Routine sedation: towards a normative understanding of sedation in palliative care

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Dedication

This thesis is dedicated to my father Mike, whose optimism, resilience, perseverance and faith has been inspirational, and without which this thesis would not have been completed.

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Abstract

This thesis explores the practice of sedation in hospice palliative care. Internationally this has been a controversial subject for over 20 years, with the use of sedation considered to be on a spectrum between euthanasia and symptom control at the end of life. This is a complex area of study, incorporating not only technical details regarding drugs and doses, but also relating to underlying values regarding end of life care. In the UK end of life care has developed from the 'hospice movement' of the 1960s, into the broad and far reaching approach of palliative care. Alongside this development, palliative care has espoused its own 'ethos' and values, evident in much of the literature in this area.

This thesis presents the data from an ethnographic study in a UK hospice. The aim of the study was to develop a normative understanding of the use of sedation in hospice palliative care. The ethnography allowed an in depth understanding of this practice through prolonged immersion in the field of study. This enabled the practice of sedation to be understood as a process, or series of decisions, based upon a tacit understanding of a patient's proximity to death. This was driven by the desire of hospice staff to bring about a comfortable and peaceful death, which was in turn motivated by the underpinning values, of the individual, the organisation, and of the approach of palliative care.

This thesis has important implications for the future: for the specific use of sedative drugs in hospice palliative care, as well as for the broader issues in palliative care concerning decision-making at the end of life. A new definition for sedation at the end of life is constructed, relating particularly to, as it is derived from, the practice and underpinning values of hospice palliative care in the UK. Furthermore, as the evolving and changing nature of UK palliative care is considered, the capacity for hospice palliative care to enable the expression of different values, which manifest as a result of the changes in palliative care, represents a challenge to one of the core principles of the approach; patient centred care. This thesis introduces and considers values based practice as an approach which may facilitate the identification of values in decision-making, and reorientate care towards a more 'patient-values-centred' approach.

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Chapter 1 Introduction

This chapter provides the context for the thesis, based on research conducted in a hospice in the UK. Interpretation of this study requires an understanding of the context of palliative care which in turn requires an understanding of its history and development. As this thesis explores both a practice and its underlying philosophy, the context provided in this chapter will provide an important reference point as themes emerge especially in Chapters 5, 6 and 7. The underlying values of palliative care are highlighted particularly, as they are seen in Chapter 7 to have a fundamental influence on current clinical practice of sedation at the end of life.

In this chapter I first consider the historical background to the current practice of palliative care, originating in the modern hospice movement of the 1960s. Second, I consider developments in two specific areas which have contributed towards the reintegration of care of the dying into mainstream medicine. These are: the broadening scope of palliative care provision and the changes in funding of palliative care services. These areas of change have an important bearing on how palliative care is understood and how its underpinning 'philosophy' is interpreted. Changes in the conception of dying and death, and particularly the nature of a 'good death' have been extensively discussed in the literature from a range of perspectives: a brief overview, as it relates to the study and impacts on palliative care, is provided next. An important debate took place in the early 1990s related to the changes in the relatively new field of 'palliative care' and to the introduction of the new medical specialty of palliative medicine: the routinization of the hospices and the medicalization of death are briefly discussed in order to set the context for subsequent developments. These debates concerned primarily the impact of mainstream medicine approaches on the hospice movement and dying: in the final section of this chapter I consider the impact of the reintegration of dying, and palliative care, into mainstream medicine. I focus especially on the philosophy of palliative care and I suggest that rather than being in a state of opposition to mainstream medicine, as commentators have suggested (Randall and Downie, 2006: 6, ten Have and Clark, 2002: 203), the central features of the palliative care philosophy have become integrated into those of mainstream medicine. In turn the approach of mainstream medicine has changed over the past 50 years from that which traditionally prized objectivity and a scientific model of care, into a more holistic approach in which

patient's opinions and values are more readily considered (Evans, 2008). Changes in both mainstream medicine and in palliative care have created a more integrated service, both in practice and philosophy. In the context of increasing integration of palliative care into mainstream medicine the role of the underpinning philosophies of these services on the care of the patient is explored. Palliative care has forged a remarkable transition from an approach to care of the dying patient which was deliberately removed from the mainstream medicine of the NHS in the 1960s, to an increasingly integrated set of practices and philosophy in 2012. This chapter will enable an appreciation of the context of the thesis, in a UK hospice in the early 21st century.

1.1   Terminology

The evolution of the modern hospice movement has been extensively considered: it is recognised to have originated with Cicely Saunders in the 1950s, and became embodied in the first modern hospice, St Christopher's hospice, in 1967 (Clark, 1998b). A detailed consideration of this evolution, from the conception of a place of care for the dying to modern day palliative care is found in particular in the many books and papers authored and edited by David Clark (Clark, 1993a, Clark, 1998a, Clark, 1998b, Clark, 1999b, Clark, 1999a, Clark, 2002, Clark, 2005, Clark, 2006, Clark et al., 1997, Clark and Seymour, 1999). The historical context of modern palliative care is important to understand, in part because its development is so recent but also because palliative care is still evolving and changing, especially in its relationship to the NHS. When considering the context of the thesis, therefore, this background and relationship must be recognised. This section will provide an overview of the relevant historical background to this study, rather than a comprehensive review which can be found elsewhere (Clark, 1993a, Clark, 1993b, Clark, 1998a, Clark, 1998b, Clark, 1999a, Clark, 1999b, Clark, 2002, Clark, 2005, Clark and Seymour, 1999, Hockley, 1997). First, however, it is important to clarify the terms which will be used in this thesis: a brief history of terminology is required.

Following the opening of St Christopher's hospice in 1967, interest in the principles it espoused developed, and several new hospices opened and adopted a similar approach. This developed into what became known as the hospice movement, incorporating the principles which had their origins in Saunders's St Christopher's Hospice. The type of care which was provided by the hospices was widely referred to as 'terminal care' and

the majority of patients cared for in the modern hospices were indeed dying and in the 'terminal' phases of life. In the 1970s Balfour Mount opened the first hospital based 'palliative care unit' in Canada; this was the first use of the term 'palliative care' (ten Have and Clark, 2002: 30). Over the following years the term 'palliative care' was gradually introduced and incorporated into the evolving approach to terminal care in the UK. The term 'palliative care' steadily became adopted in preference to 'hospice care', which seemed incongruous as a term for use in the hospital setting (ibid). Furthermore, as the care being provided was extended to beyond the care for those who were imminently dying, use of the term 'palliative care' was soon to replace 'terminal care'. This was not without debate and critical evaluation, however, as not only did this introduce a change in terms, it also marked a period of transition from hospices providing solely terminal care, to the provision of care to patients earlier in their illnesses, a move which was not uncontested (Biswas, 1993). This will be discussed in later in this chapter.   The move from terminal to palliative care also marked a move away from descriptive terminology to more euphemistic terms; this is acknowledged by Doyle as he describes the more recent turn towards use of the phrase 'end of life care' (Doyle, 2010: xxi). In his foreword to the fourth edition of the Oxford textbook of Palliative Medicine (OTPM) Doyle ultimately suggests that:

> palliative care is care for those at the end of life and embraces terminal and supportive care (ibid).

While these terms are not further defined, Doyle suggests that it is the principles which underpin the practices contained within palliative care which are of 'universal relevance' (ibid). Current 'palliative care' may be considered as both a philosophy and a series of practices delivered by palliative care specialists (Clark and Seymour, 1999: 86, Doyle, 2010: xxi). A full exploration of the definitions and scope of palliative care is beyond the remit of this thesis: it is important to recognise, however, that while the terms and definitions for palliative and terminal care have evolved over the past sixty years a precise definition remains elusive. For the purposes of clarity in this chapter where possible I use the terms consistent with the time to which I am referring. I interpret 'palliative care' as an umbrella term which incorporates a series of practices which form specialist palliative care services, as well as incorporating a set of principles, or philosophy, shared by both specialist and non-specialist services.

1.2 History

The term 'hospice' dates back to mediaeval times (Clark and Seymour, 1999: 65) and was understood to refer to a place of transition for a wide range of different people. There was little sense of conformity about these hospices and indeed they were described by Saunders as providing rest for an: 'impossible mix of patients alongside travellers and pilgrims, orphans, and the destitute with varying degrees of segregation' (Saunders, 2004a: xviii). While some trace modern hospices directly back to these mediaeval shelters, others extract only the concepts of being places of journeying and pilgrimage, as linking the mediaeval and modern hospices (Clark and Seymour, 1999: 66). Certainly hospices solely for the dying did not exist before the nineteenth century (Saunders, 2004a: xviii). In the mid to late nineteenth century hospices opened in Dublin, Australia and London, from religious and philanthropic origins (Clark and Seymour, 1999: 68). Alongside homes for the dying and nursing homes, there were many institutions providing terminal care (Clark and Seymour, 1999, Clark, 1999b). These institutions, however, undertook a wide range of different practices and employed staff of varying degrees of nursing training. This was brought to light by Glyn-Hughes in a report published in 1960 (Clark, 1999b). In this he described the paucity of medical care for the dying and emphasised that while such institutions were not lacking in care and attention for patients, they were significantly lacking in medical input and intervention. Many had few or no trained nurses and relied upon nuns or volunteers to provide basic care to dying patients (ibid). Glyn-Hughes highlighted the need for 'skilled terminal care' and argued that this would require in-patient beds which would differ from those in hospitals providing acute care (ibid). An earlier report in 1950, conducted by the Joint National Cancer Survey Committee, had been commissioned by the recently formed Marie Curie Foundation and the Queens Institute of District Nursing. They found conditions for patients dying of cancer in their homes to be poor, with uncontrolled symptoms, inadequate living conditions and limited access to treatment (ibid). In a period when the National Health Service (NHS) had recently been established and in which there was a focus on acute care and rehabilitation, the care of the dying was neglected. From the eighteenth century age of enlightenment had developed a positivist, scientific approach to medicine which was imbued within the newly formed NHS (Hodgkin, 1996). The focus on diagnosis and treatment of diseases rather than on the treatment of an individual patient and their symptoms had changed

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and was embraced in this new, publically funded, NHS (Clark, 1999b). Charitable funding for care, the mainstay of provision for preceding centuries, was rejected in this model of care which prized objectivity and focused on specific treatments for diseases rather than on symptoms. This was endorsed by those working within the new NHS and supported by the government of the time (ibid). Indeed a preference for the efficiency and objectivity of the scientific method was evident in the statement of the health secretary, Aneurin Bevin, to parliament in 1950. He said he would:

> rather be kept alive in the efficient if cold altruism of a large hospital than expire in a gush of warm sympathy in a small one (Saunders, 2003: 263).

It was in this context that Cicely Saunders, as an almoner, encountered David Tasma, a Polish man who was dying on a busy surgical ward. Appalled by the conditions and the lack of attention he received, she discussed with him the idea of creating a place more like a home for the dying. She was later encouraged by a gift of £500 which he left after his death to be 'a window in your home': thus she began her journey towards the opening of the first modern hospice (Clark, 2006: xiv). During the time in which Saunders developed and saw to fruition her plans for St Christopher's hospice, she developed her vision of a place in which the terminally ill could die in a place of comfort and peace, with their symptoms controlled. She was heavily influenced by her work at St Joseph's hospice in London, which was one of few hospices at the time providing medical care at the end of life (Clark, 2006: xv). Skills in caring for the terminally ill were developed by Saunders and likeminded pioneers over the following years and St Christopher's hospice opened as the first modern hospice which would fulfil the vision for terminal care which Saunders had developed for over a decade (Clark, 1998b). During this period Saunders made important choices about the way in which the first hospice would be run. Initially conceived of as a single place of care for the terminally ill, with a strong Christian focus, Saunders changed in her thinking, towards a more secular hospice which would have the ability to reach and influence the care of more patients as they died. This was an important decision in the shaping of the hospice movement; while the provision of spiritual care would be seen to retain strong Christian roots, its lack of exclusivity allowed the initial hospices to be able to care for patients with any belief or none (Clark, 2005: 12). Furthermore, Saunders recognised St Christopher's Hospice to be 'the beginnings of help towards death' (Saunders, 2003:

265) and embraced and advocated the evolving nature of palliative care in its early years and its interpretation and extension into other settings (Saunders, 2003: 266). Saunders had always intended that the principles from which St Christopher's hospice was developed should be interpreted according to the requirements of the setting rather than adopted wholesale (Saunders, 1999: 247). This intention was realised over the following decades as hospice day care and community and hospital support teams were developed in different parts of the UK (Saunders, 1978b: 153, Saunders, 2004b).

1.3   Developing palliative care practice: towards reintegration

1.3.1   Broadening the scope

While the hospice movement began with the aim of improving end of life care for all patients, from early in its development there was a focus on patients dying with cancer (Clark, 1999b: 235). In the 1960s care for the dying gained attention from a number of sources; a division was marked, however, between those who concentrated their efforts on care of the elderly and those who were more focused on particular diseases such as cancer (ibid). The latter group of patients were those who were readily identified as having pain and suffering, and for whom techniques for managing these symptoms could be developed. The 1960s saw an increase in publications based on research evidence of the management of the symptoms of malignant disease and it was in this area that Saunders and the early hospice pioneers developed particular expertise (ibid). Increasing research evidence for the control of symptoms in patients with advanced cancer led to marked improvements in services for this group of patients (Riley and Ross, 2005). Charitable organisations with a focus on developing services for patients with cancer became increasingly linked to the hospice movement and concern about neglected groups grew from relatively early stages in the development of hospice and terminal care (Clark and Seymour, 1999: 94). Saunders was acutely aware of the need for the extension of knowledge and expertise for managing symptoms at the end of life into wider areas of healthcare. Indeed in 1983 she stated:

> … terminal care should not be a facet of oncology, but of geriatric medicine, neurology, general practice and throughout medicine (Saunders and Baines, 1983: 2)

Several years earlier Saunders had welcomed the development of services for patients with many different illnesses in the new hospices which were opening in the 1970s. She referred to the 'mixed group of patients' in these institutions, with many caring for patients with non-malignant disease and conditions of a 'longer-term nature', emphasising her vision for communities of care as she wrote that 'a good community is usually a mixed one' (Saunders, 1978b: 153). Hinton's early work researching the symptoms of patients at the end of life found that both groups of patients experienced distressing symptoms in dying (Hinton, 1963): despite this, the emphasis of end of life care over the past 60 years has been overwhelmingly on patients with cancer. The perceived inequality of end of life care has been recognised for many years and has been increasingly contested (Bosanquet, 1997, Clark and Seymour, 1999: 96, Fallon and O'Leary, 2010: 1183, Ward, 2002). Palliative care has been recognised as an area of need in many non-malignant conditions and this is reflected in several National Service Frameworks (NSF) from heart failure to renal disease; furthermore it was considered a quality requirement for patients nearing the end of life with any long term condition in the NSF for long term conditions in 2005 (DH, 2000, DH, 2001, DH, 2005a, DH, 2005b, Riley and Ross, 2005, Traue and Ross, 2005). In 2008 the End of Life Care Strategy (EoLCS) explicitly stated the need to provide end of life care in an equitable manner for all those with a life limiting illness, with care provided on the basis of need, rather than diagnosis (DH, 2008: 33). An increase in published literature on the end of life needs of those with non-malignant diseases as well as on service developments from within and outwith palliative care has been seen over the past decade (Dharmasena and Forbes, 2001). There are still concerns, however, about developing the resources and the ability to provide equitable services for all (Fallon and O'Leary, 2010: 1183). The persistent question for palliative care is whether care for all patients at the end of life ought to be provided by palliative care specialists, or whether the principles of palliative care ought to be promoted for all non-cancer patients with care provided by the disease-specialists (ibid).

Over the past two decades there has been an increase in inter-disciplinary working, with service developments for patients with non-malignant conditions developing through joint working between palliative care teams and specialist renal, cardiology and respiratory teams in particular (Curtis, 2008, Gore et al., 2000, Gunda et al., 2005, Jaarsma et al., 2009, Murray et al., 2005). There has been an increase in integration of

palliative care into these mainstream services, driven to a large extent through national service frameworks, setting the standards and strategies for implementation and improvement of end of life care for all life limiting illnesses. Palliative care has developed and extended its sphere of influence, from an initial focus on cancer, to a need-based focus, for anyone with a life limiting illness. While this was the vision of the pioneers of the hospice movement, the focus on cancer allowed a wealth of knowledge to be generated concerning the management of symptoms at the end of life. In a foreword written for the first edition of *Care of the Dying* (Ellershaw and Wilkinson, 2003) in 2003, and republished in the second edition in 2011 (Ellershaw and Wilkinson, 2011), Saunders explicitly stated that:

> much of the now considerable knowledge base has come from the initial concentration on death from cancer but the time has now certainly come for its wider dissemination (Saunders, 2011: xii).

As palliative care has become part of the care for patients with non-malignant diseases and embedded into national frameworks and targets, further integration of services is likely. Palliative care is becoming more integral to the specialties of mainstream medicine as its role beyond care for patients with cancer is developed.

1.3.2 Funding

While the original hospices of the 1960s and 1970s were funded almost entirely from the charitable sector, gradually NHS funding grew. This was initially generated for specific projects but later NHS funding became more widely available across the spectrum of palliative care services (Clark and Seymour, 1999: 128). There was a rapid expansion of charitably-funded hospices and palliative care services across the UK in the 1970s, marking significant improvements in care for dying patients. By the time of the Wilkes report in 1980, commissioned to examine the state of service provision for patients with cancer, there had been such a growth in service provision that the report was able to suggest a more co-ordinated approach was required in subsequent developments (Clark and Seymour, 1999: 137, Parkes, 1981). They recommended the co-ordination of services and dissemination of the core principles of the hospice movement into other areas such as in hospital and community based teams, recommending an:

emphasis on coordination between the primary care sector, the hospital sector and the hospice movement (quoted in Clark and Seymour, 1999: 137).

Furthermore, in a move to reduce the rate of independent, un-coordinated hospice expansion, the National Society for Cancer Relief (NSCR, now Macmillan Cancer Support) ceased the provision of funding for new hospices built outwith NHS hospital grounds (Lawton, 2000: 17). As the NHS structure and funding changed throughout the 1980s and especially following the conservative reforms of the 1990s, hospices became more closely bound to the NHS and dependent on NHS contracts for funding (Clark and Seymour, 1999: 140). Following the recognition of the speciality of palliative medicine in 1987 and the formation of the National Council for Hospice and Palliative Care (NCHPC) in 1991, palliative care was in a position of unity and relative strength as it negotiated contracts and became thoroughly integrated into the NHS. Indeed, by 1995 only an estimated 3 per cent of palliative care services did not receive some funding from the NHS (Clark and Seymour, 1999: 142). An increase in funding for palliative care services was anticipated following the publication of the End of Life Care Strategy (EoLCS) in 2008 (NCPC, 2011). Despite the promise of an additional £286 million, however, the National Council for Palliative Care (NCPC) found that 35% of Primary Care Trusts which responded to their national survey were unable to identify the amount they had invested in end of life care between 2009 and 2010 (ibid). Local funding for services has certainly varied widely across the UK, with breadth such that in 2010/2011 one primary care trust invested £21 million in specialist palliative care services while another only £0.2 million (Hughes-Hallett et al., 2011; 20). An improved strategy for palliative care funding has been proposed as a result of an independent review which published its findings in 2011 (ibid). Having reviewed the current provision of care in England, the report found funding to be:

> overly complicated, difficult to navigate and not joined-up enough, leading to a lack of fairness and transparency for commissioners, providers and patients (ibid: 20).

A new, tariff-based system of funding is to be introduced, based upon a patient's need and determined by the complexity and level of intervention required for the patient (ibid). This will radically change palliative care funding and see it thoroughly

embedded within NHS funding streams: this lies in marked contrast to the entirely charity-dependent hospices of the 1960s and 1970s.

1.3.3 Current provision

Following the opening of St Christopher's hospice, other, similarly designed and operating hospices evolved: by 2011 there were 220 hospice and palliative care inpatient units, with 3175 specialist in-patient beds (Help-the-Hospices, 2011). A home care service was developed from St Christopher's Hospice in 1969; there are now 288 home care services across the UK, providing a palliative care service for patients in the community (ibid). There are a further 127 Hospice at Home services, providing more intensive and multi-disciplinary support for those dying at home. The first hospital-based team was developed at St Thomas's hospital in London in 1976 (Clark and Seymour, 1999: 75); since then the provision of hospital based care has expanded widely, with 343 hospital palliative care teams across the UK in 2011. Day care services originated in Sheffield at St Luke's hospice in 1975 (Saunders, 2004b: 281) and are now core services for many hospices, with 272 day care centres now in existence. These centres provide access to specialist palliative care services for symptom control but perhaps more importantly they aim to help patients to adjust to and plan for changes in their condition, as well as engaging in a range of therapeutic activities (Lawton, 2000: 23).

1.4 Good dying and death thesis

Palliative care developed as a direct response to the neglect of patients who were dying in hospitals in the 1950s and 1960s (Clark, 1998b, Clark and Seymour, 1999: 88). In contrast to the neglect of hospital dying and deaths, the hospice movement became associated with 'good dying and death' (Seymour, 2001: 19). A change in the societal approach to dying and death was recognised, with a move away from death as a collective experience shared in the community, to a more isolated death in hospitals (Clark and Seymour, 1999 : 89). In 1973 Aries detailed a history of dying from the middle ages to modern day and provided an account of dying which was once 'tamed', collective, and understood in society. This was in marked contrast to the 'dirty' and 'wild' dying of modern day, as he described:

the old attitude in which death was both familiar and near, evoking no great fear or awe, offers too marked a contrast to ours, where death is so frightful that we dare not utter its name (Aries, 1974: 13).

Many authors have similarly lamented the change from a community-based, collective and open process of dying and death, to a 'hidden', isolated experience which is inextricably linked to a medical presence (Illich, 1975, Elias, 1985, Field, 1994, Timmermans, 1998). Indeed since the 1970s there has been a growing concern about medical intervention and 'hospitalized' dying, characterized by social isolation and fear (Elias, 1985, Seymour, 2001: 19). Illich wrote of the impact of medicalization on the whole of society, leading to an inability to cope with loss, suffering and death. A powerful response to these 'bad' deaths was found in hospice care and the hospice movement. As previously stated, Cicely Saunders's focus on establishing the principles of care for the dying outwith the NHS was explicit. She expressed the need to re-establish attitudes and values in this sphere, and was deliberate in creating a 'community' within, and in the immediate vicinity of, St Christopher's hospice (Saunders, 1978a: 153). Concern arising from the 'medicalization' of dying in hospitals was the stimulus for the hospice movement; ironically, as we shall see later in this chapter, concern about the medicalization of dying in hospices was to become a later debate.

Beyond the changes in context and nature of dying described above, the good dying and death thesis also developed a stronger emphasis on the individual's experience of dying. This focus on the individual has been considered as a postmodern phenomenon, arising in contrast to the prevailing modernist approach of mainstream medicine (Philip, 2010: 104). Many conceptions of good dying and death have been explored in the literature and common themes considered as contributing to these constructs are: awareness, acceptance, a peaceful death, dignity in dying, being free from pain and other symptoms, dying in sleep, sudden death, and dying with family present (Emanuel and Emanuel, 1998, Payne et al., 1996, McNamara et al., 1994, Wiseman, 1979). In the hospice context, understanding dying as a process rather than as a single event has been found to be important to the good death construct (McNamara et al., 1994). The concept of transition, or of a journey towards death, was explored initially by Glaser and Strauss in the 1960s and has been subsequently incorporated into the hospice

understanding of good dying and death (ibid). McNamara et al conducted an important ethnographic study in an Australian hospice in the early 1990s exploring the attitudes of hospice nurses in relation to the good death (McNamara et al., 1994, McNamara et al., 1995).   They highlighted the tensions between the endeavour to achieve the ideals of a good death and organisational limitations.   They recognised nurses to be striving to uphold the concepts of a good death, while balancing organisational requirements such as cost effectiveness and 'routinization'. These concepts of routinization and medicalization are discussed further in the next section. Attributes of the good death identified in McNamara et al's study include; awareness, acceptance, preparation for death, and a peaceful and dignified process of dying (McNamara et al., 1994). Nurses experienced considerable distress when these were not achieved; such 'bad' deaths were explained through locating the 'problem' as residing with societal denial of death, or with particular aspects of the individual or their family which prevented them from interacting and participating as actively as required for the good death ideal to be fulfilled (McNamara et al., 1995).   McNamara has suggested that in practice hospice workers embrace the 'good enough death' concept (McNamara, 2004). While striving for the good death, hospice workers accept they can only 'do their best' (ibid). In a later paper McNamara quotes two palliative care physicians in providing a definition for the 'good enough death'.   This is one which is considered:

> as close to the circumstances the person would have chosen (ibid).

In recent years the medical literature has focused on drawing together the principle attributes of good dying and death. Studies have sought to account for what constitutes good dying and death from different perspectives (Payne et al., 1996, Pierson et al., 2002, Steinhauser et al., 2000a, Vig and Pearlman, 2004), while others have sought to measure the frequency with which these features are present and good dying is achieved (Cheng et al., 2008, Leung et al., 2010). Hales et al conducted a literature review of research determining the features of good dying and death (Hales et al., 2008). Seven broad domains were found to be consistent across the literature, with an emphasis, however, on the multidimensional and subjective nature of the good death concept. Kehl (Kehl, 2006) performed a concept analysis of a 'good death' and determined attributes from research studies which were most frequently related to the 'good death' concept. Considerable overlap is found in the domains and attributes in these papers

while a consistent feature is that a good death is conceptualised as being 'free from pain or suffering' and being 'comfortable' in dying. Contradictions are evident, however, once again reflecting the subjective nature of even the concept of being free from suffering: for some this means being asleep while for others it involves retaining consciousness, or at least ought not to be at the expense of consciousness (Hales et al., 2010, Pierson et al., 2002, Vig and Pearlman, 2004).

Dekkers et al considered the good death with particular emphasis on its abstract and concrete characteristics (Dekkers et al., 2002). They grouped attributes relating to a good death in the literature on a scale of abstraction; at one end of this scale is being peaceful and at the other is dying in one's sleep. Callahan's (Callahan, 1993) concept of a 'peaceful death' as an attribute for which to strive is considered by Dekkers et al in depth. Callahan's concept of peacefulness is seen to be concerned with: (i) an awareness and acceptance of death; (ii) being conscious and self-aware during dying and at the moment of death; (iii) the presence of family and friends (Dekkers et al., 2002: 117). Callahan is thus interpreted as considering it to be more peaceful to be aware of and accepting of the end of life than to be sedated or unconscious as part of the dying process; a presupposition which is contested by Dekkers. The concept of dying in one's sleep has been found in research studies to be an important characteristic of a good death for some, while for others to approach death with full consciousness is important (Vig and Pearlman, 2004). This is, however, still a descriptive characteristic and requires further interpretation, as Dekkers et al explore. They argue that if it is good to die in one's sleep the extent to which consciousness should be reduced, if it is to be artificially reduced, must be questioned. To die in such a way, they assert, may deny the ability to say a final goodbye or attend to final considerations of life. Ultimately, the authors conclude that any fixation on a particular construct of a good death puts at risk the esteemed values of patient choice and autonomy.

> Any goal in the context of palliative care is based on a number of value assumptions as well as on scientific facts and experiences about what is possible or realistic to do in relation to patients. If these goals are the focus of care without explicating the underlying value assumptions in order to get the patient to accept them then they are put to what may be called 'ideological use'. By ideological use we mean here the attempt to get people to accept

certain ideas about death and dying, particularly *good* death and dying, without allowing or giving these people opportunity to examine critically these ideas and to take a particular stand in relation to them. (Dekkers et al., 2002: 121)

A failure to be explicit about underlying values, they argue, may lead to assumptions about how an individual may wish to be treated, or the manner in which they wish to die. These normative assumptions of dying well will be seen in Chapter 7 to be crucial to an understanding of the motivations for using sedation at the end of life in a hospice. It seems that in the postmodern context, characterised by an increase in patient choice and self-determination, patients are expected to 'live well until they die and make their own choices in this process' (McNamara, 2004). The ability to 'lead… patients through a journey', McNamara argues, is lessened in this context, yet there are fewer resources and reference-points available to patients, as death is more hidden and less communitarian than at earlier points in history. The 'postmodern death' is characterised by a broad range of responses and influences, with fewer certainties, understood roles or scripts to follow (ibid). This creates a societal tension between the desire for choice and autonomy and the demise of the structures and beliefs which enable such choices to be made. Yet Dekkers et al, and other contemporary authors are concerned about the restriction of patient's values through the assumption of shared values at the end of life; the breadth of views concerning the attributes of a good death lays testament to there being very far from a universal value perspective concerning what constitutes a good death. Rather, perhaps what is sought more accurately remains McNamara's interpretation of a 'good enough death', that which is:

as close to the circumstances the person would have chosen (ibid).

An understanding of this background and the literature concerning good death and dying is important to the reading of subsequent chapters which concern the motivations and aims of hospice staff as they use sedation at the end of life. This arises in Chapter 5 as I consider the desire to bring about a 'peaceful' and 'comfortable' death and later in Chapter 7 as I consider the value assumptions underlying the practice of sedation in end of life care. This can be seen to have direct relevance to the good death thesis in practice in a hospice setting.

Notions of good dying and death have changed over time. McNamara in particular has considered the 'routinization' of hospices to be an important feature in this process; this is discussed in the next section of the chapter.

1.5   Routinization and Medicalization: changing practices

The development of services from the first modern hospice in 1967 to the current state of provision has not been uncontroversial. This is most evident in relation to the influence of mainstream medicine on hospice and palliative care and the re-integration of care of the dying into mainstream medicine. Saunders stated an explicit decision to move the care of the dying out of the NHS 'so that attitudes and knowledge could move back in' (quoted in Clark, 1993b: 24) As she later stated, it was always part of the vision to re-integrate into mainstream or general medicine.

> Hospice work is a part of general medicine and nursing and unless it is fully
> integrated with smooth continuity of care for each patient between his home,
> his treating hospital and any hospice beds, it will fail in one of its main
> objectives, to feed back attitudes and skills that any patient, anywhere, should
> expect of those caring for him.(Saunders, 1984a: 203)

As the hospice movement gained momentum and developed into a force for changing the care of the dying, terminal care became more recognised and valued within the medical sphere. There developed a growing body of physicians with an interest in creating a specialty of palliative medicine; they canvassed the royal colleges of physicians and succeeded in 1987. An independent palliative medical journal for was created and the Association for Palliative Medicine was established (Doyle, 2007). The period following the creation of the specialty of palliative medicine was marked however by questions about the purpose and nature of the specialty; how palliative care and palliative medicine were to be configured and how palliative care would withstand the negative effects of 'routinization' and 'medicalization' (Clark and Seymour, 1999: 104, Field, 1994, James and Field, 1992, Johnson et al., 1990, Kearney, 1992, Seale, 1989). This important debate took place in the early 1990s, particularly stimulated by the publication of a paper by James and Field concerned that there was a trend towards 'routinization' of hospices (James and Field, 1992). They argued that hospices were unintentionally becoming integrated and formed into a bureaucratic organisation. They

were moving away from their original aims, James and Field suggested, towards: 'the more traditional medical conceptions of disease and its treatment, to the possible detriment of other 'softer' aspects of care' (ibid). They used Weber's framework and conceptualised the development of the hospices as a charismatic movement: according to this, history alternates between 'charisma and routinization through bureaucracy' (ibid). The emergence of the hospice movement from a 'charismatic' into a 'routinized' movement was cause for concern, they argued. They focused on four key elements of the original movement which reflected its charismatic origins: the role of Cicely Saunders as a highly visible leader; the spiritual 'calling' which inspired many to become involved with hospices; the hospice vision of terminal care with its narrowness of focus; and the oppositional stance of the movement to mainstream terminal care. The move away from these core features, they argued, would lead to a potentially harmful change in direction for palliative care. They raised concern for the continued development of the hospice movement and argued that the movement would be unable to continue to adhere to the original ideals with a continued move towards routinization. One of the principle requirements of this thesis, Clark and Seymour later contended, is that the changes towards routinization which they consider to be damaging are *unintentional* (Clark and Seymour, 1999: 119). Clark and Seymour argue, conversely, that many of the concerns raised by James and Field were far from unintentional, rather were explicitly considered and formed part of the original vision. Thus, even the bureaucratic changes required as the hospice movement gathered pace were anticipated by the early pioneers (ibid). The nature of the original aims of the hospice movement is considered in particular depth by Clark and Seymour in response to the suggestion that there has been a move away from the spiritual calling of those who practice palliative care. Clark and Seymour argue that there was an explicit intention by Saunders, evident in her early writing, to avoid 'any sense of exclusivity... on matters of religion' (ibid: 110). Her intention, rather, was to allow the approach to the care of the dying to be widely disseminated.

