as well as 'stage theory'. In Britain, certain 'social classes' (and I am using the term in its broadest sense here) place a high value on a cultivated 'disposition' or *stiff upper lip* as one practitioner described it i.e. knowing how to conduct oneself in public, not outwardly exhibiting emotions, not breaking down or making a scene in public. Individuals occupying certain positions in the social stratum could be expected to feel 'at home' in this 'field of practice' whereas those of a less '*sedate*' disposition would not as this would be contradictory to their normal habitus and thus they would not have a 'sense of the game' (Bourdieu, 1992). This 'lack' would be construed as non-compliance.

For the practitioner, one becomes habituated to one's own 'field of practice' and other arenas (and the people who inhabit them) are viewed as strange, not conducting their affairs as 'we' are disposed to do. In hospice then this manifests as; '*you've got to behave in a certain prescriptive manner and you're not allowed to scream and shout and get angry and create a fuss*' and so forth or '*this is the hospice approach. Do it if you're up to it or get out*' (Nurse Daryl). Practitioners who remained or did not challenge 'received wisdom' can be said to have developed a 'sense of the game' i.e. comprehending the hospice approach' and indeed referred to it as such when they talked about '*pretending things were normal*' and '*taking part in the game*' (Bourdieu, 1992).

Patients and families were the 'subject' of and 'subjected' to the judgements of hospice practitioners who 'categorised' people according to social position; 'imposing their values' onto patients and their relatives with some hospice staff complaining when people did not match their own expectations. In this locality social class *was* highly significant in terms of how patients and families were treated and practitioners referred to '*unwritten rules*' (Felicity) with which patients and their families were expected to comply.

Patients whose 'disposition' was at odds with those valued in these hospices were rapidly referred to the social worker for discharge. Similarly, 'unruly' families or those displaying 'too much emotion' were removed from the ward into the care of a professional who made them 'safe' by helping them 'put it all back together' (Sabrina). Based on my observations and discussions with practitioners I speculate that second wave hospice provided a 'refuge' or 'safe haven' for 'exceptionally mature and intelligent' (Sontag, 1978), 'squash playing' people (Munroe, 1993) afraid of becoming a 'spectacle' as a result of the bodily deterioration wrought by cancer and thus the destruction of their 'symbolic profit'.

I know there are one or two who have poor catchments but even they give priority to middle class patients and I know because I've worked these areas. Of course no one is likely to admit this are they because there would be uproar? (.) You see working class people are not forceful like the middle class so even if they find the courage to ask about hospice, if they are told there isn't a bed, they don't pursue it Whereas a middle class person wouldn't let it lie. They would keep banging on and on until they got a bed Who could blame them, hospices are like private hospitals without the enormous fee (Fatima, Macmillan practitioner)

Middle class people don't like the mess that accompanies terminal disease in their homes, nor death, and hospice was viewed as having encouraged that. My argument that cancer turned people into a 'spectacle' with the kind of bodily deterioration and associated odours that would have been especially abhorrent to people who perceived themselves as culturally superior with 'refined taste' (Elias, 2000) seemed to resonate with many practitioners. The notion of 'safe conduct' (Wiseman, 1975) [using the masters tools] is a useful way in which to describe organizational 'norms' that that helped to maintain institutional order and prevent 'disruptive events' in this locality (Turner, 1995) manifesting as compliance, appropriate disposition, willingness to talk, and acceptance.

4.10 Conclusion

As I have shown in this chapter, generally families did not want to be involved with the practicalities of 'care' once their relative was admitted to hospice. This is hardly surprising since most patients admitted to these hospices tended to be over the age of sixty and as the literature indicates, it is likely that a large proportion of carers would have been female worn down by the 'drudgery'. Again we encountered 'unwritten rules' with which patients and their families are expected to comply. Indeed compliance was viewed as a major 'problem' for practitioners in these hospices that may have been age related as regards the 'stages' or influenced by clashes of culture related to 'habitus', whereby people occupying certain positions in the social hierarchy might be unaware of social expectations and behavioural traits associated with and natural to those occupying a different strata.

What is clear, in this locality class mattered and this manifested in different ways depending on the speaker; i.e. hospices like middle class people, Macmillan nurses are middle class and therefore 'steer' middle class patients towards hospice; middle class people are more articulate thus more likely to persuade others of their needs or gain admission to a hospice; or even, whether patients remained in the hospices depended on whether the nurses liked the patient (or rather whether the class of the patient matched the institutional identity these hospices had constructed for themselves). Meanwhile it is in the space between these varying accounts that practices and alternative discursive accounts are to be found. If one wished to test a hypothesis such as there is a link between social class and admission to a hospice; comparisons could be made between admission data in hospices against those in general hospitals, using for example, postcodes or occupation. Alternatively one could trawl through the yearly minimum data

sets maintained by the Hospice Information Service checking for a preponderance of particular occupations.

Such 'disciplinary' and 'normalising' techniques, far from helping patients 'live until they die', far from helping them to 'preside over their dying'; far from helping them 'to find their own way of dying' merely 'governed their conduct' (or indeed rendered them 'docile' as I show in chapter eight) (Foucault 1991a, Saunders 1967, 1970, 1978, Lamerton 1986). These techniques made the dying process 'manageable' – they contained it thus maintaining hospice's 'grand narrative' and public image as a 'peaceful place to die' (Du Boulay 1984, Stoddard 1978, Winn 1987, Saunders 1990). Stage theory is reviewed and critiqued in chapter seven.

Another noteworthy matter that keeps cropping up is the point made about the hospices 'changing' role - .i.e. from a 'special place' to die to something 'other' e.g. palliative care units - 'patients more often than not *came here to die*. I know its *changing* but that is what hospice was for. It was a *place to die*' [my emphasis]. I return to these points in chapters six and nine. As to whether the espoused 'grand narrative' goal of incorporating the family into the unit of care was realizable in practice, my observations and practitioner accounts resonate with Lawton's (2000) findings 'i.e. the gap between rhetoric and reality in this locality is very large. I now move on to explore how the 'goal' of non-hierarchical multidisciplinary team working is implemented in practice in this locality.

Chapter 5

Non-Hierarchical Multidisciplinary Teams

5.1 Introduction

Hospices' organisational culture is affected to greater or lesser degree by the 'grand narrative' which promoted the idea that patients could die in the manner of their own choosing in a homelike atmosphere supported by a team of multi-professionals who, respecting one another's expertise work together non-hierarchically (Du Boulay, 1984). These are the ideals to which all hospices aspire. However, hospice as a 'constellation of communities of practice' (Wenger, 2007) does not simply provide an environment for clinical practice; it also serves as a vehicle for socialisation into certain roles for a variety of professionals and the 'management' of that 'socialisation'. 'Community of practice' in this sense, is 'about learning as a living experience of negotiating meaning' (Wenger, 2007: 229). My role as educationalist enabled me to observe interactions within the multidisciplinary team including my own role in that team. However, as Wenger notes; 'one can design roles, but one cannot design the identities that will be constructed through these roles' (2007: 229).

When I use the term 'organization' I am referring to both hospices as a whole. The structure of an organization refers to all the 'tangible and regularly occurring features' which help to shape its members' behaviour (Handy, 1999). Organizational structures may be flat, where the management committee and staff see themselves working collectively – as espoused in hospices' 'grand narrative' or hierarchical with several management tiers; for example a board of trustees, management committee as a sub-committee of the board, several specialist sub-committees or working groups, several department heads, line managers and a

chief executive (Adirondack, 1998:27). Similarly, staff structures may be flat or hierarchical. All organisations have their own culture i.e. atmosphere, ways of doing things. The values, norms and beliefs that contribute to this culture will be reflected in the various structures and systems favoured by the organisation so as to maintain its existence. Such cultures are affected by the organization's history, type of work, the technology used, by their aims and the kind of people who work in them (Handy, 1999). 'The way in which an organization is managed will be a unique reflection of the organizational culture, development stage, organizational structure and the managerial style of key individuals in managerial roles' (Adirondack, 1998).

I have delineated two broad areas for exploration in this chapter: 1). Organizational structure; as regards how the teams worked together highlighting formal and informal 'norms'; and 2) the impact of the organisation's culture on team activity. I move back and forth between these areas since each influences and is influenced by the other and 'meaning' constantly 'negotiated'. Although I allude to other departments, my main focus here is mainly on the 'clinical' team. Texts derived from dialogues with staff are again utilised and italics and pseudonyms in bold are used for this material. 'Crude report categories' (Nachmias and Nachmias, 1994: 87) are used i.e. aside from titles such as nurse, doctor, volunteer I avoid specifying respondents professional role using terms such as allied health practitioner or ancillary staff instead. I omit the year to protect the anonymity of particular informants. When I use terms such as 'experienced' this means the practitioner has worked in in-patient hospice settings for ten or more years (not necessarily solely in this locality). R. means the researcher and my comments/ responses are in normal text. As before, I use ellipses (. . .) to omit material, [] to contextualise material; words that have been

emphasised are underlined and a hyphen – indicates a pause. I will start by considering my own role within the team which includes my interpretation of what I thought was happening in this locality.

5.2 Organizational Culture

It took persistence to really engage staff with my teaching practice and this had to do with the way 'power' worked in these organizations. Other than counselling, there was little on offer in-house and there was lethargy about the place. In the clinical area apart from doctors who had their own systems in place for continuing professional development (this did not include yearly appraisals), this meant that many staff were 'out of date' thus breaching codes of professional conduct.

Secretaries functioned at basic level i.e. were unable to 'take minutes', lacked 'shorthand' skills and had a poor grasp of English, particularly grammar, that manifested in letters, reports and other correspondence. Day care was like a *Derby and Joan Club* (Nurse Daryl), operating three times a week from 10 am to 3 pm; attended by between three and ten cancer patients who undertook craft activities and received complementary therapies. There was little patient turnover i.e. the same people attended week after week, until eventually admitted to the in-patient unit to die. The atmosphere was informal in that nursing staff did not wear uniform; everyone was referred to as 'love' or 'darling'. Patients, staff, and volunteers (sometimes the chaplain) sat down together at a long, perfectly laid out table for a three course lunch. In 2005 nurses were ordered to wear uniform and patients began attending for assessment or medical treatments as opposed to social care or to give carers some respite. There was also a time limit placed on attendance e.g. a maximum of six weeks but the leisurely lunches continued.

Apart from the volunteer service which was highly organised and skilfully managed, the organization overall seemed rather amateur and underdeveloped with a poor skill mix across departments where many staff lacked appropriate expertise or training to perform their roles effectively. Yearly appraisals were not undertaken in any department, whilst in the clinical arena there was absence of clinical supervision, clinical governance and audit (mandatory in the NHS). As well as developing and instigating various training and education initiatives I put in place procedures to ensure that everyone, regardless of position had a fair chance of access and kept track of these. Thus began my own 'governance' role – i.e. 'monitoring the lives of those for whom one was responsible' (Rose, 1999:226). However, not everyone welcomed my efforts. The following conversation took place between me and two experienced nurses, Daryl and Antonia. I was discussing an ongoing problem of getting clinical staff released to attend training and educational events as well as difficulty in persuading experienced clinical practitioners to contribute to in-house training in order to share their experience with other practitioners despite assurances that I would train and fully support them in this undertaking.

5.3 Teaching, Learning and Favouritism

R. Education is supposed to be integral to the philosophy of hospice yet when I first came here I got the impression that only certain people were allowed to do courses. Am I right?

Daryl. Yes. You had to be in with the right people Most of the time I did my own, paid for them and did them in my own time because I learned early on only favoured people did courses and not juniors.

Antonia. *Yes I was a bit of a maverick like that because I'd always done whatever courses I wanted at my previous job and I wasn't going to let anyone dictate what study I could or couldn't do. (. . .) would encourage you, it wasn't her that would stop you. Only a limited amount of people were allowed to go and it could only be specific people.*

R. Why? What was that about?

Daryl. *Devolving power downwards. It was hanging onto power I think. If you got the education you got the power. And it's keeping people in their place. And wanting to control which way the hospice went. That came down from the hierarchy and you weren't allowed to do certain courses. (. . .).*

R. You say it is a power issue. Is that why I experienced problems getting staff released to do my courses? As you know (. . .) recently refused to put posters up in the ward about various training opportunities, or (. . .) would say staff couldn't be released because the ward was too busy even though I knew it wasn't. This is using power?

Daryl. *Definitely. They wouldn't have wanted you to be deciding who should attend what because until you came it was only (. . .) or (. . .) who decided. Your predecessor (. . .) was in with them so she was part of the hierarchy. They saw you as a threat to their power base because you wanted everyone to have the same opportunities. That was unheard of at (. . .).*

Antonia. *I agree but it was difficult to release staff from the ward and actually to be able to get staff to cover it was difficult. But that was where you and I used to talk sense and we managed it, we arranged things. (. . .) didn't because she was single minded in control. And she had (. . .) over a barrel. She manipulated (. . .) a lot. Because (. . .) was very insecure so it was left up to (. . .) and she didn't want anyone else to know anything apart from herself and (. . .). So that was*

difficult. I think it was also a case of not wanting people to learn too quick to run too fast because they were frightened of not being able to keep up with them which is also difficult. But that impacted because people like myself came in having training and education courses and we downloaded the information to anybody else who would listen to us and that's what spread. It spread like a virus – people wanted to know and I wanted to teach them. That was good. But that meant that the healthcares would be educated and that didn't sit very well with some people

R. Because they wouldn't know their place any longer?

Daryl. *Precisely Because they had a set hierarchy that had always worked for them, and fine, maybe that was great in years gone by but it's not right for now because people have a right to education We need education otherwise we can't do our job properly. And we always have to keep up to date to give our best to our patients. And with so many changes going on it's even more important to keep up to date*

R. Absolutely. Is it possible that in the hospices the people in power were starting to lag behind?

Antonia. *Exactly right. (.) has done no training for years so they are completely out of date The last thing they want is their subordinates knowing how crap they are at their job so they keep them in ignorance Simple as that.*

Daryl. *I agree. (. .) is a case in point. She has done nothing for years. Yes, she is experienced in that she has worked here for (. .) years but what else has she done?*

R. You have (. .) who could pass on a lot of information.

Daryl. (. . .) *could do as she has a wealth of information but she just won't do it. She might do it talking to you one to one in the treatment room but she won't stand up and be counted.*

Antonia. *She is reluctant to give too much information because she is afraid of giving up control.*

R. I wondered about that. What's that about?

Daryl. *Power again, oh yes it's very much a power thing. Lack of information and then they won't be able to challenge. That's how hospice has always worked, twenty years ago, ten years ago and now. Even though we've had lots of staff changes in the last few years it still happens.*

Antonia. *I agree I think she is wary about giving over too much information because she will lose control. It's very much a power thing.*

R. Doesn't hospice philosophy state they are non hierarchical environments?

Antonia. *Dream on. Lack of information. Don't give them information and then they won't be able to challenge. Challenge is not accepted here. You must know that by now Mary (laughter). Some people are nervous of you because you question. Ha! You really mustn't question (more laughter). (. . .) But we like having you. You make us think about what we're doing and that's good. But (. . .) army mentality. Don't worry loads of staff appreciate you being here, they know you want to encourage us to question practice and be knowledgeable. I think staff are also realising they've been starved of training for years. (. . .). (. . .) dare not say anything because you've brought lots of new and well known speakers in and you've raised the profile of the hospice outside through education. (. . .). You can't treat people in our area the same way as army but that's what he does. Why do you think he keeps his door open all the time? He watches everything. He's likes the hierarchy and holding on to information.*

Daryl. Fair enough it can be scary for us staff but only because we know our knowledge is out of date so we do see what you're trying to do in a good way The only people who are really afraid of you are the ones who are crap, or who have something to hide. Mind you, there's quite a few of them. We seem to attract them Despite all the bloody changes one thing hasn't changed and that is we do seem to attract some weirdoes. We've had our fair share over the years Haven't we (...). No offence to you.

Blocking access to education or training in this locality can be considered a 'technique of governance' – 'structuring the field of possible action' - a way of controlling conduct 'for a foreseeable future' (Dean, 2006: 40); to ensure that people remained 'in their place' by preventing their access to knowledge that might give them ideas above their station which would make them more difficult to 'manage'. Education and training (and educationalists) were viewed as threatening because senior staff in these hospices viewed information as power while 'favouritism' serves as a 'divide and rule' technique to make management easier. What comes through clearly in this discussion is that the organisational structure was hierarchical, contrary to 'grand narrative' espousals.

5.4 A Services Mentality

Antonia mentioned an 'army mentality'; referred to by many others I encountered. A participant at one of my 'holistic care' workshops when talking about anger, noted strongly. *Since we're talking about anger look at who's in charge ex military man What does he know about patient care? Most of the staff who work in hospices are women. That should tell us something. Women are allowed to cry but don't dare try to be assertive because if you do you will be told you are aggressive so that should tell you something. He especially enjoys saying things to*

staff just so he can see them cry (Nurse Truda). This resonates with Walter's observation that hospices are 'stereotypically feminine in allowing tears but not anger' (1994: 89).

R. I want to ask you about management - management practices and hospices. As an outsider coming in I was shocked by the authoritarian, bullying culture. A brutal use of authority. (...). Secretaries and people working on the admin side seemed to have an awful lot of power which belied their role in the organisation. Yet other people that should have had a say seemed to not have a say. Have you got anything to say about that?

Nurse Ruth. (...) you must remember was an ex army officer and he still applied the same rules as though he was still in the army. The secretaries, I think because they were front office and they had a lot to do with the management they thought they were really mega mega important. They were no more important than we were on the ward because they can't do secretarial work if they don't have a hospice to do it and we can't do our work if they're not doing their work. But yes we did have a lot of hem hierarchical subtle bullying. Yep. Unless you were quite a strong character you got browbeaten quite quickly.

In light of these kinds of comments and others I heard from colleagues working in the hospice movement I asked Saunders why so many ex-services personnel held senior posts in hospices. At the time of interview (2003) approximately two thirds of hospice Chief Executives or senior management had a service background, i.e. army, navy or RAF.

R. Do you have any idea why do so many ex-services personnel work in hospices?

Saunders. *I've no idea. Well, I suppose when they leave they are still relatively young and they want an important job. They want to be seen to be doing something important as well as getting paid well so I suppose hospice offers them that [laughs].*

5.5 The Dark Ages

In hospices 'teamwork offers a measure of equality and status for nurses, social workers, and clergy – all professions otherwise struggling to find a clear identity and of lower status than medicine' (Walter, 1994: 90) but I would add the caveat – in theory, as the following extracts indicate.

R. Talk to me about multidisciplinary working (. . .).

Ruth, experienced nurse; *Well you all should be working together. But this kind of working together has changed over the years. In the early days the team wasn't big and everyone did whatever but there was a hierarchy with matron at the top of the tree. As the team grew this became harder because people wanted to claim their little area. (.) but I don't think its happening now. I don't think so because it's too compartmentalized. Fragmented. There's no working together any more.*

R. Can I go back to what you said about the structure because I'm really interested in that. You said when you first came to work at the hospice it was quite hierarchical. Talk to me about it.

Ruth. (. . .) *was the matron and she was like Hattie Jakes in Carry on Nursing. You almost bobbed your cap as she went by. She ruled it with a rod of iron. She had her finger in every single pie. She knew exactly what was going on (. .)*

R. Was there a chief executive when you came to work here?

Ruth. *There was (. .) the bursar who left a month after I joined. Doctor (. .) took over and not long after that (. .) started.*

R. So that was already a change in the organisation of the hospice wasn't it?

Ruth. *Yes it was, having an executive who wasn't a medical person. Yes he had been in charge of a hospice before but he wasn't a medical person.*

R. (. . .) you were at the hospice in the early days and I'm really keen to get a flavour of how things were. Many nurses now specialise as you know but I see hospice nurses as generalists. Would you agree?

Penelope, retired experienced nurse; *Yes. In the early days here we didn't have social workers for example so we did what they do now. In any case there wasn't any specialisation in those days so yes the nurses tended to be good all rounders. They had what we called common sense and the atmosphere was very informal.*

R. Did you work in a multidisciplinary way or was it mostly nurses when the hospice first opened?

Penelope. *The team was quite small. The hospice was led by a bursar who also served as a chaplain. We had no accountancy department, no hospice director, no bereavement service, no paid fundraisers and no paid manager of the volunteers. The main entrance was where day care is now. We had fewer offices and less staff in general but effectively ran a unit with the same number of beds as today. The first matron we had came from St Christopher's so we were lucky as she trained us in that model. (. . .). We didn't have strict boundaries that say this is one person's job and no one else was allowed to do that thing. We all mucked in. Matron used to roll her sleeves up when we were busy. Now it's completely different because you have people from every discipline in the team and they all have their own agendas.*

These extracts alert us to changes that were taking place in this organisations 'structure' relevant to current debates about bureaucratisation; i.e. a shift away

from a small community of practitioners where professional boundaries blurred for the benefit of patient care with everyone 'mucking in' towards the development of mono professional groups with their 'own agendas'. However, if each person works independently doing their bit and paying little attention to the other members of the team, care will be disjointed and chaotic and thus 'holistic' care will be impossible. Yet, everyone 'mucking in' does not mean that everyone's voice carried equal weight.

It's always been hierarchical right from the start even though it was smaller then than it is now. Matron was from the old school and people were afraid to question her. If she said jump, people would say 'how high'? (Pam, volunteer).

If anyone spoke out at a meeting she would collar them afterwards and say, 'how dare you bring that up' or something to that effect depending on what had been said Oh yes you didn't cross her. She could be nice but I've seen more than a few staff reduced to tears over the years (Gordon, ancillary staff).

You almost felt like tipping your cap at matron She had that effect on people If she sat in on handover you would make sure everything was spot on and even then she always managed to find something wrong. She had the ability to make people feel three inches high (Nurse Zoë).

R. How were the healthcare assistants treated?

Nurse Ruth. *They didn't do much. They did the bedside nursing; they did the washing and all that sort of thing. But they didn't do temperatures, pulses and that kind of thing because we didn't do these as a matter of routine and also because they weren't deemed fit to do it either. Or that wasn't their role. Their role was actually holding hands with the patient and putting the laundry away Things like this, and the ironing at night.*

5.6 Imagining and Constructing Identity

Since hospice proponents were 'imagining' (Rose, 1999) and constructing themselves as 'homes' and 'families' of a particular type we need to attend to the way in which identity is productive. *Nurses don't just get a job in a hospice; they have to be on probation for a period of time first. I was on the bank for two years before I was offered a post. It's a really good way of interviewing staff. If they don't like you they just don't ask you back. Even when I got the job I knew I was on probation for the first six or nine months* (Nurse Shirley).

We used to be told it was a privilege to work here, that we were privileged. We really believed that (Nurse Pat).

These provide nice examples of how 'conduct' and professional identity 'are worked' i.e. become 'shaped' at micro level, by 'guiding' and 'directing' the expectations of potential employees. Since individuals who applied to hospices were not always offered employment; those that were, considered themselves 'privileged'. Having become an employee, one's future job security depended on the 'probation' period which served as a 'device' for testing and eliciting individual compliance to organisational 'norms'. Those who were non-compliant were told they were '*unsuitable for hospice work or elbowed out*' (Nurse Niamh). Despite talk about 'mucking in' certain staff were 'deemed fit' to undertake some tasks but not others. As one practitioner noted; *on the night shift we have to do the patient's laundry. Really! Not just washing, ironing as well. If patients are awake, disturbed or need a chat, too bad, we can't spend time with them because we get in trouble with the day staff if the laundry isn't done. It's always been like that here, it's like the dark ages*' (Sophie, healthcare assistant).

Returning to my conversation with nurse Ruth;

R. What about junior nurses? Someone told me they were not permitted to answer the phone until a couple of years ago. Is that right?

Ruth. *Yes it is. No, no you weren't allowed to answer the phone.*

R. What was that all about?

Ruth. *Hierarchy again. It was power. (. . .).*

R. Did you have a routine? Because one of the things about hospices is that they weren't institutions like hospitals were supposed to be, they were supposed to be home like environments.