A second debate closely followed the routinization argument as concerns about the 'medicalization' of dying were raised. Following the recent introduction of the specialty of palliative medicine there arose concern that an increasing 'dominance' of doctors in this sphere may lead to an increase in the influence of the medical model of care, with its focus on diagnosis and treatment, to the detriment of the 'wider, holistic

approach' (Biswas, 1993). In an important essay, Biswas also argued against a change in practice (alongside a change in terminology) from 'terminal' to 'palliative care'. She asserted the view that a broader approach would result in a reduced emphasis and attention on dying, and direct a move away from the 'original ideals' of the movement. This was forcefully stated as she concluded:

> the hospice movement put death on the agenda, but palliative care has the capacity to relegate it to the sidelines (ibid: 139).

David Field shared this perspective and raised five principle concerns regarding the newly formed specialty of palliative medicine (Field, 1994): a lack of clarity about its remit; a potential change in focus away from terminal care; the 'inappropriate' use of medical technology; the potential threat of an increase in medical involvement on the role of other health workers; and finally, the potential consequences of these moves for hospice care (ibid).

In contrast to the views of Biswas and Field, Ahmedzai argued persuasively that the changes as the hospice movement developed from terminal to palliative care ought to be considered as a positive development and not harmful (Ahmedzai, 1993). Further, Ahmedzai asserted that palliative care *ought* to be provided earlier in a patient's life, for conditions other than cancer, and even that it ought to embrace development of technology and new approaches clinical audit (ibid). These views were held in marked contrast to James and Field who, on the matter of audit, considered that it may; 'pose a threat to hospice ideals of care' (James and Field, 1992: 1370). These concerns were believed to be a likely result of the 'medicalization' of death, promoted through the growth and incorporation of palliative medicine into hospices.

The continued growth and development of palliative care since these debates, in becoming more differentiated and diverse, has made systematic examination of the differences between 'conventional' and 'palliative' care difficult. Clark and Seymour conclude their detailed examination of the routinization and medicalization debates on this very point (Clark and Seymour, 1999: 123). While the scope of palliative care services is vast, and may be bound to inevitable processes of routinization and medicalization, they suggest the interpersonal relationships between 'conventional' and palliative care healthcare workers ought not to be ignored. The influence of individuals

on the provision of care for the dying, inevitably affected by their own values and by those of the organisation, is nonetheless of importance in influencing a 'co-constructed' approach to care of the dying between individuals engaged in clinical work. Clark and Seymour conclude:

> We see little value then in the polarization of debates on routinization and medicalization which are promulgated by revisionist elements within or without the palliative care movement. (ibid: 124)

Furthermore, there is some evidence that the feared outcomes of routinization and medicalization have not materialised. Spiritual care remains as one of the principle domains of palliative care, alongside attention to physical, psychological and social domains of care. While hospices and palliative care teams may not be led by professionals of the same spiritual 'calling' as its founders, 'spirituality' remains an integral part of care, provided by a number of different healthcare professionals (Cobb, 2001, MCPCIL, Wasner et al., 2005).

While 'palliative care' is now firmly established in healthcare as extending beyond the provision of 'terminal care', care for the dying remains a principle function of hospices. The remit of palliative medicine remains broad and indistinct, and has remained flexible to the development of services required at a local level (Doyle, 2010: xxi). Services, for example, for patients with heart failure, or for patients with end stage renal disease, have been developed in response to a need and willingness for interdisciplinary working (Johnson and Houghton, 2006, Kite et al., 1999, Saini et al., 2006, Selman et al., 2007). Technologies have been combined with the provision of holistic care and while interventional procedures, for example for pain control, may be provided for patients in a hospice, this is combined with a multidisciplinary approach to all aspects of a patient's care (Swarm et al., 2010).

While the routinization and medicalization debates marked a period of transition and integration of palliative medicine into the broadening sphere of palliative care, over the past decade the reintegration of care of the dying, as part of palliative care, into mainstream medicine has attracted more attention in the literature. As palliative care services have developed alongside mainstream medicine, commentators have suggested that the 'philosophy' of palliative care has been changed through the course of this

development (Randall and Downie, 2006, ten Have and Clark, 2002). As stated at the start of this chapter, palliative care may be considered as both a set of practices carried out by specialists as well as a 'philosophy', underpinning a particular approach to care. While the routinization and medicalization debates were ultimately concerned with the effect of changing practices on the underlying philosophy or 'ideals' of care, their focus was predominately on the changing nature of the *practices* of palliative care, in bringing about this change rather than on the philosophy of the original hospice movement. The changing nature of the *practices* as palliative care emerged has thus been considered; the *philosophy* will now be examined.

1.6   Developing palliative care philosophy: towards integration

1.6.1   Origins

As Saunders conceived of co-ordinated care for the terminally ill patient, she developed a detailed set of concepts of care, focusing on the patient as an individual. As she would later state, the watchwords of St Christopher's hospice were:

> you matter because you are you and you matter to the last moment of your life.
> We will do all we can, not only to help you die peacefully, but also to live until
> you die (Saunders, 2000: 257).

Even in the earliest of Saunders's writings, attention to aspects of physical as well as social, psychological and spiritual aspects of care featured strongly. Indeed, writing in 1958 for the St Thomas's Hospital Gazette, Saunders began with 4 case histories, before detailing what she considered to be the important issues in caring for the terminally ill (Saunders, 1958). Even in the case studies she provided details of the patient's occupation, dependents, religious beliefs and social situations, alongside a detailed medical history and treatment approach. Embedded in these case histories and in the text which followed was the inherent importance of recognising the individual and their particular context and beliefs, alongside the treatment of pain and other symptoms with drugs and other techniques (ibid). As Clark comments in his introduction to a collection of Saunders's publications:

> we can view this paper as the 'manifesto' for the subsequent hospice and
> palliative care movement, since it sets out almost the entire agenda of issues

that now seem so familiar: general management; nursing; the terminal stage; pain; mental distress, fear, and resentment; telling the patient and relatives about the diagnosis and prognosis; and spiritual care. It even includes a short section on the problems associated with the care of those dying from non-malignant disease. (Clark, 2006: xviii)

From this point onwards, the foundation in the literature was set for the development of modern palliative care. Only 6 years later Saunders wrote for the first time of the concept of 'total pain' (Clark, 1999c, Saunders, 1964). This was at the heart of the ethos of care for a 'whole' person, beyond physical symptoms, and was a pivotal concept in the development of palliative care. According to this 'total pain' concept, patients may be seen to suffer due to concerns of a physical, spiritual, psychological or social nature (Clark, 1999c). Each of these was developed over the following years and would later form the basis of the palliative care management of a patient. Additionally, the broader concepts required of a service for the dying were developed. By the time Saunders wrote a chapter entitled 'The Philosophy of Terminal Care' (Saunders, 1978b), the concepts were well established in her own practice. While the vision and values of terminal care were evident in earlier practices, there was an explicit attempt in this chapter to delineate the 'philosophy' of terminal care. Saunders combined two definitions of the term 'philosophy' to form an understanding of the 'philosophy of terminal care' as relating to both the study of an 'ultimate reality' as well as to the general principles of knowledge, experience and activity (ibid). Terminal care was to be considered not only as a set of practices embodying the 'knowledge' of care for the dying, but was also to be concerned with matters of an 'ultimate reality'. Saunders wrote consistently about the search for meaning as an essential part of the care for the dying patient, and considered the 'journey' at the end of life to be vital in providing adequate symptom control as she wrote:

For those who do not wish to share their deepest concerns, care is given in a way that can reach the most hidden places. Feelings of fear and guilt may seem inconsolable but many of us have sensed that an inner journey has taken place and that a person nearing the end of life has found peace (Saunders, 2004a: xx).

At the heart of Saunders's 'philosophy' was the whole person, whose symptoms were to be considered through the model of total pain. After outlining the dual sense in which she proposed the philosophy of terminal care, Saunders outlined the general principles of such care. These can be seen in Table 1:1(Saunders, 1978b).

Saunders (Saunders, 1978a)
Terminal Care has: • As its primary concern the family and patient as a 'unit of care'   • An experienced clinical team; with expertise in symptom control   • A holistic approach which embodies the 'total pain' model of care   • Skilled and experienced nurses and good inter-professional team working   • A home care programme   • Bereavement follow up   • A methodical approach to recording and analysis and the development of research   • A teaching strategy   • Skilled use of architecture to provide an appropriate environment for care of the dying   • A mixed group of patients in context and diseases   • An administration sensitive to the needs of staff in an emotive environment   • An understanding of the importance of the search for meaning at the end of life

Table 1:1: Saunders's 'Philosophy of Terminal Care'

Beyond the care of the person and attention to the 'whole', followed care for the patient's family as part of their life, extending after death into their bereavement. In this way, while situated out of the medical environment of hospitals, in the charitable and volunteer-sector, care which extended beyond that considered as part of healthcare was provided. Bereavement care was just one of the 'extended' aspects of care developed as part of what Saunders termed the 'philosophy' of terminal care. In moving out of the NHS these extended practices, considered so integral to the terminal care in which Saunders believed, were allowed to flourish and become part of the philosophy. Terminal and hospice care had to move out of the NHS in order for these extended aspects of care to be moved 'back in', and for the philosophy to be formed. This was summarised by Saunders as she wrote:

Here we are concerned with the nature of man, with living and dying, and with the whole man and body, mind and spirit – part of some family unit, with physical, practical needs for us to tackle with maximum competence (Saunders, 1978b: 147).

1.6.2 Critique

Saunders clearly conceptualised the provision of terminal care as extending beyond the provision of medical care for symptom control and believed it to require a holistic approach which allowed: 'the whole man and body, mind and spirit' to be reached.

The combination of a rigorous and scientific approach to the management of physical symptoms alongside attention to psychological, social and spiritual aspects of care has been at the core of the palliative care 'approach'. As scientific developments have become more integrated into palliative care, and the specialty of palliative medicine has developed, the equality of these non-physical aspects of care has been questioned. Retaining the distinctive features of palliative care in which all aspects are integrated into a 'whole person' approach, has become a challenge raised in the literature, as it is concerned about how to retain this philosophy within modern, 21st century palliative care. This sense of a dual and sometimes opposing philosophy has been recognised in many ways and considered from different historical backgrounds and perspectives. While the palliative care literature frequently refers to a palliative care 'philosophy' (Hockley, 1997: 84), 'ethos' (Ellershaw, 2011: xx), or 'principles' (Doyle, 2010: xxi) these terms have rarely been analysed. Two detailed considerations of the core concepts or philosophy of palliative care were, however, published in 2002 (ten Have and Clark, 2002) and 2006 (Randall and Downie, 2006). Taking different approaches, *The Ethics of Palliative Care* and *The Philosophy of Palliative Care* both argue that palliative care has changed from its original conception. Broadly following the 'philosophy' originally asserted by Saunders, both groups of authors hold this to be a patient-centred, holistic approach which incorporates the care of a patient's family and extends to provide bereavement care. They argue, however, that the 'philosophy' or 'values' of palliative care have changed following the closer integration of palliative care and mainstream medicine. Indeed ten Have and Clark even consider mainstream medicine and palliative care to hold 'antagonistic' concepts (ten Have and Clark, 2002: 6). ten Have and Clark consider the concepts of original palliative care to have changed as palliative care

moved away from providing 'just' terminal care for patients with cancer to providing care to patients at any stage in disease and with any life limiting illness. Further, they hold that the 'moral notions' of palliative care have changed: from the Christian traditions of love, sympathy and sanctity of life towards the universal bioethical notions of 'dignity', 'total care' and 'quality of life'. Further still, they consider ethical norms to have shifted, especially in areas concerned with the doctrine of double effect and withholding and withdrawing treatment decisions; that which was regarded as central to practice is now an area for debate (ibid).

In their critique, Randall and Downie consider the WHO definition of palliative care as the 'philosophy' of palliative care (Randall and Downie, 2006). Written originally in 1990, the 2002 WHO definition was developed to incorporate a broader group of patients with malignant and non-malignant disease, at any stage of an incurable illness. It included the social, psychological and spiritual concerns of the patient as well as incorporating the concerns of family and carers; moreover palliative care became an 'approach' rather than the 'total active care' of patients (Sepúlveda et al., 2002). In doing so it may be seen to represent a way of providing care which contains a statement of what palliative care does, and goes further to offer a statement of the way palliative care *ought* to be provided. This is the view of Randall and Downie as they offered a critique of this palliative care 'philosophy' which still held the original features of Saunders 'philosophy' (Randall and Downie, 2006: 19). This definition is seen in Table 1:2

WHO (Sepúlveda et al., 2002)
Palliative care: • is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. Palliative care: • Provides relief from pain and other distressing symptoms • Affirms life and regards dying as a normal process • Intends neither to hasten nor to postpone death • Integrates the psychological and spiritual aspects of patient care • Offers a support system to help patients live as actively as possible until death • Offers a support system to help the family cope during the patient's illness and in their own bereavement • Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated • Will enhance quality of life, and may also positively influence the course of illness • Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Table 1:2: WHO definition of palliative care

Randall and Downie clarify their use of the term 'philosophy' to mean a set of beliefs which determines how palliative care as an approach ought to provide symptom control and end of life care to patients and their relatives.

> This sense of philosophy is close to the idea of an ideology, since it is a statement of assumptions, beliefs, or values held by a group of people, in this case by the WHO representing health care professionals who specialize in palliative care. (Randall and Downie, 2006: 12)

They suggest that decisions in palliative care are informed by an individual's values which are themselves influenced by the set of beliefs, or 'philosophy' of palliative care, expressed in the WHO definition and held by palliative care healthcare professionals. Randall and Downie express concern that the development of palliative care has led to a move away from the Asklepian tradition towards the Hippocratic. They state that the Asklepian tradition was embodied in the skills of listening and being present, finding a sense of 'healing' through this, rather than the more traditional medical, or Hippocratic, focus on intervention and treatment. The issues raised by Randall and Downie appear similar to the concerns raised in the early 1990s in relation to the medicalization of

death. Randall and Downie are concerned that the increased integration with and influence of, mainstream medicine on palliative care, will lead to an increase in medical influence, to the detriment of the other, more Asklepian, aspects of care. The loss of the Asklepian traditions in palliative care may be considered to be similar to James and Field's earlier concern about losing the 'softer' aspect of care through medicalization of dying and death; the latter concerned with the practices of palliative care while the former more concerned with a change in the underlying philosophy motivating practice. This is stated with concern by Randall and Downie:

> [Palliative care] must resist a total take-over by the over-zealous interpretation of that ideal in terms of the Hippocratic tradition, a protocol-driven process which risks treating all similar diseases, and all biologically similar patients, in the same way.(Randall and Downie, 2006: 203)

While a similar concern was expressed in the routinization and medicalization debates of the 1990s, evidence suggests that the 'softer' aspects of healthcare have not been lost, rather are incorporated in activities which aim to promote palliative care in the mainstream medicine context. This may be seen through the example of the Liverpool Care Pathway (LCP) for the dying patient. This pathway, developed in Liverpool in the 1990s as part of a service improvement programme, has undergone eleven subsequent revisions as it has been launched nationally but the authors state its original 'ethos' remains unchanged (Ellershaw, 2011: xix). In the introduction to *Care for the Dying,* Ellershaw explicitly states the 'challenge' of the LCP national programme is the extension of the 'vision' of the original hospice movement (ibid). He considers this vision to have been conceptualised by the 'pioneers of the hospice movement' as creating:

> an environment of care where patients could die a dignified death with support from their carers. [The pioneers] embraced multiprofessional working and recognized that 'journeying with' was sometimes as important as 'problem solving'. The challenge at the start of the 21st century is to extend the vision of the pioneers to all patients in all care settings. (Ellershaw, 2011ibid)

In this statement, Ellershaw brings 'problem solving' alongside the notion of 'journeying'. Journeying conveys the sense of being a parallel presence alongside a

patient as they approach death, as on a 'journey' (Saunders, 2004a: xvii). In this sense, journeying may also be considered to convey that which Saunders described as a 'wordless presence' when she wrote:

> a wordless presence may be all that is needed to bring a whole life to a moment of dignity beyond physical loss (Saunders, 2011xii).

The 'wordless presence', in doing nothing more than being with a patient, may have a therapeutic effect, according to Saunders (Saunders, 1984b: 200). In contrast, 'problem solving' appears to be more actively concerned with the 'impeccable' control of symptoms at the end of life; more closely aligned in practice to interventions and treatment.

Ellershaw brings these models of care together, in contrast to the approaches of ten Have and Clark, and Randall and Downie. While these two groups of authors appear to agree that palliative care values have been changed by its increasing integration with mainstream medicine, they argue that this generates a 'tension', or a 'paradox' (Randall and Downie, 2006: 20) between opposing, or 'antagonistic' (ten Have and Clark, 2002: 6) values: in contrast Ellershaw appears to draw these together to form the enduring 'ethos' of palliative care. Randall and Downie appear concerned that the Hippocratic tradition is threatening a 'total take-over' in palliative care, eliminating the more Asklepian ideal of healing through focus on the individual (Randall and Downie, 2006: 203). Ellershaw appears to bring the two concepts together without concern for this tension; acknowledging the two notions of care to have existed since Saunders's original vision of palliative care in the 1960s.

Both ten Have and Clark, and Randall and Downie, argue that palliative care has developed in a different vein to the ideals of the original hospice movement, suggesting that integration into mainstream medicine is a move contrary to the original ideals of the early hospice movement. While palliative care has broadened care, from solely the care of the terminally ill to care for anyone with a life limiting illness, these concepts were evident in the early writings of Saunders and other hospice pioneers (Hinton, 1963). Palliative care has moved alongside societal changes in perspectives regarding end of life decision-making. From a profoundly paternalistic environment of the 1950s and 1960s patient involvement in decision-making has led to a broadening of the

acceptability of practices in keeping with respect for individual values. Ethical norms may have changed, as ten Have and Clark suggest, or perhaps become more clearly defined, in response to an increase in questioning and challenge, especially in response to a dominance and demand for autonomy. Perhaps rather than moving away from the original ideals of the hospice movement, palliative care concepts have developed, alongside a changing society.

1.6.3   Integration of palliative care philosophy

This chapter has considered the way in which care of the dying was taken out of the NHS in order to move 'beliefs and attitudes back in'. Services have been reintroduced and reintegrated into mainstream medicine; a philosophy has been introduced. This philosophy has been considered by some to be in opposition to that of mainstream medicine. Tensions have been identified previously in relation to the medicalization of death debate, but there appears to be a current desire to establish and advance the palliative care approach within mainstream medicine. It appears the time for end of life care to be provided outside of the NHS has past and as a philosophy of care its place within mainstream medicine is becoming established. This has been seen to be the aim of the hospice movement from its conception. While the practices of palliative care have now become established within mainstream medicine, the underpinning philosophy is perhaps still under scrutiny. For some this philosophy is considered to be in opposition to that of mainstream medicine: in particular those aspects which promote symptom control rather than curative treatment (Randall and Downie, 2006). While the key routinization and medicalization debates of the 1990s focused on the influence of mainstream medicine on the hospice approach, the debate of the 21st century is centred on the influence of palliative care on mainstream medicine. The use of the Liverpool Care Pathway for the dying patient (LCP) has influenced the care of the dying in hospitals and in the community (Ellershaw et al., 2010). It was conceived of as a document to support and drive an improvement in the standards of care for the dying outwith the hospice environment. Ellershaw and colleagues explicitly attempted to take palliative care standards and philosophy into the mainstream medicine context. With this transfer of standards of care for the dying has come the integration of a philosophy of care: not only does the LCP provide guidance for addressing a patient's symptoms of physical, social, psychological and spiritual origin, it brings a different philosophy of

care into the mainstream medicine environment. Concerns have been expressed regarding the use of the LCP: press reports of patients dying as a result of the LCP are now not infrequent, including not only concerned relatives but also senior clinicians too (Devlin, 2009, Millard et al., 2009, Rawstone, 2012, Stephens, 2012). Ellershaw and colleagues have changed the LCP document significantly through its twelve versions, while stating retention of the original ethos (Ellershaw and Wilkinson, 2011: xx). Ellershaw, in the introduction to *Care of the Dying* explicitly states the purpose of the guideline and perhaps reflects concerns about inappropriate use of the document.

> As with all clinical guidelines and pathways the LCP aims to support but does not replace clinical judgement. It is important to ensure that patients and relatives understand that the focus of care has changed and that the patient is deemed to be in the last hours or days of life. This requires skilled communication, including recognition of one's own limitations and the need to involve more specialist support where required. Using the LCP appropriately in any environment requires regular assessment and involves continuous reflection, critical decision making, and clinical skill. (ibid)

Nonetheless, end of life care has been improved through the integration of palliative care into mainstream medicine (Ellershaw, 2007). The LCP is a key document in enabling the practices and philosophy of palliative care to be accessible in different contexts. This document was identified as an example of best practice in NICE guidelines for supportive and palliative care in 2004, and further government white papers have recommended the use of such guidelines across the UK as part of the national End of Life Care Strategy (EoLCS). Palliative care and care of the dying is a political priority (ibid: xxi) and improving standards of care for the dying, through palliative care integration into mainstream medicine activities is of paramount importance. There are inevitable tensions in periods of transition: from curative towards non-curative and a more prominent palliative care approach, before a transition into end of life and finally, terminal care. It is in these areas of transition that most tension exists between mainstream medicine and palliative care: it is here that there needs to be greatest reciprocal understanding of both approaches.

These underlying perspectives may usefully be considered in relation to modern and postmodern conceptions. If mainstream medicine is considered to hold predominately a modernist perspective (Charlton, 1993, Hodgkin, 1996) where the principle aim is to establish truth and objectivity, palliative care may be considered to hold predominately a postmodernist perspective in its desire to incorporate and interpret 'truth' in the context of the individual patient, their priorities and cultural background (Bottorff et al., 1998). While these may be the underlying conceptions of mainstream medicine and palliative care, they will both inevitably contain a mixture of both modern and postmodern perspectives. These may be afforded a different weight according to the nature of a particular practice or specialty and be considered as lying on a spectrum. Considered in this way, while the weight attributed to, for example, attending to aspects of psychosocial care, may be greater in palliative care than in other specialties, this need not be in opposition to a different specialty affording less weight to psychosocial care and more to another aspect of care. While introducing psychosocial aspects of care into mainstream medicine may incorporate more of a postmodernist perspective, it is not incongruous with the modernist view; rather they may be considered to sit at different points on the same spectrum. As mainstream medicine has developed it too has evolved more of a postmodernist perspective, in particular with regard to the incorporation of patient values and choices (Charlton, 1993). Both palliative care and mainstream medicine may be seen to have changed over the past 60 years, moving towards one another on this modern-postmodern spectrum. While some have suggested this to be a move away from the original ideals of the hospice movement, I would argue that this is, rather, the embodiment of the 'vision' for transforming end of life care as palliative care is becoming truly integrated. Indeed, this brings into reality one of Saunders's 'main objectives:

> Hospice work is a part of general medicine and nursing and unless it is fully integrated with smooth continuity of care for each patient between his home, his treating hospital and any hospice beds, it will fail in one of its main objectives, to feed back attitudes and skills that any patient, anywhere, should expect of those caring for him. (Saunders, 1984a: 203).

1.7   Conclusion

This introductory chapter has provided a historical perspective of palliative care in the UK, providing an overview of its development from the original vision and the hospice movement, to the provision of terminal care, the adoption of the term 'palliative care', and the formation of the specialty of palliative medicine. The particular focus, however, has been on the developments in palliative care practices and the reintegration of these into mainstream medicine; of particular influence in this process has been the extension of services to non-malignant conditions and changes in palliative care funding with an increased reliance on the NHS. The origins of the philosophy of palliative care have been discussed, and the resulting concerns about its future following further integration into different contexts, considered in depth. All of these changes have led to an increased integration of palliative care into the NHS and mainstream medicine; that which Saunders explicitly felt the need to separate the initial hospice movement from. As the philosophy of palliative care developed, its core values have become increasingly accepted within mainstream medicine approaches. Similarly, the values of mainstream medicine may be seen to have changed, with the modernist approach, initially embraced by those working in the newly formed NHS, making way for more postmodern influences, in which the views of patients are increasingly sought (Bakitas et al., 2011, Evans, 2008, Frank, 2009). While some have considered the approaches and values of palliative care and mainstream medicine to oppose one another, perhaps as they have evolved they may rather be seen to be on a spectrum, with both modern and postmodern influences but expressing these with a different weight, or emphasis. Thus, the underpinning philosophies, considered in such a way, need not be considered in opposition, rather may be coming closer together, permitting the integration of palliative care into mainstream medicine.

This background has been solely considered from the UK perspective; this is the focus of the thesis and research study. International differences do exist, and will be considered in Chapter 2 as they become relevant to the different perspectives found in the literature, specifically concerning sedation at the end of life. First, however, the structure of the thesis is presented, before the literature is considered in Chapter 2.

1.8   Structure of the thesis

While this chapter has provided the background to situate this research in hospice palliative care in the UK, the second chapter provides the background to the literature regarding the use of sedation in palliative care. This considers the specific palliative care literature concerned with the use of sedation from the palliative care perspective. This provides an understanding of the specific concerns regarding the use of sedation in palliative care, considering the international perspective.

Chapter 3 introduces the research study and details the methodology and methods employed.   Particular concerns including research ethics committee approval and issues relating to consent in ethnography are addressed. The research environment is introduced and negotiating access and my role as a researcher is considered in detail. Finally, my approach to data analysis and theory development is described.

Chapter 4 introduces the first data chapter. In this the nature of sedation as a routine practice, embedded in hospice end of life care, is introduced. This is seen to be predominately an implicitly understood practice, expected and anticipated in relation to the interpretation of a patient's proximity to death. A conceptual model of the relationship of sedation to dying is presented, allowing an in depth understanding of the practice of sedation in a hospice at the end of life.

The underpinning rationale for using sedation in this routine manner is explored in Chapter 5. The promotion of a comfortable and peaceful death, considered as part of the broader good death thesis is discussed and is seen to be the primary motivation for staff in using sedation at the end of life. The potential for sedation to restore a patient to a process of good dying and death is considered, alongside the impact of this on hospice staff, and patients' relatives.

Chapter 6 considers those situations in which sedation was not routinely used, rather in which sedation was explicitly discussed and planned. These reveal in greater depth the considerations and motivations of staff in using sedative drugs in a hospice and provide an insight into the challenges faced when good dying is threatened.

The values underpinning this practice of sedation in the hospice are explored in Chapter 7. These are recognised as predominately reflecting the original values of palliative

care and being shared within the hospice context. The problems associated with divergent values are considered in this chapter through a further case study; this allows insight into the nature and role of values in decision-making which is considered further through the approach of values-based practice.

The impact and implications of this study for future practice is discussed in Chapter 8. This thesis impacts on practice in 3 ways. First, understanding the practice of sedation at the end of life as intricately bound to an interpretation of dying in a UK hospice allows informed ethical debate. This is of tremendous importance when considering the international literature about sedation at the end of life and the close association of sedation to physician assisted death. This links back closely to Chapter 2. Secondly, interpretation of the process of dying leads to important considerations, as it is recognised to reflect an expectation of dying which is modelled by those dying with cancer.   As palliative care expands and incorporates an increasing number of patients with non-malignant diseases, it is important to be aware of embedded and implicit processes in end of life care, as misinterpretation at this crucial time could lead to the hastening of death. This presents a challenge for palliative care as it develops and integrates further into mainstream medicine. Finally, understanding the practice of sedation as informed and shaped by values, in particular the values of palliative care, provides depth to current understanding about end of life decision-making. This is important in current healthcare as an increase in choice, even at the end of life, may expose an increase in diversity of values. This study shows palliative care values to be strong and embedded in hospice practice; expansion and integration of these values into more mainstream contexts may increase exposure to values-diversity and to potential conflicts of values. Palliative care providers need to be aware of these conflicts in order to promote what is indeed found at the core of palliative care values; patient-centred care.

Chapter 2 Literature Review

2.1   Introduction

Sedation in palliative care is a subject which has attracted much attention and controversy over the past 20 years (Engström et al., 2007). Originally termed 'terminal sedation' (Enck, 1991), the practice involves the use of sedative drugs in palliative care. Many different reasons for using sedation in palliative care have been cited (de Graeff and Dean, 2007). These include the use of drugs to treat specific symptoms, as well as the continuous use of drugs to render a patient unconscious until death (Morita et al., 1996, Quill T. E., 1997). All such practices have been described within the use of sedation in palliative care and the wide ranging interpretations of these practices have been much discussed in academic literature. As a result of these interpretations, the use of sedation either has been regarded as merely a method of providing symptom control in palliative care, or as another form of euthanasia (Sykes, 2008, Battin, 2008, Billings, 1996). The debate has revolved around this distinction, with many research studies setting out with the aim of investigating whether sedation indeed does hasten death, and whether, if it does, death is in fact intended.

This development of ideas, concepts and research around sedation in palliative care takes place within the context of an increased awareness in the medical and in the UK populations' perceptions of end of life issues. In other parts of Europe, such as in the Netherlands and in Belgium, the legalisation of euthanasia has contributed and formed the basis of the debate about sedation; primarily concerned with establishing a distinction between sedation and euthanasia (Bilsen et al., 2007, van der Heide et al., 2007). This has linked the issue of sedation and the ethical positions in relation to it, firmly to the context of euthanasia. Ambiguity and concern about this practice in the literature leads to a need for further research.

While much of the research in this area has focused on either specific aspects of sedation, such as how it is administered, or perceptions about this from family and professionals, there has been a clear lack of empirical research which has been able to address the concept of intent (Fainsinger et al., 2000b). In part, this has been related to the methodologies and methods used in previous research, with many retrospective studies looking at case note reviews, or interviews and questionnaires considering

retrospective cases (Sykes and Thorns, 2003a, Rietjens et al., 2004b). Multi-centre studies have looked at the way in which sedation has been administered in different countries and large scale surveys have (as one aspect of such studies) investigated the intent behind the administration of sedation (Miccinesi et al., 2006, van der Heide et al., 2007). None has, however, been able to observe what happens in clinical practice directly and demonstrate how this relates to the intentions and attitudes towards sedation. This is important if the true ethical nature of the use of sedative drugs at the end of life is to be evaluated.

2.2   Methodology of literature review

I conducted a systematic review of the literature. In order to identify the major research papers regarding the use of sedation in palliative care, a database search was carried out using MEDLINE, EMBASE, PsychInfo, CINAHL and Web of Knowledge. The following Table 2:1 lists the search terms used.

SUBJECT HEADINGS	KEY WORDS
'palliative care'	'terminal sedation'
'terminal care'	'continuous deep sedation'
'terminal illness'	'palliative sedation'
'hospice care'	'existential distress'
'sedation'	'terminal agitation'
'conscious sedation'	'terminal restlessness'
'terminal sedation'	'refractory symptoms'
'palliative sedation'	
'hypnotics and sedatives'	
'ethics'	
'views'	
'opinions'	

Table 2:1: Search headings and key words for literature search

Limiting this search to adults and English language articles revealed a total of 367 articles of which the abstracts were reviewed. Additionally, a manual search of journals

in which sedation at the end of life was frequently cited was conducted. These journals were: Palliative Medicine; Journal of Pain and Symptom Management; Journal of Palliative Medicine and Journal of Medical Ethics. As this study is centred not only on the technical application of sedation in palliative care, but also intentions and attitudes towards sedation, the grey literature, including comment articles and letters from experts and those working in the field, were also considered for the review. A table of research papers was created and divided into prospective and retrospective studies. 21 prospective studies and 44 retrospective studies were found and are summarised in appendix 1 and 2 respectively.

2.3   Initial Conceptions: 'Terminal Sedation'

In the early 1990s a discussion took place in the medical literature regarding the use of sedation in end of life care. This was framed in the context of palliative care and it was within this specialty that the primary work and debate took place. This was triggered in 1990 by the publication of Ventafridda et al's prospective study looking at symptom prevalence at the end of life in an Italian home care programme (Ventafridda V., 1990). In their study, which set out to determine the prevalence of uncontrolled symptoms at the end of life, they found that 52.5% of patients had 'unendurable' symptoms requiring sedation. This high prevalence caused concern and prompted the first of many studies to look at the prevalence of the use of sedation elsewhere (Fainsinger R, 1991). The following year Greene and Davis reported their review of 17 years of practice in a community urology clinic. They reported 14 cases in which patients were sedated with intravenous barbiturates for uncontrolled symptoms at the end of life (Greene and Davis, 1991). Enck commented on both of these papers in 1991 and described this practice as 'terminal sedation' (Enck, 1991). Since this report, 'terminal sedation' and many other terms to describe the use of sedative drugs in palliative care, have been discussed and debated in the medical, nursing, legal and ethical literature (Beel, 2006, Claessens et al., 2008, Craig, 2004, Tannsjo, 2004a) While initial reports related to the prevalence of the use of sedation, and concern about variability of practices in palliative care, the focus of concern shifted more towards the issue of how sedation was practiced and the outcome of this. Central to this debate was the question of whether sedation may hasten death. The literature demonstrates a development of thought about sedation and the accumulating evidence has attempted to clarify the role of sedation in palliative

care. Guidelines (Blanchet, 2002, Braun et al., 2003, Cherny and Portenoy, 1994, Hawryluck et al., 2002, Rousseau, 2001, Verkerk et al., 2007), systematic reviews (Beel, 2002, Claessens et al., 2008, Cowan and Walsh, 2001, de Graeff and Dean, 2007, Engström et al., 2007, Porta Sales, 2001) and recommendations from a panel of experts (de Graeff and Dean, 2007, Cherny et al., 2009) have focused and clarified the position; however, much ambiguity still exists. While objectively sedation has not been shown to hasten death (Claessens et al., 2008, Sykes, 2008) many reports demonstrate a widespread belief amongst physicians that indeed it does (Sykes, 2008). Furthermore, studies have determined that some physicians intend to hasten death through their use of sedative drugs (Rietjens et al., 2004b). The merging of evidence concerning what happens when sedation is used in palliative care and what it is intended will happen, has proved elusive in research to date. The difference in perspective highlighted here, between demonstrating evidence of clinical practice in the use of sedation, and seeking to clarify the intentions behind this practice, will be used in this literature review to present the evidence from these different standpoints. Intention is considered under the broader heading of ethical considerations, and considered in practice in studies which have focused on end of life decision-making. Thus the following headings form the structure of the chapter: terminology and definition, indications, ethical considerations and end of life decision-making.