Ruth. *They were home like, they were very relaxed*

R. How did 'relaxed' work with authoritarian and hierarchical?

Ruth. *They weren't hierarchical to the relatives or the patients they were hierarchical amongst the staff. Everyone knew their place*

R. So you all knew your place just like the patriarchal family of time gone by?

Ruth. *It was a nice family. But it was a matriarchal one not patriarchal*

R. So the woman had the power and not the man? **Ruth.** *It was definitely (...) [matron] because she was there for quite a few years.*

R. And were you all her servants? Like the middle class families of the nineteenth century. You were her servants?

Ruth. *Yes. Yes. I mean I didn't dare talk to the ward sisters. No, not at all when I first started there and for quite a few years. No goodness me no. That might be different for people like (...) because they had all started together a lot of them when the hospice first opened. But as a nurse coming in no you didn't talk to the ward sisters unless they spoke to you first. But wasn't bad, it was quite comfortable but you knew your place. It was like that until after 2000 and even then, this power thing was still played out by the senior staff.*

As evidenced by practitioner accounts hospice proponents endeavoured to maintain a particular kind of 'identity' and division of labour that derived from another era. For example, in a previous historical period, nursing in the voluntary sector provided a suitable occupation for the daughters of higher social classes by promoting nursing as a 'vocation' requiring duty, devotion and obedience, the epitome of the 'good' woman as espoused in the late 1880s. This manifested in the voluntary hospital as 'the reproduction of the wider Victorian class structure based on preconceived notions of the division of labour between the sexes and between women of different classes' (Able-Smith, 1960). The kind of employee that second wave hospice sought derived from concepts of the 'patriarchal' family from which ideas about duty, service and obedience became paramount for hospices' public and private image by assisting hospices to represent themselves as *homes* of a particular kind, recognizable, I speculate, to certain categories of people i.e. higher social classes (Able-Smith, 1960). The ward sister or matron complimented the authority of the doctor (until relatively recently with the exception of Saunders usually a man) in organising the nurses and domestic staff in a mirror image of how, as the 'lady of the house' she would have supported her husband and supervised the servants. As Saunders told me, *'I became a doctor because I was told no one would listen to me'* (interview with the author, 2003). What we have at the macro level is the stereotyping of care as women's 'natural' work and that becomes translated into local practices (Syde, 1987). This manifested as being prepared to subsume individual interests for the survival of the group and not challenging the 'authority' of the people in charge of this 'family'.

5.7 Negotiating Meaning: Disloyal or Dysfunctional?

Take a concrete example about attempts to manipulate the identity of hospice members; Dr Rose recounted an instance whereby they and other medical colleagues had been asked to forgo a salary increase that NHS doctors received. When the doctors offered valid reasons for their refusal they were accused of being disloyal to the hospice. Management were particularly incensed that the matter had been communicated in writing, a practice abhorred in these hospices.

R. So in fact there is the collective identity of the hospices which separates them off from the NHS – ‘we are hospice people etc’ – but there is also the individual identity of each hospice - staff were never allowed to say anything that could be perceived as nasty about the hospices – did you find that?

Dr Rose. Oh yes, it was considered very disloyal. That's why (. . .) turned round to me and said when I wouldn't accept the pay cut that she'd never have thought that of me

R. Because you were supposed to be loyal?

Dr Rose. Yes.

R. You were supposed to be swallowed in the collectivity known as (. . .) hospice.

Dr Rose. Yes and they just didn't realise that you can't do that with most doctors and they never will no matter how much you sit on them.

The aftermath of the above episode led to deterioration in relationships between the doctors and management and subsequently resignation of the former since they were not prepared to subsume their own interests in the interests of the organisation. What does this vignette tell us? That management at the hospices were so uncompromising they were prepared to lose experienced doctors thus putting its operations in crisis and patient care at risk as a result of staff shortages?

That the doctors in question were selfish for wanting to maintain their salaries in line with doctors elsewhere? That in order to *belong* to this hospice the doctors ought to have put their own interests second to those of the hospice? By not agreeing to forgo a salary increase these doctors were refusing to conform to group pressure and asserting, not similarity, but difference, and thus would have been perceived as 'unmanageable' by rejecting the group, its norms, or both.

On a more practical note, had the doctors done as management seemingly wished this would have created recruitment problems at some future date since doctors might not be attracted to work in hospices for lower salaries than they could expect to receive elsewhere. Indeed such 'vulnerability' was among the reasons along with 'absence of a career structure' that led hospice doctors to form a pressure group to have palliative medicine legitimised (Small, 1999: 299) and why most 'palliative' consultants currently insist on having NHS contracts rather than hospice ones. As one doctor told me,

I would never let a hospice hold my employment contract, did that once and got badly bitten. They're too dysfunctional. It is far safer to remain with the NHS and have an agreed input into the hospice than letting them own you. That way they have to pay the NHS for the hours we give them (Nick).

5.8 Imaginary Constructions

Yet it is worth noting what many commentators on hospice have not; Saunders merely changed how people might 'imagine' the team (Rose, 1999). By this I mean that instead of the pyramid of hierarchy representative of NHS team work, Saunders advocated a circle: 'Ideally the doctor should remain the *centre* of a team who work together . . .' (Saunders, 1958:46 cited in Clark 2002: 7, my emphasis). The *doctor* would occupy centre stage, not a physiotherapist, nurse or

an 'other'. Apart from gender issues already noted, bear in mind status and power differentials within and between members of the healthcare professions with doctors enjoying the most power and status. Remember, Saunders had become a doctor in order to be listened to i.e. increase her status. In these hospices when a patient rang their bell *it would never occur to a doctor, physiotherapist or social worker to answer that call or put a patient on the toilet* (Nurse Antonia). 'Grand narrative' designers created an 'image' of power relations that *appeared* different to the NHS and peoples assumptions followed this and thus 'the story derives the essence of its power from imaginary forms' (Foucault, 2003: 230). However the following account with Dr Alexia strips any notion of 'egalitarianism' of its 'naturalness' and 'taken-for-grantedness' (Rose, 2003).

R. Is that what happens in hospices? Do hospices attract certain types of people into certain positions?

Dr Alexia. *They certainly attract certain types of nurses, and admin [laughs]. I think the doctors who work in hospices, I mean most doctors are ok; you'll accuse me because I'm a doctor*

R. No, of course not.

Dr Alexia. *Well I've not really had a problem with other doctors in hospices. I mean doctors still in these days tend to be free spirits.*

R. They're autonomous practitioners. They're professionals?

Dr Alexia. *Yes. Yes em and they just are. That's the way you just almost trained.*

R. You're used to having power?

Dr Alexia. *Yeah I mean it's not particularly an issue although it's seen as an issue by other people but it's not, (. . .). But the ones who I've found a real pain have often been the attitudes of some of the nurses and the admin staff.*

R. Can you give me an example?

Dr Alexia. *Em well they want their presence to be felt, they want to feel they've influenced a life or, whatever. 'I've made a difference here and I'm a very important person'. Yeah, but I mean there must be some of that with doctors em.*

R. Maybe it's something to do with status. Nurses historically have lower status?

Dr Alexia. *Yes, because it seemed to give nurses a real buzz if you agreed to their suggestion. They felt powerful maybe.*

R. In that case, because I'm thinking about issues of control. Perhaps hospices can't really control dying in the way that they've claimed, collectively claimed, so maybe hospices attract people who are a bit inclined towards control or control(ish) themselves. So that manifests as nurses who want to control patients dying. What do you think?

Dr Alexia. *Yes which may manifest as nurses wanting to control the patients dying so they must go through the stages, must do this, must do that. Really because they're a bit messed up themselves and possibly freaked out by dying so they want to keep a tight rein on things. On the other hand on the management and administrative side hospice attracts people who perhaps are possibly afraid of dying, want nothing to do with it or perhaps haven't faced their own issues but they control people who work in the organisation. By that I mean who gets what, for example I remember a big fuss over office space for the doctors at one stage and what drugs are available, petty arguments. Em yes, I can't remember what is was, something very minor (. . .), myself (. . .) and (. . .) and the pharmacist at (...) [a local NHS trust] all agreed, I think we wanted to use Immeprozol instead of Ranetidine em and for quite good reasons and there wasn't much price difference I think, not much between that and Zantac but someone administratively said 'oh well we've got a contract', or 'Zantac has always been used' and they were being really awkward about doing it and it just seemed to*

just give them a bit of a buzz. (. .) I mean we're used to a bit of an argument but sometimes you seemed to be arguing just for the sake of it. You know that sort of rubbish which is about control. Yes, there's a lot of neediness in hospices whether its nurses or management and it manifests differently but ultimately it is about control and we lost the one outstanding nurse they ever had. Because I think they just let them go and that was (. .). (. .) didn't like the fact that he questioned things and wasn't afraid to stand his ground. That did not go down well at all even though other staff really liked him. Mind you the fact he was popular probably ruffled a few feathers. So the control thing is there.

5.9 Organizational Norms

Norms are standards of behaviour, informed by values which may be formal or informal. Formal norms are imposed by the organisation, such as 'the working day commences at' and are usually visible. Informal norms develop from within the group as a result of interaction manifesting as 'the way things are done'; 'everyone knowing their place'; 'junior staff not answering the phone' and thus beyond question. I did not witness much 'negotiation' (Wenger, 2007). *'You either accepted how things were done or left. You soon learned not to question* New staff were told *'this is how we do it here' and if they didn't behave they were elbowed out or told they weren't suitable for hospice work* (Nurse Sophie). People tend to conform to the prevailing norms of the workplace or risk alienation as Sherif's classic research indicates (1953).

I've given up offering an opinion on anything. They don't like people speaking out about anything here. I raised an issue about (...) and since then I've been sent to Coventry, like school kids. Whenever I go into the ward office everyone stops talking and when I go for report or

to meetings they just ignore me. If I say anything they stare at me as if to say 'how dare you speak'. It's like being bullied in the playground. From now on I'm just going to come in, do my job and go home. It's not worth getting involved (Natasha, allied health practitioner).

This person raised concerns about the 'inappropriate actions' of a junior member of the team who, in any other healthcare setting would have been the subject of severe disciplinary action or even termination of employment. The invisible 'norm' the reporting practitioner fell foul of is that if one wished to work in these hospices one must learn to remain silent even if that meant that some practitioners behaved 'inappropriately' (but got away with it because they were 'favoured' by those in authority). These 'norms' – 'favouritism', 'secrecy and silence', 'no one must rock the boat' were predominant at these hospices ensuring that anything 'distasteful' could be 'brushed under the carpet'. (Interestingly, patients who chose to 'keep their own counsel' were labelled 'pathologically abnormal'). Yet, if team members cannot communicate honestly and effectively with one another without feeling threatened or undermined this does not bode well for patient care. Another 'norm' of note was a tendency for some staff to become over involved in patient's affairs resulting in high levels of sick leave for lengthy periods.

I have to say some members of staff and not always nurses get too involved in what is happening to families. You see them crying openly and generally falling apart. Then they go off sick because they can't cope with the stress. This has nothing to do with what is happening to the patient or their family but their own issues. They're crying for themselves. This is not good practice. It's about professional boundaries. There is a big difference between being able to

empathise in a real way with patients and trying to sort out your own stuff
(Norma, allied health practitioner).

Was this a negative aspect of 'emotional labour' (Hochschild, 1983); a sign that practitioners lacked emotional intelligence, or a signal that the organisation had structural deficiencies? I consider that these hospices were attracting some staff who were not 'stable' in the sense espoused in the 'grand narrative' (Winner cited in Du Boulay, 1984: 148) indicating that selection procedures had not been robust – and thus, a structural deficiency (Child, 1977).

Saunders. *Well we're fairly selective, we've a few nursing gaps at the moment but not many. But we don't take everybody who applies, we do try to look for those sort of people em and I think there is something about work and something about the patients and their needs (. . .) something about hospice that teaches them*

R. It doesn't attract wounded healers then do you think?

Saunders. *Em [big sigh] Well [sighs] I suppose I'm one myself but em it the ones who are trying to work out their own salvation we try and spot and don't appoint.*

R. What likely implication would that have for their practice?

Saunders. *Well I think if they are going to put all their emotional capital into patient care and not have anything going on for them outside they're in a dangerous place. People who think they're God's gift to hospice are a bit - to be wary of.*

There were quite a few 'to be wary of' in this locality. Vachon (1985) undertook research to determine whether staff who worked in hospices were under more stress than those who worked in other arenas concluding that;

Those working in palliative care probably experience no more stress than caregivers working with the critically ill and dying in a variety of

other settings. In fact, palliative care staff often have the advantages of a shared philosophy of care, good staff-patient ratio, more rewards inherent in their roles, more built-in supports and more recognition than do a number of other caregivers (Vachon, 1995:111).

Conceding that 'problems do exist' Vachon's basic premise resonates with my own experience; i.e. although there may be certain stressors related to working with dying patients and their relatives to which those in hospices are exposed, (or *were* exposed) most of the stress derives from 'occupational roles' and from 'tensions in the work setting' although not all staff would be susceptible (Vachon, 1995). The employees most likely to suffer stress in this setting were those who had hidden or unacknowledged motives for working in hospice or who were at the lower end of the hierarchy i.e. those with the least resources to recognize or resist 'management' tactics.

5.10 Sleepy Hollow Awakened

We can only see the effects of time through change, but sometimes we get a glimpse of change as it is happening. What is interesting about the accounts in this chapter (and indeed chapters 3 & 4) is how they manifest tensions occurring in this locality during the crossover period between old and new hospice discourses e.g. family, community, informal values; and new (impersonal, bureaucracy, professionalization) and the unease this caused. This really was change in progress. I was privy to this 'crossover' period when certain discourses were displaced by others as the macro battle in a 'will to power' was enacted at local level where certain practices came to be viewed as 'unprofessional' or 'inappropriate'. For instance, some practitioners began meeting in one another's homes to discuss the spiritual aspect of practice which they felt was being neglected in the hospices. When management found out they were told to cease

with immediate effect as it was unprofessional. Basically speaking practices were in a process of being re-normalised and there was much confusion about matters of 'identity' at both personal and institutional levels. The following accounts are illustrative of many conversations I had with practitioners about the kinds of people who were attracted to hospice work at different historical moments.

R. But what did (...) [doctor] do. Give me a brief overview of how he changed things.

Nurse Hilda. *He made everybody re-think. He challenged everything. And he would not accept that the patient was just dying. He'd say 'OK well we can just do this, this, and this We can give this drug, we can do this for them, get the physio in, a lot more pro-active and he challenged the sleepy hollow ville attitude that we had slipped into and I think it was a good thing (. . .) he was a bloody good consultant, he was excellent on symptom control and his main thought was for the patient. He brought a much more proactive view to us. And it opened my eyes up. I was a bit taken aback at first because I'd only ever been taught to (. . .) basically and he came along and said no that's not all you can do you can do this and this and they can still have a good quality of life for a longer period of time and that was great It was wonderful. And then that's when we started to think about resuscitation issues. We thought 'we don't resus patients in hospice' but that changed too.*

5.11 A Cushy Number, Needy Nurses and Control

R. Why do you say (...) was indecisive?

Gina, experienced nurse; *I think so and also because he got to the hospice under pretences by (...). A bit nasty on (...)'s side because he told (...) it would be a nice quiet place for him to go through to his retirement and there was not a lot*

happening at the hospice. So he was hoping to come for an easy time not to be landed with all the proactive intervention that we were doing by then. I think that really shocked (. . .) and you could tell he was quite uncertain about a lot of things so he would stand back and do nothing and wait for something to happen. So he was more reactive than proactive. Unless you really stood your ground and said 'I want this, this and this'.

R. Are you saying hospice work was seen as an easy number by some people?

Gina. *Yes of course, because for a long time it was. It was quite cushy. Still is to some extent depending on your position in the food chain.*

R. During my first three years I heard certain people complain that I was making the place too busy with all the students coming in for courses. But no one said anything to me directly.

Alison, *experienced nurse; Well they wouldn't. That's not how it's done here. They prefer to talk behind your back and you can't respond because you don't know. [Laughs]. (. . .).*

R. Do you think (. . .) that some people worked in hospices because they thought it was a nice little cushy job as someone told me?

Alison. *Ooh yes. Oh yes. (. . .) Oh yes, yes a lot of people came to work in the hospice because they felt it was, they thought you just did total patient care and nothing else and that was it and you could sit and relax.*

R. You could sit and relax?

Alison. *Yes, sit and relax. And for some doctors they saw it as a nice place to pass the time until retirement.*

R. In your experience what kind of people are attracted to work in hospices?

Dr Sarah. Nurses in hospices seem to be needier than nurses I've encountered in other settings. They take everything literally and at face value. They want a recipe or prescription for everything and they just follow it and off they go. They're a bit like sheep where one goes the others follow.

R. What do you mean when you say 'more needy than others'?

Dr Sarah. Well they want to be appreciated. They seem to get a great kick if doctors seem to agree with something they recommend

R. Are certain types of people attracted into certain positions in hospices? Or even, as someone once told me, hospices are hiding places for people?

Daryl, experienced nurse; its very difficult. Yes there are difficult, malevolent people who want to manage and control things who seem to be attracted to hospices, especially into management positions But also on the caring side too, because you have control of patients because they are dying But I don't know about the control from a good or bad point whether they want to control to make it better for the patient to which I could say, 'I would like that' or whether you want to control it because you have that need to control. So maybe in their own life they are totally out of control.

5.12 Mickey Mouse Goes Professional

Dr Veronica (.) on one hand it was very necessary for the charity to become more businesslike because lots of things did happen that weren't very businesslike Well the problem is, when you've got a charity, [sighs] it's Mickey Mouse. So it was essential it be sorted out.

R. But there was carelessness about finance. (. .).

Dr Veronica. *Exactly. So there was a lot that needed tightening up. It's not like looking at the past with rose tinted specs (. . .).*

R. Once they introduced a chief executive? Is that what you're saying do you think?

Dr Veronica. *Yes, I think so. There was a lot that needed to be changed without an absolute doubt, an awful lot that needed to be changed. Unfortunately they threw out other things. (. . .).*

R. Did you?

Dr Veronica. *Yeah, (. . .) I don't think (. . .) was given the management training that someone in (. . .) post should have been offered. I feel quite strongly you know sort of that. (. . .) wasn't a strong enough person in (. . .) philosophy of the hospice to be able to influence all the administrative and nursing changes that were going on.*

R. Did (. . .) come in as medical director?

Dr Veronica. *Yeah, and then (. . .) was still there. (. . .) was made medical director. (. . .). The two groups of people that I think they're losing are the people who probably as individuals were most solid and that's medics and the chaplains and the people I feel most sorry for aren't actually the nurses, its actually for the ancillary staff who there's usually only one or two of, so like the physio and the social workers. At least the nurses can band together even if some of them are like a herd of sheep banding together [laughs]. But you can have a physio who there's only one of them, social workers usually there's only one of them and then if you think of again like a herd - yeah, that's quite a good analogy - a herd of animals, management is the fox, then if the herd sticks together like the nurses then at least they've got some bonding but the different animals on the fringe like the physio or the social worker, they're easier for the fox to pick up; and you*

could say the medics and the chaplains are on the fringes but they at least have a bit more bite at turning round or else they've got enough confidence not to bother to bite the fox just to ignore it. Yeah, I quite like that analogy.

R. Is there a type of person who chooses to work in hospices do you think?

Dr Veronica. *Yes I do think in some cases this is true particularly on the nursing side. For example (. .) I know people thought she was lovely (. .). She had been there too long and absorbed herself too much in everything. She obviously had some need which hospice provided for She used to stay long after her shifts ended say 11 or 12 o'clock at night and that caused quite a few problems. But if you think about it that could be seen as commitment but what message does it give to the others? 'I don't trust you to do it properly or I've got this information which I can't let you have because I'm a very important person'. It's very dysfunctional and sad really. So yes, hospice nurses can be quite strange.*

R. (...) what you've said is so interesting because I've had people refer to hospices as hiding places for incompetent or lazy nurses. What do you think of that?

Dr Veronica. *Yes, I can see why Yes I think there are some and I think more likely in later years than originally with the exception of (. .) who I don't think would have made it anywhere else coming back from (. .) [Laughs]. Some people employed in hospices wouldn't get jobs in the NHS. I think some see joining the hospices as a quick ride up the promotion ladder. (. .). I have met some incompetent and even downright lazy nurses if that's not too strong a way to put it. I don't mean to be offensive but yes I think that is a good description. I mean I have met some good ones but as I said before hospice nurses tend to be a bit strange. I know it might sound horrible but I think this became more likely in later years than in the original years. By that I mean when Cicely started in 1967 for*

about ten years there was a genuine groundswell of support from people who really wanted to do better for dying patients but after that the rot set in. (. . .) You see hospices have lots of supplies not available in the NHS, lots of pillows, no shortage of equipment you can have what you like, cake at breaks, nice meals, people think the nurses are angels. Well nurses especially were set up on a pedestal and actually for most of them, they did very little really. And the pay was pretty much the same as the NHS. That was pretty much how it was when hospices did care of the dying patient but as we've moved into palliative care that sort of incompetence can be dangerous. Apart from what I said about (. . .) because what has happened is that more and more staff have left in recent times and new people are coming in with no experience or claiming expertise which they haven't got, you know what I mean. That's where competence or the lack of it [laughs] shows up. It all becomes pretty meaningless. Makes you wonder about the management who employ them.

R. I have an idea of who you mean but would you care to be more specific?

Dr Veronica. (. . .), how can you be a specialist if you have never worked in palliative care or even had a position of responsibility? It seems insane to me [laughs]. How do they get these jobs? Doctors for all people might grumble about them can't just pretend to know what they're doing. If they apply for specialist posts they have to prove they have the experience and qualifications. They can't just walk into a job because their face fits. That's what I mean about nurses. They seem to be able to get away with stuff like that but I think it's really dangerous. (. . .) I feel sorry for the patients and I have heard of patients screaming in agony because no one seems to know what they're doing. They're the ones who suffer while all these others play power games. I mean em the problem as I see it is if people are incompetent em they won't appreciate people who know what they're

doing as they would probably see this as a threat like they did with (. . .). They surround themselves with like minded people or at least people who don't know any better or are inexperienced but the losers, and there are losers, are the unsuspecting patients Even if they begged me I could never go back It's too dangerous. You would be condemned by association and I wouldn't want that.

R. Your reputation would be tarnished?

Dr Veronica. *Yes definitely.*

5. 13 Conclusion: Autocratic and Authoritarian Enclosures

As one practitioner noted; *a hospice's direction was very much dominated by the personality or combination of personalities of the person or people in who were in charge* (Dr Sarah) and in this locality the people 'in charge' were and continue to be autocratic and authoritarian. Autocracy is ultimately about 'control' and can be used positively or negatively. St Christopher's 'model' was transplanted into this locality where 'control' was used negatively as an explicit management 'technique' to keep people in their place and those occupying positions of authority were not open to new ideas. 'Power misused becomes injustice; control misused becomes coercion; leadership misused becomes domination; authority misused becomes authoritarianism' (Adirondack, 1998:26). To be authoritarian is to favour obedience to authority as opposed to individual liberty.

Hospices, noted another were a deliberate attempt to remain 'stuck' in the past – *trying to keep that old approach that was disappearing in hospitals* (Zelda). However, this 'old hat' (Zelda) style management led to various structural deficiencies that impacted on how these hospices were managed as well as how adaptable they were when it came to managing change. New arrivals who stepped into 'authoritative' roles created a 'false democracy' i.e. claiming they

wanted to involve people through consultation but not giving them adequate or appropriate information, time or opportunity to participate (Adirondack, 1998:29). A favoured but often taken-for-granted 'management' 'tactic' - tactic of 'governance' was the use of 'time' to control who took part in certain activities. For example, cancelling meetings at short notice, having meetings in secret to exclude certain individuals, timing meeting in such a way that certain people were excluded by virtue of their work schedule (Rose, 1999). Favouritism is a divide and rule management 'technique' that pits people against one another and thus, instead of cohesion there is splintering and fragmentation of the team. The notion of teamwork is undoubtedly attractive but does not necessarily lead to the adoption of the multidisciplinary approach never mind egalitarianism. A disregard for people up against life at the finishing line and an embittering cynicism turned what was meant to be an exemplary clinical service into a dysfunctional bully's playground. In the next chapter I discuss my findings regarding the three 'goals' hospice set for themselves.

Chapter 6

Goals of Hospice: Rhetoric or Reality?

A basic problem for many performances, then, is that of information control; the audience must not acquire destructive information about a situation that is being defined for them. In other words, a team must be able to keep its secrets and have its secrets kept (Goffman, 1959:141).

6.1 Introduction

This chapter provides a bridge between the previous three chapters where the 'goals' of hospice were examined and the remainder of the thesis. In other words, what is discussed here will help contextualise what is to come i.e. I offer an overview of findings concerning the three 'goals' 'second wave' hospice proponents set for themselves. Mindful of Payne and Williams (2005: 305) proposition regarding 'moderatum generalizations' and to ensure the 'credibility' of generalizations; I then map these findings to specific concerns raised in the literature on hospice and palliative care; i.e. hospices losing their original focus and ethos (Biswas, 1993), becoming medicalised, (Ahmedzai, 1993, Biswas, 1993), bureaucratised and routinised (James and Field, 1992) and considering their religious roots, secularised (Bradshaw, 1996). Third, I consider a new 'technique' for managing patients that is being tested at St Christopher's hospice which is followed by synopsis of 'emotional labour' (Hochschild, 1983). Finally I offer a discussion about generalising from these findings.

6.2 Key Findings: Second Wave Hospice

The questions that informed this part of the study were:

1. Were these 'goals' achieved in practice and if so, how?
2. If the goals were not achieved, why not, what were the barriers preventing their realization?
3. Is there a disparity between the rhetoric and reality of hospice care? (Lawton, 2000).

The key findings support the central proposition of this thesis which argues that there is a gap between the rhetoric and reality of hospice care (Lawton, 2000).

None of the goals were fully achieved in practice in this locality and for all three 'goals' the gap between rhetoric and reality was very wide (Lawton, 2000). I will briefly explain why each goal could not be achieved.

6.3 Barriers to Achieving the three Goals

1. The primacy of stage-theory.
2. The manner in which allied health practitioners viewed their roles
3. The way power operated in this setting.

First, hospice practitioners had been socialised using Kubler-Ross' 'stage theory' (1969) to enable them to search out patient's subjective experiences and to re-constitute these as psychological problems to be 'fixed'. The stages were used as a technique to 'guide conduct' (Rose, 1999) through the dying process; and as a technique of 'surveillance' (Bloor and MacIntosh, 1990) to enable practitioners to decide whether patients and relatives were acting normally or

abnormally. It also meant that they did not need to expend too much in the way of 'emotional labour' (Hochschild, 1983, James, 1989, Smith, 1992) since the 'stages' became a 'script' – a prescription - that relieved them of the necessity to think too deeply; they merely followed the prescription and the messy world of dying became predictable (Chaban, 2000). It might be said that 'stage theory' provided the 'feeling rules' for practitioners in this setting (Hochschild, 1983: 56).

The good dying patients are the ones who accept their death and die with a sort of disinterested serenity. The progressivist bias evident in the sequence makes acceptance morally desirable, and places an obligation on health professionals to realize this acceptance in their patients. . . . The tranquil, accepting person causes no disturbance and is simple to manage (Churchill, 1985:168).

Therefore patients were 'governed as much through subjectification as through objectification' (Rose, 1999: 95). i.e. the 'technique' objectified them by structuring the field of possible action within a disease centred 'reductionist' paradigm and way they came to 'identify' themselves and be identified by others was predetermined (Dean, 2006) . This 'objectification and 'subjectification' was achieved through the ritual of secular confession i.e. patients and relatives were incited to talk about themselves so that others (who are experts) may validate the truth about them. Both religion and 'the stages' were 'imposed' on patients and relatives in this locality until approximately the year 2003. To 'impose' in my view, is to 'harass'. In these hospices, vulnerable patients and their relatives were the 'subjects of' and 'subjected to' – not holistic care but harassment (Randall and Downie, 2006).

Secondly the teams in this locality had become increasingly 'fragmented', shifting from what was probably (despite reliance on stage

theory) an attempt at 'holism' whereby everyone '*mucked in*' (Penelope) to one where the number of professional disciplines comprising the team had increased with each discipline protective of their area of expertise i.e. viewed their role as separate from others and therefore, this 'erodes the concept of whole person care' (Walter, 1994: 91). Patients or relatives who were viewed as 'problematic' were 'bundled off' to the social worker, chaplain, or which ever discipline was deemed appropriate (Walter, 1994: 91). This change in care practices merely 'chopped' people 'into separate analytic bits' (Walter, 1994).

Nurses in this locality were '*just worker bees*' (Nurse Ruth) precisely because hospices were an attempt to remain '*stuck in the past*' bringing us to the third barrier to achieving the goals – hierarchical and authoritarian use (abuse?) of power. Because practitioners did have preconceived notions about how dying *should* be, and because of the way the teams operated, i.e. hierarchically where only certain 'favoured' opinions mattered; practitioners were unable to treat each patient as the 'autonomous individual' 'fully in control' espoused in the 'grand narrative' thus evidencing a very great disparity between the 'rhetoric and reality' of hospice care (Lawton, 2000). More seriously even if practitioners attempted to act as 'advocate' for patients by speaking out about practices that concerned them, e.g. unethical behaviour or sedation, they were ignored, marginalised or elbowed out as I discuss presently.

6.4 Social Class Matters

Hospices inherent social class bias (recognized by all who work in hospices) tends to be 'glossed over' in the 'grand narrative'. Yet, 'the hospice movement in Britain has demonstrated an ability to generate resources of money and

property from charitable giving that is without parallel in the 20th century' (Johnson, 2000).

By region, by area, by city, by town, champions have come forward with a local vision and set about raising the funds, finding the premises, recruiting qualified staff and engineering voluntary support to open up new hospices. With legacies, donations, special events and regular revenue earning activities the funds have been found. Fund raising for charities will never be easy, but the task for the hospices has been eased by the readiness with which people generally have been able to engage their cause (Johnson, 2000:1).

What about the people who spearheaded fundraising to establish hospices in each local area? There is an over-abundance of people from the higher professional groups and the upper social strata, social groups A/B (Douglas, 1992). Hospices have relied heavily on voluntary contributions, in particular 'legacies' bequeathed from a dead person's estate, often someone who had died in a hospice or knew someone who had. Which social strata would most likely have finance or property to bequeath? If one examines the lists of patrons of the numerous hospices throughout the UK, one will notice a preponderance of titles and names from the upper echelons of society (Douglas, 1992). As for the kind of people who undertake voluntary work in hospices;

They are mainly drawn from affluent, non-working females from social groups A and B (Field and Johnson, 1993:205-6).

I suggested in chapter four that my speculations regarding social class could be tested. Studies have explored how demographic factors like age, sex and geographical distance from a hospital or hospice influence place of death e.g. Grande et al, 1998, Addington-Hall et al 1998, but 'it is less clear what role social class plays' (Kessler et al, 2005). However, Cartwright's (1992) study of life before death did indicate that more middle class people had been in hospices

or private hospitals than working class people. 'Studies looking at either the social class of individuals or social deprivation by area have demonstrated an association between lower socio-economic status and an increase in deaths in hospital' e.g. Gattrell et al (2003) and Sims et al (1997) cited in Kessler (2005: 105). Kessler's own research exploring the relationship between social class and access to specialist palliative care services makes some interesting observations that resonate with practitioner accounts and my speculations; 'some from social class 1V and V [working class] said they hoped to be offered [a hospice bed] but felt unable to ask, passively accepting hospital or nursing home admissions instead' (Kessler et al. 2005: 108)

The hospice is situated in and among the most deprived electoral wards in South Bristol. This might have been expected to make hospice death more likely in social class V. It did not, and this supports the conclusion that cancer patients from the most deprived social class are less likely to die in hospice. There was evidence that some carers from social class 1V and V felt unable to ask for a hospice bed when it was needed. This passivity contrasts with the successful pressure exerted on the hospice by other social groups (Kessler et al, 2005: 109).

Whatever point of view one takes there is no doubt that 'because of the emotive nature of this work, funds pour in and can be spent on the latest and best in hospital equipment, furniture and furnishings' (Charles-Edwards 1983: 235-6).

6.5 Governing the Governors

Being 'governed' as a hospice employee could involve any or all of the following; being 'spied upon, directed, regulated, hemmed in, indoctrinated, preached at, controlled, censored, commanded, . . . noted, registered, captured, evaluated, admonished, prevented and punished in every action, every transaction, every movement (I adapted from Oestreich's citation in Rose 1999:

226-7). Uncertainty manifested as 'structural deficiencies' and an unnatural fear of those who were knowledgeable. As one doctor put it '*dullards don't want bright sparks around them because they're afraid others will notice they're not as competent as they pretend so they spend all their energy protecting themselves from exposure instead of doing the job they are paid to do which they are incapable of doing anyway*' (Dr Veronica).

'For an institution to hang together doing recognizably patterned things there must be some sense of 'sharedness' of understanding, some kind of commonality even if it is a case of 'shut up or ship out' (Parker, 2002:75). In this locality it was, quite literally, 'shut up' or we will make your life so uncomfortable that you *will* 'ship out'. 'Secrets' (Goffman, 1959) in these hospices were maintained by an informal 'norm' that no one must rock the boat. Some people who were 'forced out' or others who 'departed' posed a 'risk' of using 'destructive information' (Goffman, 1959) (i.e. disclosing 'facts' that are 'incompatible with the image' hospice attempts to maintain before its audience – the public). Therefore management were not averse to gagging agreements to 'seal *their lips*' thus enabling hospice to maintain a 'glowing' public image, their 'secrets' safe from the public (and taxpayer) who fund their activities (Goffman, 1959:141). Gagging agreements can scarcely be regarded as indicative of social or corporate responsibility or accountability. Those who were forced or driven out I called the disappeared because they simply disappeared never to be seen or spoken about thereafter. 'Waste and diversion of resources' rampant in the hospital movement during the 1330s and the 'traditional evils of financial corruption and inefficiency' that marked charitable institutions in the eighteenth century (Risse, 1999: 155 & 293) spring to mind.

6.6 Palliative Care

I consider that the adoption of the 'new' nomenclature represents a 'rupture' or 'shift of outlook' within second wave hospices' 'grand narrative'. This led to hospice advocates making curious statements such as palliative care is 'a broad band of care, indeterminate in length, which should start the moment cancer is diagnosed, or even before. When there is a gleam of apprehension in the patient's eye' (Penson and Fisher, 1991:3). Apart from being 'illogical' (Randall and Downie, 1996) such assertions reflect quite a shift away from the 'terminal' phase leading commentators to raise concerns in the literature, manifesting as 'losing the original focus' and 'ethos' (Biswas, 1993); 'medicalisation' Ahmedzai, 1993, Biswas, 1993), 'Routinisation and Bureaucratisation (James and Field, 1992) 'Secularisation' (Bradshaw, 1996). In light of the matters highlighted in this thesis regarding 'change' I will now briefly look at each of the above whilst mapping my findings to relevant matters under each heading.

6.7 Losing the Original Focus

The initial focus of second wave hospice was on *dying* patients. Based on my observations and the practitioner accounts presented in this study the 'original focus' described by Biswas (1993) has shifted *away* from *dying* patients. Many practitioners talked about patients coming to the hospice to die; *they came here to die - it was a place to die - we used to only have dying patients - whilst one noted that it is really hard to get in to die now*'. When these hospices were formally amalgamating in 2006 they underwent a 're-branding' process which

involved updating all publicity material. The individual responsible for this Rita (pseudonym) showed me the new version she had produced. The hospices described themselves thus; (. . .) *is an independent (. . .) charity (. . .) committed to the delivery of excellence in Specialist Palliative Care across (. . .)*. There is absolutely no reference to dying or death whatsoever. When I commented on this Rita said she had been told to remove all references to dying and death. Undoubtedly the 'focus' *has* shifted away from care of the dying in this locality.

6.8 Losing the Original Ethos

This refers to the 'philosophy' of second wave hospice which manifested as the 'three goals' explored in this study.

The hospice philosophy is one that affirms life. It exists to provide support and care for persons in the last phases of incurable disease so that they might live as fully and comfortably as possible (cited from an unpublished document by Manning 1984:46).

The *last phases* of incurable illness – i.e. the patient is *dying*. As I have illustrated, the goals deriving from this philosophy proved rather difficult to achieve in practice. I concede to 'comfortable' in terms of material surroundings but there was no 'living fully', a 'caring community sensitive to needs' or 'freedom to attain mental and spiritual preparation for death' because practitioners based their actions on *preconceived* notions as to what constituted appropriate dying behaviour. The 'ethos' to which Biswas (1993) refers, was largely absent when one was in a position to observe 'backstage' activities in this locality. For patients or visitors these hospices would *appear* to have a rather nice 'ethos' – it would *seemingly* be 'self evident' because the 'material surroundings' were so nice and reception manned by charming well spoken

volunteers. But in order to 'sustain the definition of the situation that its performance fosters' this 'front stage' appearance was dependent upon – [to use the master's tools] - 'kicking the dog' backstage (Kubler-Ross, 1969) i.e. practitioner compliance to, and silence about bullying and unethical behaviour characteristic of these organizations (Goffman, 1959:141).

6.9 Medicalisation

The charge of 'medicalisation' tends to have negative overtones but as I noted earlier it is based on an *assumption* that biomedicine had taken a back seat. Hospice practice was situated within a medical model from the outset albeit with the additional claim for consideration of patient's 'subjective world'. Interestingly and paradoxically this 'holistic' concern with individual's subjectivity enabled biomedicine to extend its reach into the lives of individuals i.e. 'the whole person must be brought into visibility and control' (Armstrong, 1986: 32) so rather than viewing biomedicine as 'reductionist' (Randall and Downie, 2006) the term 'expansionist' espoused by Illich (1974) may be more relevant. Biswas's concern seems to be that 'terminal care' very clearly acknowledges that a person is in the *process* of *dying* whilst 'palliation' does not.

Palliation is the relief of symptoms, and the logical extension of this view is that death is a symptom, and with increased expertise in palliation techniques, death can be alleviated altogether (Biswas, 1993:135).

The time for active treatment is over when patients are admitted to our wards. The decision that all that can now be given is comfort and care, and that too much activity would merely be a useless disturbance of peace (Saunders, 1965: 2).

'Comfort and care' are prioritised for patients in the *last phases of incurable illness* (Manning, 1984 above). 'Too much activity' represented an accusation levelled at hospitals involving cardiac or respiratory resuscitation, subjecting patients to surgery, investigations, tests, blood or other intravenous transfusions, undertaking regular observations of temperature, pulse, respiration, blood pressure or offering them radiotherapy or chemotherapy when it was pointless. The problem as I see it; second wave hospice clearly laid claim to 'low technology' 'comfort and care' for *dying* patients and it was *this* claim that gave them currency at a period in history when commentators on both sides of the Atlantic began to voice concerns about societies' neglect of the dying.

Until relatively recently, say late 2003-2004 in this locality, patients were admitted to hospice to die whether that took days or months. Increasingly, patients are admitted to hospices for symptom management – management or containment of unruly symptoms - *not* to die. Hospices that have their services commissioned by the NHS are paid 'per episode of care' i.e. usually a maximum of 10 to 14 days (Thomas, 2006). The approach is 'active' in that observations of temperature, pulse, respiration and blood pressure are regularly taken, patients are offered 'palliative' chemotherapy, radiotherapy, infusions, tests and investigations, they are asked about resuscitation i.e. whether, if they have a cardiac arrest they would like to be resuscitated; in other words, everything they are likely to be offered in any NHS setting.

A practitioner recounted a story about a patient who had been discharged from the hospice but continued to attend the acute hospital for 'palliative' radiotherapy. Her husband had to lay her on a mattress in the back of his van for the journey to and from the hospital. On the fifth day of 'treatment'

the woman died in the van whilst returning home. The problem with 'palliation' on this occasion was that no one had made a decision about when it might be appropriate to stop 'treatment' or that 'too much activity would merely be a useless disturbance of peace' (Saunders, 1965:2) the *raison d'être* for the existence of hospice according to its 'grand narrative'.

That patients may die is incidental and probably related to the possibility that 'palliation' has hidden the extent of disease progression from both professionals and patient so successfully that death *appears* unexpected – the 'cloak' of palliation not only covers 'symptoms' but also signs of deterioration and in this sense 'palliation' has removed the sting of death. This resonates with McNamara's Australian research (2001:120). Adoption of the nomenclature 'palliation' evidences a 'shift of outlook' or rupture in hospices 'grand narrative' so I concur with Biswas (1993) that these hospices (and most likely many others) have moved away from a 'concern' with 'dying' and are increasingly becoming more explicitly like their NHS colleagues who apparently have difficulty in accepting that dying is not a symptom to be treated. Since 'second wave' practices were firmly situated within a biomedical framework, a point overlooked in discussions about 'medicalization, I suggest that it was not the employment of medical directors *per se* that led to changes in hospices' direction, (although their increasing numbers and dominance may have contributed to it) but the creation of groups of mono professionals along with employment of managers and administrators which brings us to the charge that hospices have become 'bureaucratized' and practices 'routinized' (James and Field, 1992).

6.10 Bureaucratisation

The hospices to which this study pertains are operating '*the same number of beds*' (Penelope) since they were established, (in fact less, from 21 in one hospice to 16), but the number of departments and staff with a range of disciplinary backgrounds has increased exponentially. In other words, they are becoming bureaucratised. As hospices become reabsorbed into mainstream healthcare they are becoming 'bureaucratized with increasingly rigid hierarchies and management practices' and a 'process of reprofessionalization is said to be taking place' (James and Field, 1992). This is accompanied by the re-emergence of biomedicine as the dominant paradigm and thus 'certain practices within palliative care are at risk of becoming routinised and controlled by policy and procedure' (James and Field, 1992, Corner and Dunlop, 1997:289). What is interesting about these propositions and concerns is that they are based on an *assumption* that hospices did not operate in a hierarchical and rigid manner and that biomedicine *had* taken a back seat.

How strange that commentators overlooked the fact that 'stage theory' derived from scientific research which places it in the biomedical paradigm. I suspect this is because hospices defined themselves as 'communities' which, can be 'warmly persuasive' in a way that 'bureaucracy' is not (Parker, 2002: 69-70). Based on the accounts in this thesis and my own observations I disagree with such 'assumptions' whilst agreeing bureaucratization is occurring and that clinical practices became *increasingly* routinised, task oriented and impersonal ('task' oriented means giving care by rote thus preventing staff from becoming closely involved with patients (Menzies, 1961).

However, the bureaucratisation occurring in this study's setting is merely replacing one rigid structure with another, serving as a shield behind which the hierarchical approach that had served so well could hide. Bureaucracy is not necessarily bad *per se*. It is intended to provide organizational control by ensuring a high degree of predictability in people's behaviour and that employees are treated fairly through the application of general rules and procedures - the 'rule' book applies equally to everyone (Handy, 1999). Where it comes unstuck is when the rules are applied autocratically to most employees or arbitrarily to a few but not to those who enforce the rules.

If bureaucracy is one end of a spectrum of 'control strategies' i.e. governance, then community can be viewed as the other end as 'a form of control that seems not to rely on explicit rules at all' (Parker, 2002:70). The first has negative connotations whilst the latter positive ones as exemplified in second wave hospices 'grand narrative'. Yet, these hospices, whether as 'communities', or 'bureaucracies' could be highly 'controlling' to the extent of being dysfunctional. These hospices hired several new layers of managers. Their role is to guide the hospices through stormy fiscal seas fuelled by inflation, diminishing legacies and government initiatives concerning commissioning of healthcare services. I witnessed change in progress as these hospices attempted to shake off their amateur '*Mickey-mouse*' image (Dr Veronica) to that of professional competitive organizations. For example, the fundraising department grew so large they moved into premises away from the hospices.

The dangers following on the heels of this shift include; the organization becomes over-managed; as increasing emphasis is placed on

planning, monitoring and record-keeping the primary purpose of the organization gets lost; finance, funding and legal issues may become predominant with little time for creativity, improving or developing new services. To avoid these 'risks' a fine balance between creating and sustaining effective management and responsive, creative service delivery will be essential (Adirondack, 1999: 174). I return to routinization below.

6.11 Secularisation

The hospices in this study tended to employ people with a religious disposition until approximately 2000 but remember religion had previously been imposed on patients. Religiosity was replaced by the more vague term 'spirituality'. I discussed these matters with Cicely Saunders when I interviewed her in 2003. Although religion still plays a part in the life of St Christopher's hospice, chaplaincy had been brought under the management of the department of psycho-social care and I suspect that over time the religious element will diminish further with psychology becoming dominant. More generally, the decommissioning of chapels to '*healing rooms* or '*quiet spaces*' (Saunders, interview with the author 2003) is a change worth monitoring in future research and may well be indicative of the 'secularisation of an ideal' to which Bradshaw (1996) refers. 'There is undoubtedly a profound ideological rejection of the 'traditional' understanding of the spiritual dimension of care exemplified by Cicely Saunders, (informed by Judaeo-Christianity) accompanied by a redefined concept of 'spirituality' (Bradshaw, 1996:415) which, can mean anything and everything or nothing. I concur with James and Field (1992) that 'practices are at risk of being controlled by policy and procedure'; since, as noted in chapter

five, Protection of Vulnerable Adults from Abuse legislation (POVA) from which a policy emerged was used to justify 'squashing' religiosity in this locality. 'Spirituality' as currently used has become 'performative' – a rhetorical device to bolster 'official' claims about palliative care and specialist palliative care in order to create the illusion that these services are different from others in the healthcare arena. In practice there is currently little time to engage in discussions with patients (let alone families) so spirituality is paid lip service in an environment where, following Bradshaw (1996) by borrowing from Weber 'the idea of duty in one's calling prowls about like the ghost of dead religious beliefs' (1905 cited in Lemert, 1993:113).

6.12 Routinization

Saunders spoke with me about the trend towards 'professionalization' i.e. hospice employees have moved from viewing their employment as a 'vocation' to one where *'a stint at a hospice is now considered part of professional development, a mere step on the career ladder'* (Saunders, 2003). The same was true in the setting where I was employed.

R. What's to differentiate a hospice now from a main hospital ward?

Dr Veronica. *No, there isn't anything. People just see it as a job.*

In contemporary hospices just as in the wider healthcare arena the 'whole' person is 'dissected' into pieces each of which various professionals can lay claim by espousing the appropriate expertise of the 'part' (the 'separation of tasks') illustrating an 'expansion of job specification in order to legitimate claims to a new specialty' (Walter, 1994:30). As Bauman observed 'The substitution of technical for moral responsibility would not be conceivable

without the meticulous functional dissection and separation of tasks' (1993:100). As one commentator observed; 'just one admission can involve nurse specialists in continence, nutrition, respiration and palliative care' (Hitchings, 2003:18) and thus the 'whole' person is carved up. In contemporary healthcare the 'reductionist' [expansionist?] medical paradigm 'has the upper hand: evidence based medicine is dominant in all spheres. Doctors [and other professionals] are increasingly exhorted to follow protocols, guidelines, and patient pathways. Palliative care has embraced this culture too' (Randall and Downie, 2006: 8). These changes along with the shift or 'rupture' in hospices 'grand narrative' undermine any appeal to 'holism' and represent, in my view the fragmentation of a rhetorical ideal, one in which 'technical' expertise becomes explicitly prioritised whilst retaining the garments of 'holism' but where the body remains as 'both the target and effect of power' (Armstrong, 1983:110).

The acceptance of our mortality, the idea of peace at the last and connected ideas have been medicalised and associated with training courses and measurable outcomes (Randall and Downie, 2006: 9).

In this sense then, with the current emphasis on value for money, I concur with James and Field (1992) that practices have become routinised in hospice; as well as Bradshaw who considers that contemporary hospice, under the 'cloak' of palliation is becoming an

iron cage' burgeoning with 'specialists without spirit, sensualists without heart; this nullity imagines that it has attained a level of civilization never before achieved (Weber, 1905 cited in Lemert, 1993:113, also cited in Bradshaw, 1996: 409).

I actually saw advantages in palliative care being routinised (in the sociological sense) as it takes the pressure off its leaders

and practitioners from always being seen as 'saviours' and 'angels'; and it enables palliative care to develop closer liaison with other mainstream hospital care, to its financial advantage (at least in the UK) without losing its independence (Ahmedzai, 1994:121).

'To its financial advantage' 'without losing its independence'; and this, in my view, is the crux of the problem with 'third wave' developments, lending weight to my assertion that the nomenclature 'palliation' proved useful to a hospice movement seeking to 'justify its continued existence' (Armstrong, 1986: 28).

Hospice advocates have a vested interest in preserving their 'independence', have highly developed 'lobbying' strategies promoted by well placed individuals in the upper echelons of British society for demanding a share of taxpayers money (Douglas, 1992). However, to date there has not been a public debate as to whether hospices are 'cost effective', do what they claim to, or whether they might have served their purpose. Any debates that have taken place have mainly been for the benefit of those with an interest in preserving hospice. I mentioned earlier how the nursing director in the study setting became simultaneously employed by a local NHS trust commissioning palliative care services thus ensuring the 'interests' of these hospices are prioritised. Strangely no seemed to consider there might be a conflict of interest or that it might be unethical.