2.4   Terminology and Definition

Since the initial use of the term 'terminal sedation' by Enck (Enck, 1991), many different suggestions for the appropriate terminology to describe the practice of using sedation in palliative care, have been proposed. The requirements for this terminology were determined by differences in how sedation was understood and defined. For some 'terminal sedation' was akin to a 'form of slow euthanasia' (Billings, 1996); for others, it was 'accepted medical practice' (Portenoy, 1996) and defended strongly in these early papers as providing a method of 'relief from suffering' (Portenoy, 1996). The term 'terminal sedation' came under intense scrutiny following the US Supreme Court decision against the legalisation of physician assisted suicide (Burt, Orentlicher, 1997, Quill T. E., 1997). The court ruled against physician assisted suicide but advocated an increase in the provision of palliative care and was seen to sanction the use of terminal sedation. The court acknowledged the legal acceptability of providing pain and

symptom relief, even to the point of hastening death if necessary (Quill T. E., 1997). Responses to the ruling by the Supreme Court, in describing and defining terminal sedation, understood it to mean that food and fluids were always withheld or withdrawn and as such death was considered 'inevitable' and;

> the patient dies of dehydration from the withholding of fluids (Quill T. E., 1997).

Different positions regarding the nature of sedation, particularly in light of the Supreme Court decision, prompted further research into whether physicians did indeed intend to hasten death (Morita, 1999), but also prompted a reconsideration of the terminology used (Braun et al., 2003, Bilsen et al., 2007, Chater et al., 1998, Morita et al., 2001a, Morita et al., 2002b). Broeckaert (Broeckaert, 2002) described three main areas of concern with the term 'terminal sedation'. First, the negative implications of the word 'terminal' was felt to be a concern, especially as negative and ambiguous terms were being discouraged elsewhere. For example, use of the term 'palliative care' was becoming the preferred term, in place of 'terminal care'; the further implications of this were discussed in Chapter 1. Second, it was felt that the word 'terminal' may be interpreted as meaning that patients were 'terminated', a suggestion developing in the literature (Billings, 1996, Krakauer et al., 2000) from which many wanted to move away. Third, the term gave no indication of what sedation entailed, or what the intention behind using sedation truly was (Broeckaert, 2002, Morita et al., 2001a, Morita et al., 2002b). Many have sought to clarify this in the clinical literature and have proposed new terms and definitions which will be described below. In addition to the term 'terminal sedation' (Enck, 1991), 'total pharmacological sedation' (Peruselli et al., 1999), 'palliative sedation' (Broeckaert, 2000), 'palliative sedation therapy' (Morita et al., 2002b) and 'palliative sedation to unconsciousness' (Quill et al., 2009) are some of the many other terms attributed to the practice of using sedation in palliative care. These terms have arisen predominately from reviewing objective evidence, examining clinical practice, and considering the recommendations of expert opinions. I consider this literature first, and then consider where these changing terms and definitions fit in with emerging evidence about decisions at the end of life. In addition, the use of artificial nutrition and hydration is an important part of the definition of sedation in palliative care and its use is also discussed in this section.

2.4.1 Evidence and opinion from clinical practice

In 1994 Cherny and Portenoy described the use of 'controlled sedation' and, while not formally providing a definition, they described the situation in which sedation might be considered (Cherny and Portenoy, 1994). They outlined the provision of symptom control in palliative care and the point at which symptoms may be considered to have become refractory. The provision of expert care and attention was stressed, and exhausting all possibilities to treat a cause of the symptom emphasised. A symptom, they considered, may be called refractory when:

> all other possible treatments have failed, or it is estimated by team consensus, based on repeated and careful assessments by skilled experts, that no methods are available for alleviation within the time frame and risk-benefit ratio that the patient can tolerate. (ibid)

The authors outlined an algorithm for the assessment of a refractory symptom and emphasised the need for review and treatment at all stages before considering sedation to be refractory. This attention to detail was matched in subsequent reviews which have clearly sought to mark a distinction between the practice of sedation in palliative care and euthanasia. (Cherny, 2009, Morita, 1999, Mount, 1996, Muller-Busch et al., 2003, Portenoy, 1996).

Chater et al (Chater et al., 1998) set out with the purpose of providing a literature review of terminal sedation and proposing new terms under which this could be described. This was the first of five review papers which have examined systematically the definitions and terminology of sedation (Beel, 2002, Chater et al., 1998, de Graeff and Dean, 2007, Morita et al., 2002b, Porta Sales, 2001). Chater et al conducted an international survey of palliative care experts with one of the objectives to propose and agree a definition for terminal sedation. The proposed definition for terminal sedation was as follows:

> 'Terminal sedation' is defined as the intention of deliberately inducing and maintaining deep sleep, but not deliberately causing death in very specific circumstances. These are:

(i) for the relief of one or more intractable symptoms when all other possible interventions have failed and the patient is perceived to be close to death.

(ii) for the relief of profound anguish (possibly spiritual) that is not amenable to spiritual, psychological or other intervention and the patient is perceived to be close to death .

This definition does not include the management of delirium or the use of anxiolytic/psychotropic drugs for the management of symptoms such as hallucinations, paranoia, myoclonus, etc. Nor does it include planned temporary sedation that is reversed (Chater et al., 1998).

While only 40% of respondents agreed with this proposal without amendment, a further 15% stated they would agree if changes were made. Rather than 'close to death', 'imminently dying' was preferred: others would have preferred the definition to include delirium and paranoia, while 'sedation in a dying patient' was a phrase preferred by some, to 'terminal sedation'. Four respondents agreed with the first specific circumstance only, while others requested that there was an option to lighten the sedation (Chater et al., 1998).   This was an important study which was the first to consider in depth the matter of terminology and definition. Despite the definition only being unreservedly accepted by 40% of respondents, this definition has been widely used and is still an accepted definition within palliative care (Elsayem et al., 2009, Sykes and Thorns, 2003b). An interesting aspect of this study was that while 77% of respondents had used terminal sedation in the prior twelve months, 90% did not support the legalisation of 'voluntary active euthanasia' and 88% did not support the legalisation of physician assisted suicide. From this and from comments on the questionnaires, the authors interpreted that the respondents did not appear to equate terminal sedation with euthanasia and viewed it rather as a method of 'symptom control'. With this in mind they felt terminal sedation was an inappropriate phrase and 'sedation for intractable distress in the dying' was proposed in its place.

Morita et al carried out a further literature review to consider the definition of terminal sedation in 2002 (Morita et al., 2002b). Here, however, having found only seven studies in which the term used for sedation was clearly defined (including 'sedation', 'terminal sedation', 'total pharmacological sedation' and 'sedation for intractable

distress of a dying patient') a new term was proposed. The authors felt that 'terminal sedation' was an 'inadequate' term, and proposed 'palliative sedation therapy'. The concept of providing intermittent sedation for symptom control was, they felt, addressed by this term, and it conveyed more of the intent of the practice – i.e. the alleviation of symptoms. The term 'palliative sedation' had been introduced by Broeckaert et al in 2000 (Broeckaert, 2000) however the addition of 'therapy' was made in 2002 by Morita (Morita et al., 2002b). In addition to proposing a new term for sedation, further suggestions were made to the definition and also classification of sedation. Palliative sedation therapy, it was proposed, should be defined as:

> the use of sedative medications to relieve intolerable and refractory distress by the reduction of patient consciousness (Morita et al., 2002b)

'Refractory' was defined in keeping with Cherny and Portenoy's 1994 definition (Cherny and Portenoy, 1994). That a symptom was 'intolerable' was held to be that described by a patient as intolerable; if they were not able to describe this or the patient was not competent, a proxy decision was to be sought (Morita et al., 2002b).

Morita and colleagues further classified different types of sedation into mild or deep, intermittent or continuous and primary or secondary sedation. These subcategories were considered to be ethically important as it was believed they may allow further differentiation from euthanasia (Morita et al., 2002b). Terms such as 'proportional' (Porta Sales, 2001) or 'conscious' (Cherny and Portenoy, 1994), Morita re-classified as 'mild' sedation while 'total' (Peruselli et al., 1999), 'heavy' (Quill et al., 2000a) or 'sudden' (Porta Sales, 2001) were termed 'deep' sedation. In the same way 'intermittent' sedation included 'respite' (Rousseau, 2001, Cherny, 1998), 'controlled' (Cherny and Portenoy, 1994), 'temporary' (Cherny, 1998) and 'night' sedation (Stone, 1997). Primary sedation was used to refer to the use of sedatives not believed to be efficacious to treat the underlying symptom (i.e. they were primarily used for their sedative properties) and secondary sedation was the use of a drug for its efficacy in treating an underlying symptom and sedation was a (side) effect of this.

Morita's definitions were considered important in the pursuit of improvements in research into sedation in palliative care. Frequently, all categories of sedation were included in research and the prevalence of patients requiring sedation can be said to

range from 1% to 88% (Turner, 1996). This wide range incorporates studies in which only patients continuously and deeply sedated were included, as well as those in which mild and intermittent sedation, and continuous deep sedation were used. When considering the weight of evidence for any particular type of sedation, it became clear it was impossible to draw robust conclusions as the data contained too many variables to allow any meaningful comparison between studies.

In 2007, De Graeff and Dean (de Graeff and Dean, 2007) undertook a systematic literature review. De Graeff and Dean's paper was based on the work of twenty nine palliative care experts, of whom Morita and Cherny were two, with an interest in the topic of sedation. In working groups, they produced a systematic literature review to address the key issues, and provided recommendations for standards for the practice of sedation. One of the issues considered was definition and terminology. The term chosen by the expert panel was 'palliative sedation therapy', defined as:

> The use of specific sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness.

> Intolerable suffering is defined by a patient as a symptom or state that he or she does not wish to endure. If the patient cannot communicate, proxy judgement from family and caregivers is sought.

> Refractory symptoms are symptoms for which all treatment has failed, or it is estimated that no methods are available for palliation with the time frame and risk – benefit ratio that the patient can tolerate (ibid).

These definitions were clearly outlined and had the consensus of the twenty-nine palliative care experts. The evidence for the recommendations was an acknowledged limitation of the paper as the vast majority of recommendations were based on expert opinion or 'inconsistent or inconclusive studies of any level' (ibid). Subsequent reviews and guidelines have not differed significantly from this comprehensive review. Many countries have developed their own national guidelines with the emphasis regarding the type of sedation practiced varying according to international differences. Dutch guidelines (and support for Belgian guidelines) focus on continuous deep sedation (CDS); while those in the US, Canada and France have continued to develop guidelines

for the broader concept of 'palliative sedation' (Berger, 2010, Blanchet, 2002, Braun et al., 2003, Dean et al., 2012, Verkerk et al., 2007).

While these studies considered the terminology and definitions, and proposed new terms to clarify the position of sedation, how these were interpreted more widely can now be considered. While these definitions and guidelines demonstrated how the palliative care specialists believed sedation should be practiced, and evidence was being gathered to demonstrate this, the different interpretations of this and the actions of physicians were being examined from a different perspective. This was highlighted initially through the work of the Dutch and Belgian authors in their work on end of life decision-making.

2.4.2 End of life decision-making

In 1991 the first of several Dutch studies was published relating to the frequency of medical end of life decisions (van der Maas et al., 1991). This was commissioned by the Dutch government with the aim of addressing the issues being raised in the public debate on legalising euthanasia. The intent was to inform the debate about the frequency and type of decisions being made by Dutch physicians. Medical end of life decisions were considered in the following categories: (i) euthanasia and related decisions (e.g. physician assisted suicide (PAS)); (ii) non-treatment decisions (where a decision to withhold or withdraw potentially life prolonging treatment was made); (iii) decisions to use opioids and other drugs in increasing doses to alleviate pain and symptoms, with the 'probable' effect of shortening life (van der Maas et al., 1991). This was the first study to provide national data about medical decisions which were made at the end of life. These studies have laid a framework in which sedation is examined within this context. This has been important not only in examining the terminology and demonstrating how it is interpreted in different countries, but also in widening the debate about the ethical nature of sedation in palliative care. These studies have provided important insights into the perceived intentions of physicians in using sedation and are important in highlighting international differences.

In 2004 as part of an evaluation of the notification procedure for physician assisted deaths, Rietjens et al investigated the use of 'terminal sedation' (Rietjens et al., 2004b). The aim of this study was to determine the frequency of terminal sedation among Dutch

physicians. They carried out interviews with 410 physicians in the Netherlands; these physicians were stratified according to their clinical role in order to be representative of the national group of physicians. Those who had practised terminal sedation were asked to recall the last patient they had treated. Terminal sedation was defined as:

> the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration (ibid).

The definition of terminal sedation can be seen to incorporate the withholding or withdrawal of artificial nutrition or hydration (ANH) and this was found to be a significant aspect of this study. The authors found that 52% of physicians had used terminal sedation and, if the deaths were nationally representative, they determined that 10% of deaths in the Netherlands were preceded by this form of terminal sedation. Of the physicians who had used terminal sedation, 47% had partly intended to hasten death and 17% explicitly intended to hasten death through terminal sedation. Of the 17% explicitly intending to hasten death, 14% intended this through the withholding of ANH, with 2% intending to hasten death through the direct effect of the sedative drug. It was estimated that life was shortened by more than a month in 6% of patients described by the physicians, however in 73% it was estimated that this would have been by less than a week (ibid).

Miccinesi and colleagues of the EURELD consortium conducted a study in 2001, the full details of which were reported in 2003 (van der Heide et al., 2003), with additional data relating to sedation reported in 2006 (Miccinesi et al., 2006). This study involved questionnaires being sent to physicians in six European countries. For this paper 'continuous deep sedation' (CDS) was the term chosen to describe the continuous use of deep sedation, and the term 'terminal sedation' was described as a 'special kind of sedation', in situations in which CDS was used without ANH. This was viewed to be different precisely because of the intended or foreseen life shortening effect of the withholding or withdrawing of ANH.

In this 2006 paper by Miccinesi et al, it was found that Italy and Belgium had the highest prevalence of CDS, with 8.5% and 8.2% of all deaths being preceded by CDS (ibid). Sweden and Denmark had the lowest rate of CDS prior to death with 2.5% and 3.2% respectively being preceded by CDS. In 35% to 65% of instances of CDS being

used, ANH was not given. As the authors note, however, the absolute numbers of those given ANH mean little without knowing the intent behind the decision to withhold this treatment (ibid). Some recommend the use of ANH at the end of life, believing it to improve symptoms and wellbeing (Craig, 2004). Others, however, warn against this as some evidence has suggested that problems such as ascites may develop (Morita, 1999, Morita et al., 2006). The use and withholding or withdrawing of ANH is discussed in more depth in the next section of this chapter. Miccinesi et al concluded that if life expectancy were anticipated to be longer than a week, the use of CDS without ANH may be a marker of intent to hasten death (Miccinesi et al., 2006). In the initial Dutch studies the withholding or withdrawal of ANH was seen to be integral to the practice of sedation. This perspective developed as the definitions in the medical literature changed and were clarified, and the implicit withholding or withdrawal of ANH came to be seen as being involved in one small area of sedation – the use of CDS without ANH. This was the evolved definition of 'terminal sedation' (ibid).

2.4.3   Artificial nutrition and hydration (ANH)

In studies looking at the use of ANH in patients who were sedated, there is wide variation in practice with between 0% (Fainsinger et al., 1998) and 69% (Morita et al., 2005c) reported to have received fluids while sedated. Some studies give details about whether patients have received ANH, or have been able to tolerate food or fluids, before sedation was commenced: they have then reported on whether these have been continued or withdrawn (Cameron, 2004, Morita et al., 2005c). In the main, however, details about these cases have been scanty, with little information other than in case reports about the indications, benefits and side effects experienced specifically in those who have been sedated. Similarly, no evidence about the effect of ANH on survival specifically in sedated patients has been demonstrated (Claessens et al., 2008). The use of ANH in palliative care has, however, undergone extensive discussion (Viola, 1997). The benefits and risks of its use in end of life care have been debated and there has been no evidence to support its use in end of life care as either prolonging life or hastening death (Morita et al., 2006, Viola, 1997). What is clear, however, is that the withdrawal of ANH from a patient who is not dying, will hasten death (Craig, 2004, Craig, 2008). Many papers considering sedation, particularly those using the term 'terminal sedation', refer to the withholding or withdrawal of ANH as the way in which terminal sedation

hastens death (Tannsjo, 2004a, Billings, 1996, Quill T. E., 1997, Rietjens et al., 2006a). Indeed for many this is the crucial argument in questioning the ethical validity of sedation and, for some, is important in order to capture the controversial aspects of sedation (Tannsjo, 2004a). Alternatively, others explicitly state that consideration of ANH is entirely separate from the decision to use sedation (Broeckaert, 2002, Claessens et al., 2012, de Graeff and Dean, 2007, Morita et al., 2005a, Rousseau, 2003). Interestingly, those more inclined to use this line of argument (considering sedation and ANH as separate decisions) tend to use the terms 'palliative sedation' or 'palliative sedation therapy (Broeckaert, 2002, de Graeff and Dean, 2007, Morita et al., 2005a, Rousseau, 2001): those who have defined sedation as requiring the withholding or withdrawal of ANH have tended to use the term 'terminal sedation' (Billings, 1996, Quill et al., 2000a, Rietjens et al., 2004a, Tannsjo, 2004a). If the use of sedation may include, where indicated, the administration of fluids and nutrition, arguments about its life shortening effect diminish in strength. Herein lies a divide in the literature between those who refer to sedation without it being implicit that ANH is withheld or withdrawn, and those who believe it to be integral to the definition. Some have combined both views, to an extent, in considering the withholding or withdrawal of ANH to be found in a sub category of sedation. This was described by Miccinesi et al in considering that CDS without ANH is 'terminal sedation' (Miccinesi et al., 2006). It can be seen that 'terminal sedation', so called, has been transformed and re-categorised from the original constructs, to this narrow, controversial area within a wider framework of sedation in palliative care. The wider framework of sedation in palliative care has been termed 'palliative sedation' or 'palliative sedation therapy'. From this point in the review, 'palliative sedation' will be used to describe all practices of using sedation in palliative care, while specific situations, such as the use of continuous deep sedation will be explicitly described.

2.5   Indications

The indications for sedation are once again very diverse and their description in the literature far from uniform. In this section, the main indications for the use of sedation, which will incorporate all terms previously outlined, will be described. These can be usefully divided into the physical symptoms which are deemed to be refractory, and the more controversial refractory psycho-existential symptoms. The drugs which have been

described in the literature to be used as sedative drugs at the end of life are considered at the end of this section.

2.5.1 Physical symptoms

In the literature relating to palliative sedation the prevalence of individual symptoms which are deemed to be 'intolerable' and 'refractory' varies significantly. This is unsurprising given the complications surrounding the definitions and terminology applied to the practice of using 'sedation'. This variability has been routinely referred to in the literature as a cause for concern when trying to provide any kind of consensus (Beel, 2002, Braun et al., 2003, Cherny and Portenoy, 1994, Cowan and Walsh, 2001). That symptoms should be refractory before sedation is considered, is universally held as essential (Chater et al., 1998, Cherny and Portenoy, 1994, Claessens et al., 2008, de Graeff and Dean, 2007, Morita et al., 2005a, Porta Sales, 2001). While there have been clear definitions (Cherny and Portenoy, 1994, de Graeff and Dean, 2007), the measures taken in the studies to determine this prior to administering palliative sedation are variably described. Morita et al, in their development of guidelines for sedation, outlined in depth the steps which would be considered acceptable before determining a physical symptom to be refractory (Morita et al., 2005a). Some case reports describe in great detail the measures taken before a symptom has been determined refractory (Morita, 2004b, Sanft et al., 2009); however this is not universal and acts as a potential reason for the variation in reported statistics for the indications for the use of sedation. A further reason is that, once again different definitions and classifications are used for individual symptoms. Morita has described this problem, and called for the use of more standardised and validated assessment tools in order to ensure that studies can be comparable (Morita et al., 2005b). Claessens et al, in their systematic review in 2008 (Claessens et al., 2008), found that 68% of the reviewed studies only described physical symptoms and of these, delirium, pain and dyspnoea were most prevalent. 27% of studies recorded the use of psycho-existential suffering alongside the physical symptoms. The terms used were: 'anxiety', 'mental anguish' and 'psychoexistential suffering' (ibid). In de Graeff and Dean's (de Graeff and Dean, 2007) literature review and recommendations, they found twenty two case series detailing the indications for sedation. Delirium and/or terminal restlessness was most frequent, in 55%, while dyspnoea, pain, nausea and vomiting were less common at 27%, 18% and 4%

respectively. Within these frequencies, however, lies again a wide range for each symptom considered to be refractory. Use of sedation for delirium for example, ranges from 14% to 91%; pain 3% to 49%; dyspnoea 0% to 63% (ibid). These wide ranges once again reflect the difficulties of interpretation and definitions used, and some terms in themselves have become the subject of investigation. Fainsinger recognised this and described the difficulties in defining delirium, terminal restlessness and agitation (Fainsinger et al., 2000a). Some group these together ('neuropsychological' (Cowan and Walsh, 2001)); others separate them, considering delirium a physical symptom, whilst considering agitation a psychological symptom (and excluding them from study for this reason) (Claessens et al., 2008, de Graeff and Dean, 2007). Some feel delirium is a more difficult symptom for which to justify the use of sedation (Elsayem et al., 2009). Delirium has many underlying causes and many suggest that it requires 'aggressive' attempts in order to determine the refractory nature of this symptom (Fainsinger et al., 2000a, Morita et al., 2005a, Leonard et al., 2008). Combining terms such as 'terminal restlessness' with delirium has been seen to perpetuate the problem as it may be considered implicit that the delirium is 'terminal' and fewer attempts made to find the underlying cause (Kehl, 2004).

Leonard's expert review of delirium in palliative care revealed a dearth of rigorous studies about delirium in palliative care, with ambiguous terminology and a failure to use validated tools of assessment (Leonard et al., 2008). This was found again in the systematic review of delirium incidence and prevalence carried out by Hosie et al (Hosie et al., 2012): of 8 studies meeting their inclusion criteria they found 8 different tools in use, only 3 of which were validated for use in palliative care. Terminology is a perpetual concern as terms frequently applied in the studies concerning sedation for this group of patients include the criticised words: 'restlessness, 'confusion' and 'agitation'(ibid). Indeed Cowan and Walsh's literature review found 14% of those sedated were described as being sedated for intractable 'confusion' (Cowan and Walsh, 2001). Within the indications cited for the use of sedation lies yet more ambiguity about what is explicitly involved and further concern about how far investigations are taken before a symptom is considered refractory.

2.5.2   Psycho-existential distress

One of the most controversial indications for sedation in the literature is its use for the relief of psychological or existential distress. Concern about the use of sedation in this area has been well documented, with some choosing to exclude sedation for psycho-existential distress from studies and others including them. This is universally considered to be more problematic than sedation for physical symptoms (de Graeff and Dean, 2007, Cherny and Portenoy, 1994, Rousseau, 2001, Morita et al., 2000). There have been many case studies, clinical vignettes and reports regarding the use of sedation for existential distress (Krakauer et al., 2000, Mount, 1994, Morita et al., 2000, Rosen, 1998, Shaiova, 1998, Taylor and McCann, 2005); however there is little consensus on how existential distress should be managed.

Existential distress has been described in a number of ways including 'mental anguish'(Stone, 1997), 'anxiety' and the term 'psycho-existential distress' (without clarification) (Morita, 2004b). 'Mental anguish' was first described in Stone's review of case notes in the UK (Stone, 1997). In this they found that of thirty patients sedated, eight were due to 'mental anguish', with the greatest number (eighteen) sedated for 'agitated delirium' (Stone, 1997). There is no further comment on this; however, the term 'anguish' is found again in Chater's survey, in conjunction with the terms emotional, psychological and spiritual distress' (Chater et al., 1998). In Morita et al's review and retrospective cohort study in 2000, they found only one out of two hundred and forty eight patients who required sedation for existential distress (Morita et al., 2000). This is in line with the study of Fainsinger in 2000 (Fainsinger et al., 2000b) where only one patient in each centre required sedation for existential distress (except Spain where the number was five). While distress, however defined, features highly in most studies in which it is included, it is rare that sedation is used solely for this reason, existing most often in conjunction with physical symptoms. Almost invariably, at least on this issue, great care and concern is advocated for the management of psycho-existential distress (Quill T. E., 1997, Braun et al., 2003, Cherny, 1998, Jansen and Sulmasy, 2002).

One cause of great concern, when considering the use of sedation for refractory existential or psychological distress, is the use of sedation for patients who are not dying. Muller-Bush found the use of sedation for psycho-existential distress to be

increasing and urged caution in this regard (Muller-Busch et al., 2003). Some authors feel that palliative sedation may ethically be used for psycho-existential distress and have outlined guidance for this (Fine, 2005, Rietjens et al., 2009a, Rousseau, 2004b, Tannsjo, 2004b). As described by Morita in 2002, the physical symptoms experienced at the end of life are frequently associated with end organ failure; psychological or spiritual distress, on the other hand, is no marker of disease. Patients may have a prognosis of months, but be suffering 'intolerably' – this level of suffering, many believe, can only be assessed by the patient themselves (Engström et al., 2007, de Graeff and Dean, 2007, Morita, 2004b). Schuman-Oliver et al (Schuman-Olivier et al., 2008) considered in depth the issue of existential distress in palliative care. Here, existential distress was categorised as acute (those who have a prognosis of less than 2 weeks), sub-acute (those with a prognosis of less than 2 weeks, if treatments were withheld or withdrawn), and chronic (death not imminent). This division was described in order to consider the potential treatment options which may be available to patients; a major determinant of this is time. In addition, the proximity to death was felt to determine different responses, with those in the acute category thought to experience more intense feelings of fear, panic and distress owing to loss of control than the sub-acute and chronic categories. In particular, those in the sub-acute category were considered to be more likely to have a sense of control, through the ability to control to some extent the end of life, through the voluntary stopping of eating and drinking, or 'palliative sedation'. Palliative sedation, in this paper, was always considered to take place without ANH. The authors considered the situations in which sedation may be used, ethically, for the treatment of intolerable existential distress. Existential distress was defined as:

> a constellation of symptoms manifesting the experience of existential suffering in the context of an individual's confrontation with a specific stage of the dying process (Schuman-Olivier et al., 2008).

The authors wanted to differentiate existential distress from existential suffering, which was believed to be experienced by many different groups of people, at any stage of life. Their definition of existential distress was to be marked out as particular because of its relationship to death. Schuman-Olivier and colleagues acknowledged previous definitions by Morita (Morita, 2004b) and Rousseau (Rousseau, 2001) and incorporated

these into their understanding of existential suffering. Rousseau's definition of existential suffering was quoted:

> various ill-defined psychological symptoms, including a sense of hopelessness, disappointment, loss of self-worth, remorse, meaninglessness, and disruption of personal identity (Rousseau, 2001).

The outcome of Schuman-Olivier's paper was the construction of a mnemonic as an aide-memoir for determining the refractory nature of existential suffering. 'TIRED' related to the following:

Time to death less than two weeks

Imminent death medically verified

Refractory to treatment

Etiological alternatives excluded

Differential diagnosis identified and treated (Schuman-Olivier et al., 2008).

This paper provided the most extensive consideration of the matter of existential distress, and one of the key features found to justify the use of sedation in this group, can be seen to be the patient's proximity to death.

2.5.3 Drugs

Many different drugs have been used with the intent of providing sedation (de Graeff and Dean, 2007, Porta Sales, 2001). Midazolam is the most commonly used, its use reported in two thirds of all studies (de Graeff and Dean, 2007). Others include levomepromazine (also known as methotrimeprazine), phenobarbitone, propofol, chlorpromazine, haloperidol and lorazepam (Chater et al., 1998). Differences in the use of different drugs may be due to legal and organisational restraints; for example in the USA difficulties in accessing midazolam have been described, leading to a higher usage of chlorpromazine than elsewhere (Elsayem et al., 2009, Hauser and Walsh, 2009). The use of opioids for sedation has also been described in some studies (Chiu et al., 2001, Hasselaar et al., 2007, Hasselaar, 2009, Morita et al., 1996, Rietjens et al., 2004b),

especially in Japan and the Netherlands. This has, however, long been discouraged and is considered to be inappropriate for use in sedation (Hasselaar et al., 2007, Reuzel et al., 2008). The use of morphine as monotherapy for sedation has become less prevalent in the Netherlands over the last 5 years since the introduction of a clinical guideline for the use of sedation (Hasselaar et al., 2007, Hasselaar, 2009), however a recent study of palliative sedation at home in Israel suggested its use as monotherapy is still prevalent in some countries (Rosengarten et al., 2009). In this study 25% of patients reported to have received palliative sedation received morphine alone.

2.6 Ethical considerations

Definitions and terminology concerning sedation are not only important in driving improvements in practice through guidelines, they form the basis of informed ethical debate. Two cardinal features of sedation appear to determine its moral acceptability: first, whether or not it is accepted that sedation may hasten death; second, whether the intent in using sedation is to relieve symptoms of distress, to induce unconsciousness until death, or in fact to cause death. Some consider this second feature to be irrelevant from a moral perspective, holding the view that if sedation causes death it ought to be considered alongside end of life decisions such as euthanasia and physician assisted suicide (Kuhse, 1997). This consequentialist view focuses therefore on the outcome of the practice rather than on the intention. Most, however, involved in the literature debate concerning sedation in palliative care, hold the intent in using sedation to be of importance in determining its acceptability and moral position. Thus two important questions must be asked before considering the moral status of sedation at the end of life. First, does sedation hasten death? Second, if it does hasten death, what is the intent behind its use? In the literature debate concerning the use of sedation at the end of life these features may be explicitly defined; more frequently, however, the nature of these features is assumed or left open to interpretation. Without an explicit outline of these features, there often appears to be an assumption that sedation does, or may, hasten death; the moral status of using sedation thus rests upon the nature of the intent in using sedation. This enables some authors to consider sedation to be morally equivalent to physician assisted death (either euthanasia or physician assisted suicide) or the voluntary stopping of eating and drinking (VSED) (Billings, 1996, Quill T. E., 1997). Others consider physician assisted death to be even morally preferable. They

consider death to be hastened by sedation and the slow process of euthanasia to be less desirable than ending life quickly through physician assisted death (Kuhse, 1997, Quill, 1997). Conversely, for those who consider the use of sedation not to hasten death, moral justification is required only on the basis of proportionality in symptom control (Morita et al., 2003b, Thorns, 2002). The principle distinction rests on these two features; the hastening of death and the intent of the action. These form part of the requirements for the application of the doctrine of double effect, upon which much of the justification and ethical debate for the use of sedation has been based.

2.6.1 Does sedation hasten death?

In the literature there is a general presupposition that death is hastened through the use of sedatives and opioids (Billings, 1996, Douglas, 2008, Jackson, 2002, Portenoy, 1996, Quill T. E., 1997, Quill et al., 2000a, Sykes, 2008). This is the case not only in medical literature but also amongst the general population (Portenoy et al., 2006, Sykes, 2008). Initial descriptions of the practice of 'terminal sedation' indeed asserted this as a feature of its use. Billings, for example, was clear about the nature of the use of terminal sedation as he described:

> In a stuporous state the patient can no longer eat and drink, dehydrates to death, if it's taking too long the morphine drip is increased until there is a quicker death (Billings, 1996).