6.13 A New Technique of Governance

Saunders spoke to me about a 'new' psychological technique being tried out at St Christopher's that I speculate will 'resonate' with hospice and palliative practitioner's fondness' for 'techniques' and 'spread' on into the wider healthcare arena. The new 'technique' is cognitive behaviour therapy (CBT).

R. Is there a danger that we can start using these as mere techniques though?

Saunders. *Well I think cognitive therapy is very appropriate at this stage of life I mean for a long term it's a bit of a revolving door, somebody comes back and wants to have it all over again [laughs] whereas at the end of life it may be very helpful in directing thoughts in a better line.*

'Helpful in directing thoughts in a better line' – the conduct of conduct (Rose, 1999) - here then we have the emergence of a more explicit form of 'governing' patients' minds, a technique I speculate that will prove all the more useful for governing the vast numbers of patients who, under current policy initiatives will be *required* to remain in their homes to die. In this instance, 'the public sphere continues to manage the private, but more subtly (Walter, 1991: 40). Cognitive behaviour therapy (CBT) is a generic term for describing a number of therapies that all have a similar approach to solving problems such as sleep difficulties, anxiety or depression. It works by changing people's attitudes and behaviour. Therapies focus on thoughts, attitudes, beliefs or images that people hold (cognitive processes) and how these relate to the way we react to an emotional problem or the way we behave. An important advantage of CBT is that treatment tends to be short, . . .restricting their observations to particular problem areas (Halgin and Whitbourne, 1993:129).

The professional advocates of behavioural psychotherapy hold only that 'the clients "symptoms" can be regarded as discrete psychological entities which can be removed or altered by direct means (Rose, 1999:246).

A new set of problematizations has been born, new ways of reordering the experiences of living such that new issues and

possibilities are transposed onto the field of scientific knowledge and therapeutic rectification (Rose, 1999:248).

I anticipate that cognitive behaviour therapy will become another 'fashionable' *'technique'* for palliative practitioners to contain or 'govern' the 'conduct' of their patient population, a short cut' to accessing patients 'interior' world and much less tedious than 'steering' them through 'stages'. The new breed of patients targeted by hospices to become 'in-patients' will *not* be *dying* but require 'containment' of unruly symptoms that pose some kind of 'risk' either to the patient, their carers or the community (Petersen and Lupton, 2000). As these authors argue, the concept of 'social danger' which the reader met in chapter two has been replaced by the concept 'risk' which, in contemporary society means that specialists are 'cast in a more subordinate role, while managerial policy formation develops into a completely autonomous force' (Castel, 1991: 281) during which process 'nursing' has become re-cast as 'care' provided by individuals with little if any training for their 'new' roles (Petersen and Lupton, 2000). Newly developing 'home care teams' may well find the 'technique' *helpful in directing thoughts in a better line* (Saunders, 2003) as they 'process' patients speedily through new 'care' packages that allocate specific time periods within which to complete care 'tasks' e.g. often 15 minutes per 'service user'. Palliative patients will be taught to manage (govern?) their thought world, to 'control' thinking difficulties or eliminate 'unwanted thoughts' through a 'conceptual framework' that will assist them to cope with whatever deterioration their particular disease creates (Rose, 1999, Nelson-Jones, 1991).

A therapeutics of finitude, in which grief, frustration, and disappointment at the limits of life, the tragedies of passion and

the omnipresence of death are reposed as issues of pathology and normality, or rather the points of manifestation of pathological possibilities . . . (Rose, 1999:248).

I disagree with Bradshaw's suggestion that 'the values and discourse of psychological effectiveness seem to be *becoming* more dominant' (1996:418) because Kubler-Ross's (1969) ideas dominated hospice practice since the emergence of second wave hospice. By adopting techniques such as CBT hospice and palliative practitioners will merely replace one set of psychological techniques with another.

Each therapeutic system and each therapeutic context has its own particularity. But what unites them is the calculated attempt to bring the subject from one way of acting and being to another (Rose, 1999:249-50).

6.14 Emotional Labour

'Emotional labour' (Hochschild, 1983) – is that part of a nurse's work crucial for developing 'therapeutic relationships' and gaining access to patients 'minds' (May, 1992). Emotional labour is an individual's effort to present emotions in a way that is desired by the organization which in hospice might manifest as friendliness, compassion, empathy [or chronic niceness syndrome]. However, as Walter observed, 'emotional and spiritual care are 'add-ons rather than integral to care; they may not be added on at all' (1994: 92). If they are added on, the particular danger will be that they become reduced to a formula akin to 'stage theory', CBT, the communication skill techniques of Maguire and Faulkner (1988, 1988a, 1988b) or Schon's (1983) 'reflective cycle' that anyone can apply; not necessarily with the empathy or compassion valorised in the literature but a mere prescriptive for how patients and practitioners *should* behave. I

agree with Marshall and Bleakley (2008: 33) who note that 'literature on communication skills has little to say about the consequences of failure' (2008: 33) and seems always to be based on notions that patients or relatives *want* to engage in the way 'imagined' (Rose, 1999) by so called 'experts of normality' (Walter, 1994) in communication skills

"Communication" is a dynamic and complex "activity system", an embodied cognition situated historically and culturally as "discourse". To disaggregate individual "skills" from this complex is a dangerous business, potentially reducing communication to only the communicator and an instrumental act (Marshall and Bleakley, 2008: 31).

Therefore, 'emotional labour' or 'communication skills' could become a double-edged sword contributing to new ways of discipline and control. If notions such as respect for autonomy and dignity are to have any validity in practice 'it is especially important in palliative care to note that consent is also required before pursuing treatment or interventions, e.g. 'counselling aimed at alleviating mental distress or suffering' (Randall and Downie, 2006: 59-60) and that includes 'counselling' disguised as 'communication' or 'emotional labour' whereby 'harassment by questioning in the name of compassion has little acceptability' (Randall and Downie, 2006: 153).

6.15 Generalization

Although this study pertains to one locality, I consider that many insights are more broadly generalisable to the hospice movement using the concept '*moderatum* generalizations i.e. that 'qualitative research methods can produce an intermediate type of limited generalization' (Payne and Williams, 2005: 296).

These resemble the modest, pragmatic generalizations drawn from personal experience which, by bringing a semblance of order and consistency to social interaction, make everyday life possible. Indeed, a strong claim can be made that in qualitative research (even in the interpretivist sociology loudest in its rejection of generalization) such moderatum generalizations are unavoidable (Payne and Williams, 2005: 296).

Taking inspiration from a discussion with Williams (one of my supervisors) I can offer the following parallel as regards how my findings may have wider application. This will enable the reader 'to evaluate the status of the researcher's generalizations' (Payne and Payne and Williams, 2005: 305). If we liken the hospice movement to a national chain of supermarkets, say Marks and Spencer (M & S) or an international one like Lidl we can draw some parallels. These chains have a 'collective identity' - e.g. with M & S 'not just any food, M & S food' i.e. delicious food using the best ingredients; for Lidl 'good food - cheaper', produce costs less because the customer is not paying for expensive overheads. Each chain has their own distinctive 'brand image' supported by a 'grand narrative' that tells potential customers what they can expect if they shop in their chain. Whether I shop in M&S in Edinburgh or London, or Lidl in Paris or Bristol there will be certain recognizable features that tell me which chain I am shopping in i.e. there is no chance that I could mistake M&S for Lidl. However, the kinds of produce available at different 'branches' of either supermarket may vary slightly within or between geographical areas. I am still purchasing from the same shops for the same reasons but there will be national, regional or local variations in the way in which I am served by the shop assistants for instance or in the goods that are available for purchase. It is the 'collective identity' - the 'brand' that these shops have constructed that appeal and propels me to shop there. An appropriate analogy; the 'chain' can be

likened to a tree - local 'branches' are connected to the tree trunk (head office) to form one whole tree – macro and micro are inseparable.

So too with the hospice movement which, in its totality represents the 'tree', while individual hospices represent the branches; proponents have constructed a 'collective identity' for hospices – the 'grand narrative' - and this is what people buy into. The 'brand' on this occasion, supported by the 'grand narrative' is the delivery of 'holistic care to patients and families in homely environment by teams who work together non-hierarchically i.e. the goals of hospice' This is what is asserted to differentiate hospice from other healthcare settings. It is action and discourse at national level that helps publicise and thus structure people's perception and expectation of what goes on at micro level i.e. in individual hospices. Yet, statements emanating from the national arena are not statements about *what happens* in each hospice but are statements of intent – of what *ought* to be the case which, following Randall and Downie can 'take us along two different paths. . . theoretical or practical' (2006: 13). 'The theoretical can have practical implications and the practical makes theoretical assumptions; the paths can overlap' (Randall and Downie, 2006: 13), as indeed they do.

In the case of the philosophy of hospice and later palliative care the words of 'authoritative' figures 'distil the philosophy and the philosophy directs the practice' (Roy, 2006: v-vi). For example I indicated in chapter two that calculations about similarities and differences concerning dying made at local level are collated with those of other units and all contribute to the 'whole' body of 'knowledge' about dying that is constructed. Similarly, if lots of other researchers were to undertake studies similar to mine and all the resulting

information was collated, the result would be a new body of knowledge about hospices.

The problem as I see it; unlike a supermarket chain hospices do not have a 'head office' to ensure that standards are maintained in all the branches. Hospices have been 'free to be creative' within the walls of each individual unit with '*no one looking over the shoulder*' (Saunders, 2003 interview with the author). The result; individual hospices can do what they please whilst still remaining a part of the 'whole'. For the hospice movement to be effective, it is essential that those working within it develop a mindfulness towards those causal agencies that bring disease into the lives of individual units, reflecting upon underlying assumptions, considering 'evidence for effectiveness' (Randall and Downie, 2006: vii) and putting in place appropriate structures of scrutiny if all the 'branches' are to provide harmony in the 'whole'; especially if the 'whole' is not to become 'tainted by association' with poor practice in any one of the units.

I speculate that this locality is not alone in 'hushing up' certain practices and by making such an assertion I am expressing 'thoughts that others dare not imagine' (Randall and Downie, 2006: 3) never mind voice. The response I seek is not a hysterical five minute wonder but a sustained effort by hospice and palliative proponents to examine their practices and discard those that have outlived their usefulness. As Dr Beverly noted; *I think they are actually losing what they did have. They've thrown the baby out with the bathwater and less and less do anything special. They just look more like to me, a private community hospital.*

Chapter 7

Preconceptions and Hospice's Shadow

To the extent that others claim to speak in our name, we have the right thereby to ask them by what right they claim to know us so well; to the extent that others seek to govern us in our own interests, we have the right, as governed subjects, to interrogate and even protest those strategies in the name of our own claims to know those interests (Rose, 2003: 60).

7.1 Introduction

Procacci asks that we do not revalidate what is already known historically but look at that history in such a way that it offers us 'new clues about ourselves' (1991:152). In this chapter this entails a re-reading of Kubler-Ross' 'stage theory' and honing in on matters glossed over in hospice's 'grand narrative' and to do this I will be using the 'masters tools' to challenge the 'masters voice' (Parker, 2002: 59) i.e. using the same vocabularies through which they constituted their authoritative voice in the 'grand narrative'. I illustrate *how* proponents of second wave hospice created, cultivated and sustained a myth about dying with dignity by aligning themselves with psychological concepts and theories that 'fitted in' with their own ideas i.e. to make dying a creative and positive experience. The taken-for-granted 'feel good' appeal of this 'grand narrative' spilled over into third wave developments with little contestation about ideals that were harder to realise in reality than proponents were prepared to admit and therefore, it is argued, third wave developments are built on shaky foundations.

In choosing to attempt to 'manage' (contain?) the dying process second wave hospice belongs to that 'apparatus of government' that took shape from the mid twentieth century which seeks to 'incorporate, shape, channel, and enhance subjectivity . . . through the use of techniques derived from 'psychotherapy, its practitioners, and its languages' (Rose, 1999: 218). The American psychiatrist

Elizabeth Kubler-Ross (1969) was much influenced by Carl Jung (1875-1961) who claimed that the 'self' was the most important system of the personality and represented our striving for wholeness and unity (Kagan, 1989). He wrote about the *persona* which takes the form of a 'mask' that becomes our public personality – which we show to the outside world; Goffman's 'impression management' (1950). Therapy within this school of thought attempts to get behind this mask to uncover what lies within and it is within this school that the ideas of Kubler-Ross are situated and 'stage theory' derived. Kubler-Ross postulated that dying patients go through five stages whilst dying, eventually reaching a final stage of accepting their death, which became framed as 'good death' by hospice proponents. Yet, the notion of 'good death' and the goal of death with acceptance were generally 'received uncritically' (Hart et al, 1998). Kubler-Ross was perceived as a 'leader, researcher and educator' and her status in the American thanatological movement remained unchallenged for twenty five years until Chaban's (2000) in-depth critical analysis of the body of work she amassed. During this time Kubler-Ross built a profitable industry around her activities. Considering her enormous influence, the paucity of serious critique of Kubler-Ross' theoretical ideas both within and outside the hospice movement in Britain is perplexing. Stage theory, so taken for granted by second and third wave hospice proponents, so lacking in scholarly critique by these same proponents, is not only inherently unstable, but false.

7.2 The Master's Tools: The 'Shadow'

For Jung, the ongoing development of the psyche is complicated by the presence of forces both within and outside the individual which hinder and block it. In trying to explain this Jung makes use of the concept 'shadow' to explain what he

meant by evil. The shadow is caused by light; where there is no light there can be no shadow. For example, as individuals mature they face tasks which their own nature and society's expectations impose upon them with the help of aims and ideals, partly offered by society, partly chosen by themselves. In pursuit of their personal aims the individual tries to ignore or reject impulses and emotions which conflict with these and therefore builds up an attitude which represents partly what they aspire to become, partly what they see themselves to be and wish others so to see them. Jung calls the rejected elements of the personality 'the shadow' (Bleakley, 1984: 9). These rejected elements that the individual refuses to acknowledge do not disappear or cease to exist, they merely become unconscious (Bryant, 1983).

Because it is unacknowledged or remains unconscious, the shadow naturally distorts and disables, and then carries 'negative' content. This seeps through to our personality actions and is seen in anything from mild spite, resentment and bullying, to murder, persecution and mass oppression of liberty (Bleakley, 1984:13).

In the shade of the glowing image that second wave hospice fostered lies its dark side – its 'shadow' – which 'remains inferior, mainly unconscious and unacknowledged' (Bleakley 1984: 9) – subjugated. The 'shadow' in this instance concerns the manner in which Kubler-Ross' ideas infected the thought worlds of hospice practitioners in Britain and in the process violated their own stated ethics. I turn a spotlight on hospice's dark side – its 'shadow' with a view to pinpointing some of the distortions and contradictions within the 'grand narrative' that disabled local practices in the setting where this study was undertaken.

7.3 Challenging the Taken-For-Granted

I used my educational practice to explore how ideals postulated in the 'grand narrative' were translated into practice by questioning practitioner perceptions of

what they were doing, i.e. questioning how they used 'stage theory' as I illustrated earlier. The way they viewed matters at that time had become so ingrained and taken for granted they saw it as perfectly natural. No one, it seems, until that moment had questioned what was being done in practice. Why would they since the only courses available to these practitioners had been counselling which merely inculcated and confirmed Kubler-Ross' ideas. For practitioners, what they did and the way they did it was merely 'the way things are done in hospice' - beyond question. However, what practitioners were actually doing was using Kubler-Ross 'stage theory' *not*, as postulated in the 'grand narrative', to get closer to the dying patient, nor to attempt to understand what such patients were experiencing, but as a '*standardized technique*' (Chaban, 2000: 26) to 'contain' a particularly troublesome form of dying.

7.4 Preconceptions and A Meta-Narrative.

The text within which Kubler-Ross' 'stages' appear *On Death and Dying* is a meta-narrative; 'the master text in most major medical and nursing schools and graduate schools of psychiatry and theology' and *the* 'clinical paradigm' for hospice practice in the UK and abroad (Chaban, 2000).

With the publication in 1969 of *On Death and Dying*, Elizabeth Kubler-Ross forcefully called attention to the need for better care of the dying. Her portrayal of dying individuals as passing through stages has become, if not an official doctrine, the dominant, exemplary paradigm (Churchill 1978:167).

In this study setting the 'stages' became a mantra and prescription for dying, imposed on patients (Dr Veronica) The idea of 'imposing' something upon a person implies that one is exerting influence or taking advantage of a person by bending them to one's will – it is negatively repressive in that authority and power are used to 'control' and is therefore an extreme form of 'governance' – of

'shaping conduct', of 'cutting experience' in a particular way (Rose, 1999).

Others decide what an individual will do and they have no option but to do it (Adirondack, 1998). To 'impose' cannot be considered as treating a person as an 'active' subject, as equal, as 'autonomous', 'in control' or indeed with 'dignity' whatever this might mean. This seems ironic considering how and why second wave hospice staked its claim in British culture. How can patients be 'empowered' to remain in 'control' of their dying if they are forced to succumb to another person's *preconceptions* of how the process *should be*?

Having a formalized staging structure risks pre-determining the experience of dying which would result in patients, families and caregivers experiencing death according to an imposed and superficial structure that would lessen the personal authenticity and meaning of the experience (Chaban, 2000: 27).

7.5 Acquiring the Status of Truth

How does it happen that 'certain constructions acquire the status of truth?' asks Rose (1999: xi). There was obviously something about Kubler-Ross' discourse which put it in a 'relation of complementarity' with other discourses of the period (Foucault 2002). Kubler-Ross (1969) asserted that 'stage theory' derived from research with 200 dying patients and this gave it credibility. All research whether in the natural or social sciences makes knowledge claims and therefore raise epistemological issues which are often taken for granted. To ask an epistemological question is to ask what counts as knowledge. If the claim is based on systematic and methodological observation, then epistemologically this 'constitutes good grounds for considering the knowledge claim to be valid or true' (Chaban, 2000). What is considered the 'best' or most strongly grounded knowledge in Western culture is that which emerged from the 'scientific method' – the most powerfully valorised epistemology in our culture (Usher and Edwards, 1997). As a psychiatrist, Kubler-Ross would have been 'educated in processes of

scientific investigation established by her medical and psychiatric predecessors'. Assuming these discourses informed Kubler-Ross's work; 'an evaluation of her research and practice should be done within the context of these traditions' (Chaban, 2000:67).

Staging is a technological term. It is a term that medicine would be familiar with. As such it may be user friendly to medicine. However, its roots lie in a commitment to disease, rather than to person-centred care. It is perhaps a valuable model for defining pathology but not necessarily the best conceptual frame for humanizing care of the dying (Chaban, 2000:67).

First problem, 'stage theory' is rooted in a biomedical disease centred *not* a person centred epistemology. What follows from this is that, contrary to assumptions in the literature, (Biswas, 1993) the 'grand narrative' of second wave hospice was also rooted in a disease centred not person centred paradigm and therefore biomedicine had not taken a back seat. Second wave hospice seemingly set its sail against 'dehumanizing' 'reductionist' medicine and the techniques it favoured which makes 'stage theory's' uncritical acceptance in hospice all the more puzzling. I have already indicated that certain stages were denied expression (no pun intended) in this local setting, namely denial and anger, while bargaining appeared to be glossed over. What did Kubler-Ross have to say about denial, anger and bargaining?

7.6 First Stage: Denial

Among the over two hundred dying patients we have interviewed, most reacted to the awareness of a terminal illness at first with the statement, "No, not me, it cannot be true". This *initial* denial was as true for those patients who were told outright at the beginning of their illness as it was true for those who were not told explicitly and who came to this conclusion on their own a bit later on. . . Denial, at least partial denial, is used by almost all patients, not only during the first stages of illness or following confrontation, but also later from time to time (Kubler-Ross, 1973:35).

Firstly, the chapter from which this extract derives is called 'Denial and Isolation' but only denial is dealt with leaving the reader to wonder about 'isolation'. Kubler-Ross contradictorily suggests that that; 'denial, at least partial denial is used by almost all patients'; yet later claims that only 'one per cent of the population' needs 'denial' and that the more patients use denial the more 'difficult' it will be for them to reach the final stage of 'acceptance'. Secondly, what is the likelihood that patients in the 1960s were fully cognizant of their diagnosis and prognosis? The literature suggests otherwise. Was this not the *raison d'être* for the emergence of hospice in Britain and the 'death awareness movement' in the US – i.e. patients were not informed? Thirdly, the stages are 'recommended further by being grounded in work with over two hundred dying patients' (Churchill, 1985:167). As I noted earlier, many factors can contribute to a patient or family's silence or seeming withdrawal; inadequate pain or symptom relief, suffering, fatigue, cultural, class or age variables, absence of social or communication skills, yet be misinterpreted as 'denial' by practitioners.

Surprisingly, and considering America's multicultural diversity the way different cultures approach dying are not discussed nor are age or religious differences considered by Kubler-Ross; strange omissions leading one to question the demographics of Kubler-Ross' sample population since it would be unrealistic to apply a model based on a homogeneous population to that which is heterogeneous as it would lack 'construct validity' e.g. what concepts may be used to interpret the test performance (Nachmias and Nachmias, 1994: 161). Even if social and cultural facets were accounted for, which they were not, a model developed for populations with specific disease may not be successful when applied to populations with other disease states. Kastenbaum (1975) observed that Kubler-Ross' theory 'does not sufficiently account for the nature of various

diseases, sex and age differences, ethnicity and other subcultural backgrounds, personality or cognitive styles, or the sociophysical milieu' (cited in Kalish 1978: 220). Chaban (2000) notes that 'denial' is not clearly distinguished from avoidance behaviours or 'shock', both of which may 'mimic some of the attributes' of 'denial and isolation' nor does Kubler-Ross discuss 'denial' as a 'behavioural aspect of communication theory' or as a constructive 'defence mechanism' or a natural consequence of 'linguistic factors' (Chaban, 2000:42).

Kubler-Ross's pathologizing of denial may be the pathologizing of a very healthy and well-supported personal choice or attitude towards death. With the advent of attitudinal healing entering into medical science and medical research, clinicians are now recognizing that denial must be assessed to determine if it is a defence to be supported or a defence to be changed with psychotherapy and psychoeducation (Chaban, 2000:42).

Although I agree with Chaban on her first point I have reservations about her latter assertion which to my mind situates her firmly within the discourse of the 'psychotherapeutic'. Why is it so difficult to accept that so called 'denial' may well be a thoroughly reasonable response to one's forthcoming annihilation or merely indicative that patients don't wish to talk for whatever reason and leave it at that? Why should patients, who are already vulnerable i.e. dying, be subjected to psychotherapeutic techniques so that professionals might *judge* whether 'denial' 'is a defence to be supported or changed'? (Chaban, 2000: 42). It seems the dying cannot escape the clutches of 'therapeutic expertise' which refuses individuals the 'right' to think their own thoughts and feel their own feelings without reference to the 'judges of normality' (Walter, 1994:10). Whereas in previous historical periods the established Church had a central role in guiding the population in the rituals and beliefs surrounding death, in more secularised contemporary society this task falls to professional experts most of whose knowledge derives from the social sciences, psychology and psychiatry. As

Walter argues 'psychiatrists were, from the 1950s, laying successful claim to be the experts on grief, while the bereaved themselves were more likely to go and see a doctor than a priest or social worker' (1994:13).

7.7 Second Stage: Anger

When the first stage of denial cannot be maintained any longer, it is replaced by feelings of anger, rage, envy, and resentment. The next logical question becomes: "Why me"? . . . (Kubler-Ross, 1973:44).

So stage one 'denial' is 'replaced' i.e. *followed by* 'anger' stage two. Kubler-Ross then offers a case study (of a particularly angry woman whom she had invited to an educational seminar group where she was 'interviewed') to illustrate the points raised. Kubler-Ross proposed that patient's 'anger' derives from 'envy and resentment' of people able to continue to enjoy life 'What else would we do with our anger, but let it out on the people who are most likely to enjoy all these things'? She asks that practitioners 'tolerate' such anger because it is a catalyst towards 'acceptance and dying' (Kubler-Ross, 1973). She concludes the chapter on anger by stating that 'in the interview' the angry woman had been 'understood rather than judged' (Kubler-Ross 1973:70). One can see how this 'theory' would have appealed to hospice advocates although 'anger' was not allowed in this local setting. '*We don't deal with anger, we never have. We had to take patient out of the building if they were angry or we would have them prescribed a sedative*' (Prudence). In my view practitioners were unable to utilise 'stage theory' to 'understand' patients and merely used it to pass 'judgement' so as to *drive* patients through each stage. Kubler-Ross 'believed that the rich and successful cannot accept anger' as readily as others but does not elaborate on this'. This is a pity because 'having an understanding of how social and economic status impact

upon the individual's response to dying would have been helpful for the users of her theory' (Chaban, 2000:46).