It was clear to Billings and to others that sedation hastened death. The available evidence, however, does not support this assumption (Chiu et al., 2001, Fainsinger et al., 2000a, George and Regnard, 2007, Morita et al., 2001b, Rietjens et al., 2008, Sykes and Thorns, 2003a). Studies which have reported on the survival of patients after receiving sedation at the end of life have been carried out. These have been conducted using different methodologies and thus comparison between studies is difficult. In particular, interpretation of the term 'sedation' varies with some considering this to mean the use of sedative drug to induce unconsciousness, while others mean simply the use of sedative drugs, regardless of effect. Some studies have been retrospective and used an estimation of the prognosis of patients (Rietjens et al., 2004a), while others have looked at survival from admission in sedated and non-sedated patients (Sykes and Thorns, 2003a). None has demonstrated a significantly shorter survival in sedated

patients. Indeed the only study to demonstrate a statistically significant difference showed that patients who were sedated for a period longer than a week survived longer than those not sedated, and also longer than those who were only sedated for the last 48 hours of life (ibid). There were many variables in this retrospective study, including the drugs and doses used, and the condition of patients before having sedative drugs. While there are no studies which provide evidence that sedation hastens death, equally there are none which provide clear evidence, which can account for variables, that sedation does not hasten death. Nonetheless, some descriptions of practice in the literature do suggest that sedation may hasten death (Anquinet et al., 2011, Claessens et al., 2011, Rietjens et al., 2004b). Once again, different practices of using sedation abound, with widespread international variation (Fainsinger et al., 2000b, Rietjens et al., 2004a, Sykes and Thorns, 2003b). It appears that certain practices of using sedation, such as CDS, may hasten death, while others may not. The answer to the question of whether or not sedation hastens death depends on which practice of sedation is being considered. Perhaps the more nuanced question of whether sedation *may* hasten death allows a more useful account of the moral nature of sedation at the end of life.

Sedation at the end of life may be considered to hasten death when artificial nutrition and hydration (ANH) are, as part of the normal practice of sedation, withheld or withdrawn. While there may be a separate decision that this is the appropriate action to take, the automatic withholding or withdrawal of ANH may be considered to cause a patient to dehydrate or starve to death (Craig, 2004, de Graeff and Dean, 2007). This has been addressed in guidelines advising that the decision to use ANH ought to be independent of the decision to use sedation (Cherny et al., 2009, Dean et al., 2012, de Graeff and Dean, 2007, Verkerk et al., 2007). An interesting distinction is found in the Dutch national guidelines for the use of palliative sedation. This suggests that 'in general' fluids should not be given to a deeply sedated patient (Verkerk et al., 2007). This is based upon the expectation that a patient who is deeply sedated should have no more than two weeks left of life, and that by the time they are deeply sedated they would naturally have stopped drinking; thus they are not considered to have dehydrated to death as a direct cause of the withholding or withdrawing of ANH (Verkerk et al., 2007). While this forms part of the Dutch national guidelines, international guidelines consider the decisions to use sedation and to use ANH at the end of life to be separate decisions (Cherny et al., 2009, de Graeff and Dean, 2007).

Even when the decision to withhold or withdraw ANH is considered separately to the decision to use sedation, there remains a concern about the possibility of hastening death through the use of drugs which may remove consciousness. A distinction is established between those who *intend* to hasten death and those who do not. Those who intend to hasten death through the use of sedation, when voluntary, may be considered to practice euthanasia. Euthanasia may be defined as:

> A doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request (Materstvedt et al., 2003).

When sedation is used with the intention of hastening death in the absence of a patient's 'voluntary and competent request', the practice is either non-voluntary euthanasia (when a patient is unable to consent, and this is recognised to be a valid distinction), or murder. It is not the intention or within the scope of this thesis to consider further the question of euthanasia, rather to consider in outline the moral nature of sedation based upon definition and exploration of terms. This is in order to set out the position of the practices of sedation when considering the results of the study of sedation in a UK hospice.

2.6.2   What is the intent in using sedation?

Those who believe sedation may hasten death, but consider the intent not to be to cause this directly, frequently appeal to the doctrine of double effect. Many commentaries and discussions about sedation have concentrated solely on a critique of this (Boyle, 2004, Quill, 1997, Williams, 2001); indeed , this reliance on one moral framework has been criticised (Billings and Churchill, 2012). Some believe it to be a flawed doctrine which cannot be applied to sedation in palliative care (Billings, 1996, Billings, 2011, Quill, 1993); others believe it is not required as death is not hastened (de Graeff and Dean, 2007, George and Regnard, 2007, Sykes and Thorns, 2003a), while others still defend its use when considered appropriately (Rousseau, 2004a, Schuman-Olivier et al., 2008, Sulmasy and Pellegrino, 1999). In brief, the doctrine states that where an act is morally good or at least indifferent, it is permissible that a bad consequence can occur as a side effect, provided that what is intended is the good effect and the means to that effect is not achieved through the bad (side) effect. In addition to this the act must be proportional in two respects: first, there must be adequate reason to harm and, secondly,

the harm must only be required when there is no alternative but to so act (McIntyre, 2004).

Much discussion about the applicability of this doctrine to the use of sedation at the end of life has taken place in the literature. In many of these papers death is assumed to be a 'bad' effect. This has, however, been disputed (Allmark et al., 2010). Allmark et al argue that when a patient is acknowledged to be dying, death may be anticipated and desired, rather than fought: a patient may have accepted their death and be 'ready' to die. In this situation death is not considered to be a 'bad' effect; rather may be sought. This does not require death to be hastened for it to be good, merely is not considered a 'bad' outcome. In this way Allmark et al have argued that the doctrine of double effect is not applicable in the situation of using sedation at the end of life, where death is not considered to be 'bad'(ibid). A further way in which death may not be considered to be bad, in the terms of the doctrine of double effect, arises if one considers that death ought, in fact, to be hastened when there is no meaningful life left to be lived: if the remainder of life is to be 'lived' either suffering or unconscious, it is not a life worth living and thus the imperative becomes in fact to bring death forward. This is the argument advanced by Kuhse: it is *more* morally right to hasten death and relieve suffering than it is to allow continued suffering when there is no meaningful life left to be lived (Kuhse, 1997). Sedation to unconsciousness in this circumstance is not an alternative to relieve suffering until death, it is a less morally acceptable act because death is not to be delayed or even allowed to take place 'naturally', rather it *ought* to be brought forward to relieve suffering where there is no hope of recovery.

In the majority of the literature concerning the doctrine of double effect and its application to use of sedation at the end of life death, has been considered a 'bad' effect. A further understanding of what is interpreted as 'good' still must be explored.

If death is to be avoided and is considered to be a 'bad' effect, yet is *foreseen*, for the doctrine of double effect to be valid in a particular instance of sedation, sedation must be considered 'good': or at least the effect of sedation must be considered good. Once again, terminology is important. If sedation means simply the use of sedative drugs, without an implicit requirement for consciousness to be reduced significantly, or even completely, it may be that sedation can be used to relieve symptoms without inducing complete unconsciousness, or coma. If sedation is simply the use of sedative drugs

used proportionally in relation to symptom severity, consciousness may not be affected. Symptoms may, however, be so severe or intense that their relief *requires* unconsciousness or near-unconsciousness: in this context the relief of symptoms may still be considered the good effect to be sought. Alternatively, unconsciousness may be the good effect to be sought. There is an important distinction, subtly recognised in the literature, to be delineated here. Sedative drugs may be used with the intention of treating symptoms, proportionally in relation to the intensity of symptoms experienced; this may include the use of sedative drugs to treat symptoms even to unconsciousness, if this is the only state in which a patient obtains relief from symptoms. The intent is to treat symptoms. Alternatively, sedative drugs may be used with the intent of causing unconsciousness; the good to be sought, in the terms of the doctrine of double effect, is unconsciousness. This, indeed, appears to be the explicit intention behind the use of continuous deep sedation, described earlier.

This distinction is important when considering the final requirement of the doctrine of double effect: proportionality. The use of sedative drugs at the end of life to treat symptoms may be considered to be proportional to the symptoms experienced and to the imminence of death (Schuman-Olivier et al., 2008). This requires that the symptoms experienced by a patient are sufficiently severe to warrant the response of using sedative drugs, and suggests that the imminence of death carries an additional weight, requiring action to prevent further suffering. The use of sedative drugs is described in the literature as being used proportionally when sedative drugs are used according to the extent demanded by symptoms, including the use of drugs to cause unconsciousness, when this is the only way in which to achieve symptom control (Cellarius and Henry, 2010). The use of sedative drugs to induce unconsciousness, as the primary intention, is also described (Miccinesi et al., 2006, Quill et al., 2010, Reid et al., 2010, Rietjens, 2008). Some consider this to remain a proportional response (Quill et al., 2010), while in other studies this is less clearly defined (Miccinesi et al., 2006, Rietjens, 2008) and may indeed be considered disproportionate if death is not imminently expected (Verkerk et al., 2007). If sedative drugs are used in a situation in which death is not imminently anticipated, (frequently cited as being anticipated in less than two weeks) (Braun et al., 2003, Cowan and Walsh, 2001, de Graeff and Dean, 2007, Quill et al., 2000a), concern arises that a patient may be sedated without ANH and dehydrate or starve to death (Verkerk et al., 2007). When hastening of death is to be avoided, the

anticipated imminence of death is important in contributing to an assessment of the proportionate response of using sedative drugs. Thus for a proportionate response to severe symptoms to be justified, both the use of drugs to achieve the relief of symptoms, and anticipated imminent death, are required.

This is mirrored in the many definitions and guidelines for sedation, requiring a patient to have a terminal illness before considering sedation. As described above, the use of sedation for existential distress brings this into sharper focus (Morita et al., 2002b, Muller-Busch et al., 2003, Schuman-Olivier et al., 2008). Without exception guidelines refer to the use of sedation in patients with a short prognosis (Berger, 2010, Blanchet, 2002, Braun et al., 2003, Cherny and Portenoy, 1994, de Graeff and Dean, 2007, Hawryluck et al., 2002, Rousseau, 2001, Verkerk et al., 2007). This is described in various ways. Terms such as 'end stage disease' (Blanchet, 2002), 'patient…close to death' (Braun et al., 2003), 'advanced cancer' (Cherny and Portenoy, 1994) 'terminal illness' (Rousseau, 2001) and 'imminently dying patient' (Verkerk et al., 2007) are typical. This proximity to death is considered important in justifying its use on the basis of proportionality. Several authors have indeed highlighted the importance of proportionality in the consideration of the practice of sedation, especially in contrast to a reliance on the doctrine of double effect (Claessens et al., 2011, Quill et al., 2009, Reid et al., 2010, Rady et al., 2011). In a recent prospective longitudinal study Claessens et al indeed considered the principle of proportionality to be of central importance in understanding and using sedation (Claessens et al., 2012). They found for the first time evidence that sedation evolved over time, in keeping with the level of a patient's reported distress and suffering. While 70% of sedated patients received benzodiazepines and neuroleptic drugs before palliative sedation was commenced, these caused no reduction in consciousness; in contrast palliative sedation, when commenced, caused a reduction in consciousness, to somnolence or to coma. The interpretation of the intent of using sedation was thus distinguished in this study, between intent to reduce consciousness, or intent to relieve symptoms. This is an important distinction which is explored throughout my research presented in this thesis. Thus far, the application of the DDE to the use of sedation at the end of life has been considered in relation to its good and bad effects, and to its proportional nature. In the literature, however, most attention concerning the DDE has rested upon the nature of intention and foresight. Those who consider the doctrine of double effect to be insufficient or flawed

comment particularly on two aspects of the doctrine: whether it is possible to know one's intention and, if it is, how far one can distinguish between what is foreseen and what is intended (McIntyre, 2004, Quill, 1997). Whether one can foresee that a patient may die as a result of using sedation, but not intend it, has been contested (McIntyre, 2004, Quill, 1993, Quill, 1997). A small qualitative study demonstrated that physicians were unable, or were reluctant, to make this distinction (Douglas, 2008); yet this distinction is required when invoking the doctrine of double effect in justifying clinical practice. Despite this, it is argued that it is indeed possible to foresee and not intend death (Boyle, 2004, Forbes and Huxtable, 2006, Sulmasy and Pellegrino, 1999). Morita et al attempted to assess objectively the ethical concerns of palliative sedation in a multicentre trial (Morita et al., 2005c). In this, prospective observational study carried out in 21 palliative care institutions, physicians were asked to complete an investigation sheet for any patient who received continuous deep sedation. The authors sought to determine the ethical validity by examining objectively how far clinical practice went in satisfying the concepts of autonomy, proportionality and the doctrine of double effect. Autonomy was assessed by determining the proportion of patients or family who gave consent for sedation. That sedation was proportional was assessed by considering whether a patient had expressed intolerable suffering, refractory symptoms, and whether the patient's general condition was poor. The intent of physicians was acknowledged as being difficult to determine, however measures such as the gradual administration of the lowest possible dose of sedatives to relieve symptoms, as well as the documentation of reasons for not using ANH, were considered. They found that sedation was administered predominately in low doses and gradually increased, according to symptoms. Artificial fluids were not automatically removed, indeed a third continued to receive, or were commenced on, artificial fluids once sedated. The majority of patients had expressed the intolerability of symptoms and, relating particularly to physical symptoms, they were deemed to be refractory. They found, however, that over half did not receive the required standard of treatment for psychological symptoms prior to sedation. Two thirds of patients and all family members consented to the sedation; cognitive impairment was the predominant reason for not gaining consent from patients. They concluded that palliative sedation therapy 'generally' followed the principles of double effect, proportionality and autonomy.

While Morita et al and others (George and Regnard, 2007, Sykes and Thorns, 2003a), have attempted to objectively assess intent, some consider intent to be beyond even one's own knowledge (Boyle, 2004, Quill, 1993). Others, however, consider intent to be objectively identifiable to some extent; indeed citing this to be well demonstrated in law (Boyle, 2004, Gillick, 2004).

If one accepts that sedation may hasten death, and that it is possible to foresee but not intend this, sedation may be justified by the doctrine of double effect: when death is considered undesirable, and relief of symptoms desirable; when causing death is not the desired outcome but rather control of symptoms is; and when sedative drugs are used to treat symptoms with consciousness reduced only to the degree required to bring about the relief of symptoms and when death is imminently anticipated.

Instances of sedation may not match these requirements, of course. As described above, death must be considered undesirable; if death is considered desirable the DDE cannot be invoked. Intending to induce unconsciousness may not fulfil the requirements of proportionality, if symptoms could be sufficiently treated at a lower dose of the sedative drug. Death may be hastened through the use of sedation in a situation in which it was not intended, nor foreseen. For example, if a patient was anticipated to be imminently dying, and their symptoms treated proportionally according to this expectation, and to the severity of symptoms, death could be hastened with neither intention nor foresight. In this situation, where the intent in using sedation may be seen to be proportional both to symptoms and to anticipation of imminent death, even if wrong, the hastening of death may be considered to be morally acceptable because the *intention* was to relieve symptoms and to act proportionally, yet the DDE would not be applicable.

In clinical practice, if sedation is used with the acceptance and understanding that it may hasten death as an unintended but foreseen effect, where death is a 'bad' effect to be avoided and relief of suffering (if necessary to unconsciousness) is a good effect, in the context in which there are severe and irreversible symptoms causing distress and a patient is imminently dying, sedation with the reduction of consciousness may be justified using the doctrine of double effect. I would suggest, however, that in daily practice, the requirement of foresight may not be present, and rather than the doctrine of double effect, the use of sedation at the end of life may rely upon proportionality when used in such a way in which death may, *unintentionally* be hastened.

Intent has been seen to be of central importance in determining the moral nature of sedation at the end of life. A series of studies conducted predominately in the Netherlands and Belgium have considered physicians' intent in end of life decision-making, including decisions regarding sedation. These are described in the final section of this chapter.

2.7 End of life decision-making

In the many studies which have investigated medical decision-making at the end of life, the intent behind decision-making has been considered (Bilsen et al., 2007, Deliens et al., 2000, Onwuteaka-Philipsen et al., 2003, van der Heide et al., 2007, van der Maas et al., 1991, van der Maas et al., 1996). Indeed one of the central questions in the very first study to investigate end of life decisions, in 1991, considered whether decisions were made not to treat (e.g. by withdrawing or withholding ANH) or to use high doses of drugs with the intent of hastening death (van der Maas et al., 1991). In addition, these studies have considered the possibility of a 'partial intent' to hasten death. These have been important concepts in the studies and have influenced the debate about sedation, especially when there have been reports of sedation with the intent of hastening death (Rietjens et al., 2004b). Rietjens et al's 2004 study prompted much discussion in scholarly journals for a number of reasons (Gillick, 2004, Glick, 2004, Rietjens et al., 2004b, Zylicz, 2004). The deliberate hastening of death through the use of terminal sedation, rather than euthanasia led some to consider that it might be considered preferable, or as an alternative to euthanasia (Gillick, 2004, Zylicz, 2004). This hypothesis was later strengthened by evidence that in the Netherlands, the rate of euthanasia was reduced significantly while the use of terminal sedation increased (Rietjens et al., 2008). Another concern was that patients were not able to give consent in 41% of cases, due to incompetency or being in a coma in the majority; however, other reasons cited included: 'deep sedation was clearly in the best interest of the patient'; 'patient had dementia'; and 'discussion would have done more harm than good' (Rietjens et al., 2004a). While the involvement of surrogates was reported to have taken place in 93%, the practice of sedating in the way described above, without consent has, appropriately, been called 'involuntary euthanasia' (Gillick, 2004). In addition to this it was suggested that there may have been 'ethically preferable alternatives' to the use of sedation, implied in Gillick's editorial by the infrequent

referrals to palliative care and the high number of patients sedated for inadequate pain control (ibid).

Rietjens et al concluded that, in the limited number of cases where it occurs, when a physician administers terminal sedation with the explicit intent of hastening death by withholding or withdrawing ANH, this 'approximates' euthanasia (Rietjens et al., 2004a). In cases where there was no intent on the behalf of the physician to hasten death, the authors considered it not to be a medical end of life decision, as defined in the earlier Dutch studies as (i) euthanasia (ii) alleviating pain or other symptoms with the probability of hastening death or (iii) a non-treatment decision (e.g. the withholding or withdrawal of ANH) (ibid). It can be assumed, therefore, that if terminal sedation was only the use of CDS without ANH, the intended life shortening effect would be viewed by Rietjens and colleagues as euthanasia, while the foreseen but not intended life shortening effect would not. Once again the issue of intent was regarded as crucial.

Further important research studies looking at end of life decision-making have emerged from the Netherlands (Onwuteaka-Philipsen et al., 2003, van der Heide et al., 2007, van der Maas et al., 1991, van der Maas et al., 1996), and Belgium (Bilsen et al., 2007, Deliens et al., 2000), and also in a study considering a comparison of six European nations (van der Heide et al., 2003). In addition, the same questionnaire has been used in studies in Australia (Kuhse, 1997) and New Zealand (Mitchell and Owens, 2003), and also in the UK (Seale, 2006b, Seale, 2009a), however using a slightly different methodology as dictated by national differences in the practice of death registration. In the Netherlands, 5 year follow up surveys have allowed a comparison of practices of medical end of life decision-making over a period of 15 years. Major developments and changes over this period of time have been found relating to the use of sedation. Questions about sedation were first incorporated into the research questionnaires in 2001 (Bilsen et al., 2007, van der Heide et al., 2007) but were reported later, when comparisons could be made to demonstrate changes in practice. In 2007 van der Heide et al published a follow up study from 2005 on end of life decision-making, with the same methods of data collection as in 1991, 1995 and 2001 (van der Heide et al., 2007). In 2001 a question about the use of sedation had been added which was:

> was the patient continuously and deeply sedated or kept in a coma before death? (ibid)

They found that 8.2% of respondents reported using this form of 'continuous deep sedation' (CDS) and in 7.1% this was done in 'conjunction with decisions that possibly hastened death, such as decisions to withhold nutrition and hydration'. This was reported to have increased since first asked in 2001, from 5.6% to 7.1% (ibid). Rietjens et al, later commenting on this increase in 2008 (Rietjens, 2008), considered that the other significant change in this time period had been a decrease in reports of euthanasia from 2.6% to 1.7%. The incidence of CDS has continued to rise as follow up studies have been published; the incidence of CDS rose from 8.2% in 2005 to 12.3% in 2010 (Onwuteaka-Philipsen et al., 2012). The relationship of CDS to euthanasia continues to cause concern as euthanasia has become less frequent and CDS more frequent. Avoidance of the legislative requirements for euthanasia has been a perpetual cause of concern, especially as the use of sedation with at least a partial intent to hasten death approaches 20% in some studies and higher in a recent small interview study (Anquinet et al., 2011, Onwuteaka-Philipsen et al., 2012). Although other studies have considered there to be differences between the groups of patients who are treated with CDS and those who choose euthanasia (van der Heide et al., 2007), there was the suggestion that Dutch physicians may be favouring the use of sedation over euthanasia (Rietjens, 2008). Additionally, 9% of deaths preceded by a decision to use CDS followed a request for euthanasia; the most common reason for this not being granted was insufficient time. In 9% of cases in which euthanasia had initially been requested, the request for euthanasia had been withdrawn and CDS was used in its place (ibid). Considering that most deaths from CDS occurred alongside a decision which would 'possibly' hasten death, the hypothesis that physicians may be favouring the use of CDS perhaps had some grounding. In Belgium, a study using the same methodology found 8.2% of respondents reported using CDS prior to death, with 3.2% using it without ANH and in 3.6% it was undertaken with the intent to hasten death (Bilsen et al., 2007). In a study carried out by the EURELD consortium, a similar questionnaire was disseminated to physicians in 6 other European countries (van der Heide et al., 2003). Concerning the question about the use of CDS, as defined above, the countries using this most frequently were Italy and Belgium, with 8.5% and 8.2% of deaths, respectively, involving a decision to use CDS. Sweden and Denmark had the lowest frequency of use, with 3.2% and 2.5% respectively. The Netherlands and Switzerland reported a decision to use CDS in 5.7% and 4.8% of deaths, respectively. The decision not to use

ANH was most frequently reported in the Netherlands and Denmark with 64% of those sedated not receiving ANH while this was true in only 35% of deaths in Italy (ibid).

In the UK, two similar studies have been undertaken by Seale, published in 2006 and 2009 (Seale, 2006b, Seale, 2009a). The study published in 2009 was the first to include a question about sedation and the same wording was used as in the Dutch and other European studies (Seale, 2009a). Of UK physicians, when considering the most recent person to have died under their care within the previous 12 months, 16.5% reported that they used CDS. This figure was remarkably high in comparison to other European countries, almost twice that of the Netherlands at the time. The intent of the use of sedation was not reported in this study. Considering the alleviation of symptoms with the possibility of hastening death, or non-treatment decisions (withholding or withdrawing treatment), however, the intent to hasten death was considered a small fraction of the total number of decisions made. The majority acknowledged the potential to hasten death without direct intent. Physicians working in hospital specialties reported using CDS most frequently, with palliative medicine physicians and GPs reporting the next most frequent use (Seale, 2009a). In the Netherlands a similar pattern has been seen, with those in hospital specialties reporting the highest use of CDS and those who would most frequently care for patients at the end of life, GPs and nursing home physicians, reporting it as a less commonly used practice (van der Heide et al., 2007). One of the factors which has been linked to the inappropriate use of palliative sedation has been inexperience as well as burnout and fatigue (Maltoni et al., 2009, Morita et al., 2002a). A related aspect of this was noted in the ethics committee of the Association for Palliative Medicine (APM) response to Seale's paper (Grogan et al., 2009). They remark on the concerning feature of Seale's paper relating to those in hospital specialties 'other than palliative medicine' reporting the highest rate of decisions involving the alleviation of symptoms with 'possible life shortening effect' (ibid). This they attribute to misconceptions about the use of sedatives and opioids at the end of life.

These studies have provided important international data regarding the use of sedation at the end of life. They provide large-scale data about physicians' intentions in using sedation at the end of life. Just as the objective evidence regarding intent could not address fully the intent behind physicians' actions, these studies cannot demonstrate the actual outcome of the physicians' intent. In other words, that a physician intends to

hasten death through the withholding of ANH does not necessarily correlate with the hastening of death: in contrast to euthanasia the causal link has not been demonstrated (Seale, 2009b). All of these studies asked physicians to recall cases of up to 12 months previously; in the Australian, UK and New Zealand studies this was through asking them to recall the last patient who had required sedation. The tendency to remember 'memorable' cases is acknowledged, and this recall-bias may be responsible in part for the high rate of CDS found in the UK study (Seale, 2009a, Seale, 2009b, van der Heide et al., 2009). In addition, criticisms of these studies concern the 'fallacies' which are thought to exist in the perceptions of physicians regarding decisions which are made at the end of life (Ashby, 1997, Forbes and Huxtable, 2006, George and Regnard, 2007). These lie, in particular, in the (mis)understanding that death is hastened through drugs such as opioids; but fallacious thinking may also emerge in the (mis)understanding and (mis)interpretation of phrases such as:

was the patient continuously and deeply sedated or kept in a coma before death? (Seale, 2009a)

Misconceptions about the end of life, especially the life shortening effects of drugs, are highly prevalent (Sykes, 2008). This may prove to limit the extent to which these studies can be seen to be representative of the way in which deaths actually occur, rather than are thought to occur.

2.8 Conclusion

This chapter has considered the literature and research base for the use of sedation in palliative care. While the research is limited in many respects, and the desired 'multicentre, prospective, longitudinal, international' (Claessens et al., 2008) study has not been carried out, much progress has been made and studies are indeed underway (Seymour et al., 2011). A clearer sense of terminology and definition has been determined, with 'terminal sedation' largely being reserved for cases in which continuous deep sedation is given without artificial nutrition or hydration. The broader term of 'palliative sedation' can be seen to include a range of different uses of sedation, from continuous deep sedation, to intermittent light sedation. This remains a concern if palliative sedation is to be used as an umbrella term and not further classified for the purposes of research studies. That all types of sedation are included in research studies

is important to emphasise as the context in which these treatments are given provides a perspective on the sorts of decisions and practices which take place at the end of life (Broeckaert et al., 2009). Assessing the intention in the use of sedation is the most difficult area of the literature to assess. It is recognised to be one of the most important, not only in clinical practice, but from ethical and legal perspectives too. Problems have been demonstrated in both the use of prospective observational studies relying on quantitative data to determine intent, as well as the use of large-scale survey data to determine the subjective nature of intent although the direct influence has yet to been formally examined.

Few studies have been conducted in the UK, with much of the literature arising from European countries where physician assisted dying is legal. Many studies regarding medical end of life decision-making are conducted within a different legislative and social context to that of the UK; this may have an impact on the applicability of these research studies for UK end of life decision-making. As discussed in Chapter 1, the UK approach to end of life care is directly linked to the hospice movement, as palliative care has developed from this. The principles, or philosophy, of palliative care in the UK are considered to underlie its practices (Doyle, 2010), although this direct influence has not been formally examined in research. This is, however, considered in the final chapters of this thesis as I consider the influences driving the clinical practice of using sedation at the end of life. Chapter 8 considers the impact of this influence on the clinical practice of sedation at the end of life, reflecting on these first two chapters and the data presented in chapters 4 to 7.

The research project described in the following chapters addresses some of the issues raised regarding palliative sedation. Through participant observation and interviews the study describes the way in which decisions are made. It is concerned with how decisions about sedation are made, the intentions behind its use, as well as the direct observation of the indications and effects of sedation on staff. This research is able to combine the direct observation of practice with observations of discussions taking place around this, as well as incorporating interviews with those involved in sedation. A more detailed description of the study is provided in Chapter 3.

Chapter 3 Methodology and Methods

This chapter introduces the research study, conducted in an inpatient unit of a hospice in England. The purpose of this chapter is to provide as full a picture as possible of the structure of this study. This includes the underpinning methodological assumptions as well as details of the research methods employed. The aim is to enable a full understanding of the research context in order to allow an assessment of the 'trustworthiness' (Lincoln and Guba, 1985) of the study and to facilitate reading of the subsequent chapters. First I introduce the research methodology and underpinning assumptions; second I introduce the research methods and key concerns arising from these. Third, I describe the research environment and daily routine at length to allow an understanding of the structures within which the research was conducted. The methods of participant observation and in-depth interviews are then discussed before, finally, the data analysis strategies are presented.

3.1   Research Methodology

The aim of this study is to explore how sedation is used in palliative care and develop a normative understanding of this practice. The methods are ethnographic and include participant observation and in-depth qualitative interviewing. These methods are based upon some important epistemological and methodological assumptions, some of which were explicit from the start of the research; others have been developed through the research process. The four principle objectives of this research study are:

- to understand and describe how 'sedation' is defined in the literature and in practice

- to understand how the practice of sedation reflects thoughts about its indications, the intentions behind it and attitudes towards it

- to develop a normative understanding of the practice of sedation

- to examine how sedation relates to the broader aims of palliative care

These are generated from assumptions about how knowledge is created. This study takes a social constructionist approach to the generation of knowledge, considering knowledge about this subject as residing not in a single, discoverable form but rather as

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a construction: created through shared meanings, constantly interpreted and reformed by human, or social, interaction (Charmaz, 2006: 127). This moves beyond the epistemological position of constructionism to attend to some theoretical assumptions about ways in which this knowledge can be accessed, namely through:

> the culturally derived and historically situated interpretation of the social life-world (Crotty, 2003: 67).

These approaches are most strongly embedded in the second objective which asks about attitudes and intentions. If we are to understand the normative practice of sedation in palliative care through studying attitudes and intentions of participants, we must assume the following: first that this knowledge is in fact accessible and, secondly, it is valid as a method of forming knowledge. These assumptions are supported by the theoretical perspective of symbolic interactionism, embedded within an interpretivist approach, inspired by G. H. Mead and codified by Blumer (Atkinson and Housley, 2003: 3) . Here, the 3 basic principles of Blumer are adopted:

- Humans act towards things on the basis of the meanings they hold for them

- The meaning of such things is derived from the social interaction one has with others

- These meanings are modified through an interpretive process (Blumer, 1969 : 2)

This gives an account of meaning as being central to understanding social action, that meaning arises through the process of social interaction and, crucially to symbolic interactionism, the use of meanings is formed through an interpretive process (Blumer, 1969: 2-4). At the heart of symbolic interactionism is the use of 'significant symbols', or use of language and other tools of communication through which meaning is conveyed. Indeed Crotty states:

> only through dialogue can one become aware of the perceptions, feelings and attitudes of others and interpret their meanings and intent (Crotty, 2003: 75).

These principles are seen to guide an approach to understanding and framing the research methodology and thus the research methods and data collection. They form a theoretical perspective whereby, through participant observation, I can observe the

'significant symbols' of language and gesture in relation to sedation and, through a process of interpretation, gain an understanding of their meaning. Reflexivity is crucial in this process. This can be considered as the act of turning in on oneself: considering one's influence on a social interaction or, in research terms, the researcher's awareness of his or her own relationship to the research situation and effect upon it (Aull Davies, 2008: 7). For the symbolic interactionist, failure to recognise one's influence may lead to the setting up of a 'fictitious world' (Blumer, 1969 : 51). Engagement in this process is therefore considered to be crucial in order to avoid such a position and underpins the research process described below.

3.2   Research setting

This study was designed to take place the inpatient unit of a hospice. Hospices have been studied through ethnographic methods previously (Dean and Gregory, 2004, Lawton, 2000) however not with the intention of examining the practice and attitudes towards sedation. The hospice selected was local to me and a site where one of my supervisors held a senior clinical role. There were pragmatic reasons for choosing this research site in that it was likely that the initial access would be possible and it was a site where, at least in theory, research would be supported. This was known through both my previous personal experience and the close links with my supervisor in his working relationships with other members of staff. Additionally, having a supervisor on site helped both to negotiate access and to provide safeguards when considering potential problems in carrying out research in a sensitive context. The hospice inpatient unit has 22 beds and patients are admitted for a range of different reasons and conditions. While the majority of patients have a malignancy, patients with neurological conditions, heart failure or chronic respiratory conditions may also be admitted. Admissions may be for a fixed period of time (short planned admission – SPA- or 'respite') or more open-ended, with the focus on treating symptoms until they are controlled. Some patients are referred for end of life care and will die during their admission; others are referred for symptom control and may be effectively treated and discharged. Alternatively those referred for symptom control may deteriorate and die during their admission whereas those referred for end of life care may in fact be discharged.

The hospice was purpose-built with the inpatient unit on one floor. There are three four-bedded rooms and twelve single rooms. It has a day care unit which runs during the week; patients come into the hospice for part of the day, share stories, engage in activities, physiotherapy, complementary therapies, or see a doctor if they wish. Many patients admitted to the inpatient unit have attended day care in the past and are known to staff through the close links between day care and the inpatient unit.

The staff in the hospice include: healthcare assistants, staff nurses, nurse practitioners, junior doctors on training contracts (rotating through the hospice as part of more general training, e.g. in general practice), registrars training in palliative medicine, consultants, social workers, physiotherapists, occupational therapists, children's worker and complementary therapists. All of these groups may be represented on the inpatient unit in different numbers – clearly those represented in the greatest number are nurses and doctors. For the purposes of maintaining confidentiality, they have been grouped, in the data sections of this thesis, into larger groups of nurses, doctors, and allied health professionals. Seniority of nurses or doctors is indicated where relevant, but the overriding concern in the presentation of the data is to protect confidentiality.