It is not clear if this is the result of rare feelings of powerlessness felt by those who are usually in a position of social and economic power or if other factors are involved. Socio-cultural thanatological theories such as the "Multiple Impact Factors" (MIF), suggest that a family's position in the social structure, their occupational and financial status are factors that could combine to construct the experience of death (Chaban 2000:46).

This resonates with my earlier speculations about possible reasons for difficulties in 'coaxing' patients to talk or conform to the 'stages'; that the patients these hospices 'tended to favour' were positioned in the middle and upper echelons of the social hierarchy or were in the older age range and thus culturally habituated to keeping their own counsel. If this is the case, and I think it is highly probable if somewhat unpalatable, any theories which have been developed by second wave hospice proponents on the basis of Kubler-Ross' work and currently being applied to an ever more diversely heterogeneous population in third wave are likely to be flawed if these variables are not given due consideration.

If she had a relatively homogeneous group of dying patients then her results would be specific to this group. The homogeneity of the group would likely speak to the possibility of retrieving a high quality of data. Contrarily, if she had a demographically diverse group of participants this might speak to the broad base from which data were collected. However, if data on the dying, bereaved and occupational health of caregivers were gleaned from a demographically diffuse group then the data could be compromised by the diversity of the participants (Chaban, 2000:44).

In the numerous books written by Kubler-Ross since *On Death and Dying* (1969, 1970 [1973 reprinted fourteen times] 1989, 1991, 1992) are to be found several conflicting descriptions of the stages, e.g. *In Living with Death and Dying* which the Guardian newspaper described as 'The best PRO the dying ever had'; the stage of 'anger' becomes 'anger and rage' – 'When a patient has one human being

with whom he can talk openly, he is then able to drop his stage of denial and go on to the second stage, the stage of rage and anger' – note the patient is 'moving' from one state to another (Kubler-Ross, 1992:35 – 9th reprint). However, like 'denial and isolation' it is unclear if the two concepts are to be viewed as separate dimensions, collapse into one or whether one should be given priority over the other, nor as Chaban (2000: 46) notes does Kubler-Ross account for the change. Yet 'anger' does seem to be prioritised in her varying accounts but denied expression in this locality. Or might it perhaps manifest in another form? Kubler-Ross states that families and staff go through their own 'anger' which becomes displaced and projected onto the environment and this makes it difficult to deal with other issues related to family or staff.

What is your gut reaction to these nasty, critical patients? We either kill them with kindness, which is the worst kind of hostility, or we control our anger, but let it out on the student nurses. If we don't have student nurses we let it out on our husband when he gets home, and if we don't have a husband we kick the dog. Somebody always gets it, and to me this is very tragic, because we should teach our students that this anger is a blessing not a curse (Kubler-Ross, 1992:35-6).

7.8 The Master's Tools: Chronic Niceness Syndrome

Perhaps the master's tools can be used against them? (Parker, 2002: 59). I noted earlier that hospice practitioners have been labelled with what is called both within and outwith hospice as 'chronic niceness syndrome'. Indeed there was an incident whereby a patient described hospice staff as 'clones' and 'a bit too saccharin' before making their escape by discharging themselves. In light of Kubler-Ross comments above, perhaps this so called 'niceness' is merely a form of disguised 'hostility', 'the worst kind of hostility' - a collective public 'persona' – (Goffman, 1959) - a mask - a way of keeping all the anger at bay? It would make an interesting study. Those who managed dying in these local hospices were themselves subjected to inflexible, authoritarian and bullying management tactics.

Viewed from the same psychological perspective perhaps it is a form of 'projected' 'anger' deriving from an inability to 'control' dying in the manner *prescribed* by the 'grand narrative, which then manifests as particular styles of management by people who are themselves out of control or terrified of death but dare not acknowledge never mind admit this at a conscious level? Since, according to Kubler-Ross 'somebody always gets it', maybe the 'chronic niceness' which helps maintain the public *persona* of hospice institutions manifests backstage as 'kicking the dog'? Perhaps even, this 'dark shadow' which hovers in 'light', 'airy' hospice buildings could be deemed a form of denial? – a denial of the ability to 'contain' dying which is then projected onto others in the form of 'control? (Bleakley, 1984). Kubler-Ross refers to the denial stage as the 'no, not me' stage so it would not be unreasonable to anticipate the same response from hospices practitioners in other settings who may wish to protest 'no, we are not like that' because such assertions are too painful to bear. Returning to Kubler-Ross, following the stage of 'denial' comes the stage of 'anger' - the 'why me' stage – 'don't I deserve a year with my wife in retirement? Wasn't I a good Christian? Wasn't I a good father?' - And so forth. Next comes bargaining.

7.9 Third Stage: Bargaining

If we can help them to ventilate their feelings of grief, anguish, rage, and anger without judging them, then they will proceed very quickly to a peculiar stage of bargaining. During this time they have stopped saying, No, not me. They have stopped questioning, Why me? They are now saying, yes, its me but . . . The buts usually include a prayer to God (Kubler-Ross, 1973:39).

Kubler-Ross devotes a meagre two and a half pages to 'Bargaining' in *On Death and Dying* where she states 'maybe we can succeed in entering into some sort of

an agreement which may postpone the inevitable happening: 'If God has decided to take us from this earth and he did not respond to my angry pleas, he may be more favourable if I ask nicely' (Kubler-Ross, 1973:72). It remains nebulous whether dying patients 'develop a relationship with God' or whether 'this relationship is an amplification, renewal, or initiation of the patient's religious belief' (Chaban, 2000:52). These are important omissions bearing in mind the likely diversity of the population in Kubler-Ross' Chicago catchment area and the kind of populations to which 'stage theory' was applied in the UK. Compared to the other 'stages', bargaining is given a cursory place leading Chaban (2000) to ask; if bargaining is so unimportant why bother to include it in stage theory? However, I view 'bargaining' as *productive*, it is performative - what 'bargaining' *does* is to plant 'God' firmly into the picture despite Kubler-Ross' distaste for institutional religion or as her biographer put it 'her prejudice against the established churches and the clergy' (Gill, 1980:280). Bargaining evidences Kubler-Ross's drawing from traditions outside of medical science and 'straying into a theological paradigm' (Chaban, 2000:50) who does not successfully resolve her puzzlement as to why Kubler-Ross took this theological turn but I think I may have a plausible reason; Chance brought Kubler-Ross and Cicely Saunders (who was devoutly religious) together in 1966 courtesy of Dr Murray-Parkes and a mutually satisfactory collegiate relationship developed. Is it possible that Kubler-Ross was merely ingratiating herself into Saunders good opinion in her own self-interest? Perhaps bargaining was incorporated on account of its potential resonance for the patient population targeted for hospice care in Britain e.g. middle class older individuals with religious beliefs?

7.9.1 The Role of Chance

Chaban (2000) was puzzled by Kubler-Ross' shift towards theology. She argued that Kubler-Ross's work 'shows a progressive openness to theological issues that were not an integral part of her initial years of practice' (2000:52). What Chaban failed to consider was Kubler-Ross' relationship with Cicely Saunders, who as we know was deeply religious. Dr Colin Murray Parkes, a psychiatrist, encountered Kubler-Ross while he was working at Harvard and 'was clearly eager for her and Cicely Saunders to meet', which they did at Yale University in April 1966 (Clark, 2002:103). Murray Parkes later went to work at St Christopher's hospice as a consultant psychiatrist further developing 'stage theory' in relation to bereavement although I don't deal with that in this thesis. Material comprising extracts from letters written by Cicely Saunders to Kubler-Ross during the period 1966 to 1973 now follows. The letters appear in Clark (2002) *Cicely Saunders, Founder of the Hospice Movement, Selected Letters*.

(1) *Dr Elizabeth-Kubler-Ross, Billings Hospital, Chicago, USA, 29 March 1966*

I have recently had a letter from Dr Murray Parkes . . . who I understand recently saw something of your work with dying patients. I understand he mentioned that he had seen something of what we had been trying to do in this field. . . I am shortly coming over to the States to spend about a month . . . I do not know if there will be a chance of seeing you at all during this time. If there is I would so much like it because I am sure there is a great deal I could learn from you. . . If you have written on this subject I would be very grateful indeed for any reprints you may have (Saunders in Clark 2002: 103-4).

(2) *Dr Elizabeth Kubler-Ross, Billings Hospital, Chicago, USA, 20 February 1967*

Thank you so much for sending me your reprint, which I was very glad to have. In exchange I am sending one of my own, and I am glad to tell you that our new Hospice is likely to take its first patients in June, so I hope I will be welcoming you there one day. I hope your work goes well and that you will send me anything else that you write because I think it is most valuable (Saunders in Clark, 2002:120).

(3) *Dr Elizabeth Kubler-Ross, Flossmoor, Illinois, USA, 24th December 1970*

Thank you very much for your card. . . . I have wanted to have news of you . . . I hear from Bob Neale that you spoke exceedingly well at the Euthanasia Educational Fund Conference. I understand you focused on the distinction between a 'good death' and killing people. As I am on the Church of England Commission which is trying to write a pamphlet on this subject I was delighted to hear this too (Saunders in Clark, 2002:145-6).

(4) *Dr Elizabeth Kubler-Ross, Flossmoor, Illinois, USA, 15 September 1971*

I am absolutely delighted to hear that you are going to the special conference at Katholische Akademie in Bayern on Oct 23rd/24th. I much look forward to seeing the second film taken at the hospice – still more to the chance of meeting you again. . . . I wonder if you will have a chance of visiting St Christopher's. If you can come back with us on October 25th and come down and meet some of the staff on October 26th, staying with us if you wish or in London if you would prefer it, that would be a great delight to us all. Dr Colin Murray-Parkes asks me to give you his greetings and to say how much he hopes we shall see you here. We normally have a big staff meeting on the afternoon of Tuesday and if you are not too tired, and if it were not an imposition, we would love you to join us and talk a little. I know that a large number of our staff have read your book [*On Death and Dying*] and have found it extremely helpful. . . . (Saunders in Clark, 2002: 149-150).

It can be seen from these extracts that Saunders and Kubler-Ross began to enjoy an excellent collegiate relationship, meeting at or sharing conference platforms, mutually appreciative of one another's work i.e. Saunders grateful for Kubler-Ross' public endorsement of St Christopher's, reciprocating with the comment that many staff at St Christopher's had read Kubler-Ross' first book *On Death and Dying* finding it 'extremely helpful'. In other words, they enjoyed relations of mutual complementarity. Is it possible that Kubler-Ross appropriated legitimation for her own activities via her friendship with Saunders and the British nascent hospice movement? Although St Christopher's education department was rudimentary at the time, it did not take long for Kubler-Ross' ideas to plant themselves firmly there and then spread throughout the hospice movement as illustrated in practitioner's accounts in this thesis.

7.10 *Fourth Stage: Depression*

His numbness or stoicism, his anger and rage will soon be replaced with a sense of great loss. This loss will have many facets. (. . .). All these reasons for depressions are well known to everybody who deals with patients. What we often tend to forget, however, is the preparatory grief that the terminally ill patient has to undergo in order to prepare himself for his final separation from this world. If I were to attempt to differentiate these two kinds of depressions, I would regard the first one a reactive depression, the second one a preparatory depression. The first one is different in nature and should be dealt with quite differently from the latter (Kubler-Ross, 1970: 75).

Kubler-Ross sub-categorises depression with the former requiring 'active interventions on the part of people in many disciplines' (1970:77). Since she does not offer any detail about what this might entail one is left to make their own assumptions. Readers are warned not to try to 'cheer' the patient up or 'encourage them to look at the bright side of life' – merely 'an expression of our own needs' because this is a depression that manifests as silence when the patients needs to 'contemplate his impending death'. 'If he is allowed to express his sorrow he will find a final acceptance much easier' (1973:77).

Although Kubler-Ross states that 'preparatory' depression /grief (or anticipatory grief as it came to be known) can be influenced by gender with men finding it harder to express than women (Chaban, 2000: 55) she again does not explain how exactly gender influences such processes. That men may be socialised not to express feelings openly may be a legitimate assumption but it also implies that women are more effective at grieving which 'may not be a clinically accurate depiction of grief' (Chaban, 2000: 55) that has since been challenged (Brennan and Dash, 2008, Klass, Silverman and Nickman, 1996, Martin and Doka, 2000, Strobe, Strobe and Hansson, 1993). Apart from pathologizing patient's feelings Kubler-Ross does not offer any suggestion as to

how to treat individual factors. Hardly surprising then that in my study setting depression whether reactive or preparatory was treated with medication.

7.11 Fifth Stage: Acceptance

If a patient has had enough time (i.e. not a sudden, unexpected death) and has been given some help in working through the previously described stages, he will reach a stage during which he is neither depressed nor angry about his "fate". . . .Acceptance should not be mistaken for a happy stage. It is almost void of feelings. It is as if the pain had gone, the struggle is over, and there comes a time for "the final rest before the long journey" as one patient phrased it. . . . While the dying patient has found some peace and acceptance, his circle of interest diminishes (Kubler-Ross, 1973:101).

In other writings Kubler-Ross appears to contradict the above by introducing 'hope':

There are a few patients who fight to the end, who struggle and keep a hope that makes it almost impossible to reach this stage of acceptance. (. . .) the harder they struggle to avoid the inevitable death, the more they try to deny it, the more difficult it will be for them to reach this final stage of acceptance with peace and dignity' (Kubler-Ross, 1970:101).

However one chooses to view the matters raised there is no doubt that the stages are progressive – i.e. one follows another so as to eventually arrive at the 'final' stage. If it is otherwise why should patients 'work' to get through the other stages? When patients display that they have reached the 'stage of acceptance' how should practitioners treat requests for euthanasia or physician assisted suicide?

7.12 Theory practice Gap

Kubler-Ross (1969, 1970, 1973) stated that 'stage theory' is neither progressive, goal oriented, nor does one stage permanently precede another. Yet in her first book *On Death and Dying*, as well as laying out the stages in progressive or

developmental form i.e. Denial, Anger, Bargaining, Depression and Acceptance and because of *the way* each stage is discussed, with patients having to 'work through' each one, the reader is led to 'imagine' (Rose, 1999) that one stage follows another. The notion 'stage' in healthcare and medical literature *implies* a linear progression from one point to another. Disease progresses in stages, cancer being a perfect example; one speaks of stage 1, 2, or 3 cancers and one of the reasons it was so appealing to hospice advocates was its fairly predictable trajectory. Hospice practitioners certainly seemed to think stage theory was progressive and goal oriented. Take 'bargaining' 'they will *proceed* . . . to a peculiar stage. . . .' People who proceed are usually on a course of action, i.e. *moving*, in this instance *forward* to the next stage. The *way* Kubler-Ross presents the stages leaves the reader to *assume* that people *do* proceed from one to another; she states that 'dying in stage five, having been offered help in working through the previous stages', is preferable as 'it allows the patient to die with peace and dignity' (Kubler-Ross 1973:112). How clear can it be?

If the staging components do not function in isolation and if they are randomly related to each other, then how does one affect the other and how does their order affect the outcome of the experience of dying? Regrettably, Kubler-Ross neither acknowledges nor enters into a discussion of the diverse outcomes that can be experienced when there are randomly ordered stages (Carter and McGoldrick cited in Chaban 2000:49)

Perhaps this accounts for difficulties encountered by practitioners in this study setting in applying stage theory to practice as they endeavoured to achieve the 'grand narrative' prescriptive of a 'good death'? Since practice and theory inform one another if the theory is flawed then its application will be flawed. If one reads "texts" in a certain way, one perceives that they speak clearly to us and require no further supplementary sense of interpretation (Foucault cited in Burchell 1991: 57). Stage theory obviously spoke very clearly to practitioners in this local setting

since they were expected to 'learn it off by heart'; their practice was informed by hospices 'grand narrative' which in turn was informed by 'stage theory'. If the theory and its author fail to convey a consistent understanding of the stages then subsequent users, like the practitioners in this local setting will enhance the inconsistency as they apply it in practice, as indeed they did (Chaban, 2000).

Medical and nursing professions tend to view the stages as fixed points in a developmental progression. Kubler-Ross exacerbates this tendency by borrowing from developmental psychology in titling her last book *Death: The Final Stage of Growth*. The temptation is to engineer the process of dying for patients. Expectations become shaped by the progressivist philosophy so that the genuine experiences of the dying are pre-empted by a sense of how people ought to die. Along with the progressivist bias is carried an implicit norm, such that people even feel the obligation to move the dying patient along – to get them through denial, anger, bargaining, and depression to acceptance. There is a feeling of frustration or failure, of having been cheated if this does not happen. Obsession with these stages as normative protocol transforms dying into a technical problem rather than a human experience (Churchill, 1975, 1985:167-8).

Precisely and based on my own observations I agree. Our reading of texts in any particular era depends upon what the discursive fields make available to us and the discursive field around hospice was constituted in such a way as to make 'stage theory' *seem* natural. Kubler-Ross' ideas matched the 'profile of truth' that was being constructed about our subjectivity in the mid twentieth century that hospice proponents found so useful (Procacci, 1991).

7.13 Criticism

A number of individuals did challenge Kubler-Ross claims'. Kirshenbaum (1975) noted that, 'clinical research concerning the dying process by other investigators does not clearly support the existence of the five stages or of any universal form of staging. A recent review of the literature, scant as it is, finds no evidence for five predictable stages of psychological adaptation'. Schulz and Aderman's data

show the 'process of dying to be less rigid and even stageless. There is some consensus among all researchers that terminal patients are depressed shortly before they die, but there is no consistent evidence that other affect dimensions characterize the dying patient' (1974, 1978: 221). While Chaban notes that 'staging' has been criticised as being highly subjective and idiosyncratic (2000: 71). Yet propagation of 'stage theory' continued unabated thus illustrating the power of discourse to silence those voices that do not fit the picture of truth that has been constructed.

Although I agree that practitioners have used the stages blindly, I disagree with Churchill (1978: 167) that the fault does not lie with Kubler-Ross but with 'those who have taken the model literally and ossified the stages' since, in my view, stage theory is inherently unstable, a point which Kubler-Ross could not have failed to be aware of given her psychiatric training. Just as Saunders' authority to speak about the dying derived from her status as a physician, Kubler-Ross' authority to speak derived from her position as a psychiatrist. 'To gain credibility with science-based practitioners Kubler-Ross would have had to use terminology and criteria familiar to her colleagues' (Chaban, 2000:50) and in so doing she blinded them with their own discourse. However, theories should be 'testable' and those who attempted to 'test' 'stage theory' as noted above, were confronted with an absence of a theory – data- relationship whereby the latter should have provided counterfactuals to amend the theory. As a result, hospice proponents used the stages as one might use a 'cookery book recipe'. As Kalish noted, Kubler-Ross' 'sudden surge to international fame and her personal charisma have tended to detract from a careful analysis of the heuristic value and psychological validity of the stages she defined' (1978:220).

7.14 Conclusion

The stages then, became a convenient 'technique' – a prescription - with which to control dying in this locality as practitioner accounts attest. Reduction of the experience of dying into five recognizable and distinct dimensions offered a 'standardized formula' for 'expectations to follow' (Chaban, 2000, Churchill, 1978); '*It meant they didn't have to think*' (Dr Sarah). In knowing what to expect the dying process became predictable; '*they like the idea of a prescription that they just followed and off they go*' (Dr Sarah). Stage theory 'fixed' dying patients in 'time and space' whilst disciplining individual differences (Rose, 1999). It altered the dying process from an unpredictable, messy, and subjective experience to one that was predictable and standardized, (seemingly) scientifically observable, and in so doing, *objectified* patients because they were viewed as a 'constellation of cognitive-behavioural traits' (Chaban 2000).

Kubler-Ross's stages 'created a window for the world to observe from, enter into, and manage death' (Chaban, 2000: 14). Kubler-Ross' (1969) 'stage theory' is an excellent example of how ideas become 'naturalised', taken-for-granted, and accepted at face value. 'The vocabularies of the therapeutic are increasingly deployed in every practice addressed to human problems' notes Rose (1999: 218) and in British hospices, patients, their relatives and the professionals caring for them were socialised to rely on 'stage theory' to understand their own psychological processes as they dealt with dying, death and bereavement. They 'offered a common reference point from which all participants could experience dying and death' (Chaban, 2000). However, practitioners were unable to utilise the stages to 'understand' patients 'holistically' merely using it to pass 'judgement' so as to *drive* patients through each stage; accordingly patients were processed just like goods on a factory conveyor belt.

The friendship between Saunders and Kubler-Ross may be the missing link that puzzled Chaban (2000) and possibly holds the key to shifts in Kubler-Ross's thinking that seem strange. Kubler-Ross' claimed her first book in which 'stage theory' appears was based on research which she undertook with 200 dying patients and Saunders had no reason to suspect otherwise. However by the late 1970s and certainly the 1980s she should have had reason to doubt that this was the case.

Everyone but Kubler-Ross agrees that Kubler-Ross's book *On Death and Dying* was not based on any research and therefore is neither grounded theory nor a theory which would produce grounded practice (Chaban 2000: 174).

The use of 'stage theory' was not confined to this locality and reference to it can be found throughout second and third wave hospice's 'grand narrative' literature; including the 'meta' text *The Oxford Textbook of Palliative Medicine* (Chaban, 2000: 51) evidencing not merely a 'gap between rhetoric and reality' in this locality but a nationwide abyss within which patients were 'harassed' (Randall and Downie, 2006: 153) until death. One wonders how many patients died in despair that they were unable to be the 'good patient' who 'achieved' the 'goal' of dying with 'acceptance' (Churchill, 1985).

The application of ungrounded practices on the dying would lend itself to standards of care that are either experimental or which verge on malpractice. The acceptance of ungrounded research would speak to a lack of critical scholarship in the hospice and death awareness movement and to unsatisfactory standards of practice in the field (Chaban, 2000: 67)

The question that remains is *why* stage' theory continued to be taught to hospice practitioners for so long, and indeed continues to have currency in healthcare and counselling settings?: e.g. in the region within which this study was undertaken, although not explicitly acknowledged, it underpins the medical curriculum.

'Stage theory' was, as Churchill (1985:167) argued, 'attractive because of its utility'. It helped to establish 'a grid of codeability of personal attributes' which was used to 'chart and judge' human conduct during the dying process (Rose, 1999: 135-6). Calculations were made at local level, collated at national level and in the process 'knowledge' about dying was constructed. Now masquerading as 'best practice' this 'knowledge' is currently being applied to all dying populations throughout Britain i.e. hospices 'best practice' have become transformed into specific 'end-of-life 'tools' such as The Liverpool Care Pathway' (the discourse not of 'holism' but technical rationality i.e. biomedicine) to manage a heterogeneous population dying from numerous diseases, despite second wave hospices' concentration on one particular disease and reliance on a false theory. I return to these matters in the final chapter. Meanwhile, another dimension of hospices' 'dark shadow' is brought to light in the next chapter.

Chapter 8

Metaphors and Euphemisms – The ‘Shadow’ Continued

An analytics of government removes the ‘naturalness’ and the ‘taken-for-granted’ character of how things are done. In so doing, it renders practices of government problematic and shows that things might be different from the way they are (Dean, 2006: 38)

8.1 Introduction

This chapter explores metaphors and euphemisms that hospice practitioners in this research locality used to describe certain activities. Second wave hospice advocates were not merely concerned to offer more humane care to dying patients, they were also creating what they perceived would be a viable alternative to euthanasia, the proponents of which also cultivated a ‘grand narrative’ about death with dignity as they sought to make legal the option of an assisted death. Despite their differences both movements do share many similarities. For example, drawing on discourses of ‘choice’ and ‘control’ both claim to seek circumstances conducive to ‘death with dignity’ but differ in the manner by which proponents perceive how this can be achieved. In this chapter I illustrate how patients were propelled towards death through the application of pharmaceutical techniques i.e. medication, when psychological techniques failed or merely to make handling patients easier for staff. These ‘techniques’ rendered patients completely ‘docile’, cutting them off from significant others thus compromising any notion of ‘autonomy’ espoused in the ‘grand narrative’.

Over the next several pages a series of material is presented which utilises metaphor or euphemism when describing certain practices. Other than when I ask questions or offer responses to informants I refrain from offering additional commentary since my concern lies with exposing any mismatch between the ‘goals’ of hospice as espoused in the ‘grand narrative’ and actual

practices. As before, practitioner dialogue is in italics and pseudonyms in bold used. R. stands for researcher whose comments are in normal text. I do offer interpretations, challenges and discuss several important matters that arise following presentation of the accounts. To further preserve confidentiality and anonymity I do not offer any dates as to when these conversations took place. Information that might identify a particular person or place has been removed thus (. . .). Words that are emphasised are underlined, a hyphen – indicates a pause whilst [] is used to contextualise material, ‘experienced’ refers to practitioners who have worked in in-patient hospices for ten or more years.

8.2 ‘Tucking Down’, ‘Cloaking’ and ‘Out for the Count’

R. Take me back to the early days. How many doctors did the hospice have?

Daryl, experienced nurse; *Right from the start the hospice always had about two. Most of the time they were almost part-timers and also we didn't need doctors there all the time because, you'll love this phrase, patients were tucked down a lot quicker. (Laughs)*

R. I want you to talk to me about tucked down because it's not the first time I've heard this expression.

Daryl. *It's a really good thing to do when the patient has reached that point where you cannot do anything more for them and you cannot make them more symptom controlled and they are mentally distressed and its distressing for the relatives as well and you what they call tuck them down which just means that you sedate them. Now you're not sedating them like someone accused me once you're sedating them out of it You're not, you're keeping them at a level which they are mentally settled and you leave them at that level and they will die in their own time. But you tuck them down. We used to tuck them down a lot earlier, nowadays they don't like the phrase tucking down. I think it's quite a good thing to do because you're, like palliative care cloaking the symptoms, you're cloaking the symptoms but we were cloaking them earlier. So we didn't allow them to get to that point where it is distressing because we knew what it was going to be like. It may sound a bit patronising but if you have enough experience and you know the state they're going to get to you don't want them to suffer that, you don't want the relatives to suffer that so we would be more proactive with our sedation Also, when I first started there wasn't the amount of intervention; there wasn't the amount of medication used People either didn't have it, or they weren't comfortable to use it or didn't have the knowledge and skills so it wasn't there. The, the extensive symptom control we have today they never had then. You were*

limited as to what you could do. So you ended up just sedating them and that was the tucking down.

R. Were there any other expressions that were used to signify that because I've heard people talk about zoning out or keeping them below the surface?

Daryl. *I've not heard zoning out but yes, keeping them below the surface which is basically what I was saying, keeping them below a level where they are mentally or physically distressed. You actually then take over. You are not giving them the autonomy but sometimes it's a good thing to be proactive like (. . .). They are very paternalistic. Sometimes it's good to be that. Not always and I think with the legislation and the people suing you and all the court cases and all the stuff on the internet now people have got to be really careful because you can be paternalistic in a very positive way but it can be interpreted as being Dr Shipman. So you really have to be very, very careful. When I first started there none of that was around. You went to the hospice to enjoy the time you had and then to be tucked down when it was appropriate. (...) was apparently really good one at this would judge when it was the right time and (. . .) just tuck them down and away you were.*

R. Did they have any discussion with the patient that this was what was going to happen?

Daryl. *(. . .) But the family used to look to you i.e. the nurses and the doctors to say when it was the right time. They would put themselves in your hands and we never had many discussions but anyway it wasn't a two way discussion often, it was a one way discussion.*

R. For me that raises an interesting point, hospice ideology has a definition of care which includes the patient and family. So where is the family voice then?

Daryl. *The family were nine times out of ten putting the patient in your care. They were handing over responsibility for it to you for you to make the decisions. Which was very awe inspiring at times? I used to think (. . .) am I going to make the right decision here?*

R. To me that's quite interesting because all these metaphors I hear hospice practitioners use make me think twice about what hospice actually does in practice. For example, an accusation has been levelled at the hospice movement, not once but lots of times, as you know, over the years that actually what hospice is doing is slow euthanasia.

Daryl. *Yes I've had that levelled at me several times.*

R. Basically then hospice is aiming for the same thing as the euthanasia movement, a peaceful death.

Daryl. *Yes, yep.*

R. They want the law changed but the hospice movement are saying all you need is a building like this and everyone is nice and comfortable.

Daryl. *But they're saying hem, ah, we use double effect. We're actually aiming for symptom and you've done it for symptom control and the patient dies because of the symptom control. Now I know of several occasions where it was not done for symptom control and I know of one with (. .) that used to work with us and now is (. .) in (. .) [another hospice] who said to me 'I'm doing this because' and I said 'fine go ahead' because the patient was in such distress and nothing we were doing to this patient was helping and I knew that within an hour or so of having that injection they would be dead We'd watched that patient roll about that bed in agony, physical and mental for days and there was nothing we could do and it, you say you wouldn't put a dog through that , well you wouldn't have done.*

R. What about Cicely Saunders concept 'total pain'?

Daryl. *You can't cure total pain You can't cure it. No hospice can cure total pain. I don't believe it. Because there is always some vestige of pain, mental, physical or something and I think to say that we cure all pain is rubbish. We don't. All we can do is cure a proportion of them, mask some others, and help them deal with what's left. (. .) Years ago that wouldn't have happened because they would have had their 25 milligrams of midazolam and they would have been out for the count. So is it a better thing?*

R. But then again I've also spoken with hospice nurses who've said some nurses would tell fibs to doctors about patients being agitated or patients being in distress or suffering.

Daryl. *Oh yes. Yes. I've encountered that, definitely*

R. What is that about?

Daryl. *A lot of the time it's the staff person's anxiety. It's also having watched other patients go through that type of pain or distress and you don't want that patient to go through it any more so you'll do everything you can to stop that patient going through that pain*

8.3 'Tucking Up', 'Waiting for the Inevitable' and 'Seeing Them Off Sooner'

R. Did you have multidisciplinary team meetings?

Dr Veronica, *experienced hospice doctor; We had them most weeks but when (...) came, (...), (. .) wasn't always comfortable with it but dealt with it by not being there So anything the MTD decided could be changed by (. .) the next day. Like (. .) changed anything the doctors decided at the weekend (. .) would come and change on a Monday.*

R. So whatever you prescribed no matter what day of the week was changed by (. .) when (. .) returned?

Dr Veronica. *That's right*

R. What would you talk about at MDT meetings?

Dr Veronica. Em basically well anyone could bring a query about a patient. But it was problem solving. It was trying to problem solve.

R. Ok so you might have a patient who wanted to go out raging against the night and a nurse might be thinking we should be sedating that person and they would bring that to the meeting and you would discuss it, that kind of thing?

Dr Veronica. Yes. That's right. That would be discussed but the only problem is (. . .) might opt out of the decision [laughs]. So you might have discussed it but that doesn't mean the issue has been resolved. And the other person who might opt out at that time was (...).

R. Why?

Dr Veronica. (. . .) was an interesting personality. Her heart was probably in the right place, how she saw it [laughs]. (. . .) but (. . .) a very dominant character. This was pre (. . .) and (. . .) was one of the em tucking them up ones but I think it was actually in a relatively innocent way. She didn't, I don't think it was anything of seeing them off sooner type thing. I think she genuinely just wanted them to be comfortable while they waited for the inevitable to happen.

R. She just didn't want them to suffer what she knew was coming?

Dr Veronica. Yes. I don't think she had it in her, brain wise to think beyond that.

R. But then she would have taught all the juniors that 'this is how we do it here' wouldn't she? So that's what they would have expected?

Dr Veronica. Yes.

R. So that is what they would have expected to happen?

Dr Veronica. Yes.

R. But the 'tucking down' is fascinating. (. . .). There were lots of pain and lots of intractable suffering but there was nothing hospices could do about it.

Dr Veronica. Yes. I actually remember (. . .) and (. . .) had a big argument. It was mostly between (. . .) and (. . .) and I was piggy in the middle. It was about a patient who had renal failure; he had early prostate cancer so was only in about his forties (. . .). It was one of those things that you don't even till this day know the entire rights and wrongs of it and it would have been easier if we had been in the grounds of (. . .) [acute hospital] in some ways. He began to slide very fast one week(. . .) and (. . .) was all for shipping him up to (. . .) [acute hospital], to be de plumbed. He had blocked very very fast and I though yes, that's probably a good idea but we might have left it too late and (. . .) just wanted to tuck him down. [Laughs] (. . .) And we had this almighty row but I think by then the debate was three days too late.

R. He was considered young?

Dr veronica. Yes *If he had been in his nineties I don't think there would have been a debate.*

8.4 The Midazolam Queen – Power Zones - 'Drifting Off' and 'Knocking Out'

R. Rosemary, you were telling me about practices that troubled you when you were working at (. . .). Since our initial discussion you are now aware of my research interests. So, would you mind if we go over what you told me previously just for the record?

Rosemary, experienced nurse, I used to do nights and it took me a long time to realise what was happening. I didn't even understand when people talked about 'tucking patients down'. They would say, 'it's time to tuck so and so down' or 'I think we should tuck them down'. It was quite creepy really. Now I wonder if the patients were 'tucked down' for the staff's convenience. I don't think it was for the patient's benefit. 'Tucking down' was really a euphemism for 'sedation'. They would sedate a patient and the effect was that the patient stopped eating and drinking becoming more and more drowsy and then die. It reminded me of how people used to be treated in nursing homes and I didn't like it at all.

Over time I became very uncomfortable working with (. . .) as I felt her practice was very unsafe. She was in from the start and had got used to working with (. . .) and she could do as she liked. She was the boss. She had a difficult home life and the hospice was her power zone (. . .) and I ended up working with her. She used to come on duty and sedate everyone, she would go straight for the highest possible dose of everything, 300 – 400 mg of morphine none of this 10 -15 mg dose and as much midazolam as possible. Then when the various jobs were done she and the (. . .) would make themselves comfortable in reclining chairs, wrap themselves in blankets and sleep for the night. It was awful as I was the only one who didn't sleep on duty and used to do regular checks on patients. She used to laugh at me and say to me 'you need valium (. . .)'. It was a terrible situation because I was always afraid I would find patients dead during the night and I did because they would just 'drift off' as a result of all the medication.

The stress of working like this was terrible and no one wanted to hear I did tell (. . .) [matron] but she didn't want to know. She was friends with (. . .) she knew I was right but she didn't want to do anything. One night a patient said to me 'I know what's going on here. I hear what they do. She knocks them all out and then goes to sleep'. I was so ashamed. It was so unprofessional. I started demanding that the night staff have a break which they weren't entitled to in those days (. . .) Eventually the night staff were allowed to have three quarters of an hour break which was paid but (. . .) and (. . .) still slept on duty. One night she said to me, 'I can't remember if I gave mogadon [a sleeping tablet] to (. . .) [a patient]. We didn't used to record it at the time. I told her I was certain she had but she wanted to give him more so she did. She was in with (. . .) and (. . .) because they had all started together when the hospice opened and had supported (. . .) [a matron who had been sacked]. (. . .) knew her practice was dodgy but wouldn't do anything about it. Anyway (. . .) went behind my back told (. . .) that I wasn't happy on nights but (. . .) already knew I had made claims about incompetence of this person and played her cards. (. . .), even (. . .) who had also

experienced problems with (. . .)'s practice did not back me up. I suppose people want to protect their own interests. But then quite a few staff started to refuse to work with (. . .). Eventually things got so desperate that eighteen months later I was asked if I would go back on nights and work with (. . .). I was furious and refused. No way was I going to work with (. . .) again. It was too dangerous. I couldn't believe they asked me to work with her again after all that had happened. I told them (. . .). Eventually the doctors complained about her practice and after lots of rows she was put on days. In fact, all the night staff was changed to days so they all got tarred with the same brush just to cover up one person's incompetence.(. . .).

8.5 'Knocking Out' and 'Turning a Blind Eye'

R. I've heard that nurses can be very manipulative, what do you say to that?

Dr Sarah, *experienced; Yes, actually I have been on the receiving end. Say they've got a doctor that wouldn't prescribe what they wanted to prescribe they would tell fibs. That's where the stages came in handy for nurses especially anger. Hospices are not very good at dealing with that. Well they tend not to like any public display. They would then go to this doctor and say well he or she patient has become verbally aggressive and agitated, they're upsetting the other patients in the ward or if the patient is in a single room they are upsetting all the staff, lashing out at them, that kind of thing so they really need more sedation. That's true because they didn't always actually like it if you as the doctor then went to see the patient which I always did.*

R. Because they've told you this story?

Dr Sarah. *Yes. And now you're going to go and prove it. Whereas in some hospices the doctors just listened to the nurses and wrote up what they were told. (. . .). (. . .) and I had a very similar philosophy.*

R. Which was?

Dr Sarah. *Which was the old fashioned one patient rights basically, the rights of the patient.*

R. To go whatever way they wanted?

Dr Sarah. *Exactly.*

R. When you talk about the rights of the patient, if that meant a patient wanted their sedation or medication increased, would you go with that?

Dr Sarah. *Only if it was appropriate. I'd talk it through with them. Because often if a patient wanted their sedation increased, that wasn't actually what they were asking and I don't mean that to sound presumptive. It sounds oh the doctor knows best and that's not actually what you're asking. It was more a signal there's something else to this story.*

R. Would families ask?

Dr Sarah. *They would imply it.*

R. What would they say or how would they do that?

Dr Sarah. *They would say 'oh I wish the end was coming' or 'they've had enough' or 'isn't there something you can do?' you know that sort of thing and em (. .) was fierier about it and (. .) would argue with (. .). The big problem with (. .) that we would find was that if (. .) or (. .) or I were on weekends on call we would come in on Monday and (. .) would have changed all the drugs em medication that we had written up for the weekend*

R. (. .). They had a (. .) at (. .) that they used to call the midazolam queen – do you know who I'm talking about?

Dr Sarah. *Yes, yes.*

R. She worked there for a long time.

Dr Sarah. *Yes (. .). Was it (. .)?*

R. No, she wouldn't have been the queen but there were several of them who were midazolam – we don't do discharges type persons but this was a midazolam queen. The staff called her that. In those days the prescription and until relatively recently, the prescription the PRN prescription left lots of leeway didn't it?

Dr Sarah. *Yes, yes it did*

R. So the patient would be prescribed a certain amount of stuff and then the PRN side gave lots of leeway for the staff to use their initiative, their expertise to make a judgement – is this patient unsettled? Do we need to give more? That kind of thing. (. .) That only blew up very recently and there were lots of people who didn't like working with her and there were lots of patients who never did wake up for their breakfast in the morning.

Dr Sarah. *Yes, there was an awful fuss. I don't know why the management didn't do something much sooner. You see for a long time quite a few people though it was appropriate or turned a blind eye (. .) But you see many of the nurses were pretty meek so with them I think it was just poor practice. Mind you they would have to be pretty courageous to stand up to that lot so I think the ones that didn't like it just left.*

8.6 Discussion

I don't intend to get drawn into judging the rights or wrongs of what has been articulated although perfectly aware that one could discuss the ethics of the practices that have been described. For now, my interest lies in exposing any

mismatch between the 'goals' of hospice as espoused in the 'grand narrative' and the translation of these goals into practice in this local setting – and thus pointing out 'inconvenient facts' (Dean, 1999:40) – and there are many. These accounts provided by informants of varying levels of experience are, I believe, indicative of such a 'mismatch' and speak to different perspectives of the same theme i.e. assisting death, whether that be through what is commonly called 'terminal sedation' (Mount, 1996); 'euthanasia' (ten Have, 2001, Keown, 1995) irrespective of intent, motive or reasons. 'Medical literature bears witness to the controversy over the clinical and ethical foundation of pharmacological sedation' (Fondras, 1996:17). This is a topic that tends to be 'glossed over' in the 'grand narrative' of second wave hospice but I suspect it has been deliberately 'subjugated'. Although a plethora of commentators are increasingly writing about terminal sedation, as recently as 2001, by which time third wave developments i.e. the speciality of palliative medicine / care were well under way an article entitled '*Moral Problems in Palliative Care Journals*' appeared in the *Journal of Palliative Medicine* from which the following extract derives.

Palliative care seems specifically connected with moral concerns about the quality of care, the characteristics of care providers and respect for the autonomy of patients and their relatives. The controversial issue of euthanasia also provokes ethical reflection on the proper care for dying patients. The multiprofessional nature of palliative care, the difficulties of caring for the terminally ill, the complicated medical and nursing problems involved, and the balancing of competence with compassion, all foster a specific sensitivity to moral issues in many palliative care professionals. Although the interest in ethics seems to parallel the growth of palliative care, systematic analysis of the moral issues that are typical for the context of palliative care is relatively scarce (Hermsen and ten Have, 2001:425).

Why should 'systematic analysis of moral issues' be 'relatively scarce'? Second wave hospice was established in 1967, the specialty of palliative medicine was legitimized in 1987. Therefore at the time of the above publication, Britain's

hospice movement had enjoyed 31 years being 'specifically connected with moral concerns about the quality of care', 'difficulties' and 'proper care for dying patients'. Yet, rather than sharing how these moral concerns had been resolved through research and teaching, the very things asserted to differentiate second wave hospice from its predecessors, we have 'scarcity'. The question these authors set out to answer was; '*which moral issues are raised and discussed by the palliative care community in professional journals?*'

The majority of articles submitted to journals which specifically focus on palliative care between 1984 and 1999 were produced by authors from university departments (33.5%) and hospitals (30.8%). The contribution from authors from hospices is lower at 13.5%. Of the 23 topics that were identified 16.3% are concerned with euthanasia and assisted suicide' The authors suggest that 'the focus on these related topics is not surprising, given the fact that palliative care, and in particular hospice care, has articulated itself as an alternative to euthanasia' – quite so; yet surprisingly the authors did not comment on the low level of contributions from hospice professionals nor seem to consider it strange that so few articles were submitted by hospice practitioners (Hermesen and ten Have 2001: 431). Only 4% of topics concerned terminal sedation, 7.4% non treatment decisions, 1.9% nursing dilemmas, 1.5% principle of double effect, 0.7% medical futility and 1.7 on morphine / use of medicine. Bear in mind that by 1984 second wave hospice was seventeen years old; long enough one might speculate, to have learned something about these end of life issues worth sharing. If anyone could be expected to hold an opinion on the above ethical issues, one might reasonably speculate that it would come from hospice practitioners. Yet they remain strangely silent. Why might this be? Let me take the reader back to the days when the

'grand narrative' was being formed where we meet Saunders being rather less reticent.

Cicely Saunders was active in commenting on and expressing opposition to Baroness Wooton's Incurable Patients Bill of 1976, wherein she feared the *right* to die might be interpreted by some as a *duty*. Likewise in 1977 and 1978, she took part in debates at the Royal Society of Health and the Union Society, Cambridge; where in each case the motions in support of the legalization of euthanasia were defeated. Her position was clear: euthanasia is not a matter of desisting from active treatment; it is a killing act (. . .) (Clark, 2002: 128).

The topic of sedation has always been played down in second wave hospices' 'grand narrative' and it is well known *assumption* in British society that to be 'for' hospice is to be 'against' euthanasia. I say assumption because of course one does not necessarily imply the other at all.

8.7 Trading on 'Difference'

Both hospice and the Voluntary Euthanasia Society (VES) share similar concerns regarding the need to avoid a 'bad' death (however defined) and that patients should maintain control over their own death. According to the 'grand narrative' hospice practitioners are committed to alleviating symptoms in such a way that patients retain control of their minds to the end. For both movements 'death with dignity is death with control' (Smith, 1982:118). Yet, clinical practice in this setting suggests otherwise. What was to differentiate second wave hospice from that which went before? To reiterate;

We want to carry out research in the relief of distress such as has not been done anywhere else, so far as I have been able to discover. It is often easier in a specialist setting to go on learning in this way and by building what we think is an ideal unit we hope to be able to help not only our own patients but to raise standards generally and also to stimulate others to think about these problems (Saunders 1965:2; pamphlet).

The hospice will try to fill the gap that exists in both research and teaching concerning the care of patients dying of cancer and those

needing skilled relief in other long term illnesses and their relatives (Saunders 1967b:2127 cited in Clark 2002:10).

This represents what was to set St Christopher's hospice apart from its predecessors – not only *care* of, and for, the dying patient (and family) but, unlike first wave hospice, where the role of medicine was minimal, this endeavour would combine *research* and (the dissemination of this through) *teaching* (so as to educate colleagues in other healthcare settings) 'to raise standards generally' and, one might reasonably speculate – through publication of findings. Given the 'unplanned' proliferation of hospices in the 1970s and 1980s, taking into account that early research efforts were mainly 'descriptive and anecdotal' (Clark, 2002:129), based on these claims espoused in the 'grand narrative' it is surely not unreasonable to suggest that thirty one years of caring for dying patients *ought* to have provided much research which was publishable to enlighten colleagues employed both within and outwith hospice thus filling the 'gap' that was claimed to exist. Therefore the paucity of research contributions by hospice practitioners in Hermsen and ten Have's (2001:431) literature review is all the more mystifying. Other authors have commented on this lack.

At one level, hospice is one of the most self-consciously "moral" and "ethical" sectors of the entire health care system. Its origins lie in a social and ethical movement, and an ethic of compassion, dignity and service. Paradoxically, however, perhaps due to this value based heritage, systematic reflection on ethics in the hospice field is curiously underdeveloped. In the past the value commitments of hospice may have been seen as self-evident, noncontroversial, and in need of little explicit analysis and examination. If that assumption was ever true (which I doubt), it is certainly no longer true today (Jennings, 1997:2).

As I proposed earlier in this thesis, care of the dying in contemporary society is generally said to remain poor which speaks to hospice's failure to 'raise standards

generally' either through research or education (Saunders, 1965, Brown, 2000, Edmonds and Rogers, 2003, Thomas, 2006).

8.8 Doctrine of Double Effect

Briefly, the doctrine of double effect – 'if one act has two consequences, one good and one evil, then the act may be morally acceptable in certain circumstances, for example, administering drugs to relieve pain, but which would eventually lead to death if administered in large doses' (de Cruz, 2005: 226). The rules for health professionals are no different to any other person who acts intentionally to kill another; they may still be prosecuted for murder or manslaughter under the Homicide Act 1957 as there is no defence in law for mercy killing. Only doctors have had a special defence with regard to pain relief since *R v. Bodkin Adams* (1957).

Mr Justice Devlin's direction is responsible for introducing the doctrine of double effect into English and Welsh law. He is reported to have stated, if the first purpose of medicine, the restoration of health, can no longer be achieved there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life (Palmer, 1957). Thus, the 'administration of strong painkilling drugs is justifiable in Law even though repeated doses will over time, have the effect of cutting short the patient's life' (McHale and Tingle, 2004:215). Talking about nurse's duty of care Dimond points out that 'to be responsible it is necessary to have knowledge and this includes legal knowledge. Ignorance of the law is no defence and the nurse should be aware of the limits that the law imposes on her and also the power it gives her' (2005:4).

8.9 By Any Other Name - Slow Euthanasia?

Euthanasia is defined as purposeful shortening of human life through active or direct assistance, with or without medical assistance. Under the present legal system this is classified as murder (de Cruz, 2005). Many people who work in hospices and palliative care believe sedation has nothing to do with euthanasia and would argue that as the 'ultimate therapy' it is the best form of pain and symptom control thus making euthanasia superfluous.

In palliative care, sedation is often used in another context, meaning the reduction of the level of consciousness of the patient to alleviate intolerable symptoms and distress. If this is done intentionally, it has been named 'terminal sedation' or 'end-of-life sedation' (Radbruch, 2002:237).

In 1990 Ventafridda et al claimed that more than fifty per cent of cancer patients died with physical symptoms that could only be controlled by the use of deep sedation.

The distinction between terminal sedation and voluntary active euthanasia is based in part on whether the dose of sedative is maintained or increased once sedation is achieved and whether a lethal injection is given. In some western traditions, it is also based on the physician's intent to hasten death, which is subjective and never absolutely knowable (Quill, 2000:492).

Thorns and Sykes (2003) studied how sedative doses change at the end of life and how often the doctrine of double effect might be relevant. They concluded that sedative dose increases in the last hours of life were not associated with shortened survival overall, suggesting that the doctrine of double effect rarely has to be invoked to excuse sedative prescribing in end-stage care (2003: 344). However, there are others who are convinced that sedation as practiced by hospices is nothing other than 'slow euthanasia' a 'disguised, hypocritical and barely humane form of euthanasia or ending of life' and as such is illegal (Broeckaert, 2004). In 2005 Dr Gillian Craig produced an article for debate entitled *Sedation without*

hydration can seriously damage your health which appeared in the International Journal of Palliative Nursing. Her initial comments are worth noting.