On the inpatient unit, nurses are divided into two different 'teams' or 'sides'; the Don and the Dee (fictional names) teams. On arrival to the hospice patients are allocated to a team. This is largely geographical – the ward is arranged in an 'L' shape where one arm is the Dee side, the other the Don. Nurses for one side would look after the patients on their side and not be involved in the other side unless it was necessary. Generally, nurses would be a 'Don' or a 'Dee' nurse and would expect to be on this side for every shift. On average there would be two 'qualified' nurses and two 'unqualified' nurses on each side; falling to one of each overnight. Staffing levels of nurses were problematic during the period of observation, with several recent departures and absences due to sick leave. This meant that frequently nurses would switch between the Dee and the Don side, depending on where there was greatest need. In addition, the number of qualified nurses was often reduced and this created practical concerns about both care for patients and the ability to dispense drugs. This also led to some bed closures during the period of observation.

There were two consultants with clinical responsibility for patients on a day to day basis. Many other consultants did out of hours 'on-call' work, in the evenings and over

weekends. There was considerable restructuring of senior medical cover during the study period, with two senior members of staff leaving, some interim cover and a period of significant uncertainty. Registrars training in palliative medicine changed over on average every six months, with some staying on for longer periods. Some would be in the hospice on a full time basis but most spent only part of their working week in the hospice, with some only spending one morning or afternoon session based in the inpatient unit. Junior doctors training in General Practice would also change over every six months, but would change at a different time to the registrars. They would either be part time (spending two to three days in the hospice) or full time. Thus doctors would be present on the ward every day, in varying numbers and levels of seniority. Consultants, like nurses, looked after one side of the ward – the Don or the Dee. They were responsible for all of the patients' care on their side. Unlike the nurses they did not change sides frequently but would be called upon to 'cover' in periods of absence. Consultant ward rounds occurred once a week, with more regular 'catch ups' occurring through the week, or if there were patients about whom the junior doctors were concerned.

In addition to the consultant ward rounds, medical 'handovers' of patients occurred regularly. Nursing handovers occurred at 0730, from the night shift to the early shift. Representatives from the nurses on the morning shift would then handover to the doctors, social workers, physiotherapists, occupational therapists and sometimes ward or unit manager at 0930. Planning of admissions would occur at this meeting in addition to handing over anything which they felt the assembled group needed to know or to action. Further handovers occurred between nurses from the early shift and those on the late shift, and again from the late to the night shift. In general these handovers lasted approximately half an hour. In addition, once weekly multidisciplinary team (MDT) meetings were held with all professions represented. These 'MDTs' were held separately for the Dee and Don team, so approximately eleven patients would be discussed over the course of an afternoon. The scope of these meetings was much broader and focused more on non-medical aspects of care, the impact of a situation on family and on discharge planning.

3.3   Research ethics approval

Having established the nature of the study to be carried out, and considered the methods and theoretical perspectives, approval was sought from the regional research ethics committee (REC) and the research and development (R&D) department of the NHS trust sponsoring the research. There have been many perceived barriers and ethical concerns about undertaking research on palliative care patients (Duke and Bennett, 2010). These ethical concerns have been summarised into five broad groups concerned with: patient vulnerability; the moral acceptability of carrying out research in this group of patients; gaining informed consent; barriers such as gate-keeping and finally; having a research structure in place to support research in this context (Duke and Bennett, 2010). Ethical issues and methodological concerns have been considered by researchers to be inextricably linked (Seymour et al., 2005); it is important to emphasise at this stage that I share this view and as such ethical concerns are considered to be an integral part of this research methodology.

Major ethical consideration was given to two particular aspects of this research:

- consent process for patients

- access to patients who lacked capacity

3.3.1   Consent from patients

This study sought to use the methods of participant observation and qualitative interviewing to gain an account of sedation in palliative care. Participant observation involved predominately an observation of clinical staff as they performed their daily tasks in caring for patients. Crucial to this study was that I could gain access to patients, to include them in the observation through their interactions with clinical staff. In this way I could witness the discussions taking place with regard to sedation rather than receive a second hand account after the event. One perspective considered was that patients were not necessarily the focus of the observation: rather the clinical staff were and it was their intentions and interpretations which I sought to access. In this way I could have argued that consent was not required from patients at all. Indeed Julia Lawton, in her study of patients in a hospice, used an 'opt out' approach whereby patients were given information about the research by staff members and could opt out

if they wished (Lawton, 2000: 31). She acknowledges however, that this 'opt out' may not have included all patients as it may have been impossible in an emergency situation to ensure that this happened (Lawton, 2001). I decided, however, that I would take more of an overt stance to gain consent from patients. The environment of the hospice was important in this decision; with ten single rooms and three shared bays, many patients were in single rooms. The single room environment is different to that of a main bay: it becomes more of the patient's domain and I considered it more of an intrusion to enter than it would be to walk into a bay. Even within the public space of a hospice, great care is taken to make the hospice environment more like a home environment. Thus entering into a private space within this, I felt, should be considered differently; more of a negotiated act wherein expressed permission is sought. I decided to seek consent from patients prior to undertaking observations for the above reasons. In addition, concerns about not doing so were raised by the medical director at the time, in one of many pre-study meetings with staff members.

When approaching patients I wished to be explicit about the nature of the study, however recognised that patients may feel uneasy or anxious about being admitted to a hospice and did not want to heighten anxieties further by introducing a study about sedation in an insensitive manner. In addition, just prior to starting the fieldwork, the concerns of physicians working in palliative care about sedation came to the fore in the media. The headline 'Sentenced to Death on the NHS'(Devlin, 2009) was particularly emotive and I was concerned about some of the associations between sedation and hastening death made explicit in the media.

I decided a staged approach to consent would be appropriate, with the first approach to patients coming from a member of staff involved in their care. Ideally, this would occur 24-48 hours after their admission but frequently it was later on in their stay, depending on the busyness of the unit. The staff member would ask if I could speak to them about a research study which was going on in the hospice. If they received a positive response, I would then go to see the patient to explain the study and address any questions they had. The ethics committee accepted that patients may prefer to give consent sooner than is 'standard' for research studies, and accepted a negotiated approach to the cooling off time. This was expressed in the following terms in the REC form:

The 'agreed time' referred to above would be agreed between the researcher and the patient. Patients admitted to a hospice rely on the flexibility of their clinical team and those around them to adjust to their energy levels and fatigue, pacing the day to suit their needs. The researcher would wish to be responsive to this and be flexible in timing, according to the patient's wish, her visits to provide information and gain consent. This may mean that a patient would wish the researcher to provide information about the study and come back the following day, as would normally be expected in a research study with 24 hours allowed as a 'cooling off' period. Patients in a hospice, however, may have a different sense of time and urgency. They may wish to participate in the study and yet be aware of a short prognosis or of continued deterioration and fatigue. We would want to accommodate these patients in the study to allow their participation in a dynamic and changing clinical situation. While a cooling off period of 24 hours is ideal, this study aims to adapt to the patient's needs and this would be to allow the patient to have as much time as they individually required in making a decision. The researcher would be acutely aware of the issues involved in, and guidelines for, gaining informed consent and take every step to ensure this consent process is rigorous in adhering to these.

The approach to the study was always centred on being as unobtrusive as possible and carrying out this research with as little interruption to patients and their family as possible, while giving the opportunity to participate to all.

All patients admitted to the hospice who were aged 18 years or over were considered to be eligible for the study, with the exception of those admitted for a short planned admission (SPA). Those admitted for a SPA would be in the hospice for only a short period of time and going through the process of consent for a matter of two or three days was felt to be overly burdensome for these patients, with little perceived benefit or contribution to the study. The rationale for including all patients, while being interested primarily in those receiving sedation, was to incorporate the changing nature of patients admitted to a hospice. Limiting the scope of the study to just those receiving sedation may have captured the views of some of the patients, their significant others and healthcare professionals, but would not have been able to capture the decision-making

processes from its origin. Through the inclusion of all patients, I kept open the potential to see decision-making as it happened, rather than simply the outcome of this process. In addition, this method potentially allowed more patients to make a decision for themselves about their participation in research: those sedated to the point of losing capacity required a decision to be made by a 'consultee' (Mental Capacity Act, 2005).

3.3.2 Patient lacking capacity

Inclusion of patients who lacked capacity was a further area which required negotiation. The Mental Capacity Act (2005) required that certain criteria were met prior to the inclusion of patients lacking capacity in research. These were assessed by the REC. The inclusion of those who lacked capacity was considered as crucial in a study which was investigating sedation. While patients may be sedated to varying levels, it was inevitable that some would be sedated to the point they lacked capacity to consent to research. Their inclusion was vital in seeking to understand not only the processes of decision-making about starting sedation, but ongoing reviews and attitudes of those around a sedated patient. Thus two patient groups were considered: those who lost capacity during the course of observation (for which they had given consent) and those who lacked capacity from the onset. The former were asked to indicate their preferences in the situation where they lost capacity: to allow the observations to continue or to cease, and for the information previously gathered (when they had capacity) to be used or destroyed. All patients were given a pseudonym so removing this data from the data set would have been possible. All patients involved in the observations consented both for the observations to continue should they lose capacity and for data previously gathered (when they had capacity) to continue to be used in the research study. Clearly there are concerns about accepting what a patient states at one point in time and assuming it holds for the future when they are in an incapacitated state. Lawton shared this concern:

> just because patients had given me their consent to be included in my research on their admission to the hospice, such consent could not necessarily be taken for granted in my later encounters with them (Lawton, 2000: 32)

The process of gaining consent for observation of a patient who once had and subsequently lost capacity, took into account their statement about future wishes. In

addition I considered any expression which may have indicated that they did not want me to continue with the observation in the present. I also took into account the wishes of their significant others and the advice of the medical team; if they felt it inappropriate for me to observe an encounter I respected this, while acknowledging that this may have limited some of my exposure. This process of gaining consent may be regarded as a form of 'process consent' (Usher and Arthur, 1998). The research process may be regarded as a two way process, under constant negotiation. Thus a patient's role in the research was considered at each point of encounter in that they were asked each time if it they were happy for me to stay and observe. In this interaction there was a reminder that I was a researcher and this was my role in the interaction; this was how I was introduced on ward rounds or when observing staff with patients. It is clear that my role as a researcher was explicit on a day to day basis. This may not be the ideal position when conducting ethnography, however when conducting research in this field, I felt the ongoing disclosure of my role was worth the 'risk' of influencing behaviours taking place in front of me (Hammersley and Atkinson, 2007: 87-89). I do not consider these disclosures to have undermined my research, however through a reflexive process am highly aware of their influences on what I was able to observe. Clearly I chose a position which may well have changed the nature of what was observed but in doing so, maintained trust and integrity in the research process.

The process of gaining consent from patients who lacked capacity from the start of the observation was managed differently. Relatives or significant others of patients who lacked capacity were asked by a member of staff if I could speak to them about the study. I would introduce the study to this person and ask if he or she felt it might be something which the patient, when they had capacity, would have wanted to participate in. If they felt the patient would have wished to participate, I asked if they would be willing to act as a 'personal consultee' and provided further written information about this. I explained that a significant other would have to agree to become a personal consultee and then agree that they felt participating in the study would be in keeping with the patient's wishes. They were given a cooling off period to digest this information; the duration of which was negotiated between myself and the potential consultee. For those without anyone able to act as a personal consultee the process of obtaining a nominated consultee was considered but not required in the data collection period.

3.4   Gaining access

Obtaining access into the field can be seen as a process of negotiation (Hammersley and Atkinson, 2007: 41). This began several months before fieldwork 'proper' started and involved a series of meetings with key stakeholders. These included the hospice manager and medical director, ward manager, senior nurses, senior doctors and social workers. Access to meet these people was undoubtedly influenced by the role of my supervisor within the hospice and my own previous experience in working as a doctor in this setting. There was no concern about being able to meet with them, or even about carrying out the research. There were key areas to be negotiated however and these meetings were important in setting the groundwork of acceptance as a researcher into the unit. Issues pertaining to confidentiality and gaining consent from patients were the two areas which produced the most concern. Reassurance and tightening of the processes of maintaining confidentiality (including combining groups with small numbers where professionals worked in isolation) eased many of these concerns. Having met these senior members of staff, I originally planned to hold a series of meetings to allow nurses and doctors working different shifts on different days to be introduced to the study. Following advice, however, from senior nurses, it was much less disruptive and proved easier to come in to the hospice regularly for several days to talk to nurses in a more informal manner. In this way I managed to speak to all nurses in an informal atmosphere. They were able to ask questions in a way, I realised with hindsight, they would not necessarily have done if part of a larger and more formalised meeting. I carried out the same process for registrars and junior doctors, often speaking to them individually in a more conversational manner. Specifically, I spoke to both doctors and nurses about approaching patients or their significant others on my behalf, before I could speak to them about participating. There were no objections to this and most seemed keen, having heard about the study for some time, for me to get on and begin the fieldwork. In addition I spoke to the other members of staff, such as social workers, physiotherapists and occupational therapists on a similarly informal basis. After each meeting I would give potential participants an information sheet and gain consent for observation from them at a later date. Over time I gained consent from all staff who regularly worked on the unit. An interim consent process was also in place for situations where new staff started, to enable me to observe meetings which they were part of, for a limited period prior to gaining full consent.

The above details the process of gaining access and negotiating consent from members of staff, but of course negotiating access is an ongoing process, not only involving consent to my being physically present, but also becoming involved in unit so as to be in a position to observe instances of sedation. This process took longer; while the information sheet detailed what would happen, what I would be observing and how, it became clear that acting this out was part of an ongoing negotiation. For instance, when I began my fieldwork I had consent for the observation from all current members of staff. I spent time in the nurses' 'team office' and in the 'MDT room' where the doctors and allied healthcare professionals spent their time. Initially I was greeted a little nervously, and with uncertainty it seemed. Conversations would be halted, or, if talking about sedation, staff would glance at me or smile nervously. Others asked if they could speak to me or not. I was definitely regarded as 'different', but not quite 'an outsider'. This will be discussed in more depth later in this chapter. Negotiating access to patients through the first approach from staff, took some time. This was partly because of some issues of gate-keeping: patients were said to be 'just settling in', 'too poorly', or their significant others were 'too upset'. I understood it would take time for staff to become used to my presence and to learn what my role was, before stepping out to ask patients something about which they were still uncertain themselves. Thus in the first few weeks of fieldwork I did not gain consent from many patients and focused on establishing myself with the staff on the unit. I did feel some concern and tension about this and considered different strategies to improve this situation. The most successful of these was to enrol the assistance of the senior nurses, two of whom in particular, were extremely helpful in approaching patients and improving the rate of patient consents. They would speak to all of the patients or significant others on their 'team' who they considered would be 'appropriate' for the study. In general, they would approach all patients or significant others on the ward.   From the start of the study it was important to involve members of staff in the consent process and rely on their judgement regarding who it was appropriate or not to approach. Clearly this may have limited access to patients and highlights the issue of gate-keeping. Reasons given by these nurses for not speaking to patients or their significant others tended to be related to where a person was geographically (e.g. away for some form of treatment or scan) rather than subjective concerns about how a patient might react. Of course, there were patients who the nurses felt would be unable to take in information or whom it would be

inappropriate to speak to about the research. Reasons for this were often related to other issues going on for these patients such as recently receiving bad news or having difficult discussions about the future. Clearly the nature of the research topic may lead into discussion or trigger thoughts about future issues and what may happen: sensitivity to this was important. I believe, therefore, that this approach was justified in this group of patients not only because of their potential vulnerability but also because of the sensitive nature of the topic under consideration. In addition, maintaining the trust and cooperation of staff in these early stages could have been undermined by challenging their opinions potentially restricting access further.

3.5   Ethnography in palliative care

Ethnography has its origins in anthropology and the work of Malinowski (O'Reilly, 2005: 7) and has been used as a means of understanding a wide range of different phenomena. Its methods have been adopted in many fields beyond the social sciences and in more recent years this has occurred especially in educational and medical settings (Hammersley and Atkinson, 2007: 2). Indeed ethnography has widely been used to illuminate aspects of the medical world; from the adaptation of medical students to fit in with their environment (Becker et al., 1961), to the awareness and organisation of dying (Sudnow, 1967, Glaser and Strauss, 1965a) and more recently, patients' experiences of hospice care (Lawton, 2000). Using participant observation in areas of medicine such as palliative care has been advocated by researchers as a unique way of accessing knowledge, which would otherwise be impossible to obtain (O'Reilly, 2005: 1, Lawton, 2001). Alternative methods such as the sole use of formal interviewing would not be able to contribute the same depth of knowledge, it is argued, especially around sensitive issues such as death and dying (Lawton, 2001).

As previously stated, the comfort and trust of patients was my utmost concern. Patients were admitted for a variety of reasons but predominately they had significant illnesses and many died in the hospice. I was anxious to be able to conduct this research in a manner which was as unobtrusive as possible for not only patients and their relatives, but also for staff. I considered various different roles I could adopt to enable this to be the case. I had previously worked as a palliative medicine registrar for a year in the hospice in which I undertook this research. I had had a period of 18 months away before starting the research, but in a small unit with approximately 50 staff it was not

unsurprising that I knew a great number of staff from my previous role. In addition to these previous working relationships I had ongoing relationships with many of the doctors on both a professional and a social basis. Thus it was clear that my role was not only to be negotiated and constructed as a researcher, but also that work would have to been done to renegotiate roles as doctor and friend in the hospice. I had to be clear about where the fieldwork started and finished and who I was in relation to others. This was a constant script in my mind; trying to act reflexively in a dynamic situation where I may be required to move from researcher to friend, from observation to discussion about a social event. This may not be so radically different to the relationships which have been described in other ethnographic work where participants do become friends (Hammersley and Atkinson, 2007: 95); the crucial difference was the pre-existence of my relationships and walking in to start fieldwork with these other roles already playing out.

The work of Goffman in 'The Presentation of Self in Everyday Life'(Goffman, 1959) is helpful to understand the different roles I was required to fulfil. Goffman states that people ask others to treat them in respect of the way in which they present themselves. The way in which this presentation is conveyed to others is through one's 'personal front', which Goffman separates into appearance and manner. Appearance may concern factors which convey an impression of the individual's social status, or what they are doing. Manner conveys more of what another person could expect from the individual, something of their attitude towards them. In general, Goffman asserts, we expect appearance and manner to be congruent and when they differ, the person to whom the individual is addressing his performance, may experience uncertainty and doubt about the sincerity of what is being portrayed. In addition, Goffman refers to 'front' and 'back' - stage performances. The 'front' stage, refers to 'the place where the performance is given' (Goffman, 1959: 32). Ideas about one's personal front and presentation of this in dramaturgical form can be useful when considering my role as a researcher in a familiar environment and also the nature of reflexivity.

As a participant observer I had to define my role as participant. I would act as a 'participant-as-observer', using Gold's classification from 'complete participant' to 'complete observer' (Gold, 1958). Many researchers have taken on different roles as participant observer when undertaking fieldwork, and for valid reasons. Indeed Mead

himself argued, to be able to 'take on the attitudes of the community' we must be able to 'take on the role of others' (Mead, 1934).

In order to understand the environment and processes which one is observing, one must participate and become familiar with the environment and its actors. To continue use of Goffman's dramaturgical approach, one can consider a number of different 'stages' within the hospice, from which I could have chosen to view the nature of sedation. I decided that I would not perform any medical tasks or responsibilities, or be involved in any aspect of personal care for patients. I did not want to cause any uncertainty or ambiguity about what I was doing: I recognised, however, that this decision to be very overt in my role as a researcher would affect the data I collected. Lawton, in her ethnographic study in a hospice, decided to take on a role as a volunteer and engaged in tasks on the ward such as befriending, talking to patients and visitors and serving drinks. These activities gave her an 'ideal excuse' to enter the ward area (Lawton, 2000 p.31) . While she did not take on a medical role, Lawton has referred to some disquiet she felt when realising that a patient had clearly considered her in a role other than of researcher:

> during our day-to-day interactions it became very apparent that on some occasions at least, patients perceived and interacted with me first and foremost in my role as a volunteer (Lawton, 2001).

While Lawton attended to this concern by being sensitive about the way in which she handled information in the writing up process, I wished to avoid this confusion by taking a more overt approach which would necessarily put me into more of an 'outsider' role. From the research perspective, I was most interested in the attitudes and perspectives of those who were involved in using and prescribing sedation. I may have been able to access patients more easily had I acted as a volunteer, however may have narrowed my focus to being more of an observer of patient behaviours, rather than participant in a group which was involved in decision-making about sedation. Thus to gain access to nurses (both qualified and unqualified) as well as doctors, and not limit myself to either of these groups, or appear to be changing sides and fitting into neither, I adopted more of a role as an 'accepted incompetent',(Hammersley and Atkinson, 2007: 79), a novice, or student. Goffman asserts that it is rare to find a new 'front' which has

not previously been established (Goffman, 1959: 38). Although this 'front' was new to me in this setting, this was a role which would be familiar to both groups of staff. While it may have been incongruous initially, through interaction and modifications, influenced by those around me, I developed in this role and, I believe, became more accepted through this. I was an interested observer, participating insofar as I would make tea for the group and participate in conversation about both work and more general matters. For example I would chat about celebrities, Christmas shopping, house buying and a number of different subjects. This 'mundane small talk' (Hammersley and Atkinson, 2007: 70) can be seen to help to establish my identity and role as a reasonable or 'normal' person, without constant reference or discussion about sedation. This was important in grounding my identity and role in the hospice. While I did not perform role-specific tasks, through which I could be easily identified, I believe this to be justified by being able to take more of a global perspective and allowing me to move more easily between groups. I think there may have been significant inconsistency had I chosen a different approach, and a cynicism about my 'performance' which may have undermined the research process. Through being overt and, as far as possible, sticking to the one role as researcher/student, I was as sincere as was possible, while still being aware of projecting myself to appear in a certain light.

When considering this 'front' as being similar but not identical to that of a student, it can be seen that my previous experience and others' preconceived ideas about me, may make my performance insincere. Perhaps, however, my personal front may have assisted this presentation. When considering my appearance, I chose to wear smart clothes rather than another 'uniform'. Hammersley and Atkinson refer to the importance of different dress codes 'in the field'; not only to 'fit in' to the field environment but also, in other circumstances, to be marked out as not belonging to particular categories (Hammersley and Atkinson, 2007: 67-68). I decided not to wear a uniform which was immediately identifiable with a particular group. I did, however, feel it was appropriate to wear clothes in which I was smart and professional enough, as a researcher, to encounter patients. This may have, in itself, put me into an identifiable group within the hospice – of the non-uniformed staff. Various people wear similar smart clothes, including administration staff, social workers, doctors and students. My manner may also have contributed to an impression of a student at times. I was overtly an interested observer at times, listening and asking questions, as unobtrusively as

possible. I would be quiet but appear interested when the business of work was going on, participating more in the times of informality and discussion, especially when this related to matters other than the business of the hospice.

When considering the hospice as a whole to be a stage, the front and backstage performances may illuminate something of my participation. There may be many different ways in which this stage could be constructed: one would be simply to consider the patients' rooms and the ward to be the front, with the private meeting rooms as being backstage. Here, there may have been a clear distinction in what was said about or to a patient front of stage and that which was said back stage. The stage does not have to be physically bound however; the morning handover meetings may themselves be a front stage performance, while chatting to nurses and reading magazines may be more of a backstage activity and insight. Clearly this is taken from the perspective of the staff rather than individual patients; indeed this can be seen to be the perspective I was predominately able to access in this fieldwork. In some ways I was able to access the back stage – the:

> place, relative to a performance, where the impression fostered by the performer is knowingly contradicted (Goffman, 1959: 114).

I was able to be party to 'insider secrets', to observe emotional moments and outbursts and, I felt, share a sense of loss at times when a patient died. This access was, of course, managed and structured by the participants, or 'performers' and would be dictated by them. This could fluctuate on a moment by moment basis and I considered myself as almost in constant motion between front and back stage. This movement may have allowed my observations to be considered from different perspectives; whilst moving between front and back stage I was, perhaps, more aware of where I was on stage than if I had been perpetually front or back stage. As an insider, backstage, my observations may have been more acute and contextualised, coming in from an outsider's perspective.

These concerns about my 'performance' link in with the concept of reflexivity. This functions on a continuum between 'going native' and becoming autobiographical. In the former one ceases to consider one's role as an influence; the latter one is so concerned with one's influence that the work becomes more concerned with the

ethnographer's relationship with the data than about the phenomenon under investigation (Aull Davies, 2008 : 217). An awareness of self is important and one construct of this is Mead's separation of the 'I' and the 'Me' within 'Self'. He situates Self as inherently a social being, involved in a constant, dynamic process of construction and interaction with the social world, one which is never a completed product ((Aull Davies, 2008: 25, Atkinson and Housley, 2003: 6-7) The 'I' is the aspect of self which is impulsive, while the 'me' is aware of culturally and socially accepted norms, and adjusts the presentation of 'I' accordingly. This duality, Mead asserted, is what enables us to be able to interpret or take on the role of another; we can react to another individual with respect to the way in which we expect them to view a situation and subsequently act. The changing and progressive nature of the 'me' of Self, Aull considers as being informative in developing the reflexive nature of ethnography.

> If the self is continually under construction, then ethnographers' experiences when they participate in social interaction in another society clearly alter their own selves in accordance with the cultural expectations of others. (Aull Davies, 2008: 26)

Thus my 'self' changed through this process, in order to adapt to the cultural expectations of participants; I attempted to fit the model which was required of me, and adapt into a role which allowed me to access backstage while maintaining a sincere and consistent performance myself. In being constantly aware of changing between my Self as researcher and as friend or colleague I was constantly open to and aware of the impact of my actions and words on what was said and done. While initially I was aware of silences or pauses in conversation when doctors or nurses talked about sedation or sedative drugs, this changed as the research progressed. I became more comfortable in my researcher role and others perhaps more familiar with my presence, albeit in a different role to that which they expected. For example, initially nurses and doctors asked regularly, if there was a pause in conversation or I walked into a room, what I wanted to do or see, or if I wanted to ask anything. Later in the fieldwork, this was extremely infrequent and we would engage in small talk rather than default to an overt awareness of me being present as a 'researcher'.

3.6 Observing Sedation

When I commenced fieldwork, initially my focus was on the ward in general and getting to know the daily processes and tasks which staff carried out. I was interested in the accounts staff gave of patient symptoms and treatments required. I spent time in the nurses' office, the doctors' office and observing nurses and doctors in their daily routines. I attended handover meetings at different times of the day and also the twice weekly MDT meetings. After some time I was able to gain more access to their involvement with patients as the process for approaching patients improved. Thus I developed a routine of attending meetings, spending time with members of staff, and going with them as they saw patients. I followed the different working patterns of nurses and doctors, from the early morning handover shift to the night shift. I became aware that there were differences in the nature of what I would hear in these different settings. In the handover meetings a formal account was given of what had happened on the previous shift; this was regarded as objective, factual information, of what had occurred. In MDT meetings several accounts were given about the same patient and while often similar, it would sometimes be openly acknowledged that different professionals received different versions of events, or interpreted them differently. These discrepancies or differences in interpretation were discussed and provided different insights into the dynamics of a situation.

These formal accounts were substantiated by observations in the 'backstage' areas of the MDT office (where doctors and some allied healthcare professionals worked) and the nursing office. When handovers were not taking place these were informal meeting rooms where staff gathered between jobs, or between seeing patients, pausing to write in notes or to discuss what to do next. In the MDT office doctors often discussed patients, both before and after they had been to see them. They may have discussed what had happened or been done in the past, or tried to convey a general impression of what was going on. When they returned after seeing a patient they would often debrief, either mulling over or asking one another what to do.

Nurses, qualified and unqualified, rarely talked in their office about what was going on from a medical perspective, or discussed what to do for a patient. They would talk about the emotive nature of a situation, or describe some detail about a family member which compounded a tragic situation, or even talk about how difficult a patient was

being. In general they did not talk about what drugs patients were on, or what was happening from a clinical perspective. Instead, conversations in the nurses' office were more often about the personal lives of patients, their own personal lives, or those of celebrities. Occasionally if I walked into the office after being away and asked what had been happening in a general way, I would receive an account of the 'difficult' patients of the time. These patients were 'difficult' because they were demanding in some way; I came to realise this may be physical or emotional in nature. A difficult patient may be one who demands a lot of attention, or who has some trait which marks them out as being different. They may have needed attention because of uncontrolled physical or psychological symptoms; or it may have been the impact which they had on staff which marked them out as being 'difficult'. A young patient with children, for example, might be 'difficult' simply by the nature of their situation – this may be more emotionally demanding of staff and thus make them more 'difficult' to look after. This marking out as being difficult was a combination, therefore, not only of the patient's traits but also of the impact of the situation on staff. While the 'difficult' patients were discussed in the nurses' office, it became clear that it was hard to access their 'backstage' accounts of other patients by simply being in their office; I had to engage in some way with what the nurses were doing. I found a useful way of doing this on the early shift was to go with one of them on their drug round. Here, whilst staying quiet and observing during drug dispensation, nurses would often give more of a personal account of what they thought was happening, or why they were giving a particular drug. This was especially the case overnight, when they were not only dispensing drugs, but anticipating problems overnight. They would describe this, what they were seeing and how they would try to manage this.

From the start of the observation I wanted to be able to be in a position to observe as freely as possible, and change environments throughout the course of a day. I did not stay with one individual for a full shift, which would have been one way to approach this. I felt this may limit my exposure as well as being more likely to directly influence decisions which were subsequently taken. By moving around I felt I was in more of a position to observe front and backstage; observing directly what was seen from one perspective, then changing to another's, then hearing the accounts given to other members of the team.

Consultant ward round were another opportunity to observe ward processes and decision-making. One or more junior doctors, a nurse and sometimes a medical student would be present. Consultants, either before or during their ward rounds, would ask for an update of what was happening. This would normally be given by a junior doctor while the nurse present may add further information. The interaction with the patient, in the presence of at least 4 or 5 people, created a different perspective, and the subsequent decision or clarification of the decision, was made again outside the patient's room.

Through all of these processes I became aware of patients who were receiving sedative drugs. I began fieldwork with the intention of gaining an overview of how sedation was defined in practice and an account of the attitudes towards and intentions of staff regarding sedation. Therefore I had to be able to take an overall perspective of which sedative drugs were used, the reasons stated for giving them, their effects and outcomes. I became aware of a number of different ways in which sedation was prescribed and reasons given by staff for sedation being administered.

One of the main distinctions formed early on in fieldwork was between patients who were considered to be dying and those who were not. While continuing to observe in a general sense, I focused my observations regarding sedation towards those who were considered to be dying, or for whom there was uncertainty about whether or not they were dying. While I was still in a position to observe those who were receiving sedation and not considered to be dying, I was able to examine in more depth those situations where patients were receiving sedation at the end of life. In addition, I was able to observe the transition into the dying phase and changes in the use of sedation from one phase into another. I came to understand this transition to be of great importance as I analysed the data and developed a theoretical understanding of how sedation was used; this will be appreciated in the following data chapters.

I observed situations in which sedation appeared to be unproblematic, as well as those in which sedation was considered to be of great concern. I identified this concern in different ways; through observation of discussions, comments in handover meetings, or I would be told about an 'interesting case' by an 'informant'. Reasons for concern or a heightened awareness of sedation taking place varied; what was clear however was that they were not 'everyday' cases of sedation. It seemed important to access what it was

about these cases which marked them out as 'deviant' cases, from which I could expect to learn more about 'everyday' sedation (Hammersley and Atkinson, 2007 p.169, Silverman, 2010 p. 281). I followed these cases more purposively; I observed nurses or doctors at different times as they interacted with these patients and their significant others. Having been alerted to a more unusual situation in which sedation was being used, I selected ways in which I would be able to observe interactions with staff. This may have been to attend nursing drug rounds, consultant ward rounds or junior doctor consultations. In this way I gathered more information about specific cases in which sedation was used.

In total, 45 patients consented to participate in the observation phase of the study. 289 hours of observations were carried out, over 51 days, spread over a period of 11 months from September 2009 to July 2010. Periods of time away from the field were required to fulfil teaching requirements, for analysis or for leave.

3.7   Interviews

3.7.1 Patients

Informal interviews, or 'unsolicited accounts' (Hammersley and Atkinson, 2007: 99) in the manner described in ethnographic texts, occurred very infrequently with patients. This was due to the design of the study and access. In the research ethics committee form I specifically stated I would observe staff and my contact with patients would be limited to observing interactions with staff. This was in order to minimise any disruption to patients and any intrusion on their time. However, this did mean that my direct contact with patients was limited to the contact I made at the time of explaining the study and gaining consent for the observation or for a formal interview. In these interactions patients did, however, give 'unsolicited accounts'. If they agreed to participate in the study I felt able to record these interactions; if they did not wish to participate I did not include or record details of these interactions.

In addition to these informal interviews, I sought initially to formally interview patients and/or their significant others. These were patients whom I had observed as discussing or receiving sedation. The first two patients I approached in this way both agreed, as did their significant others. However, after agreeing to be interviewed and setting a date

both of these patients deteriorated and died. Much thought and discussion has taken place in supervisory meetings about this issue and about interviewing both patients and significant others. I conducted one patient interview successfully; this was a patient who had received sedation for anxiety and was interviewed in relation to this. During the interview, he also expressed his thoughts about sedation at the end of life.

Throughout the interview the patient talked in hypothetical terms about sedation and his wishes for the future; his experience of sedative drugs were those he had been given for anxiety. By this stage in the fieldwork it had become clear that concern about sedation in practice related to sedation of patients who were dying, or about whom there was uncertainty about whether they were dying. Sedation as an end of life practice was only considered in those who were dying; this was a theme which developed strongly through the observational data and interviews. Therefore considering a patient's preferences for sedation at the end of life was conceptually a different matter; it asked about future wishes rather than being ground in the present.

I approached a further three patients during the time of the study who had received or were receiving sedation; all agreed however two of these deteriorated before I could interview them, the other was transferred to hospital for further treatment. The time stipulated in the REC application between inviting patients to take part in interviews and carrying them out was to be negotiated between myself and the patient. I did not feel in any of these instances, that the patients wished to participate in the interview immediately. It may, of course, be the case that they did not wish to take part at all and wished simply to 'stall' for time. I rather felt, however, that they wanted to have more time to speak to others before participating, and this caused a delay which meant they were unable to participate. Accessing patients for whom sedation was a reality, and who could give accounts of their understanding and wishes, was not possible because: (i) those receiving sedation at the end of their lives lacked capacity; (ii) those who had capacity and for whom sedation was required at the end of life deteriorated rapidly after initial contact.

Others have managed to interview dying patients more successfully (Lawton, 2001), while acknowledging this as a rare voice to be heard. The distinctive feature of this study which presented difficulties was the requirement that patients be able to talk about the issues regarding sedation in the present rather than consider them in hypothetical

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terms. Concern for the future and presenting wishes for the future is of course of the utmost importance; it does, however, go beyond the scope of this study to consider this alongside the practice of sedation in the present. The present remains the main focus of the study.

3.7.2 Significant others

I spoke to several significant others over the course of the fieldwork; many were happy to chat informally but only one was prepared to be formally interviewed. Many who did talk informally in the corridor were relatives of patients who were not sedated. The one interview conducted with a significant other was an exceptional case, as it took place after the death of the patient. This was discussed extensively with the supervisory team and care was taken to ensure this fell within the terms of the research ethics committee application.

3.7.3 Staff

Informal interviews with staff occurred frequently throughout the fieldwork however I also sought to formally interview staff in relation to the observed use of sedation. As previously described, those cases which proved to be more problematic were pursued; initially with observation and then followed up with interviews. I observed the course of the use of sedation over time and subsequently interviewed healthcare professionals after the event. All patients whom I observed in this way subsequently died. Purposefully, I did not interview or seek to interview those involved in the patient's care while they were still being treated; this may have influenced subsequent decisions. The duration for which I was able to observe, prior to a patient's deterioration or death, was highly variable, from a matter of hours to many days or weeks. In three instances, while I had been present in the hospice prior to their deaths, sedation occurred when I was not present. Two of these instances occurred at night and the other over a bank holiday period.

Interviews were conducted as closely as possible in time to a patient's death. This was not always possible due to the nurses' shift pattern and days off, demands of the ward as well as my other commitments. Interviews were carried out, with two exceptions, within the hospice building. This was to fit around the participants' wishes and accommodate these as far as possible. The exceptions were consultants who worked

both in the hospice and at another site: the interviews were carried out at their alternative places of work which was more convenient for them. Participating in the interviews within the hospice may have influenced what was disclosed and the nature of this. Participants may have been more likely to have talked about their personal responses or motivations outside of their work environment. I found that which they did disclose, however, surprisingly honest on many occasions. Only on one occasion did I find a direct contradiction between what I had observed and the account given in interview. The interviews were carried out in an iterative manner, reflecting the previous observations and interviews and following the iterative-inductive nature of ethnography. The nature of the initial interview questions differed little from the original interview topic guide but I allowed the interviews to progress naturally to discuss aspects of the case as freely as possible. I would direct the interview towards more specific issues arising from the observational data as the study progressed and made use of a variety of different interview techniques.

Interviews were digitally recorded and sent electronically for transcription. I initially intended to transcribe at least one interview in full, however, while establishing myself in the field I felt that the time invested in this was more fruitfully spent in the field rather than in transcription. I recognise that transcription itself can be part of familiarising oneself with the data and a stage of analysis. I did spend time in checking transcripts for accuracy, proof reading and note-taking before re-reading the transcript in full before coding. Transcripts were recorded verbatim for analysis.

3.8   Data Analysis

Analysis of field notes and interviews has taken place at different stages throughout data collection. From the start of data collection I engaged in an iterative process of analysis, in keeping with the ethnographic tradition (Hammersley and Atkinson, 2007: 158). This was not a formal process, whereby time was regularly taken in blocks to allow for this; rather it was a constant, informal approach, attempting to manage a balance between time spent in the field and time for other ongoing commitments. I was anxious to spend as much time as possible in the field in the early stages, familiarising myself with the environment and allowing myself to develop relationships. Field notes were written contemporaneously when possible but further notes were added and then typed at the end of each day. Reflective notes were written in addition to this, and after

each interview. These were also typed and stored together in a computer software programme, NVivo. In this way much of the early analytical processes took place 'in the field' (Oakley, 1994).   Through this process of daily transcription I was constantly engaging with the data. I recorded issues which emerged during fieldwork which challenged or raised questions of previously gathered data. This was a constant process whereby I asked questions of myself and the data I was gathering; asking how the situation I was observing was similar or different to previous observations, or brought in issues or questions raised in interviews.

The process of analysis held much in common with the principles or methods of grounded theory. While not following classical grounded theory methods, there were many similarities in approach. Many authors have written about the core concerns of grounded theory and how these have been understood and interpreted in different ways since the publication of Glaser and Strauss's 'The Discovery of Grounded Theory' in 1967 (Charmaz, 2006, Corbin and Strauss, 2008, Glaser and Strauss, 1967, Hammersley and Atkinson, 2007). This original construction has been accused of being overly mechanistic, or at least has been interpreted as such: recently authors such as Charmaz, have considered it from a different perspective (Charmaz, 2006). Glaser and Strauss themselves subsequently disagreed about the central assumptions of grounded theory: Strauss in recognising the role of the researcher (and previous experience and influences) in constructing theory; Glaser in advocating that theory should be generated more independently from the researcher (Charmaz, 2006: 8, Hammersley and Atkinson, 2007: 167). Indeed, while my research followed predominately an inductive process in seeking to generate theory from the data, my previous knowledge, experience and reading made deduction an important aspect in this process as well.

I adopted the perspective of Charmaz in viewing grounded theory methods as 'principles and practices, not as prescriptions or packages' (Charmaz, 2006: 9). Charmaz advocates the use of the tools of grounded theory, while adopting more of the approach of Corbin and Strauss than the classical techniques of Glaser and Strauss.

Supervision meetings were of particular importance during fieldwork, during which I would discuss sections of field notes or whole transcripts of interviews with my supervisors. During these meetings I would describe my own impressions and issues which I believed to be emerging from the data and discuss these and develop new ideas

to challenge and develop back in the field through observations and interviews. In this way these meetings impacted on my fieldwork and the research developed in different directions through this process.

All written field notes and interview transcripts were transcribed and entered into NVivo, a qualitative software programme to assist with data management. This enabled me to be able to handle the large volume of data generated. The 'constant comparative method' was used informally in the field and more formally through the stages of coding to challenge assumptions and 'taken-for-granted understandings' (Glaser, 1965, Charmaz, 2006). Following the approach advocated by Charmaz, interview data was coded initially in a line by line fashion; field notes were coded 'incident by incident'. Six interviews were coded in their entirety line by line; all field notes were coded incident by incident. Initial coding on a line by line basis was difficult to manage and produced an unwieldy coding frame. Codes were reviewed and compared in supervision meetings to ensure inter-rater reliability. Although I was the only researcher these discussions were crucial to challenge assumptions and question what I was seeing, throughout the period of fieldwork. Initial codes were then compressed and having generated a coding frame in this way, it was applied to the rest of the interview data. I then engaged in focused coding whereby one codes 'using the most significant and frequent earlier codes to sift through large amounts of data'(Charmaz, 2006). Through this process I re-examined the data with a view to bringing to the fore those codes which made the most analytical sense. This was strengthened and developed through discussion in supervisory meetings. I took considerable time over this process, being particularly concerned about falling into the pitfalls found at this stage and described by Charmaz:

- Coding at too general a level

- Identifying topics instead of actions and processes

- Overlooking how people construct actions and processes

- Attending to disciplinary or personal concerns rather than participants

- Coding out of context

- Using codes to summarise not analyse (Charmaz, 2006: 69)

I began analysis whilst still 'in the field'; because of this I was able to understand and refine these codes as I engaged in 'theoretical sampling'. As I analysed the data and subsequently collected further data, I was able to test the analysis in an iterative manner. In addition I engaged in memo writing, using various techniques to enhance this such as clustering and free writing (Charmaz, 2006). These memos helped me to consider the data from different perspectives, clarify details within codes, generate new ideas and also direct me towards more theoretical coding by pointing to relationships between the focused codes.

Time invested in this process enabled me to generate robust categories and feel confident as I reached 'theoretical sufficiency'. This term, originally used by Dey (Dey, 2007: 257), is distinct from the term 'theoretical saturation' which many grounded theorists strive for and attain. Dey challenges the concept of theoretical saturation as he questions the ability to truly 'saturate' categories when relying on partial rather than complete coding of a data set. Additionally he argues that saturation relies on the researcher's assumption, or estimation that categories are fully saturated. Instead he argues that categories are suggested by the data, rather than being assumed to be products of the data (Charmaz, 2006: 114). Data are coded and categories populated to the extent that there are no new categories emerging but this is acknowledged to be on the basis of a partial coding of the data and thus the term 'theoretical sufficiency' is a more accurate representation of this process. Data is still comprehensively treated (Silverman, 2010: 280) but the product, I believe, is a more accurate interpretation of what is represented by the data.

The major 'categories' suggested by the data were developed at a theoretical level into drafts which have subsequently been worked into the chapters which form the basis of this thesis. This has been an iterative process, with several changes in direction occurring as I analysed the data. Throughout the research process I kept a record of research decisions and thoughts through detailed supervision notes and a research diary. This was stored alongside my data in an NVivo software package, allowing easy access and a clear trail of information. This is important to be able to attend to concerns regarding 'trustworthiness'.

3.9   Research 'Trustworthiness'

Throughout the design, fieldwork and analysis it was important to ensure the 'trustworthiness' of the study through consideration of four key areas: credibility, dependability, confirmability and transferability (Lincoln and Guba, 1985). Some have considered these to act as equivalents to the quantative measures of internal validity, external validity, reliability, and objectivity (ibid). These are attended to through the detailed descriptions of the study methods above, however the way in which the methods directly relate to this is found below.

Credibility is the extent to which the researcher engages with the phenomenon or environment and how representative the data is of the range of perspectives and contexts under study (Charmaz, 2006). As ethnography requires a prolonged period of time within the research environment the ability to collect data over time from a wide range of perspectives enhances credibility. My own previous work in the hospice as a doctor ensured access to discussions and informal interviews in the field as participants talked openly; while this enriched the data, simultaneously I had to attend to concerns of being too involved to consider different perspectives. Credibility was enhanced through regular meetings with my supervisors who came from a range of different backgrounds including medical sociology, psychiatry and palliative medicine.   My assumptions were challenged through these meetings, as I considered the different perspectives presented; in this way these meetings also acted as a 'peer debrief' (Lincoln and Guba, 1985).

Dependability relates to the consistency of the data collection and the recording of research decisions. Throughout the research I kept a research diary and charted key decisions, incorporating these, as well as notes from supervision meetings, alongside the data in an NVivo software package. This allowed easy access to the data as well as a record of the influences apparent to me at the time; in this way I ensured there was a clear trail of research decision-making alongside the data.

Confirmability concerns the extent to which the researcher's own experiences or views influence the data. This was an important issue in this study as I had previously worked in the hospice as a doctor. My role and how I negotiated this has been discussed within the main body of this chapter and is an important area to highlight. I was acutely aware

of the need for reflexivity throughout the research process and found the research diary helpful as I considered each day how my role may influence what I saw, or recorded.

Transferability relates to the degree to which the findings of the research are transferrable to the population under study, and the degree to which the results can be transferred into other populations. Throughout my field notes and interviews I endeavoured to build a 'thick, rich description', as described by Lincoln and Guba, to enhance the transferability of the research (Lincoln and Guba, 1985). I took extensive field notes throughout the period in the field. Initially these were descriptive, delineating how the hospice was set up, what the different rooms consisted of and where different people were in relation to one another. I recorded many verbatim comments, especially in handover meetings, to capture what was actually said rather than my interpretation of what was said. This was important to me as a new researcher, especially so because much of what was said was familiar to me in my previous work as a doctor. Being able to analyse and consider the precise words which were used enabled an insight into both my own underlying assumptions and those of staff. Had I taken a broader approach in these first few weeks of data collection I may have missed what became central to my analysis; the detail of the precise use of words and language in the hospice which developed into an understanding of the framework within which decisions about sedation were made. This 'thick data' set facilitates external assessments of transferability and understanding of the results of this study; the impact of this is discussed in Chapter 8. In the next four chapters, however, I present the research results with the emergent major categories forming their structure: routine sedation; good dying and death; threats to good dying and death and, finally in Chapter 7, values.

Chapter 4 Routine Sedation

This chapter introduces the way in which sedation was used in the hospice. I explore the way in which sedation came to be understood as *routine* in this fieldwork. Subsequently, the *process* through which the routine use of sedative drugs came to include an acceptance of a reduction in a patient's consciousness will be explored. This is considered in relation to a sequence of dying in the hospice, understood within a framework of dying as a 'non-structured status passage' (Glaser and Strauss, 1965b).

The ways in which sedation was prescribed and administered provide further insights into the underlying motivations for using sedation and allow decisions about sedation to be revealed as taking two forms: prescribing decisions about regular sedation and decisions about using sedation on a 'p.r.n' basis[1]. While these decisions were shared and agreed in most situations, disparity between these types of decisions was observed, especially in situations of uncertainty about whether or not a patient was dying. Situations in which sedation, even to unconsciousness, was driven by p.r.n. decisions are shown through further case studies. Potential concerns about this type of decision-making, and the importance of these in situations of uncertainty, are explored in the final section of this chapter.

4.1.1 Routine use of sedation

Through the fieldwork it became apparent that one of the most challenging issues was to determine what was meant and interpreted by the term 'sedation'. In keeping with the literature, this was seen to be a complex issue, filled with individual variations of interpretation and meaning. Applying the terms found in the literature, it was possible to sort the different forms of sedation into categories. Many of these arose from the data; for example, the indications for using sedation, the duration for which sedation was given and the accounts for giving sedation all formed part of the initial coding frame. It became evident, however, that to look beneath a simple structure or organisation of sedation in this way required a different approach. To be immersed in

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[1] 'p.r.n.' (pro re nata): as the circumstance arises. Drugs are prescribed 'p.r.n.', to be given by nurses as required, for indications which are specified on the drug chart.

the culture of the hospice was to become aware of a more complex *process* of sedation, filled with evaluative assessments and decisions, individualised and often so routine as to appear to be almost unseen. Sedation, it appeared, formed more of an integral role within the hospice than was initially apparent. I had anticipated being able to recognise when sedation was given; through the course of the fieldwork, however, it appeared that my broad interpretation of that which could be considered as sedation was not the way in which sedation was considered in the hospice. Sedation, it seemed, was not simply recognised as the administration of sedative drugs as I had anticipated. Rather, the term 'sedation' was regarded as an explicit, overt decision to use sedative drugs in a way which was unusual, or out of the ordinary pattern of the hospice. There was a difference it seemed, between an implicit, daily use of sedative drugs which I came to observe over time, and that which was regarded as 'sedation' by staff in the hospice. In time, just 'being there' enabled me to see daily instances of sedation, enacted so easily and without fuss or discussion, they appeared to be a matter of routine. Indeed, it appeared sedation used in this way, as the treatment of symptoms with sedative drugs, was considered in no way different to other forms of symptom control. Sedation which occurred in this 'routine' way, it appeared, was not considered by the staff to be 'sedation'; rather it was considered to be simply part of the practice of symptom control, treated in the same way as the management of pain or nausea. Developing an understanding of this routine form of sedation revealed a form of sedation which was, it appeared, accepted within the hospice as normal practice. Further, it appeared to change in nature; that which was routinely accepted for some patients was unacceptable for others. This was closely linked to a developing understanding of the processes of dying. First, an understanding of the nature of symptom control in the hospice will be formed. Subsequently, the changing nature of sedation in relation to the process of dying will be considered.

4.1.2   Routine symptom control

'Symptom control' forms one of the principle functions of palliative care (Doyle, 2003: xx). Routine symptom control occurred in the hospice in a relatively structured way, it appeared. In response to a patient describing a symptom, a doctor or nurse would assess that symptom and its likely cause, before providing a treatment, if possible. The assessments and treatments were numerous and varied according to the symptom, from

a bedside test and giving a drug, to blood tests and a blood transfusion: the overall process of 'symptom control', however, was the same. The most commonly observed symptom in the hospice was pain and often its immediate treatment appeared to be straightforward. For example, I observed one of the staff nurses, Carol, as she gave a patient her regular medication on the drug round at the start of a night shift. The following extract from field notes shows her response.

> *4:1 As we went in, Paula was sitting in her chair with her head slumped forwards. She woke up as Carol* [staff nurse] *spoke but still appeared a bit drowsy. She said she'd had a good day and was feeling OK but had some pain in her back. Carol asked if she'd like some Oramorph[2] for it and she said she would. Carol then poured it out into a medicine pot and gave it to her with her other medications. Carol asked if she'd manage to take the medications herself and she said she would. On the way out Carol said she would go back to check the Oramorph had worked and that she'd managed all of her drugs after she'd finished the drug round.*

[FN 07/12/09 line 85]

This extract recorded a very routine interaction, repeated several times during the course of the night and was observed as forming part of the everyday work of the nurses in the hospice. Carol knew the patient and, having looked at her drug chart, offered her what she thought was the appropriate treatment, the drug which was prescribed for her to give 'if required', or on a 'p.r.n' basis. In the same way other symptoms were assessed and treated, with varying success, but following a 'routine' pattern of symptom control.

4.1.3   Routine use of sedation for symptom control

Sedative drugs were used to treat a variety of symptoms in the hospice, from breathlessness to seizures. The process of symptom control using sedative drugs appeared to be similar to that described above for pain. For example, Simon was a 44 year old man with an aggressive lung cancer. He was very breathless, and became anxious as a result of his breathlessness. He was given a variety of different treatments

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[2] Oramorph: oral morphine immediate release liquid

to help his symptoms, including benzodiazepines[3]. A typical night for him was described during a nursing handover as this extract from field notes shows.

> *4:2 Simon was 44 and had a pulmonary adenocarcinoma. He had been admitted because of panic attacks and anxiety, with increasing breathlessness. He had a 'usual night', and had required Oramorph and midazolam[4], lorazepam[5] and paracetamol, at different stages through the night, for anxiety, headaches and breathlessness.*
>
> [FN 16/02/10 line 39]

I observed one of the nurses, Jane, as she went in to see him after he had pressed his buzzer. I stood just inside the doorway as she went in.

> *4:3 He was sitting up in a wheelchair with an oxygen mask on, breathing very quickly. He couldn't speak in sentences, only managing to get one or two words out at a time between each breath. He said he couldn't breathe. Jane crouched beside him and asked if he had any pain or if anything else was going on. Simon shook his head and said no, he just couldn't breathe. Jane said she'd get him 'something' and be back soon. Simon looked straight ahead the whole time and didn't turn at all to look at Jane. He looked very anxious and frightened with his eyes wide open and just staring ahead.   Jane looked at his chart as we walked back up the corridor – she said it was horrible, wasn't it? She said she would try some lorazepam - the girls[6] at handover had said it worked better than the Oramorph.*
>
> [FN 17/02/10 line 23]

The lorazepam which Jane was planning to give to Simon for agitation was considered in a similar way to the use of oramorph for Paula's pain in the first extract. Indeed, it appeared that having first tried oramorph to treat Simon's breathlessness, the lorazepam was considered to be more effective.   These symptoms were assessed on the basis of

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[3] Sedative group of drugs

[4] Injectable benzodiazepine

[5] Oral benzodiazepine

[6] 'the girls' was a term used by the nurses to refer to other nurses collectively

what the patient volunteered to the nurse. A further 'routine' use of sedation for symptom control was the use of sedation for behaviours which appeared to be indictors of distress. Staff in the hospice regularly used the terms 'unsettled', 'restless' or 'agitated' to describe a patient's behaviour in situations in which a patient was unable to communicate their symptoms. These behaviours conveyed a sense that a patient was in some way distressed, and these behaviours were manifestations of this distress. The treatment of these behaviours could also be regarded as a form of routine symptom control, it appeared. On a daily basis in the nursing handover meetings a description of which drugs a patient had 'needed' during the previous shift was provided. Almost invariably this included a patient who had received a sedative drug for one of these 'distress-behaviours'. For example, during a handover meeting one of the nurses described giving some midazolam to a patient:

> 4:4 *He was a bit agitated so I gave him some midazolam and it settled him lovely*
> [FN 16/10/09 line 12]

Similarly, another nurse, in the same meeting described a different patient who had been restless and had '*needed a couple of extras but settled in the end*' [FN 16/10/09 line 20]. The 'extras' were injections of midazolam, I realised later, after going with one of the nurses to give out the regular drugs later in the day. The fact that the sedative drugs were simply referred to as 'extras', enhanced an impression that this form of sedation was routine and a formed a normal part of work in the hospice. Handovers of this nature occurred every day without question or challenge.

Assessments of these distress-behaviours were carried out by both doctors and nurses. A further example of the routine use of sedation to treat distress behaviour was for Charlie. He was a patient who was 76 years old and had a form of lung cancer. He had been admitted to the hospice for symptom control of pain. He had rapidly deteriorated and was described in the handover as being very 'agitated' overnight. One of the registrars, Gillian, had been to review him and came to talk to one of the senior doctors, Julia, about him in the MDT office. She told Julia about the change in his condition and her assessment of him.

*4:5 Overnight he had had nearly 20 mg of extra midazolam and so they had
increased the syringe driver[7] this morning to 20 mg of midazolam over 24 hours.
She had been back in to see him and he was still not settled. He had been moving
about the bed and looked 'unsettled'. His arms were constantly moving and
fidgeting, she said. He was on some levomepromazine[8] 6.25 mg for nausea but
she had just asked Lisa* [staff nurse] *to give him 12.5 mg for his agitation.   She
was wondering about adding levomepromazine into the syringe driver now for
agitation.*

[FN 11/02/10 line 43]

Gillian's description of the patient's agitation was typical of this type of 'distress-
behaviour' which I observed in the fieldwork. The use of sedative drugs to cause
cessation of the behaviour described was part of everyday practice. If a patient was
breathless, a nurse would make an assessment, look at what had worked before and treat
with whatever had been given before or was prescribed to be given as a 'first line'
treatment. In the same way if a patient looked restless, the nurse made an assessment,
looked at what had been given before and treated the restlessness with whatever had
worked in the past or was prescribed as first line. These were described as part of
normal practice in the handover meetings as simply the 'extras' which had been
required overnight or since the previous shift. Thus sedation used in this way, it
appeared, was considered as simply a matter of symptom control. A difference
however, emerged when observing the treatment of breathlessness with lorazepam and
the treatment of distress with midazolam; a difference which did not appear to be
explicitly acknowledged by staff in the hospice. It appeared that a reduction in
consciousness was acceptable when restlessness and other distress-behaviours were
treated, but this was not acceptable at the point at which lorazepam was given for
breathlessness. The patients were at different stages, it seemed, in their dying
processes. Lisa, one of the staff nurses, expressly stated the staff's aims of avoiding
drowsiness with Simon's use of lorazepam in an MDT meeting.

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[7] A small machine frequently used in palliative care to deliver a set dose of an injectable drug, normally
over 24 hours, into the subcutaneous tissue

[8] An antipsychotic drug used for control of nausea in low doses and agitation in higher doses as its
sedative properties increase

> *4:6 Lisa said, as a positive statement, he was having less lorazepam and*
> *Oramorph now that he was on MST[9], and he was managing his panic attacks a bit*
> *better. The lorazepam had been making him a bit drowsy so they were avoiding it*
> *as far as they could and trying to engage him with complementary therapies.*
>
> <div align="right">[FN 17/02/10 line 96]</div>

An alternative to the lorazepam was sought in order to reduce his drowsiness, it seemed.
In contrast, the doctors who discussed the use of sedation for Charlie appeared to accept
that it would make him sleep, although were still concerned they didn't give '*too much*'.

> *4:7 Julia* [senior doctor] *then asked what Gillian* [registrar] *was worried about in*
> *adding the levomepromazine into the driver now. Gillian wasn't sure what she*
> *meant. Julia then asked whether part of the reason she was hesitating was that*
> *she was worried that if the levomepromazine which he had just had worked, and*
> *made him more relaxed and made him sleep, that in adding 50 mg to the driver, it*
> *would perhaps be more than he needed. In other words, was it that she wanted to*
> *give him the lowest dose possible of a drug which was effective, and not give too*
> *much and over sedate him? Gillian agreed that that was what she wanted.*
>
> <div align="right">[FN 11/02/10 line 84]</div>

It seemed that both Julia and Gillian accepted that they wanted to give the drugs to
make Charlie '*more relaxed*' and '*sleep*'; this would be the measure of whether or not
the drugs had '*worked*'. Simon was not acknowledged to be dying; from the hospice
perspective he was still expected to improve and be discharged. Charlie was thought to
be dying; as Gillian said later in the conversation to Julia, she didn't think; '*it would be
long*' [FN 11/02/10 line 61]. Both practices of giving sedation, for breathlessness and
for agitation, appeared to be routine, but were very different in consequence.   The
routine nature of giving sedation for agitation, with a reduction in consciousness,
appeared to occur as a patient progressed towards imminent dying. That which was
acceptable as a patient was dying was unacceptable, it seemed, when they were not
thought to be actively dying. This relied implicitly upon the interpretation of the dying
process; this process has been explored and delineated perhaps most clearly by Glaser
and Strauss in their original work on the 'transitional statuses of dying'. An

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[9] Morphine Sulphate Tablets – morphine slow release tablets

understanding of the changing nature of sedation in relation to the 'transitional statuses of dying' is explored next, relying, I suggest, upon an acceptance of a reduction in consciousness as a patient comes closer to death.

4.2   Transitional Statuses of Dying

The recognition of temporal aspects of organisational dying was first observed by Glaser and Strauss in the 1960s (Glaser and Strauss, 1965a). Their ethnographic work in a number of different healthcare settings in the United States of America provided an understanding of the transition from living into dying as a 'non-scheduled status passage' (Glaser and Strauss, 1965b). They recognised the uncertain nature of the non-scheduled passage: the difficulties of recognising when a patient was in transition between one status and the next and that the patient and those around him or her may have different perceptions about where in passage the patient was. They found through their studies that patients and those around them formed 'death expectations'; a certain or uncertain understanding, after recognition of a potentially terminal diagnosis, of when their death would occur. In forming these expectations Glaser and Strauss recognised two important features; certainty and time. They conceived the expectations of a patient's death (from all perspectives, including the patient) as forming 4 different groups:

- Certain death at a known time

- Certain death at an unknown time

- Uncertain death but at a known time when the question will be resolved

- Uncertain death and unknown time when the question will be resolved (Glaser and Strauss, 1965a: 18-19).

Glaser and Strauss conceived these 'transitional statuses of dying' as non-scheduled passages through which patients were expected to pass between living and dying. The transition between these statuses was fluid and recognised through the accumulation of 'cues'. These cues were provided by the patient's physical condition and by the recognition of changes over time; the 'physical' and 'temporal' cues. A patient's physical condition could be determined by the doctors, and their assessments were used to provide cues about the progression of the disease. The rate of change in a patient's condition was measured through the relationship between the *expected* progression of a

disease and the patient's *actual* progression through this. The accumulation of cues provided increasing evidence of the timing of a patient's death and of their transition from a status of 'certain death at unknown time' to 'certain death at known time' (Glaser and Strauss, 1965a: 21). Recognition of dying as a transitional status passage is relevant when considering the process through which the use of sedative drugs, *with the acceptance of a reduction in consciousness,* can be seen to become routine. A process through which the reduction of a patient's consciousness became acceptable occurred as a patient came to be recognised to be imminently dying.

4.2.1   Organisation of dying in the hospice

Patients were admitted to the hospice for one of three reasons; respite care, symptom control, or end of life care. A respite admission was an admission for a set period of time, normally for one week, after which the patient returned home. An admission for symptom control was more open-ended; it was an admission to the hospice for an indefinite period, until symptoms were under control, with the expectation that the patient would return home. This group included those who were admitted for the treatment of psychological symptoms and those who had difficulty in coping at home due to a lack, or difficulty in providing, social support. Some of those admitted for symptom control changed during the course of their admission and stayed for end of life care. When a patient was admitted for end of life care it appeared to be expected that they would stay in the hospice until they died. These reasons for admission were stated regularly at handover and MDT meetings and amended according to the initial assessments carried out by nursing and medical staff. In this way a patient admitted for end of life care whom the staff subsequently assessed as not dying, would then be referred to as staying for a period of symptom control; those admitted for symptom control who were subsequently thought to be dying would be referred to as 'staying for end of life care'. These labels were applied to the patients on a frequent basis. In MDT meetings, for example, the reason for a patient's admission was announced and a decision was made about the future status of the patient; either to plan to discharge the patient, or for them to stay for end of life care. It appeared to provide staff with a way of recognising what was required of them, a form of shorthand to guide what patients may need in terms of different levels of care or intervention.

4.2.2 Status of dying in the hospice

In the hospice the majority of patients had a diagnosis of a progressive incurable illness. In this sense, that they were dying was recognised, and death was expected with certainty. The expected timing of their deaths, however, varied markedly. Some patients were undergoing 'disease modifying' treatment with the aim of prolonging life. The timing of their death was often considered unpredictable, dependent as it was, upon their responses to treatment. Many, however, had progressive incurable illnesses for which there were no expectations of further disease modifying drugs. The certainty of their death was known and the timing of their death too, in the 'expected' sense, was known. In the absence of treatments which would alter the 'disease trajectory', the timing of death was an expected, known, entity and as such patients could be considered as being in the final transitional status of 'certain death at known time'. This status of 'certain death at known time' was seen through the observations to be further defined in practice; it appeared an expected 'sequence' of passing through the status was observed. This, I suggest, created an implicitly recognised temporal structure of dying, of passing through this final status. This was not institutionally prescribed, rather was institutionally recognised and anticipated. This recognition enabled those working in the organisation to identify where the patient was within the status and how they ought to be treated. Furthermore, where a patient was in this sequence was vital in determining how sedation was used; the influence of this on the acceptance of a reduction in consciousness is crucial.

Dying in the hospice, it appeared, was shaped by temporal requirements of the organisation. The organisational expectations of the length of a patient's admission (for symptom control or for dying) and the nature of the work of the hospice could be seen to frame the expectation of the duration of dying in the hospice. There was, for example, an expectation of the average length of a patient's admission. When patients were anticipated as likely to stay in the hospice for a longer period, it appeared that some justification for their continued admission was required. During an MDT, for example, one of the consultants agreed with the rest of the team that a patient, Harry, should stay for end of life care. Harry was a 42 year old man with a brain tumour who was admitted to the hospice for symptom control of seizures and because he had been 'deteriorating' at home. He was bedbound and unable to eat and drink by himself. His

communication also fluctuated on a regular basis; he was unable to communicate due to unconsciousness at times but he was said to be lucid at other times too. His family had decided they would not be able to manage to have Harry at home again as he was so dependent and the consultant in charge of his care, Michael, agreed that he should stay in the hospice. The following extract was from field notes at the time of the MDT.

> *4:8 Michael* [consultant] *commented that it didn't help the figures but there really wasn't any option for him to go anywhere else. He was still unstable and fluctuating so they agreed he should stay at the hospice for end of life care – which is what his family wanted.*
>
> [FN 19/05/10 line 219]

Michael referred to *'the figures'*; this was a reference to the length of Harry's admission and appeared to convey an expectation that he would not die quickly. Indeed, 2 weeks later, the MDT had a similar discussion about Harry's ongoing admission, once again concluding that he should stay in the hospice until he died.