Sedation without hydration came to my notice in 1990. I felt that I had witnessed euthanasia and was dismayed. Others have expressed similar concerns and have called the practice 'terminal sedation' or 'slow euthanasia' (Billings and Block, 1996; Shea, 2004). . . . Yet despite a decade of debate, terminal sedation appears to be on the increase. Syringe drivers primed with diamorphine, midazolam and haloperidol are widely used at the end of life. In some hospices anticipatory prescribing of this sedative cocktail appears to be almost routine if patients are thought to be dying (Craig, 2005:333).

Craig encountered terminal sedation in 1990, the article was published in 2005 so one presumes the increased use of terminal sedation occurred during this fifteen year period but I speculate that the practice was well established long before that – so well established that practitioners had developed metaphors and euphemisms when referring to it. In their search of the literature, Hermesen and ten Have (2001:425) found 458 ethics articles during the period 1984 to 1999 (15 years) of which only 4% were on the topic of terminal sedation. Bearing in mind that palliative medicine was recognized as a speciality in 1987, this would suggest that terminal sedation was not a topic of major interest or concern for hospices or in the palliative care arena during that period. Craig (2005) asserts that some hospices are routinely undertaking this practice. Is this really a new development or is it only now coming to light? She discusses a case where 'anticipatory prescribing' on a geriatric ward was criticized by the Commission for Health Improvement in 2002.

Police and expert witnesses expressed concern about inappropriate combined use of diamorphine, midazolam and haloperidol. Clinical staff failed to recognize the potential adverse effects of the drugs prescribed, namely over sedation and death. There were no clear guidelines to prevent staff from assuming that patients had been admitted for palliation rather than rehabilitation. Palliative carers should try to curb the use of syringe drivers and sedation at the end of life (Craig 2005:333).

Leaving aside the last sentence, the questions one is now prompted to ask are; assuming that patients had been admitted for palliation and not rehabilitation, would anticipatory prescribing have been viewed as acceptable? Would terminal sedation have been acceptable? The anticipatory prescribing of drugs is a practice that hospices support as evidenced by the recent introduction of the Liverpool Care Pathway (Ellershaw, 2002). This end of life 'tool' is currently being transferred to other settings including home care with the declared aim of ensuring that in the last hours / days of life there is no delay responding to a symptom nor will patients be on the receiving end of unnecessary techniques (Ellershaw and Roberts, 2005). It is this practice that Craig (2005) is concerned about and in my view, rightly so. Home care deserves serious consideration since the potential for abuse is greater due to the fact that most care is undertaken by lone workers. Someone with less than honourable intent could give doses of drugs which, after the event would be very difficult to challenge. Therefore, palliative care as currently practised is open to real abuse. I return to this matter in the final chapter.

8.10 Metaphors and Euphemisms

According to the 'grand narrative' 'freedom from pain while in a conscious and alert state, allows dying patients to retain control over as much of their lives as possible and to complete unfinished business prior to death' (du Boulay, 1984). One is then prompted to ask, is there a point at which patients are 'judged' by hospice practitioners as having sorted out their affairs satisfactorily and thus as one individual put it, become ready to be '*tucked down*'? (Daryl) - A practice that occurred so regularly over many years that practitioners had contrived metaphors

and euphemisms to convey their understanding of the practice if we are to believe these accounts.

Using euphemism involves substituting one concept for another. A metaphor is a way of describing something by saying it *is* something else, to draw an analogy between them. Either can express in few words what might otherwise take many and may also act as a buffer against anything likely to cause distress. For instance, the military sanitizes its lethal activities by dehumanizing its enemies who are 'exterminated', or 'wasted' like vermin. In *Doublespeak* (1989) William Lutz distinguishes euphemism, which covers the unpleasant, from doublespeak, whose purpose is to deceive and mislead. To illustrate the latter, he noted how the US State Department replaced 'killing' with 'unlawful deprivation of life'. Dead enemy soldiers are 'decommissioned aggressor quantum'. Deaths of innocent civilians are referred to as 'collateral damage'. In *Illness as Metaphor* (1978) Susan Sontag describes the military metaphors applied to disease – the 'battle' against cancer - alien invaders that breach body 'defence systems' necessitating surgical, chemical or radiation 'counterattacks'. The 'frontline' in the cultural 'war' against death is the medical establishment where death has long been viewed as failure, giving rise to numerous clinically detached euphemisms. Patients are 'brown bread' (dead) 'go sour' (respirations cease), 'no longer with us' (dead), 'off their legs' (bedridden), 'bagged' (on a respirator), 'toes pointing up' (dead), gone to meet their maker (dead). For those opposing euthanasia or assisted death 'active euthanasia' is a euphemism for murder. For proponents of euthanasia keeping terminally ill patients on high-tech support is called 'technological torturing'.

Perhaps hospice practitioners buffeted themselves from the horror of what they were doing through the use of metaphor and euphemism in much the

same way that lay people use such expressions to make death abstract. For example people who die are described as having 'passed away', 'kicked the bucket', 'pushing up daisies'. Metaphors and euphemisms for death are employed as both 'shields and weapons, to cover the unpleasant or distasteful aspects of mortality, or to apply the power of death to reinforce the significance of certain events among the living' (Kearl, 2006). For example old people are called 'golden oldies' or 'senior citizens' who die in 'care homes' where, far from being cared for they are deindividualized by underpaid staff (in some). People can also 'die' symbolically. For instance, I used to refer to hospice staff who were useless in their role as 'dead wood' while some employments are referred to as 'dead end' jobs.

For those whose job it is to deal with the dying and dead metaphors are developed from the 'black' humour they use 'backstage' (Goffman, 1959) which acts as a desensitization technique in order to cope with society's 'dirty work' (Lawler, 1991). 'Issues of dirt, decay, disintegration and smell are rarely, if ever written about by hospice professionals' (Lawton, 2000: 143). The metaphors and euphemisms that people apply to the dying and the dead 'shape the way people in contemporary society see their connection with the dead'. 'They can sanitize the profound pollution posed by the decaying corpse (e.g. hospice narratives that posit dying as a positive, fulfilling experience) and assuage the profound moral guilt of collective murder during times of war. They can reaffirm the meaninglessness of the deceased's life (he lives with us all) or degrade their very existence (the vermin were whacked)' (Kearl, 1989, 2006).

For hospice practitioners the use of metaphor and euphemism helped them to deal with what lurked at a subconscious level, that which might have induced horror at a conscious level – hospice's 'shadow'. They reassured themselves that they were

'saving' patients from suffering by '*not allowing them to get to that point where we knew what it was going to be like*' (Daryl) but in reality they were saving themselves from what they considered too horrific to manage.

Were the practices described above a 'one off' in this particular locality, or might it be the case that the practice is covertly widespread but not openly discussed? Although not included in this thesis, I have evidence to the contrary. This was 'a way of doing things' and seemingly accepted by many who worked in hospices as I discovered (Foucault, 1991b:75). Not everyone agreed with such practices as we saw above but they were part and parcel of the hospice approach albeit unsurprisingly not ones which they wanted to shout about in public.

8.11 Autonomy and Handing Over the Body

At its simplest autonomy means rule of the self by the self – 'or having the capacity to be self-governing' (Randall and Downie, 2006: 53). 'When patients are dying . . . they relinquish responsibility for body care and body functions to the nurse and 'hand over' the body' (Lawler, 1991 181). Not according to hospice 'grand narrative' where the patient is declared to remain at the helm fully in control right to the end. Practitioners declared that relatives were happy to 'hand over control' to hospice staff and this may be true to some extent but because clinical practices were underpinned by Kubler-Ross' (false) 'theory' any choices that might have been possible for patients or relatives were already determined and thus any notion of 'autonomy' compromised. In any case, for patients in this locality any such 'decisions' did not involve two way discussion but were '*one way*' monologues (Daryl). Therefore I agree with Lawton that hospice 'takes over' patients' bodies and 'converts the patient's body into a 'docile body' which is 'subjected and used' (2000: 118).

In removing a patient's sentience through sedation the last vestiges of their personhood are also erased; aspects of person and self which involve patients' ability to 'act', choose and make decisions for themselves (Lawton, 2000: 120).

8.12 Ethics in Historical Context

Ethics has a long history; Socrates asked 'what sort of person ought one to be?' and thus relates ethics to personal morality and character. Kant proposed that one should act so that, were one to be a member of a community who all acted that way, one would be satisfied. Kantian ethics focus on rights and duties, and tend to stress the absolute nature of both. Where these ideas influence medical ethics, we will hear that patients have a 'right' to life, a 'right' to information or indeed, a 'right' to palliative care. Relativists object to such absolutism, pointing out wide divergences in moral codes across cultures. The greatest weakness of Kantian theories is that one can always produce situations where duties conflict (Russell, 1974, Vardy and Grosch, 1994).

The subject of ethics is best thought of as 'the critical scrutiny of moral thought and morality as it affects our ideas of right conduct, (Campbell 1984). Raanon Gillon defines medical ethics as 'the analytic activity in which the concepts, assumptions, beliefs, attitudes, emotions, reasons, and arguments underlying medicomoral decision making are examined critically', (1985:2). He considers medicomoral decisions to be those that concern norms, or values, good or bad, right or wrong, and what ought or ought not to be done in the context of medical practice, (1985:2). The stated ethic of pro-euthanasiasts, like hospice advocates, is one of compassion with concern for human dignity associated with freedom of choice. Hospices caught public and professional imagination because they returned dignity to dying, and placed value once again on the qualities of human caring, at a time when medicine had become increasingly technological

and cure-oriented (Winn, 1987:25). However, 'dignity' can be usefully called upon to perform numerous functions but it is a nebulous and elusive concept.

The aspiration to "respect dignity" is virtually ubiquitous. Everyone agrees that human dignity is important and should be respected but nowhere – in any of this proliferation of codes and mission statements – is dignity defined (Seedhouse and Gallagher, 2002:368).

It is the tension between differing ethical positions that lies at the heart of debates between pro-euthanasiasts and hospice proponents with each movement drawing on particular discourses to support their arguments whilst in reality there is little to differentiate them.

8.13 Conclusion

In this chapter I have pursued hospice's 'shadow' to the very edge of life by exploring a major contentious issue for hospice staff – use (abuse?) of sedation in attempts to manage patient's symptoms. This, despite 'grand narrative' claims; *we devised new methods of administering narcotics and analgesics which made it possible for patients to be kept free of pain whilst still remaining alert and lucid* (Saunders 2003). Meanwhile the case of Dr Shipman ensured that doctors began to practice defensively and clinical reasoning had to be made much more explicit. The contemporary means of getting round 'problems' involves re-defining them using concepts such as 'existential distress' (Morita et al, 2000), 'intractable terminal suffering' (Quill et al, 2000), 'intractable distress' (Chater et al, 1998), 'terminal restlessness' (MacLeod et al, 2004), 'refractory symptoms' (Tai-Yuan Chiu, 2000), terminal agitation, delirium and restlessness (Stirling et al, 1998), 'uncontrolled symptoms' (Fainsinger et al, 2000). All of which rely upon practitioners making 'subjective' judgements whose 'intent' is 'never absolutely knowable' (Quill, 2000: 492).

Regardless of how one may choose to view the matters addressed in this chapter they were 'techniques' to 'manage' and 'contain' what was perceived as unmanageable with the aim of steering conduct in a particular direction. What was being sought was 'transformation' since patients became totally objectified - cut off from families or significant others and therefore 'socially dead' (Lawton, 2000). These 'disciplining techniques' re-constituted patients' identities from 'active' to passive' – from 'subject' to 'object' (Lawton, 2000) to make them more manageable thus maintaining hospice's 'grand narrative' and public image as a 'peaceful place to die'; a place of 'safety', 'openness, freedom from tension' where the asserted aim is to 'enhance the quality of living and of relationships for patient and families where there is only a limited time left' (Du Boulay 1984, Stoddard 1978, Winn 1987, Saunders 1990). Based on the above accounts it seems fairly reasonable to suggest that contrary to claims made in the 'grand narrative' hospices patients in this setting 'lacked care in any significant sense' since practitioners resorted to techniques that 'rendered [patients] unconscious until death' (Du Boulay, 1984). 'There are times when it seems you can do almost anything to patients and get away with it as long as you are seen to care' (Hinton, 1981:32). The disparity between rhetoric and reality in this locality was very wide indeed.

R. *Have you ever heard the expression 'tucking down'?*

It's what used to happen in hospices when patients were sedated. There is absolutely no excuse for it. I have never been able to condone such practices (Clarissa, palliative medicine consultant).

I now move on to conclude this thesis in the next chapter.

Chapter 9

Conclusion

One of the first tasks of any new discipline is the construction of a history which will explain the inevitability of its arrival, justify its existence and promote its future (Armstrong, 1986:28).

9.1 Introduction

This thesis has offered a critique of the history of hospice; the hospice movement and palliative care by adopting a critical approach to the 'grand narrative' espoused by proponents. My study of hospice entailed exploring the social landscape within which it emerged, examining 'received opinion' concerning how dying was perceived and managed during specific historical moments, whilst suggesting 'new ways of looking at things' (Randal and Downie, 2006: 216). The central aim of this study was to ascertain whether there was or is a mismatch between the 'rhetoric and reality' (Lawton, 2000) of second wave hospice's 'grand narrative' and more recently as it applies to palliative care. Overall the findings of this study support that assertion. This chapter now serves to synthesise various matters discussed within the thesis. Following a brief review of the subject matter addressed in the study, my perspective is reviewed. I then go on to speculate about the future, including implications of this study for policy, and finally, offer some concluding thoughts.

9.2 Review

The first part of this thesis, chapters one and two, provided the background to the study; setting the scene regarding theoretical and methodological perspectives that informed the approach to this study and the interpretation of findings. Chapters 3, 4, and 5 explored how the three goals hospice advocates set for themselves; (1)

'holistic care'; (2) 'patient and family as the unit of care'; (3) 'non-hierarchical multidisciplinary team working' were translated into practice in the study's setting. In chapter six I discussed the results of my findings regarding these goals, none of which were met in practice, leading me to suggest that perhaps hospices were not and are not offering anything 'special' or significantly different from that available in the NHS or other healthcare settings. However, because of their 'independence' they are able to operate in ways that would be unacceptable in other healthcare arenas. In particular, and in light of the way these hospices were organised and managed, I hope I have paved the way for opening up hospice practices to 'questions they do not normally have to answer' (Parker, 2002: 14). As a result of my observations and discussions I was led to explore two significant matters neglected in the literature Kubler-Ross' 'stage theory' (1969) and sedation practices.

9.3 Violating Their Own Ethics

In chapter seven I offered a critique of 'stage theory, which, it seems, was not a 'testable' theory. No one was able to replicate Kubler-Ross's theory and no methodology was ever made available (Chaban, 2000). 'A good theory' is 'specific', offers evidence, uses known and well understood 'principles' and 'makes testable predictions' (Blackmore, 1993 cited in Chaban, 2000: 263). Nor was her 'theory' based on research as Kubler-Ross had claimed, since 'despite her medical training, she did not adhere to scientific methodology' and thus her work 'would fail to satisfy scientific research standards'. Kubler-Ross, it would appear, merely used the 'authority of science' (Rose, 1999) to support the claims she made. Despite being the subject of dispute and refutation since the 1970s, the 'theory' of stages continued to be used in Britain where there is a dearth of critical

scholarship on Kubler-Ross's work by hospice advocates and sociologists. Bearing in mind the hospices to which this study pertains were still using Kubler-Ross's 'stage theory' in 2001, there are implications for the 'evidence base' that second wave hospice built since its emergence, because a way of seeing and learning became a way of knowing and teaching (Foucault, 1991). Since St Christopher's hospice acted as the initial, and then 'core', 'producer' and 'distributor' of information and knowledge about care of the dying in Britain, including Kubler-Ross's 'theory' which was endorsed by Cicely Saunders, the hospice movement that subsequently emerged 'adopted ungrounded research and ungrounded theory to care for the dying' (Chaban, 2000: 117 & 116) and in the process produced what are now perceived as thanatological or palliative 'experts'.

In these hospices 'stage theory' was imposed, unreflectively, as a convenient 'technique of judgement' (Rose, 1999) to 'steer' patients and their relatives through the dying process; useful for disciplining i.e. making people more manageable thus maintaining organisational order – it 'fixed them in time and space' within an ideology of 'good death' thus evidencing a 'breach of evidence' in the 'grand narrative' (Rose, 1999). Patients and their families were 'governed' on the basis of their capacity to think but, 'the capacity to think is always a danger to the practice of giving and receiving orders' (Dean, 2006: 15) and therefore they were socialised into very specific ways of thinking with the assistance of stage theory. For example, *we don't give them what they want its what we tell them they want. We tell them what they want* (Ella)

The ethic of hospice care is first and foremost an ethic in which the individuality of terminally ill patients is respected. Any professional framework or protocol in which uniform expectations are placed on patients, violates this ethic (Churchill, 1985 cited in Chaban, 2000: 114).

Since the 'field of possible action' for patients and their relatives was 'structured' by preconceived notions -- a prescription - concerning the dying process derived from Kubler-Ross, - *hospice people like the idea of a prescription where patients do this followed by that* (Doctor Sarah) - the above ethic was indeed violated. In this study setting, employees *just accepted that's how it's done here* (Daryl); *we learnt from listening to them but we were not encouraged to question their judgement* (Ella).

9.4 Constructing the Rules

In chapter eight the metaphors and euphemisms that practitioners in this locality drew upon to refer to sedation practices were examined. Despite public proclamations against euthanasia and physician assisted suicide by hospice advocates; it is difficult to conceive how the practices that regularly occurred in this locality might be differentiated from euthanasia. Practitioners in this locality had developed very specific ways of referring to sedation practices that at first glance *seem harmless*; e.g. *I'd only ever been taught to sort of tuck them down* (Hilda).

When someone asks for euthanasia or turns to suicide, I believe in almost every case someone, or society as a whole, has failed that person. To suggest that such an act should be legalised is to offer a negative and dangerous answer to problems which should be solved by better means (Saunders, Nursing Mirror Sept 4, 1980).

The 'better means' refers to hospice and the ability of hospice practitioners to alleviate pain and suffering within the ideology of 'holism'. What is interesting and usually overlooked in debates about terminal sedation, euthanasia or physician assisted suicide was Saunders' *active* role in constructing the rules (regarding what is to be done) which would henceforth determine end of life practice.

Between 1970 and 1974 a working party of the Church of England Board of Social Responsibility sought to develop an Anglican contribution to the debate on euthanasia and two of the chapters in the group's report were drafted by Cicely Saunders (Saunders 1975). All members endorsed the recommendations, including the undesirability of extending the term euthanasia to incorporate the withdrawal of artificial means of preserving life or to include the use of pain-relieving drugs which may marginally shorten life (Clark, 2002: 128).

The commission 'endorsed' her 'recommendations' (regarding what is to be known) including the '*undesirability of extending the term euthanasia*' to practices which 'included the *use of pain-relieving drugs which may marginally shorten life*' (as used in hospices). Saunders occupied a pivotal position within relationships of power that enabled her to define and delimit what would, and would not, be possible to do; and how it should be judged; because her status as a physician, religious beliefs and thus her ideals placed her in 'relation of complementarity' with those of the Church of England which, as the 'established Church' is in turn, in a 'relation of complementarity' with the legal system. These were the people who defined and decided what would be considered as 'truth' on this subject matter. Here then is an example of practices of 'governance' in action, power relations revealed, Saunders 'structuring the field of possible action', 'attempting to direct, with a certain degree of deliberation and calculation, the conduct of others for a foreseeable future (Dean, 2006:40). The battle lines had been drawn between pro euthanasiasts and hospice proponents. In addition, the latter would be able to call upon the 'doctrine of double effect' (and they do) to justify practices that might be construed otherwise.

The material discussed in chapters seven and eight I call hospices' 'dark side' – its 'shadow' (Bleakley, 1986) because it represents unsavoury practices that tend to be 'glossed over', played down or ignored in the vast literature that comprises the 'grand narrative' of second and third wave hospice. The term

'shadow' seems apt in light of hospices' penchant for psychological theories that are derivatives of the Jungian school that Kubler-Ross was so enamoured with providing, as it did, a means with which to use the 'masters' tools' to challenge the masters' voice (Parker, 2002: 59). There is, in my view a hospice mentality, aside from chronic niceness syndrome, a way of looking at the world. A mentality or in Durkheim's terms 'collective consciousness' might be described as a 'community of ideas' (Cited in Zetlin, 1968: 236) or 'a condition of forms of thought and is thus not readily amenable to be comprehended from within its own perspective' (Dean, 2006: 16). Hospices violated their own ethic (Churchill, 1985) and not, I speculate, solely in this locality, but through a 'collective mentality', within the hospice movement as a 'community of practice' (Wenger, 2007), or 'knowledge community' (Henry and Pinch, 2000, Lave and Wenger, 1991); i.e. the bodies of knowledge, belief and opinion in which we are immersed 'not readily examined by those who inhabit it' (Dean, 2006: 16). Hospice practitioners were borne along by waves of thought emanating from Kubler-Ross – that remained unexamined - through which 'the collective mentality' emerged and in this locality ended up drifting into unethical practices. In this study setting those who dared to examine 'bodies of knowledge' or 'received opinion' and who committed the ultimate crime of 'speaking up' were viewed as a threat; they were construed as 'dangerous' – a threat to the collective mentality - and were subsequently either 'elbowed out', forced out, or marginalised in such a way that they had no choice but to resign.

9.5 My Perspective Reviewed

The impetus for undertaking this study in the chosen manner stemmed from employment at these hospices and the topic of sedation which was drawn to my

attention shortly after I commenced in post. A newly appointed senior clinical practitioner (i.e. commenced six months prior to my arrival) found prescribing practices problematic and approached me to discuss their concerns. What I did not realise at the time was how 'taken-for-granted' and thus 'normal' such practices were to most clinical staff in these hospices which, in retrospect, explains why staff were seemingly reluctant to heed the person who raised it as a 'concern'. They were constructed as 'other' – 'matter out of place' – (Miller, 1997) - a 'dangerous' individual whose voice was 'silenced'. Reason enough for them to seek my advice as a new 'uncontaminated' senior staff member. This 'normality' was incomprehensible to the concerned practitioner who eventually resigned rather than collude daily with what they considered unethical.

I had worked alongside senior NHS practitioners for a number of years and was familiar with clinical governance systems that at least prevented 'rogue' practitioners from 'doing their own thing'. Such structures were non-existent at these hospices evidencing their organizational underdevelopment at the time. It was as though staff were 'playing at' being professionals, and because the hospices lacked systems or expertise to deal with crises, relationships became adversarial when things went wrong. This meant that some employees became 'scapegoats' whose disappearance would solve (or so it was perceived) what were in fact, structural deficiencies. What this unfolding episode did was to alert me to the incongruence between hospices' public face and 'inside secrets' and thus to my decision to continue observing covertly (Goffman, 1959:142).

As I noted in chapter one, Marshall and Bleakley ask 'in a team setting, how is an "atmosphere" or "climate" initiated, distributed, maintained, resisted and felt collaboratively'? (2008: 33). In this setting the 'atmosphere' in keeping with the 'grand narrative' was one of patriarchal (even matriarchal depending on

one's point of view) homeliness (to a point) with a small number of people in positions of 'authority *and* power' (authority does not necessarily imply power). This 'atmosphere' was 'maintained' by hierarchical bullying but 'felt collaboratively' as '*being loyal*' by not rocking the boat and accepting '*that's how its done here*' because some people who were offered jobs in a hospice perceived themselves to be '*privileged*' (Pat). [I was not one such individual!].

My period of employment at the hospices was situated neither in the 'old' discourse of second wave hospice nor in the 'new' one of 'third wave' - palliation; it straddled both, whereby 'old' discursive practices had not been relinquished nor had the 'new' ones been completely re-formulated. This is evident in the sometimes contradictory nature of practitioner accounts which offer us a window through which to observe change as it occurred. This five year period heralded enormous change for these hospices as they were catapulted into the 21st century for a number of reasons. Despite having the hallmarks of palliative care i.e. consultants, medical and nursing director, these hospices were late developers to palliation and only from approximately late 2003 as 'specialist palliative care providers'. However, as models of hospice during its 'second wave' period when the focus *was* on care of the *dying* - because they were '*stuck in the past*' they were exemplars - offering many insights into 'what happens' (Seale, 1989) in hospices as well as how the goals of second wave 'grand narrative' were translated in practice. If one is earnest about wanting to know *what happens* in hospices then the practices highlighted in this study (some unsavoury or unpalatable) are 'an integral part of the strategies' that 'underlie and permeate' hospice discourses (Foucault, 1998). I have highlighted the underbelly of hospice, its 'dark side' - its 'shadow', (Bleakley, 1984:3) what Foucault would call 'the dark twins' (1998:59) which remains unacknowledged in the literature.

As to my moral justification for 'spilling the beans' – 'nothing is so sad as silence' (Leo Black, President of Reichsvertretung der deutschen, 1933-43 cited in Bauman, 1993).

'Discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling block, a point of resistance and a starting point for an opposing strategy' (Foucault, 1998:101). Considering the influence of Kubler-Ross' work on hospice practice for at least 25 years (Chaban, 2000) longer in this study setting; it is necessary to ask a question of hospice in Britain, 'to what extent can hospice measure any success if its theoretical foundation and quality of critical thinking is based on a false theory and a false history?' (Chaban, 2000: 343).

How credible are its safeguards if it allows questionable scholarship, research, and clinical practices to have prevailed? Who evaluated Kubler-Ross's research claims and demanded accountability for her claims, for the sake of the dying? (Chaban, 2000: 343).

A second question also needs to be asked, to what extent can we regard current 'professionals' in hospice and palliative care as thanatological experts - who were 'users of a theory' without 'examining the underlying research methodology' (Chaban, 2000: 344). Yet, Kubler-Ross's books continue to be advertised on palliative care sites, e.g. <http://www.pallcare.co.uk> ; *Living with Death and Dying* was reprinted in June 2008 within which the 'stages' remain paramount so we have not managed thus far to 'bury the staging theory' as proposed by Fitchett cited in Chaban, 2000:349).

This thesis might be viewed as 'a point of resistance' to the 'grand narrative' of hospice and palliative care. By undertaking this study in the chosen manner I have been able to form a 'reverse' discourse about hospice thus offering the reader a glimpse through the cloak of secrecy that hospices in one locality

wrapped around their practices; using the 'same vocabulary and categories' that hospice proponents use in order to make the 'familiar' seem 'strange' (Marshall and Bleakley, 2008). In this way I was able to highlight matters (as Bauman succinctly put it in his study of the Holocaust) we

prefer to leave unspoken' and explore the 'mechanisms that allow for the co-operation of victims in their own victimization and those which, contrary to the vaunted and moralizing effects of the civilizing process, condition a progressively dehumanizing impact of coercive authority (Bauman, 1993:xiii).

And, make no mistake some recipients of care in these hospices were 'victims'. After all, the dead can't noise abroad and if hospices proponents are to speak of 'rights' then individuals (and nowadays the taxpayer) who generously give of their time and finance have a 'right' to know if their effort is being spent prudently and not wasted 'sealing the lips' of those who might alert them otherwise. As I noted at the outset, my purpose has been to 'disrupt' the 'self evidence' and 'naturalness' of the dominant statements that hospices make about their activities, not to 'discredit' them but so that others can use my findings to consider how they might be 'viewed differently' (Foucault, 1991).

9.6 Speculations About the Future and Policy Implications

The dissemination of the philosophy of terminal care has led to others having adapted the initial ideals and grafted them onto already existing organizations and traditions (James and Field, 1992 cited in Biswas, 1993:136)

Although I dispute this, an appropriate question might then be is it reasonable to expect the British taxpayer to finance 'bricks and mortar units' called hospice, most of which can only accommodate a tiny number of patients?

Government financial support for the independent hospices has been roughly doubling each year through the early 1990s. . . . the allocation

for 1993-4 was announced at £43 million, representing a five fold increase since 1990' (Clark, 1993:7).

A survey undertaken by the National Council for Palliative Care in 2006 indicated that approximately 60% of hospices are experiencing a decrease in the value of the funding contribution from the NHS and concluded that 'in competition with other health care activity, palliative care is slipping down the priorities for PCT commissioners'. Perhaps that explains why in this locality the nursing director has feet in both camps? More recent policy initiatives are shifting focus away from in-patient care in *any* setting towards 'home care'. As a result many hospices are developing home care teams but home care services are also provided by the health and social care sector. Meanwhile the problem of funding hospices 'bricks and mortar' units still remain but they should be viewed in light of the following:

1. Hospices only ever served the interests of a tiny minority of patients many of whom, I argue, occupy the more privileged positions in the social hierarchy. As Kessler et al's recent study illustrates, 'cancer patients from social class V were less likely than others to die in the hospice (2005: 105).

Too often hospices appear as white, middle class Christian institutions serving a carefully selected group of patients, which the 'odour of goodness' (Smith, 1984) surrounding them cannot fail to disguise (Clark, 1993:15).

In its current form even *if* social class and disease barriers dissolved, hospices still only accommodate a tiny minority of patients - '4%' of those dying at any one time (Field and James, 1993) – that is, if one can get into a hospice to die. Hospices are making increasing demands on the public purse, yet most people will never be able to access hospice services or indeed even need to (Doyle, 1997, 2006).

2. Despite *seeming* to merge with mainstream services, as I have illustrated hospices are determined to maintain their 'independence' and there is inadequate external scrutiny of hospice practices.
3. Despite claiming to offer 'specialist palliative care'; apart from doctors who do undergo 'specialist' training, practitioners in this locality merely appropriated the title without any additional training, relevant experience or qualifications. If this situation is widespread, patients would be more safely cared for in the NHS.
4. These units claim to offer specialist palliative care, which is not disease specific. Yet there remains an overemphasis on patients with cancer despite claims to the contrary. This echoes Thomas's (2006) and Doyle's (2006) observation of other units. The hospices in this study setting became as busy as any NHS unit and, in my view, function as 'laboratories' for experimenting with new 'technologies' for palliating symptoms (Foucault, 1991, Rose, 1999). There is no time for 'talk' about dying since there is a limit to how long patients can remain.
5. Despite Field and James' (1992) assertion to the contrary, how successful have hospices *really* been in their goal to 'raise standards generally' through 'teaching and research' (Saunders, 1965) since there continues to be concern about the care of dying patients in contemporary society? (Edmonds and Rogers, 2003) More recently;

Health professional's behaviour towards people who are dying and their attitudes to death and dying need to change'. Further, 'research is needed into the development and evaluation of new approaches to the clinical assessment of need for palliative care in the context of uncertain prognosis in a range of diseases (Royal College of Physicians : 2007: ix & xiv).

What does this say about hospice's position on the social landscape for the last forty years? What does this tell us about hospice's claim to provide 'specialist

palliative care' for the last twenty years? Not forgetting 'scarcity' of research on ethical issues mentioned by Hermensen and ten Have (2001) and 'lack or absence of research on cost effectiveness (Randal and Downie 2006). In current parlance, it would appear that hospices are not 'good value for money'.

6. Hospices have now adopted a business culture and apart from nice material surroundings offer nothing that is not already available in the NHS. This represents a vastly expensive duplication of services.

7. Under current 'end of life' policy initiatives, dying patients (irrespective of disease) are now encouraged to remain in their own homes supported by 'reductionist' 'tick-box tools' e.g. The Liverpool Care Pathway (Ellershaw, 2002); developed by hospice practitioners and conceptualised as 'best practice' (whose 'expertise' derived from patients in the terminal stage of cancer – that has a specific trajectory - underpinned by a 'false' theory). This is complemented by the Gold Standards Framework which acts as a guide for care of the dying in the community because that is where most people want to die – in their own homes (Thomas, 2005, 2007, Storey, 2007) – seemingly. This illustrates how 'techniques' perfected in one arena 'spread' to colonise other areas (Rose, 1999). Despite recent claims by the Work and Pensions Select Committee that the country saves £876 billion per year through the work of unpaid carers (Skills for Health Bulletin, Sept 1st 2008), this 'end of life' policy neglects to consider the massive demographic shift during the last forty years;

Smaller families and the fragmentation of the family unit due to increased social and geographical mobility of its members, coupled with increased involvement of women in the labour market, have had the effect of causing 'a progressive reduction in the availability of unpaid lay carer's able to look after a dying patient at home (Field and James, 1993:7 cited in Lawton 2000:9).

No amount of 'hospice at home' staff will be able to compensate for this deficit in 'informal' and 'unpaid' care the pool of which is shrinking considerably year on year. Viewing the current healthcare climate sociologically, I speculate that contemporary hospital practice of maintaining league tables, propelled by macro policies that urge hospitals to reduce their mortality statistics, do so in order to create a favourable image (much like their ancestors in the nineteenth century), i.e. people who are dying are discharged home so that their death will not be included in a hospital's mortality statistics. This evidences the privatization of dying and the sequestration of dying patients in their own homes. A situation unlikely to be conducive in assisting professionals to 'change their attitudes' (RCP, 2007) since a vast number of those who will be providing this care will either be, 'unpaid' (e.g. relatives) or underpaid, poorly trained 'carers' working for the private sector (being commissioned by health and social care) while 'expert' professionals such as those offering specialist palliative care will only be required to administer drugs or undertake specific 'advisory' 'tasks' to 10% of the totality (Doyle, 1997).

8. Finally, in contemporary society where pluralities of views prevail, debates about euthanasia and physician assisted suicide continues. Should there be only one morally correct way to achieve a 'good death' and if so, whose moral perspective is to acquire the 'status of truth'?

9.7 Concluding Thoughts

This thesis will provide a distinctive contribution to both the sociology of health and the literature produced by proponents of hospice and palliative care. By adopting a critical approach to the philosophy of hospice and subsequently

palliative care I have been able to give voice to what, up until now has been

‘unsayable’ as well as challenge assumptions that were taken-for-granted.

Our unspoken assumptions . . . may well have the force of revelation. However, when these assumptions are spoken, the revelation may well be of how blind we have become (Roy, 2006: vi).

The assumptions enshrined in a philosophy of palliative care may well – if they are *both* unquestioned and unexamined *and* persistently repeated and amplified – blind us to what we should not be doing, and are continuing to do; may blind us also to what we should be doing, and are failing to do (Roy, 2006: vi).

As I noted at the beginning of this thesis, if the philosophy of palliative care is flawed this is because it is a direct descendent of the philosophy of ‘second wave’ hospice, which, despite being well intentioned was inherently flawed. Randall and Downie (2006) advocate a ‘return’ to the simpler ideas expressed in this philosophy, but should it be abandoned? For instance, aside from nebulous terms such a philosophy incorporates e.g. quality of life; the patient *and* family are the declared unit of care. Therefore, if the patient’s autonomy is to be valorised, what then of families’ autonomous right to demand that their loved one be ‘eased out’ of their suffering or who insist the patient carry on with unnecessary ‘treatment’? This places an unrealistic burdens on medical and healthcare practitioners, burdens not evident in other healthcare practice or ‘specialties’ where the patient has primacy. A philosophy is merely a distraction as well as a source of confusion.

Many practitioners I encountered referred to changes that have, and continue to take place in the micro world that each hospice represents; with some lamenting the passing of ‘the good old days’ when hospices were supposedly nicer than they are now becoming. In chapter one I illustrated how a conception of patients as ‘individuals’ with ‘subjectivities’ – i.e. ‘holism’, emerged in the

mid twentieth century within which discourse individuals were viewed as 'autonomous' i.e. having the potential to become self-realizing and self-fulfilling drawing upon a 'new vocabulary of the emotions' backed by the authority of science, (Rose, 1999: 117). It was within this social milieu that the work and ideas of Kubler-Ross and Cicely Saunders found congruence. Mirroring fashionable ideas at this historical juncture, 'second wave' hospice represents an approach to dying that was highly individualised' whilst simultaneously 'highly managed' as were the individuals who worked in hospice (McNamara, 2001: 125).

For example, since the 1960s organisational management was 'based on a different image of the person'; work practices were 'transformed' in order to 'positively utilize the psychological energy of individuals' (Rose, 1999: 115 & 114). 'Lasting commitment could be obtained by fostering conditions that built intrinsic motivations, for when people feel that a task was inherently worthwhile they would commit themselves to it' (Rose, 1999: 116). The hospice movement drew upon this new 'pool of discursive resources' (Potter and Wetherell, 1987) to assist the creation of organisational structures that *seemingly* offered rewards through 'intrinsic motivation' using notions such as 'goals', 'vocation', 'homelike', 'family', and 'staff support'. Hospices endeavoured to 'work on the ego' of their employees in order to release their 'psychological strivings' so that 'adaptability, innovation, responsibility, and commitment could be channelled into organisational success (Rose, 1999: 113).

The best companies did not suppress what is non-rational in people, they used it. Their managers spontaneously drew on the holistic and intuitive qualities that psychologists had shown to comprise one-half of our brains. They reasoned by stories as much as by data, they solved problems by gut feeling in an innovative and creative way never possible through rational decision making structures. They allowed for the emotional, more primitive side of human nature (Rose, 1999: 116).

In this way those who were 'selected' to work in hospices came to view hospice as a 'privileged space' for 'the satisfaction' of their individual and 'social needs' as exemplified in the over-involvement of some employees in the affairs of patients in this locality (Rose, 1999: 119). Yet, when one examines these idyllic spaces that people want to return to, they turn out to be rather less fabulous than one might assume from the 'grand narrative' or rhetoric emanating from such places – illustrating, as Foucault proposed, how a certain kind of historical approach 'preserves us from that sort of ideology of the return' (1991:250).

The question still remains; should the aim be to provide the best possible service for a limited number of patients, and if so, how should this be financed? Or should there be a focus on, for example, 'excellent symptom control for everyone, even if this means there are insufficient resources left to deal with all the fears and anxieties which patients may be experiencing'? (Garrard, 1996:94). These days funds are not 'pouring in' to hospices with the speed of earlier years; they are, I propose, 'pouring out' on salaries for the many newly created posts and an ever expanding bureaucracy resulting in hospices incessant demands for an ever increasing share of the NHS budget to maintain their tastefully furnished ambience.

The development of 'home care teams' apart from duplicating existing services is merely the latest ruse to 'justify the continued existence' of the bricks and mortar units in much the same way that hospices jumped on the bandwagon of 'palliation' to 'justify their continued existence' (Armstrong, 1986). A Royal College of Physicians report in December 2007 noted that 'funding for palliative care services is unsatisfactory with the NHS contributing only about 30% of the costs of specialist palliative care' and that 'this reliance on the voluntary sector, and charitable funding, exacerbates inequalities and has led to poor planning and

overall integration of services'. What seems to have become obscured in this kind of posturing is that these (fabricated?) 'problems' stem precisely from the fact that hospices deliberately established themselves ad hoc *outside* of the NHS where the majority of care whether of the dying, palliative or specialist actually takes place. Indeed, hospices may be viewed as having exacerbated them.

The reader may recall concerns about the *unplanned proliferation* of hospices (Lunt and Hillier, 1981) highlighted in chapter two; e.g. in the decade 1977 – 1987 there was a 'huge mushrooming in the number of hospice services. . . in spite of the Working Party in 1986 saying, 'please, no more hospices', . . . (Doyle, 1997:3). Hospices then, were not established in response to need and were highly selective regarding the kinds of patients they 'choose' as recipients of their 'care' (Harris, 1990, O'Neil, 1989, Clark, 1993, Seale, 1989, Douglas, 1992). Therefore, hospices can be viewed as *creating* 'inequalities' and 'poor integration of services' as a result of the 'poor planning' of advocates.

Furthermore, and rather ironically considering their apparent financial 'plight', I consider hospices to be rather better off i.e. have more 'disposable income' than NHS counterparts providing the same service. Up and down the country hospice advocates are 'rebuilding' and 'refurbishing' those same 'bricks and mortar' units that 'sprang up' and 'mushroomed' in the 1970s and 1980s with some moving into completely new buildings. Many of these re-builds' and 'refurbishments' will have a higher ratio of single rooms and fewer multiple occupancy bays (a potentially fruitful area for future research). As I write, a hospice in another region received one hundred thousand pounds from the Department of Health to be spent by April of this year. They responded to this 'windfall' by *closing beds in order to replace flooring – for the third time in the*

past ten years (Adele, January 2008). Douglas, a doctor and novelist made some observations that still seem relevant:

For three decades it has traded successfully on voluntarism and the fear of dying badly. Its bluff is about to be called. It will take some time but the squeeze is on. There will be letters, petitions, and well bred squeals of protest. Royalty, if badly advised, will rally. But if good sense prevails a conspicuous aberration in British health care provision will be relegated to that of homoeopathy. And - more importantly - the 700,000 people who die each year in the arms of the National Health Service will be rather better served. . . . Why should only the minority who die of malignancies - and precious few even of them - be singled out for de-luxe dying? And why should a large and general need be left to the scanty and scandalously choosy efforts of a patchwork of local charities with one hand in the coffers of the NHS and the other in the church bazaar economy? The hospice movement - with all its paraphernalia of flower arrangers, charity balls, committee loads of duchesses and agreeable secluded little places to die amid leafy glades - no longer has a useful role. It is now a distraction from the main business of improving the everyday care of the ordinary dying. . . (Douglas, BMJ 1992:579).

'Good sense' obviously did not 'prevail' in the locality where this study was conducted. These hospices served as a '*hiding place for [some] incompetent or lazy practitioners*' and frittered away charitable and taxpayer finance in order to '*seal the lips*' of those who might 'spill the beans' on their dubious practices. In addition;

Hospice is often held out as an alternative to the need for assisted suicide. To date, those in the hospice movement have made any discussion of assistance off-limits on the grounds that proper palliative care can address the concerns about pain that the terminally ill face. But the movement towards assisted suicide raises questions about the future viability of the hospice movement in its current form. Many who seek assistance in dying are concerned, not about pain, but about suffering and loss of dignity. Many are not terminally ill but terrified at the prospect of disability and loss of cognitive capacities. Unless hospice addresses these concerns it is not likely to survive in the face of pressures to legalize assisted suicide (Caplan, 1997:17).

One of the 'complaints' made by 'second wave' hospice proponents about general hospitals concerned the way some dying patients 'lacked care in any significant sense having been so heavily drugged they remained unconscious or semi-conscious until death' (Du Boulay 1985: 1). How ironic that the same complaint can now be levelled at the hospices where this study was carried out, where patients were turned into 'docile' (Lawton, 2000) '*uncomplaining residue*' (Wiseman and Hackett, 1962 cited in Saunders 1978: 3) where they could 'hardly be involved in any decision while . . . swamped in treatment' (Saunders 1978:3). Contrary to the 'grand narrative', these hospices did sedate patients to 'oblivion'. Is it possible this practice was routine throughout the hospice movement? If not, why would Hargreaves, a palliative consultant make the following comment when making the case for the 'use of autopsies in palliative care in certain situations'; 'maybe we have become too used to our death rates in hospices – in these post-Shipman days, however, perhaps more questions will be asked as it may be all too easy for us to 'bury' our mistakes' (2005:503). If sedation *was* common in the days when hospices cared solely for 'dying' patients, this smacks of hypocrisy since it would suggest that practitioners offered a 'speedy exit' (with or without consent) to a tiny minority of certain social position – part of the 'de-luxe' package perhaps? (Douglas, 1992) - while for the rest of the population honest discussion about euthanasia and physician assisted suicide are 'off limits' (Caplan, 1997). 'If hospice is going to criticize, it must begin by being critical of itself' (Chaban, 2000: 323).

Saunders said that 'if you have a microscope on a very limited area, you may, in fact, get the truth, but you've got to look and see if this is your own bias, or whether it is supported by other evidence' (cited in Du Boulay 1984: 83). Although not searching for 'truth' but that which was *considered* true, I trust I

have provided the reader with sufficient evidence to support the claims I have made in this thesis which, in the final analysis, is a 'counter narrative' (Petersen, 2003) to the 'grand narrative' of hospice and palliative care that I am convinced will have 'resonance' (Baxter and Eyles, 1997: 180) for many in the healthcare arena.

If patients cannot die in their own way with the help of a hospice, it is highly unlikely that they will be able to do it anywhere else. Any problems faced by hospices are likely to be faced *a fortiori* by other organisations. . . .Hospices have set themselves up as a social experiment onto which the eyes of researchers and the public are invited (Walter, 1994: 88).

But in these 'Laura Ashley' (Walter, 1994) 'enclosures' (Foucault, 1991) common courtesy dictates that one should telephone first - to 'warn' of their arrival thus ensuring the 'mask' of 'impression management' is firmly in position (Goffman, 1959) - (those of appropriate disposition would automatically know about such matters). Hospice, it would seem, served as a laboratory that could be 'used as a machine to carry out experiments, to alter behaviour, to train or correct individuals. To experiment with medicines and monitor their effects' (Foucault, 1991: 203). Finally, bearing in mind the 'privatization' of dying noted in this thesis, Bradshaw's observation is rather apt;

We may be in danger that care for the dying will become again a kind of macabre play in which the patient is 'jollied' along until the final curtain falls. In which case, the effect of the hospice movement will have been to make the play a more elaborate one (Bradshaw 1996: 418).

A play, I contend, that will have an increasingly small audience as people are persuaded to remain at home to die, solely for the purpose of 'cost containment' and not, as asserted in the literature because that is 'where most people would like to die' (Storey, 2007, Thomas, 2005, 2007) where, like their workhouse ancestors in the 1800s they will be 'out of sight and out of mind' (Manning, 1984).

9.8 ENDNOTE

As a result of my engagement with practitioners throughout the hospice movement, I am convinced that many of the matters highlighted in this thesis will have 'resonance' (Baxter and Elyes, 1997) for practitioners in other hospice settings or those who may have worked in hospices in the past and that is why I include the account below; one of many I recorded. This may assist the reader 'to evaluate the status of the researchers generalizations' (Payne and Payne and Williams, 2005: 305).

Certainly if the general public were to know the truth about what 'went on' and I am assured still 'goes on' at the hospice where I was employed, then things would be quite different and I am sure the financial generosity upon which it depends would diminish and the lawyers would have a field day. Hence my decision to do what I did when faced with the reality of my being a hospice nurse and that was to leave. In terms of damage limitation it was the easiest option and before doing so, I expressed my concerns with the hospice director, minister, social workers and the matron, I did not leave easily, nor quietly, but I know in spite of my warning shot fired across their bows, the hospice will continue to operate as it always has done, safe in the knowledge of its arrogant, deluded, self-appointed superiority and justification of its work. Evidenced by the fact there is no where else for people who need its services to go and because people like me just do not have the stomach to go public and be 'scapegoated', whatever the legal provisions for doing so. Thus I can pin my colours to the mast of professional cowardice and only hope that one day the truth will out and God help the person that does it.

(Kira).

Appendix 1

Recommendations for Reform

1. 'Bricks and mortar' hospices privatize and charge for their services instead of relying on taxpayer's money and 'fundraising'. There is enormous waste in the current fashion for creating massive fundraising departments and paying high salaries to those employed within them. This would make little difference to the kind of patient hospices seek to attract.

2. Hospices become totally incorporated into the NHS, join the queue for resources and undergo the same level of scrutiny. Hospice buildings could be sold and the resulting money ploughed into service provision for the growing ageing population and care of the *dying* in local community hospitals which are currently underused. Hospice staff could apply for suitable positions in the NHS based on their qualifications and 'volunteer' fundraisers encouraged to use their skills for more egalitarian purposes. Alternatively, hospice buildings could be donated to society to provide 'delightful' surrounding for the frail elderly who have no relatives in the final years of their life.

3. If the 'unit of care' as currently defined in *The Oxford Textbook of Palliative Medicine* (2006) – a meta narrative - is to be both patient *and* family, irrespective of the setting within which it is to occur, this should be complemented by thorough and comprehensive education of the population at large so that they understand the decisions they make in the name of patient comfort. Similarly, health professionals need to be educated about the ethical dilemmas that arise as a result of this configuration. Preferably this notion should be abandoned as it is out of sync with other healthcare practice.

4. Abolish the conflation of palliative care / specialist palliative care with cancer care. Better still, abandon the terms 'generic' palliative care and 'specialist' palliative care as they only add to confusion regarding which patient population is to be served by either. They also prevent practitioners from making decisions about 'stopping' treatment 'which would only be a useless disturbance of peace' (Saunders, 1965:2).

5. Current use of the term 'end of life' care denies the reality of death and refers roughly to the last year of life but in some diseases it is difficult if not impossible to determine *when* organ failure *will* occur. For example, 'clinicians must recognise that end-of-life care does not mean that someone is going to die imminently but that the approach to care should change' (RCP, 2007). What is wrong with 'care of the dying patient'? – it is usually fairly obvious when patients enter the '*last phase*' of life i.e. are *actually* dying or that organ failure *has* occurred - the *raison d'être* for establishing hospice.

6. Many hospices are developing home care teams – an unnecessary duplication of services. Furthermore, home care deserves serious consideration and re-evaluation since the potential for abuse is greater than in an institution because most care is undertaken by lone workers. Someone with less than honourable intent could give doses of drugs which, after the event would be very difficult to challenge. Therefore, palliative care as currently practised is open to real abuse.

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