> *4:9 Eve* [social worker] *said she hated it when they got patients with brain tumours because you always knew you'd end up with decisions like this to make, they go on for so long and it's so hard on their families. Izzy* [staff nurse] *agreed and said that they were all young and no-one else wanted them, but they couldn't all stay indefinitely otherwise they would have no beds for anyone else.*
>
> [FN 02/06/10 line 217]

Harry's ongoing admission for end of life care created problems, it seemed, for the organisational structure of dying as he took longer to die than was expected and planned for within the hospice context. Harry's case was not unusual but illustrates that the dying process in the hospice was framed within the temporal structure of the organisation. A further requirement of dying in the hospice was that it be an active process. Dying in the hospice, it seemed, required the patient's physical condition to be changing and progressing towards death within a certain timeframe. Patients who were 'stable' were not considered to be actively dying and, where possible, they were discharged. Patients who were able to stay in the hospice until they died had entered a phase whereby they were thought to be 'actively dying', and were changing daily. This

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was represented by the acknowledgement that a patient was to stay in the hospice for 'end of life care'.

4.2.3 Announcing the transition

The hospice structure of dying was framed by an expectation of the overall duration of dying and by an active state of change in a patient's condition. The acceptance of a patient as staying for 'end of life care' could be seen to be the point at which the status of certain death at known time was explicitly announced. This decision was often taken at MDT meetings, on ward rounds or during handover meetings but frequently involved both nurses and doctors. The sequence through which patients were expected to pass before death was recognised through similar 'announcements' of transition. These announcements did not mark the actual point at which patients were thought to have made a transition, rather the point at which this was made explicit, in the familiar language of the hospice. These words were used in everyday handover meetings and their interpretation appeared to be shared by staff. The sequence was marked by the announcements of the transition from; 'aiming for home', to 'deteriorating', to 'heading for the LCP' and finally being 'on the LCP'. This is seen in Figure 4:1, and will be demonstrated in subsequent chapters to be important, indeed fundamental, to the hospice understanding of the way in which sedative drugs ought to be used. These 'announcements' were heralded by 'cues' which accumulated prior to the recognition of transition; this announcement of transition appeared to create a form of shorthand which was recognised by all staff. The change in 'routine sedation', or the way in which sedative drugs were given on a daily basis, as a patient passed through the expected sequence of the status passage is considered below.

Figure 4:1: Understanding of the process of dying

4.3 'Aiming for home': treating symptoms, avoiding reduced consciousness

Patients in the hospice who were admitted for a period of respite or for symptom control were not necessarily considered to be dying in the hospice. They received sedative drugs, however, for symptoms they described. For example Emma was a patient who had been admitted to the hospice for a period of respite care. She had metastatic[10] lung cancer, chronic obstructive airways disease (COPD) and suffered from breathlessness. I observed the morning handover as her problems were described by Helen, one of the nurses.

> *4:10 She* [Emma] *had been to day-care yesterday but had a 'panic attack'. She had been given lorazepam for this while in day-care and told Helen* [staff nurse] *that she wasn't if sure she was still panicking but she found she could talk much more easily afterwards. She told Helen that she hadn't been able to talk as easily in quite a while and had asked her what it was that she had been given and if she could have it again. Helen said that 'they' had encouraged her in the hospital to try lorazepam to help her breathing but she had refused it and hadn't wanted to be drowsy. She felt that, having tried it and found that she could talk more easily, she would want to try it again. Helen said that her breathlessness made her panic rather than panic made her breathless.*
>
> [FN 27/11/09 line 36]

Emma was expected to be discharged and had been given sedation as a way of treating her symptom of breathlessness. In the extract above it was clear that she had not wanted to become drowsy and had avoided this drug in the past; having taken it she found that it had helped her breathlessness without the anticipated side effect. The use of sedation had been 'encouraged', Helen said; it appeared to be a standard way to treat this symptom. In this situation, it appeared that the sedative drug had been given to treat a specific symptom without causing a reduction in consciousness.

In a similar way, sedative drugs were frequently given at night to help patients to sleep. This form of sedation was not expected to cause any reduction in consciousness during

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[10] Spread of cancer from its primary to source to non-adjacent organs or tissues

the day. For example, James was a 60 year old man who had metastatic oesophageal cancer. He had been admitted for symptom control as he had been vomiting and unable to swallow. His symptoms had been treated, recurred and been treated again during his admission. I observed a morning handover meeting where his treatment of insomnia with sedation was discussed.

> *4:11 He had got into a new habit, Izzy* [staff nurse] *said, of having midazolam at 11 o clock. It started a few days ago when he couldn't swallow his night medication. Instead of the temazepam[11] he was on, he had been given midazolam in its place to help him sleep. He was now able to swallow (as steroids had helped with this) but, in addition to the temazepam which he was now able to take again, he wanted to have the midazolam too (2.5 mg). He had been having an extra dose through the night as well, which had made him drowsy in the morning. Izzy said they had refused to give him any extra though last night and he had been unhappy with them.*
>
> [FN 13/01/10 line 53]

James was a patient who was considered to be ready for discharge. This was not straightforward, however, as he had nowhere to go and did not want to go into a nursing home. He had begun to ask for sedative drugs which then made him drowsy in the morning; the nurses felt uneasy with this and appeared to be trying to limit his use. Over a week later this tension still existed.

> *4:12 He was still asking for subcutaneous medication and extra lorazepam although the plan was to give everything by mouth now, and discourage the use of extras and injections, in preparation for transfer to a nursing home.*
>
> [FN 22/01/10 line 37]

While the use of injectable medication may have been influenced by practical considerations of not being able to provide them in a nursing home, it appeared that there was also an attempt to reduce his need for extra medication such as lorazepam through the night. This approach, to limit or reduce a patient's use of sedative drugs

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[11]Oral benzodiazepine routinely given to treat insomnia

can be seen to be characteristic of this group of patients who were expected to be discharged. Indeed, the aim of discharge appeared at times to motivate a reduction in sedative drug use. For example, Paula was a 63 year old lady who had a small cell lung cancer[12] with extensive disease at her initial presentation. She had been given chemotherapy to treat the cancer but it hadn't responded to treatment and she was admitted to the hospice for control of her symptoms. She had become used to taking sedative drugs to treat her anxiety and requested these frequently, appearing at times to become very drowsy after taking them. The following excerpt from field notes was from an MDT meeting which took place six days after her admission to the hospice. In this discourse between Susan (a senior nurse) and Julia (a senior doctor) the aim of discharge can be seen to focus treatment:

> *4:13 She* [Paula] *had improved over the weekend…. She had needed a lot of lorazepam, however – she had had 6 mg of lorazepam yesterday and was really quite sleepy; Susan said she 'couldn't keep her eyes open'. Julia* [senior doctor] *said that on the ward round it was discussed and agreed that they would try to use less lorazepam and instead try to use alternatives such as relaxation therapy or breathing exercises. The fact that she wanted to go home at some point seemed to be important in this too – if aiming for home then it would be much better and safer for her not to be requiring so much lorazepam, Julia said. The team agreed that they should begin to make plans for her to go home – she was as stable as she could be – to have this time at home would be important before she deteriorated again.*
>
> [FN 24/11/09 line 20]

Paula's desire to go home appeared to be adversely affected by her requests for sedative drugs; the aim, however, of the MDT was to enable her to go home if she could. It appeared that despite having a terminal illness and a poor prognosis, they didn't expect her to die imminently, and expected to be able to discharge her, even if they anticipated that she would 'deteriorate' soon after. For Paula too, it seemed, the drowsiness, or reduction in consciousness she experienced with the sedative drugs, was considered as a side effect at this stage of dying.

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[12] An aggressive form of lung cancer

The effect of sedation was seen to be important in this group. Paula became drowsy after taking the extra lorazepam; Simon, described earlier, was also found to be drowsy after having a sedative drug for insomnia at night. Mollie, one of the staff nurses, told me how Simon was after his first night of having a syringe driver with midazolam at night as we chatted in the nursing office.

> 4:14 he was much better last night with the midazolam overnight, but he had woken up a bit groggy, so the timings of the syringe drivers were going to be changed from tonight.
>
> [FN 17/02/10 line 18]

Drowsiness, or feeling 'groggy', as a result of sedative drugs, in this group of patients who were expected to be discharged, was considered as an adverse effect. This was similar to the experience of patients who became drowsy after taking analgesic drugs; it was considered as a side effect and the drug was reduced, or stopped.

Thus for those who were not actively dying sedative drugs were used to treat specific symptoms but a reduction in consciousness was not intended and was actively avoided. This is seen diagrammatically in Figure 4:2.
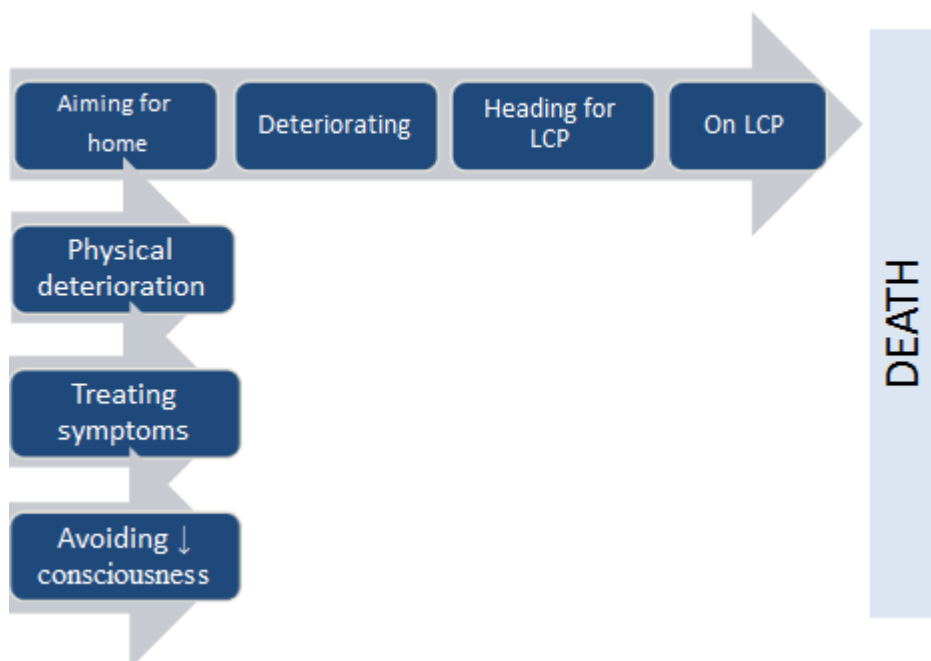
Figure 4:2: Use of sedative drugs in patients not dying

4.4   Deteriorating: reversing the reversible, treating symptoms

Patients in the hospice were either admitted for 'end of life care' or went through a process of change through which they became recognised as dying and were said to be 'staying for end of life care'. It became apparent that something changed between a period either of indecision about whether a patient would be discharged or not, or a reversal of a decision to discharge a patient. There was a change in the patient's condition which prompted staff members to consider the patient as, now, dying. This was a frequent discussion point in MDT meetings and a decision appeared to be formed in relation to observations of change in the patient's condition. These changes may be regarded as 'cues', originally described by Glaser and Strauss (Glaser and Strauss, 1968: 9). For staff, cues at this stage were most often related to a patient's physical condition. Patients who were ambulant began to have difficulties walking and getting out of bed; others were observed to simply be more tired, more fatigued than they had been. Often after a few days of this being observed, they would be described as 'deteriorating'. Frequently this was observed after a member of staff had been away for a few days; they would return to work and observe 'a change'. The terms 'changing', or 'deteriorating' appeared to announce the transition into the status of 'certain death at known time' (Glaser and Strauss, 1968: 8). Indeed the term 'deteriorating' appeared to herald a different type of care for a patient, geared towards an expectation of a known sequence of dying.

The word 'deteriorating' was used frequently in the hospice to convey an impression of change, of a worsening in a patient's condition as well as going further, it seemed, to indicate that they were dying. It was used on almost a daily basis in handover meetings and informally amongst staff. The term 'he's really deteriorated' was a very common phrase to be used in the course of handover or MDT meetings, and in informal discussions between staff in the nursing or MDT office. It was almost invariably used in the context of a patient who was thought to be dying. For example, Keith was a 56 year old man who had metastatic prostate cancer and was due to be transferred to another centre for a specialist form treatment for lymphoedema[13]. He had become less

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[13] Lymphoedema; swelling in a limb caused by impaired lymphatic drainage. In palliative care often this is secondary to lymphatic obstruction due to cancer or its treatments.

mobile and on the morning he was due to be transferred in the handover meeting some of the phrases in the conversation between the doctor and nurses looking after him were transcribed verbatim. He was said to be *'very very drowsy'*; one of the nurses said it would be a *'shame to transfer him if he was dying'*. Rachel, a registrar, said he *'probably is deteriorating';* she added further; *'I think he's changing'* [FN 17/11/09 line 30].

It appeared during the course of this discussion that being very drowsy was an indicator of a change in his condition while the word 'deteriorating' was an agreement with the previous statement that he was 'dying'. Indeed, over the course of the fieldwork this was a very common discussion to observe. At times the word 'deteriorating' was used on its own, at other times qualifying statements followed, indicating whether there was thought to be any reversible cause for the patient's deterioration. It appeared that 'even' when a patient was thought to be dying, if a reversible cause for a more rapid change in their condition was identified, it may be treated.

As the term 'deteriorating' was introduced, the physical changes, or cues, which prompted the recognition of the transitional stage of dying, were observed. For example, Claire was a 49 year old patient with breast cancer. She was noticed to be 'deteriorating' as she became more easily fatigued, less able to mobilise and finally ceased to be able to wash herself. As a fiercely independent woman, this was regarded by the nursing staff as significant. In a morning handover meeting these specific changes were reported on 2 successive days, as the following field notes extracts show:

> *4:15 Anne* [staff nurse], *turning to me, said: 'she's really not well'. She looked sad as she said it, with some emphasis. She went on, after a long pause to say: 'she let me wash her today, that's not Claire'.*
>
> [FN 16/11/09 line 72]

The following day:

> *4:16 Claire was thought to be 'really deteriorating' and was 'not so well'. Jo* [staff nurse] *said that she was so drowsy that she accepted a bed bath from staff this morning... She had also been assessed by the physiotherapist that morning and told not to get out of bed by herself as she wasn't safe.*
>
> [FN 17/11/09 line 41]

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These physical changes, it seemed, provided cues for the staff to base their assessment of her 'changing' condition.

When a patient was said to be deteriorating and physical changes corresponding to this were observed, such as increased fatigue, reduced ability to mobilise or a worsening of symptoms, they were observed to go through a period of 'testing'. Staff, when recognising that a patient was 'less well' attempted to determine if they were less well because of a 'reversible' cause or if they were less well because they were dying. If they were thought to be dying without any reversible cause this was often said to be due to 'disease progression'. The most common causes attributed to a deterioration in a patient's condition, it seemed, were drugs, dehydration or an infection. Indeed, as Claire deteriorated and became drowsier, that it was thought to be most likely to be due to the fact that she was dying, rather than because of the drugs she was taking was made explicit. Claire was clear that being drowsy was something she definitely did not want. I observed Julia, one of the senior doctors, explaining that she thought Claire was so drowsy because of 'the disease' and not because of any drugs she was on. She went on, however, to ask if Claire would want the drugs to be reduced 'just in case'. Claire had been having a syringe driver overnight to help her sleep for several weeks and this was the only drug which Julia could identify as potentially causing her drowsiness. As I observed the consultation Claire's husband and son were in the room, sitting on the far side of her bed, with Julia sitting the near side while I was sat towards the back of the room.

> *4:17 She* [Julia] *asked if Claire was still having midazolam at night. Her son said that she was, and she'd had an extra overnight. Julia asked whether, as she was sleeping a lot during the day, and still sleeping at night, she would like to reduce the midazolam overnight. She said she'd like to try. Her husband checked with Julia that the midazolam was stopped in the morning – Julia confirmed it was, but that as the body changes, the drugs may 'hang around' for longer during the day and it would be worth trying to reduce the midazolam just to see if it had any effect. She said she didn't think it would, and that it was most likely that this sleepiness was just related to 'the disease', but was worth trying. She also asked if another drug had had any effect on her sweats – as it hadn't, and could sometimes cause drowsiness, she stopped it.* [FN 18/11/09 line 158]

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While expecting that the change in Claire's condition was due to the process of dying, the possibility that the drugs may cause her to be more drowsy and appear to have deteriorated was considered and the drugs duly reduced and stopped.

In a similar way, Olivia was a patient who had lung cancer, angina and COPD. She had been admitted for symptom control as she had had an increase in chest pain and vomiting at home. Her pain had increased but she had become very fatigued and was thought to be 'deteriorating' and staying for end of life care. She was disturbed by her profound fatigue and her drugs had been altered to see if they were responsible: like Claire, however, it was expected that her fatigue was due to progression of her underlying disease rather than the drugs. Field notes were recorded from an MDT discussion;

> *4:18 The vomiting 'frightened' her, Eve* [social worker] *said. She was sleepy and this bothered her a lot. She had been started on levomepromazine for nausea and vomiting but as she had become even more sleepy – and concerned about it – this had been stopped. On stopping it her drowsiness did not seem to improve but she did start vomiting again. John explained he had restarted the levomepromazine because of the recurrence of the vomiting… George* [consultant] *said he had had a conversation with her yesterday about the drowsiness – and the fact that it seemed unrelated to the drugs – but was probably more to do with the fact that her disease was more active and she was deteriorating. It was agreed that she was staying for end of life care 'but she's not LCP yet', George said.*
>
> [FN 16/02/11 line 107]

The 'testing' of reversible drug causes for an apparent deterioration was a frequent process, it seemed, when patients were recognised as becoming more unwell and, in particular, when they became more fatigued. In addition to reducing drugs, 'testing' also appeared to involve treating infections and dehydration when these were suspected to be causes of a patient's deterioration. For example, Susan was a 76 year old patient who had metastatic lung cancer and had been admitted for symptom control of breathlessness. She had developed a chest infection while in the hospice and had become more unwell overnight, I gathered as I observed the nursing handover in the morning. She was said to look '*awful*'; she had been '*chesty*' overnight and had been

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given hyoscine[14] and midazolam for her chest and agitation. After this, she had a catheter inserted which seemed to *'settle her'*, the nurses reported. Later that morning I went on the ward round as the doctors and Sophie, one of the nurses, went to see her. The field notes extract shows the decisions which were made, in this 'testing' stage; it was apparent that there was an expectation that she would not respond to antibiotics but they would give them 'just in case' they did.

> *4:19 George* [consultant] *asked how she was, to which she responded by saying she felt unwell and wanted a drip. George acknowledged this and said he wanted to ask her a bit more about how she was feeling before they discussed management. She said she felt tired and not well. George paused for a while but she wasn't able to be more specific. ... George said that he thought she looked more tired than when he last saw her. She kept closing her eyes during the consultation. ... She repeated her wish to have her medication intravenously, and George agreed that this would be necessary if they were to be able to get on top of the infection.*
>
> [FN 11/01/10 line 108]

It appeared that Susan, while very unwell, was clear that she wanted to be treated with intravenous medication; this seemed to be in keeping with her previous wishes, as the ward round discussed later outside the room.

> *4:20 ...everyone agreed that Susan was looking more unwell. She had previously been clear that she would want to be treated aggressively for an infection and George said because of this he felt they should treat her with the intravenous antibiotics and see how she gets on. ... they all agreed she was more unwell would stay in the hospice now but they'd just have to wait and see what happened with the antibiotics.*
>
> [FN 11/01/10 line 117]

Occasionally, having considered potentially reversible causes for a patient's deterioration, a decision would be made not to give further treatment. For example,

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[14] Anticholinergic drug used to treat excessive secretions, especially in the dying patient. There are 2 forms: hyoscine hydrobromide which is sedative and hyoscine butylbromide which is not. Hyoscine butylbromide is normally referred to as 'Buscopan'.

Janice was a patient who had a metastatic renal cell carcinoma. She had been increasingly drowsy and spent most of time in bed. As I sat in an MDT meeting the group considered what they thought was happening to Janice and how they would treat her. The following extract from my field notes recorded one of the senior nurses in the hospice, Linda, checking that they had considered the potential causes of her deterioration and setting the limits of treatment. Many verbatim statements were recorded, in keeping with the style of my early field notes.

> *4:21* [Linda said] *'this lady is deteriorating really'* and that she was *'spending long periods on the bed'*. *Izzy* [staff nurse] *said that she was not mobilising and was nursed in bed. Linda asked if there was 'anything we can get our teeth into that is reversible?' Sally, a registrar, said 'having not seen her since the weekend I think she's more sleepy'. She went on to say 'I think she's deteriorating'* [probably]... *short weeks* ... [I think she is] *'entering the terminal phase'. Linda asked if they would treat an infection again if a urine test was to suggest an infection again - to which Sally said that they wouldn't 'unless she was really symptomatic'.* [Sally] *said that 'she had quite severe renal failure' (a few weeks ago) and 'we didn't feel at that point, you know, she's performance status 4*[15] *and we didn't feel there'd be any urological interventions'. Linda asked if everyone agreed that she should stay in the hospice for end of life care, at which point everyone nodded. Linda added that 'she wasn't 'quite LCP yet'. In rounding up Linda said 'so we've dotted the 'i's' and crossed the 't's', she'll stay here for end of life care.*
>
> [18/11/09 line 240]

Having acknowledged that Janice would stay in the hospice for end of life care and was dying, they discussed their approach to managing her as she progressed to dying more imminently and decided they would not treat an infection. A discussion about withholding treatments at the end of life is outwith the scope of this thesis; of importance, however, is the process of identifying the reversible, the 'testing' process within this sequence of dying. While death appeared to be expected, the outcome of

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[15] European Cooperative Oncology Group (ECOG) performance status: a scale which measures a patient's activities of daily living. A performance status of 4 indicates the inability to carry out any self-care and being bedbound.

'testing' was anticipated as being a patient's continued deterioration; it seemed to be important, however, to have 'dotted the i's and crossed the t's' 'just in case' there was a reversible cause. It seemed to be important that sedative drugs did not cause a reduction in consciousness, or further fatigue. When they did, this was considered as a side effect and the effect was minimised. This changing, fluctuating and uncertain stage in the sequence of dying is seen in relation to the way in which sedation was used in Figure 4:3.
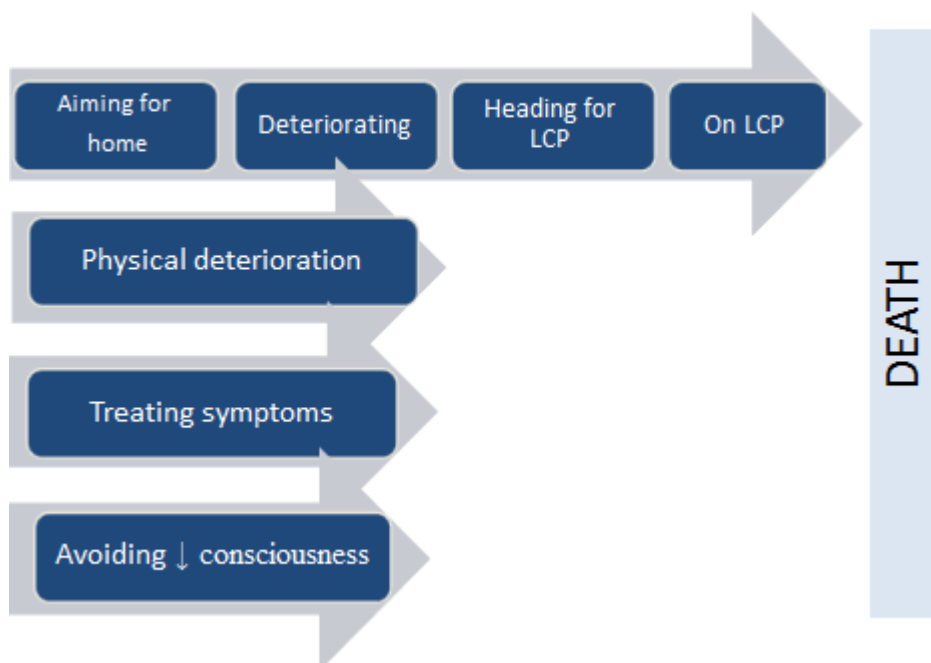
Figure 4:3: Reversing the reversible; avoiding reduction in patient consciousness

4.5   Heading for LCP: accepting dying, accepting reduced consciousness

Patients who were said to be deteriorating and who were staying in the hospice for end of life care were seen to pass through a further two sequences in their transition to death. The cues which heralded this passage appeared to be related to a patient's continued physical decline, towards becoming bedbound and drowsier. Patients at this point in the sequence of dying were said to be 'deteriorating daily' in handover meetings, without, it seemed, the need for qualification or explanation of what was meant. It appeared that this was the next expected part of the sequence of normal dying. Over time, the continued deterioration, it seemed, accumulated towards there being a

discussion of whether or not the patient was 'ready for the LCP'. For example, as Paula, described earlier, became more drowsy over time, a discussion took place about whether or not she was 'LCP'. Indeed this conversation took place on several occasions between different members of staff. Initially I was in the nurses' office as 3 nurses discussed informally how she was:

> *4:22 Lisa, Anne and Gemma* [staff nurses] *talked about how much more unwell she'd been and that she was heading for the LCP*
>
> [FN 07/12/09 line 15]

Later in the morning handover meeting one of these nurses reported to the doctors.

> *4:23 It was said that it was remarkable that she was hanging on so long, and it was hard to know if she was ready for the LCP yet or not – she would be very sleepy one minute and then the next would be quite alert. She wouldn't be far off, however*
>
> [FN 07/12/09 line 113]

Later still:

> *4:24 Miranda* [registrar] *said she wasn't sure she was quite ready for the LCP yet and Anne* [staff nurse] *agreed. She said it was hard to tell as she changed so much on a daily basis. Miranda said 'yes, she was quite alert this morning*
>
> [FN 07/12/09 line 198]

It appeared that the recognition that a patient was 'heading for the LCP' occurred after a period of 'deterioration', through which patients' physical condition worsened as well as there being a change in their alertness and communication. This appeared to be an important aspect of the recognition of a further decline in a patient's condition and was also marked by a change in the way in which symptoms were recognised.

4.5.1 'Natural' sedation

As patients were said to be 'deteriorating' and their physical condition worsened, with an increasing inability to mobilise, their levels of fatigue and drowsiness appeared to increase. Through the stage of testing for reversible causes, reasons for this drowsiness were sought and often drugs were reduced to see if they were the cause, rather than 'just the disease'. It appeared that becoming more drowsy was acknowledged to be part of

the process of dying. The discussions about whether the increasing drowsiness was 'simply' because they were dying were so frequent as to appear to be a matter of routine; if the drowsiness was not found to be due to a reversible cause, the cause was said to be 'just the disease progression'. Indeed, it seemed to be expected that patients became more drowsy, or sedated in a 'natural' sense, as they came closer to death. The routine way in which this was acknowledged was highlighted by discussions with patients and relatives about what was likely to occur as patients deteriorated further. For example, I went to see Claire, the patient described earlier, with Julia, a senior doctor. Claire was in a single room and she and Julia had a long discussion about what was happening to her, especially in relation to her becoming so sleepy. They discussed what Claire would want to happen as she became 'more unwell'. Claire asked Julia what would happen to her '*from now*':

> *4:25 Claire then asked Julia what would happen. Julia paused and asked her what she meant. Claire said: 'from now?' Julia said it was likely that she would become 'more sleepy for more of the time', that she would probably need to start to conserve her energy for more important times in the day, like seeing family. She said it was likely that she would just become more sleepy and at some point would just not wake up. Claire then asked about pain: 'would I be in pain, or be suffering?' Julia responded that they would continue treating the pain with drugs and though sometimes, especially with difficult pain like hers, the drugs may be used in doses that could make her more sleepy, they would still use them if she needed them.*
>
> [FN11/11/09 line 131]

Claire was very clear that she would want to be given sedation if she was 'suffering' when she responded to what Julia had said.

> *4:26 Claire said that she would want to be sedated, she said that she would not want to be 'aware', that she would want to be 'out of it' and that she did not want to suffer.*
>
> [FN11/11/09 line 145]

Julia seemed to distinguish between a natural sleepiness which she had described earlier, of becoming more unwell, from the drowsiness caused by the use of drugs to try

to treat other symptoms like pain. While in many situations the use of drugs was observed as contributing to sedation, this form of naturally occurring sedation during dying appeared to be recognised as an expected part of the dying process. Indeed, during a ward round I observed another doctor, Miranda, using the same phrase when Paula's daughter asked what was likely to happen as Paula became increasingly more unwell.

> *4:27 Miranda said it was hard to know exactly what would happen but it was likely that, as the periods of being drowsy were becoming longer, and her periods of being awake were much shorter, she would continue to just become more sleepy for more of the time and at some point she just wouldn't wake up.*
>
> [FN 07/01/10 line 177]

It appeared that these expected changes in consciousness marked part of the transition through the sequence of dying, in which patients became more easily fatigued and less able to actively communicate for sustained periods of time. Consultations became shorter as patients tired more easily; this was recognised as being part of the normal process of dying.

4.5.2 Delirium

As well as this 'natural' sedation occurring as a patient neared death, patients were also recognised to be more likely to become confused, or develop a delirium. Patients who had shown signs of a 'deterioration' prior to becoming confused were considered at times to have developed a 'terminal agitation'; those who were confused in the absence of a prior physical deterioration were not, however, considered in this group. Rather, in the absence of physical deterioration delirium was investigated and treated as at an earlier stage in the sequence of dying and a reversible cause sought. For example, Rick was a 71 year old man who had a form of lung cancer and had been admitted for symptom control of pain. He had become confused during his admission as his drugs had been adjusted and he had had several doses of different benzodiazepines to help him to sleep at night instead of 'wandering'. An MDT discussion was observed.

> *4:28 Since admission, he'd been started on Ketamine but was wandering a lot overnight. Annie (S/N) said he'd had a lot of pain - for which he'd been having*

hydromorphone[16] - and had needed 5 extras. He had been sleeping during the day - switching his days and nights around. They'd tried a midazolam syringe driver which he'd pulled out at 3 am and gone wandering around the garden. He'd 'come-to' around 5 am and hadn't remembered being out in the garden at all. Lorazepam hadn't worked last night and he'd tried temazepam and zopiclone[17] previously too. He had Parkinson's disease as well, and had been started on quetiepine[18]. Annie (S/N) asked about his bloods – Michael (consultant) said his bloods had been checked twice and were normal… Michael said 'its classic delirium isn't it? He fluctuates in his capacity'. He said he planned to arrange a CT of his head. Previously he'd been on 42 mg of hydromorphone but was now on nothing – almost all of his drugs had been stopped when he became confused.

[FN 11/09/09 line 371]

In this situation, several causes of Rick's delirium were investigated. In contrast, when considering another patient exhibiting similar behaviours, Gillian, one of the registrars, said she thought that he had a 'terminal delirium'. Charlie was introduced at the start of the chapter as a 76 year old patient with a form of lung cancer. He had become 'agitated' and I observed Gillian and Julia, a senior doctor discussing in the office how to treat this. After deciding to wait to assess his response to an 'extra' of levomepromazine, Gillian said;

> *4:29 she wondered if this was a terminal delirium, she didn't think it would be long.*

[FN 11/02/10 line 61]

Gillian's assessment of Charlie was that he was dying, rather than having a potentially reversible cause for his delirium. It appeared that for delirium to be considered irreversible required there to be initial recognition of a physical deterioration.

As patients became more drowsy, staff could be seen to communicate more with the family members in the room than the patient. After trying to communicate with the

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[16] Strong opioid

[17] Sedative drug normally used for insomnia

[18] 'Atypical' antipsychotic drug normally causing less sedation than traditional antipsychotic drugs

patient, they would then turn to ask the relatives about what had been happening. For example, as I went on the drug round with Jen, one of the nurses, I observed how she tried to communicate with Paula but found she couldn't.

> *4:30 Paula looked up … and followed us with her eyes as we walked in … looking blank but she did say hello this time. Jen asked her how she was and she said 'OK', staring straight ahead. Jen then turned to her sister and asked how she had been. Her sister said she hadn't had such a good night, she had been really restless but seemed a little bit better just now.*
>
> [FN 07/12/09 line 79]

Establishing a patient's condition by asking relatives became increasingly more frequent as a patient became less aware and able to communicate. Specifically, asking relatives about a patient's symptoms, or if they were showing any signs of distress, became a routine part of consultations. As patients became less able to communicate, relatives who were present were consulted about the patient's behaviours, or appearance. For example, whether or not a patient had been 'agitated' or 'restless', or if they appeared to be 'settled. These behaviours increasingly became the indication for treatment, while attempting to identify the underlying cause. As patients became steadily less able to describe symptoms it was these behaviours which were treated; their effect was assessed by cessation of the 'distress-behaviour'. Staff referred to these behaviours as being 'unsettled', 'restless' or 'agitated'. A patient's inability to express their symptoms was most often due to difficulty in communication. This marked a significant change in approach regarding the use of sedation. Prior to this, a patient, describing a symptom, would be given a sedative drug to treat it, with the avoidance of a reduction in the patient's consciousness. Patients who were 'heading for the LCP ' had often begun or were beginning a process of becoming more fatigued and many had a reduced conscious level; the treatment of a distress-behaviour such as 'restlessness' with sedative drugs, it appeared, could result in a further reduction in consciousness. At this stage causing a reduction in consciousness through the use of sedative drugs appeared to be of less concern than it was prior to reaching this stage; it was of less concern than treatment of the distress-behaviour. Indeed, these behaviours were described in such a way as to appear to convey a duty to treat and to relieve them. In discussions observed in handover meetings and informally between staff in the

offices, there appeared to be more of an imperative to eliminate these distress behaviours. For example, James was a patient who had deteriorated very quickly and become drowsy; he was subsequently reported to have become very agitated and Annie, one of the senior nurses, was clear that he ought to be 'settled'.

> *4:31 He was getting really agitated, she said, moving his arm out to the side and looked restless. They really needed a plan to make sure he settled, she said.*
>
> [FN 24/02/10 line 13]

Later that day I saw James lying flat on his bed, and Annie told me he had been started on 15 milligrams of midazolam which had 'settled' him.

It appeared that in the transition from 'deteriorating' to 'heading for the LCP', a change in the 'routine' way in which sedation was used emerged. It appeared that the treatment of distress-behaviours became of more importance than a requirement not to reduce consciousness. The use of sedation to treat distress-behaviours at this stage, with an acceptance of a potential reduction in consciousness, was becoming 'routine'. Once again, this process is seen in Figure 4:4.
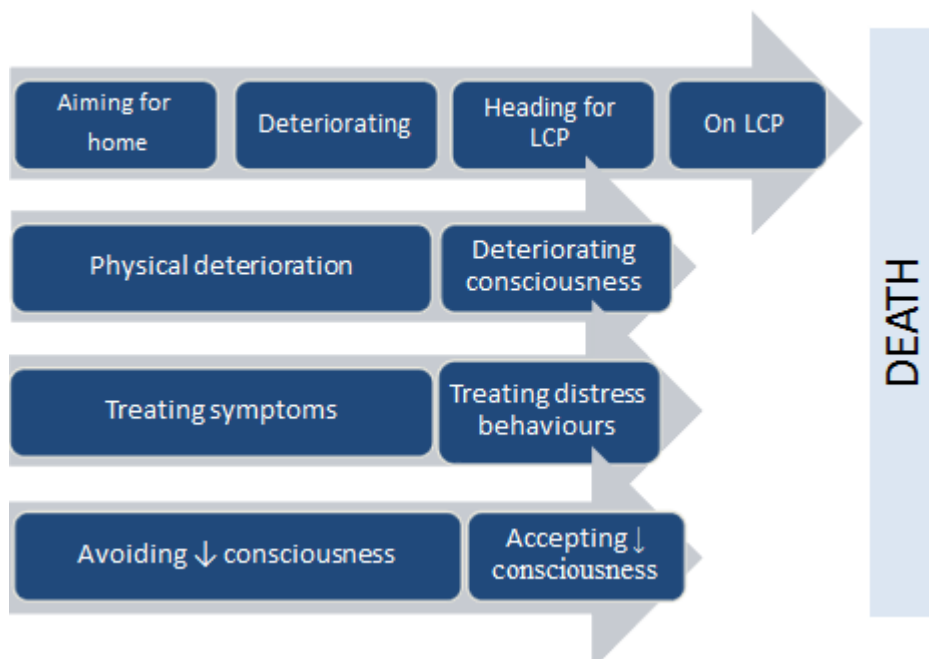
Figure 4:4: Heading for the LCP and acceptance of reduction in patient consciousness

4.6 'On the LCP'

Patients who were heading for the LCP differed subtly from those who were considered to be '*on the LCP*'. It appeared that staff attempted to differentiate between those patients who were dying soon and those who were dying imminently. Certainly, there was a distinction between those 'heading for' and those 'ready for' the LCP. The processes of physical and sentient deterioration appeared to progress in those who were 'on the LCP', with more patients having difficulty or an inability to meaningfully communicate. The use of sedation to treat distress-behaviours became more frequent and treating a patient's symptoms, with explicit avoidance of a reduction in consciousness was less common. Indeed, once a patient was recognised as being 'LCP' the apparent imperative to treat distress-behaviours became more evident. The handovers which took place daily almost invariably contained reference to at least one patient who had been 'unsettled', or 'agitated' overnight and been given one or more doses of sedative drugs to 'treat' the distress-behaviour. 'Treatment', it appeared, was the elimination of the distress-behaviour. The aim of treatment at this stage, therefore, was for a patient to be 'settled', or 'peaceful'. It appeared to be still important, however, to use the lowest dose possible to treat the perceived distress. For example, in their discussion about Charlie which was described earlier, the two doctors, Julia and Gillian, decided upon the best way to treat his agitation and discussed which drugs might help him to be less agitated. Their caution in using sedation, at this stage, appeared not to arise from a potential reduction in consciousness, but rather from a caution about giving more than was needed to treat the distress. A desire to give a proportional amount of sedation, to treat the distress but not more, was evident in this extract from the field notes.

> *4:32 Julia* [senior doctor] *then asked what Gillian* [registrar] *was worried about in adding the levomepromazine into the driver now. Gillian wasn't sure what she meant. Julia then asked whether part of the reason she was hesitating was that she was worried that if the levomepromazine which he had just had worked, and made him more relaxed and made him sleep, that in adding 50 mg to the driver, it would perhaps be more than he needed. In other words, was it that she wanted to give him the lowest dose possible of a drug which was effective, and not give too much and over sedate him? Gillian agreed that that was what she wanted.*

A clear balance between giving enough sedation to relieve distress and not more than was needed was observed in this conversation. While Julia recognised that the aim of the treatment was to make Charlie 'more relaxed' and sleep, there appeared to still be a distinction between this and giving 'too much'. This balance, it appeared, was not always met as the following extract from an MDT meeting shows. At the end of each MDT the deaths from the previous week were discussed and any concerns about the manner of the death, in particular in relation to relatives' bereavement, were raised. Annie, one of the staff nurses, described what happened to Charlie after Julia and Gillian's discussion above. He had died 3 days after their discussion.

> *4:33 Annie said it was awful because she couldn't get him settled. She said she had asked about changing his drivers but had been told because he hadn't had any extras that she should leave it at present and wait. She repeated that the experience had been 'awful', she couldn't settle him, he'd had his catheter out and then in again and then out. By the following day she 'got Miranda* [registrar] *to review him' and she 'whacked the driver up'. He settled at last and she was pleased that when she came in the following day he was 'lovely and settled'.*
>
> [FN 17/02/10 line 119]

The caution taken not to give too much sedation, not to 'over-sedate' had, from Annie's perspective, meant that he was not 'settled'. She used emotive language, describing the situation as 'awful'. It appeared that the need for patients to be 'settled' and not distressed or agitated was strong; that to achieve the state of being 'settled' was the 'right' state for patients to be in once they reached the stage of being 'on the LCP'. While the doctors in this situation were cautious about using too much sedation, there was the 'risk' of not achieving the desired 'settled' state, through this approach. In contrast, as another MDT discussion showed, there was a sense of comfort, once a patient who was on the LCP became settled.

> *4:34 Ella was introduced by Nicky* [staff nurse] *as someone about whom there wasn't much to say. She had been admitted for end of life care, had lung cancer, bone metastases and COPD. She had been 'terminally agitated' when she came in, but 'quite flat' since then. She repeated that she was 'quite flat and unwell'*

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and had started the LCP. She reported that she was 'lovely and settled now'; the driver had been 'tweaked' yesterday and 'levo[19]' had been added in to the 50 mg of midazolam she already had for agitation, as well as hyoscine and diamorphine. She once again said she was 'lovely and settled' with her driver now. George [consultant] *asked if there was anything that needed to be done for her family – Nicky didn't think so – they all knew what was going on and had no particular concerns. George said: 'hopefully she'll remain peaceful until she dies'.*

[FN 16/02/10 line 70]

The use of sedation in this extract, to treat agitation, appeared to be accepted and unproblematic. Ella was said to be 'flat', a term often used in the hospice to describe patients who were unrousable or were limited in their responses. It appeared that by this point in the sequence of dying this was acceptable and, occurring as it did on a daily basis, could be seen to be an intrinsic part of routine clinical practice. The changes occurring through the process of dying are seen in full in Figure 4:5, the motivations and underlying values for such a practice are discussed in the following chapters.
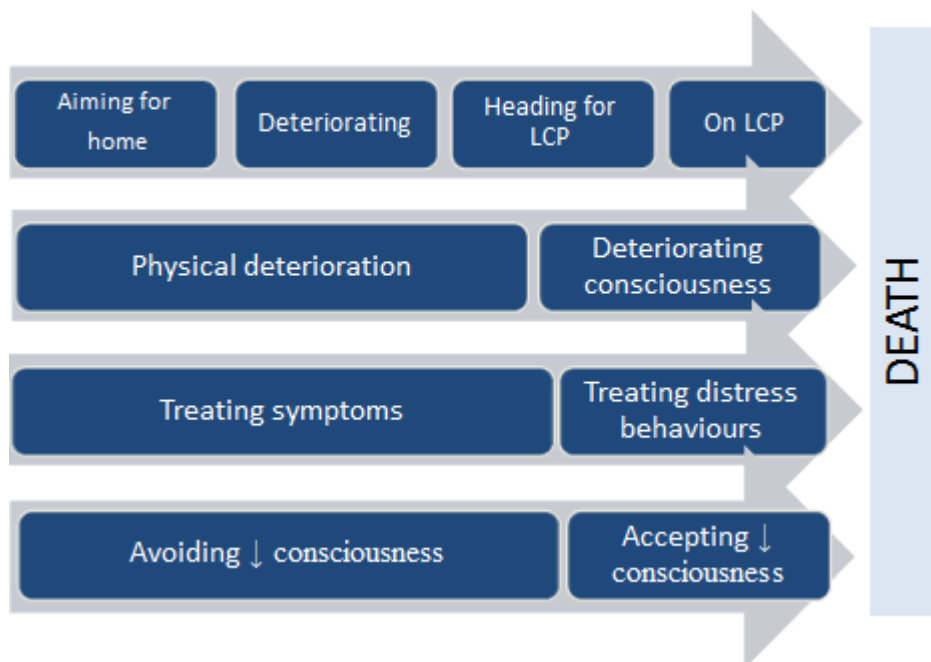
Figure 4:5: Process of dying in the hospice: the routine acceptance of the reduction in patient consciousness

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[19] Abbreviation for levomepromazine

4.7   Conclusion

This chapter has explored the way in which sedation was used in the hospice setting. Through the fieldwork it became apparent that sedation was a routine part of the daily work of the hospice inpatient unit. Sedation was seen to be used in different ways and this was bound to an understanding of the expected sequence of dying in the hospice. This sequence has been considered to sit within the final status passage described by Glaser and Strauss, of 'certain death at known time'. An understanding of this was formed through an interpretation of significant phrases which announced a change in a patient's condition. The physical and sentient deterioration which preceded these changes appeared to enable an acceptable form of sedation at this stage to include, or permit, the reduction of a patient's consciousness. This sequence has thus far been described in a linear fashion with a shared interpretation of the cues of transition. In practice, however, this process is much more complex, with sometimes different interpretations of the physical and sentient cues, leading to differences in approach to using sedation amongst staff.   The implicit understanding of where a patient was in the sequence of dying enabled staff to use sedation in a particular way, justified, it seemed, through an understanding of how a patient ought to be treated and cared for as they die. The way in which sedation is given in the hospice has been described in this chapter, the reasons and motivations for this are discussed in the following chapters.

Chapter 5 Sedation: Restoring Good Dying and Death?

The previous chapter focused on the sequence through which patients were expected to pass when dying in the hospice. The sequence of transition, from not dying to imminent dying was important in developing an understanding of the way in which sedation, with a reduction in consciousness, was regarded as routine practice in the hospice. Crucial to this sequence was the recognition of changes in a patient which were interpreted as signs of dying. Physical changes such as a reduced ability to mobilise were prominent, as well as the recognition of an increase in drowsiness and fatigue as being part of the dying process. The essential stage of determining the reversibility of such symptoms or signs was emphasised, prior to these changes being attributed to the dying process. There was a universal understanding that this increase in drowsiness related to the natural process of dying and furthermore was an *expectation* of 'natural' dying. This process was seen to inform the interpretations and actions of staff as they recognised the dying patient in part through their physical deterioration but also through their increasing fatigue and drowsiness. This expectation of the process of dying was also seen to drive a desire to achieve this 'natural' way of dying. The importance of the diagnosis of dying was evident when considering the changes in the way in which sedation was used through the different sequences of dying, with an increasing acceptance of a reduction in patient consciousness as patients came closer to death. Indeed, recognition of dying, in the very final stage of being 'on the LCP', allowed some patients to be sedated by drugs to unconsciousness until they died. Through recognising the sequence of dying it became evident that staff associated increasing fatigue and drowsiness of patients as being signs of imminent dying and furthermore that patients were expected to become drowsier as they approached death.

5.1 Good Dying and Death

In this chapter I explore the normative underpinnings of the use of sedation and the ways in which these are manifest in clinical practice. Sedation, I will suggest, is used with the overall aim of bringing about an aspect of 'good' dying and death. As discussed in Chapter 1, concepts of good dying and death are broad and originate from a variety of sources. Originally conceived of in contrast to the 'bad' deaths in hospitals where death was hidden and patients isolated, 'good' dying and death has been synonymous with hospice care and the original hospice movement. In recent years, conceptions of good dying and death have been focused more on individual preferences and choices, than on there being an idealised, shared, version of what this is in practice (Hales et al., 2008). This change has arisen alongside an increase in the availability of services and ability to fulfil choices in dying. Primarily this is achieved through ensuring patients have a 'comfortable', symptom-free dying process; this is shown in turn to influence other features of good dying and death such as enabling family to be present in the dying process and even to facilitate patients to be able to die at home. While good dying and death are very broad, multidimensional concepts, this chapter focuses on the impact of sedation on the hospice construct of good dying and death, rather than on the broader issues espoused in the large volume of literature on the subject (Aries, 1974, Clark and Seymour, 1999, Dekkers et al., 2002, Hales et al., 2010, Kellehear, 1990, McNamara et al., 1994, Payne et al., 1996, Seymour, 2001, Steinhauser et al., 2000b). In this chapter I first consider the importance of the attributes of 'being comfortable' (Kehl, 2006) and 'being peaceful' in dying in the hospice. These key features of dying were important to staff to be able to achieve, and contributed to the hospice construct of a good dying process or death. The interpretation of this and impact on family and also on hospice staff concludes the first section of this chapter. The interpretation of dying was seen in Chapter 4 to be a crucial step in enabling sedation to be used with the acceptance of a reduction in patient consciousness. That the point at which a patient was interpreted as dying could differ between staff is expanded in this chapter through looking at the way in which sedation was given; in a regular or p.r.n. manner. The distinction between the way in which sedative drugs were prescribed and given allowed a discrepancy to exist at times between what was intended by one member of the clinical team and another. This is of importance in relation to Chapter 6 where the difficulties in decision-making about

sedation are explored, and variances in interpretation of dying, if unchecked, could indeed have led to differences in outcome for patients.

5.2   Good dying in the hospice

5.2.1   Being comfortable

In the hospice there was a clear sense of how the concept of good dying and death was constructed for hospice staff. This related to the broader attributes of good dying, such as awareness and acceptance, as well as what was understood by control of pain or suffering at the end of life. Being 'comfortable' was a well-recognised concept in the hospice and the motivation to achieve this state was bound to the desire to bring about good dying and death. In the hospice 'being comfortable' appeared to take two forms: the absence of motor restlessness and the appearance or being peaceful, or serene. The first related to the interpretation of a patient's physical comfort while the second related to an interpretation of their psychoexistential 'comfort'. There was a very clear change in purpose once a patient was acknowledged to be dying; staff changed their focus away from promoting comfort in living, and striving to ensure that treatments could be maintained in a patient's own environment, to ensuring that a patient was 'comfortable' in dying. Being comfortable meant not exhibiting any distress-behaviours or appearances such as restlessness or agitation. This was recognised in Chapter 4 as patients were said to be 'settled', 'comfortable' and even 'peaceful'. As an illustration of this, one of the nurses, Judy, even sought me out to tell me of two 'good deaths' which she felt had been achieved over the previous weekend.

> *5:1 I went along the corridor and met Judy (staff nurse) who stopped me to chat. She said she'd been on over the weekend and spoke about a really 'good death' – one that they had really got right. It was Bryan. She said they'd (the nurses) noticed on Saturday he wasn't so well; something had changed in him and they felt he was deteriorating. They had had time to prepare his family for this and the next day he looked awful. He had had a bad night but they did 'what we do' and then he was lovely and settled. His family, Judy said, were fine - upset but prepared because they'd had the time, spotted his deterioration and got drugs in to him in time so he looked comfortable. They'd got it right this time, she said. And she went on to say that Zoe had also died. She'd been fine too - she*

hadn't started vomiting, thank goodness, Judy said, because that would have
been awful... It was lovely, she said, to get it right.

[FN 05/07/10, line 8]

Dying in such a way, to be 'settled', was considered as an achievement, a demonstration of what staff expected a good dying process to be. There was an expectation in the hospice of being able to achieve this good dying for patients. Although the patient described above was said to have had a 'bad' night, the restoration to being 'lovely and settled' enabled the death to be considered as 'good', from Judy's perspective. While she described other features of good dying such as preparation for dying and family involvement, one of the principle attributes was the patient's physical comfort in dying. Having physical symptoms causing distress when dying was considered to challenge this comfortable state; bringing them under control was a way of redressing the balance, of restoring the patient towards a 'settled', 'good', dying process. This ultimate aim of bringing about a 'comfortable' dying process was seen throughout the fieldwork.

Some spoke explicitly about what they hoped for patients at the end of their lives.

5:2 I think… you're just helping [them to] *stay calm, to meet their end in a*
dignified and, you know, peaceful manner, rather than be thrashing all over the
bed

[Judy, staff nurse, interview line 273]

Judy described how she felt sedation brought about the 'dignified' death so desired, and contrasted this with what had been the alternative – a patient 'thrashing all over the bed'. This description of an agitated patient was considered the antithesis of how a patient ought to die in the hospice. It presented a challenge to staff trying to ensure a patient was settled as they died. An auxiliary nurse, Gwen, described this in her interview as she talked about a patient who had become very distressed by vomiting as she died.

5:3 … she was just all over the place and not knowing where to put herself, so
agitated, like a wild animal at times… we got her... we got her washed and we got
her comfortable and settled and to me, when I look at it that way…, she was
alright, she was settled. She was clean and we got her comfortable and that was
it.   [Gwen, auxiliary nurse, interview line 186]

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The physical appearance and behaviours of patients thought to be imminently dying were of crucial importance; such agitated behaviour described above was interpreted as a sign of distress which had to be treated. When patients did not look comfortable there was an expectation that they should be made so and sedation, for signs of distress at the end of life, was the means to this end. One of the auxiliary nurses, Gail, put this particularly strongly in an interview.

> 5:4 *there's no need for people to be unsettled because there's the right drugs are there, you've just got to make sure that they're written up because to me, you know, it's not fair to them. And if people, you know, aren't on them… you've got to make sure that they are.*
>
> [Gail, auxiliary nurse, interview line 25]

Staff in the hospice felt a duty to facilitate a comfortable, settled, dying process: the control of distress-behaviours was part of this concept and was achieved in the final stages of dying through the use of sedative drugs.

5.2.2 Being peaceful

Distress-behaviours were recognised to be of a physical and of a psychosocial or existential nature. Recognised as a feature of good dying in the literature, acceptance of dying was considered important and a source of potential distress when not present. This was seen to contribute to distress-behaviours and appearances when patients were dying, as one of the senior nurses described in an interview.

> 5:5 [Some patients] *are not accepting and are in an awful place. And I think there's some who will never be in a good place… And there's some who are in this lovely serene place and you just think that's nice and...And I think you always want to try and achieve that and you don't always manage. And I think psychologically is always the hardest you know... But I think you just want people to be peaceful without pain and not being agitated and frightened. When they haven't accepted it it's harder and somehow they're more restless… unsettled…*
>
> [Susan, senior nurse, interview line 505]

Indeed, a patient's acceptance of dying was seen to impact on the way in which they died; in a 'peaceful' state, or in an agitated and distressed state. Additionally, social and

existential issues were thought to contribute to distress-behaviours. One of the doctors, Sally described a patient's difficult relationships prior to his death, as I recorded in my early field notes.

> *5:6* [He was] *described as having been 'settled in the end'. He had been agitated prior to death. There was a discussion about unresolved issues with his family, and it was agreed that this may have been partly responsible for him being 'in angst' as he died. 'He just wasn't peaceful', Susan* [senior nurse] *said. Sally* [registrar] *described having discussed this with a relative and encouraging them to say that they forgave him – she felt that this was important to have been said, but it wasn't.*
>
> [FN 12/10/09 line 184]

This patient was said to have been 'in angst', attributed at least in part to his uneasy relationship with a relative. The impact of troubled relationships or of other sources of psychological, or existential distress was frequently considered when patients were said to be agitated in dying. Furthermore this was interpreted in their appearance and behaviour as they died and different descriptors of distress were used to convey the nature of their distress. Being 'serene' or 'peaceful' or even 'calm' in dying was considered positively and appeared to convey more of a patient's psycho-existential wellbeing than simply their physical condition. Acceptance of dying was considered important in achieving this state as Susan alluded to above; further, having a sense of completion of life was also seen to drive forward this sense of calm in dying as one of the nurses referred to when describing the way a patient, Elliot, had died.

> *5:7 Elliot had been 'very at peace about dying'. He hadn't felt there was anything he needed to complete, or to get done.*
>
> [FN 24/11/09, line 171]

Good dying in the hospice was seen to be a process in which a patient can be said to be 'comfortable' in a physical sense and 'peaceful' in a psycho-existential sense. The appearance and behaviours of the patient enables staff in the hospice to determine whether a patient is comfortable and peaceful in dying and sedation is considered, in these final stages of life, to be the means to the end of a comfortable and peaceful dying process.

5.3   Impact of good dying on family

While a patient's distress from physical, psychological, social and existential sources was afforded great importance in itself, the impact of a patient's appearance on others was also a prominent consideration for staff in the hospice. This was seen especially in the case of Andrew. Andrew was a 78 year old gentleman who had a colorectal carcinoma and had been 'well known' to the hospice inpatient team for a number of years. He had previously been an inpatient for respite admissions and was in the hospice for this reason when he became more acutely unwell. In addition to his cancer, which had metastasised, he also had a degree of renal impairment. This deteriorated acutely over the course of a weekend and he developed profound myoclonus[1]. This myoclonus was due to the accumulation of opioid metabolites which could not be excreted by his kidneys because they were failing. One of the nurses who had looked after Andrew described in an interview feeling especially concerned about the impact that Andrew's myoclonus would have on his closest relative, his brother.

> *5:8 It was distressing for us to watch, I thought if it's distressing for us who've...who are used to seeing lots of different, you know, horrific sights in nursing careers then for, you know, a member of the lay public who doesn't...has never seen anything like this and it's his brother who...they're extremely close. I didn't want him to see the jerking cause it looked so horrible and it would look...and it didn't look like he was comfortable and settled and I just didn't want him to think that he was suffering in any way. We wanted to just...you know, so it was for him and...and for Andrew.*
>
> <div align="right">[Carol, staff nurse, interview line 210]</div>

Similarly, the doctor who had looked after Andrew felt a responsibility towards Andrew's brother. She described in an interview how Andrew's symptoms impacted on his brother.

> *5:9 ...and at this point, he* [Andrew] *was still really...distressed and jerky and I think that was very distressing for his brother. So I think, that was an added*

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[1] Myoclonus is the brief, involuntary contraction of a group of muscles, associated with many conditions. It is a recognised sign of opioid toxicity.

element, that the nurses were feeling that as well, that, you know, we hadn't got
him settled to a point that his brother could sit with him 'cause it was too
distressing really for his brother to be there, so he didn't stay very long.

[Sally, registrar, interview line 347]

Andrew's myoclonus was reported to be so distressing for his brother that he was unable to spend time with him as he died. Eventually, however, he 'settled' in response to the sedative drugs and died in what was described as a 'peaceful' way in the hours before his death, with his brother able to sit with him. The importance of controlling symptoms for the benefit of family members has strong roots in palliative care; bereavement is considered as an essential part of care of the 'whole' person, continuing to care for relatives after a patient has died (Panke and Ferrell, 2010: 1437, Saunders, 1965, Saunders, 1993). Recognising the impact of a 'bad' death on those surviving a patient was seen throughout the fieldwork. Indeed at each MDT meeting as all of the patients who had died the preceding week were discussed, the relatives of those who had died were also discussed and any particularly distressing aspect about the manner of the patient's death was described. Throughout the hospice there was a keen awareness of the impact of the manner of a patient's dying on the bereavement of relatives; this was seen as a further motivation to enable a 'comfortable' dying process. As one of the auxiliary nurses put it in an interview:

5:10 because that's your last memories of them if you've got awful thoughts –
like them thrashing around and things, how will you ever get that out of your
head? If somebody's nice and settled then you can say well they were peaceful

[Gail, auxiliary nurse, interview line 56]

Similarly, there was an explicit awareness of the dual role of managing both a patient's symptoms and also relatives' bereavements:

5:11 although our primary duty of care is to the patient, we are keeping an eye
on what might happen to the patient in terms of how that might distress and
impinge on the future bereavement of the family all of the time as well.

[Alison, consultant, interview line 507]

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5.4   Impact of good dying on staff

In addition to the impact which a 'bad' death had upon the relatives of patients in the hospice, staff also recognised the impact which it had on them as they cared for and developed relationships with patients. One of the nurses, Carol, described how she felt about Andrew's symptoms and the effect it had on her as a nurse:

> *5:12 If he'd died in the condition he was in on Sunday night, I would have just felt that was a bad death and I would have felt...I would have personally felt that I was failing him, like I did feel, even though I knew I'd given him everything I could possibly give him, done everything we could, took every measure we could, you know, getting him in comfortable positions and everything and...but I still would have felt it. You know, and I know you can't always give people the perfect death but it just would have been horrible to think he'd gone like that.*
>
> [Carol, staff nurse, interview line 242]

Carol felt a very personal responsibility to Andrew, to controlling his symptoms and ensuring he did not die in the distressing state in which she found him that Sunday night. She described a feeling of failure and throughout her interview there pervaded a sense of helplessness, that despite giving Andrew everything she possibly could he was still enduring a 'bad' dying process. While acknowledging that they were not always able to achieve the 'ideal' death, clearly dying in the manner which Andrew was, with uncontrolled symptoms, was unacceptable to Carol. Nurses formed strong bonds with patients and some considered themselves to act as advocates for the patients – ensuring that they were given what they 'needed' in order for dying to be considered as 'good'.

'Good' dying in the hospice was expressed primarily as a process of being comfortable and peaceful in dying. This was seen as the process of becoming drowsier as death approached, before the cessation of breathing, with family members able to be present. A discussion of the broader features recognised to be important to good dying and death is beyond the scope of this thesis: prominent features in the literature, however, such as patient and family awareness and acceptance of dying were evident in the fieldwork. Sedative drugs have a crucial role in ensuring a comfortable dying process: first in enabling a patient to be comfortable and peaceful and, second, in enabling family members to be present through the control of otherwise distressing symptoms. A

further role is shown to be the important role of maintaining staff morale and allowing staff to continue their work of caring (McNamara et al., 1995, Kovan and de Vries, 2010). This is motivated by the desire to ensure a comfortable and peaceful and therefore 'good' dying process. One doctor described this succinctly:

> *5:13 a good death is, is that patients are ...comfortable, a settled patient in a place of their choosing, surrounded by people of their choosing. That is a, so to speak, good death. ...and I kind of live by that I think. Practice by that.*
>
> [Erin, registrar, interview line 227]

Bringing about a process of good dying in the hospice required a patient to be both comfortable and peaceful. This was important to staff to achieve not only for the patient, but also for the patient's relatives and indeed for themselves. Being able to bring about this good dying process enabled a sense of achievement, and fulfilled the purpose for many, of working in the hospice. One of the nurses expressed this in an interview:

> *5:14 I really feel that we're good at… making sure people die comfortable and settled like, because we're in such a specialised area for making sure people… have a dignified death and this is what we do and this is what we do well… if a family walks out of here and they're just grateful for the care and [they sometimes say] she was lovely and peaceful and she wasn't in pain and things like this, this is what makes us satisfied that we've done our job right.*
>
> [Jen, staff nurse, interview line 307]

The risk of not achieving good dying for a patient engendered a feeling of guilt, as Carol described in the above quote (5:14). Thus being able to ensure a patient appeared comfortable and peaceful was important to staff in the hospice; the ability to use sedation for those who approached dying in a distressed, or restless, state may be considered to be of the upmost importance. For some patients, indeed, the use of sedation in this situation could be seen to 'restore' a patient to a 'good' process of dying and death. This is seen in Chapter 6 as situations in which sedation was used in a 'non-routine' way, in order, I suggest, to preserve or restore good dying, are discussed in depth. Next, however, I explore the need to ensure a good dying process through using

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sedative drugs and consider the impact of differences arising in the interpretation of the dying process.

5.5   Decision-making in uncertainty

The use of sedative drugs has been described in two ways; as a regular dose of a drug, often given continuously by means of a syringe driver, and on an 'as required' basis. Patients were prescribed p.r.n. sedation on admission for 'shortness of breath', 'anxiety', or 'agitation' in the same way that analgesic drugs were prescribed in case a patient developed pain. If a patient was felt to require a sedative drug it could thus be given by a nurse, at any time of day or night.   If a patient had required a p.r.n. dose of a sedative drug, and was assessed as being likely to continue to require sedative drugs regularly, a regular dose of sedation would be prescribed. In practice this was seen to occur after one or more p.r.n. doses had been given and the dose of the regular sedative drug was based upon what had been given in the prior 24 hour period. In the same way, changes in the regular dose of sedation were directly based upon what had been required as p.r.n. sedation.   Thus p.r.n. decisions to use sedation influenced decision-making about the use of regular sedation, especially concerning the dose which would be required. I observed a conversation between one of the junior doctors and a nurse discussing the dose of sedation to be added into a syringe driver.

> *5:15 Lisa* [staff nurse] *suggested to Ann* [registrar] *that she add in 25mg of Levo* [Levomepromazine] *at night and said that they could always use p.r.n.s if they were needed – then they could just see what was needed tomorrow again. Ann agreed and said she'd feel happier doing it that way rather than risk giving him more than he needed. She said at least she knew if he needed the extras he would get them* [from the nurses].

<div align="right">[FN 11/02/10, line 101]</div>

Ann was anxious not to give her patient too much sedation and appeared to rely on the nurses' ability to give extra doses if they were needed, feeling a sense of security and reduced 'risk' in making the decision, *because* he would be able to have the p.r.n. doses if needed. Nurses recognised the role of p.r.n. drugs in determining what patients required as they 'handed over' the p.r.n. requirements in morning handover meetings.

As I recorded I my field notes, one patient was said to have been very unsettled overnight and 'needed' their sedation to be increased. One of the nurses said:

> *5:16 She had been unsettled again overnight… [she] had been given diamorphine for what may have been pain, then midazolam, then levomepromazine, then she finally settled with diamorphine and midazolam together at 0340… She really needed to be reviewed, Annie* [staff nurse] *said, and needed her midazolam to go up – she'd had 20 mg extra overnight as well as 12.5 mg of levomepromazine.*
>
> [FN 13/01/10, line 7]

The use of drugs on a p.r.n. basis was integral to symptom management in the hospice. Doctors made prescribing decisions based on the availability of p.r.n. drugs which could be administered by nurses out of hours; similarly nurses expected to be able to give patients drugs as they were needed. Indeed, nurses were so familiar with the drugs and doses they expected to be prescribed they became surprised and even indignant when they were not. One of the nurses, Annie epitomised this as I was with her on an evening drug round as she read a patient's drug chart.

> *5:17 She looked at the drug chart and said: 'that's ridiculous!'*
> *I asked what and she said 'they' had only prescribed 6.25 mg of levomepromazine for agitation – with a range from 3.125 to 6.25 mg. She said that was a dose for nausea, not agitation. She always liked to check that she had something else to try, just in case the midazolam stopped working – but the levomepromazine wouldn't be of any use at that dose. She went on to say that she liked the doctors at the moment but they were cautious prescribers. She said they're not here dealing with it overnight – then they'd start prescribing more sensible doses for agitation.*
>
> [FN 06/07/10, line 65]

Annie 'knew' what this patient needed, having been on the night shift the previous night; she expected to be able to give certain doses of drugs if they were needed overnight. For the most part, it seemed that there was a process of decision-making about sedation, based upon this p.r.n. administration and subsequently what the doctors felt was appropriate to prescribe on a regular basis. The two types of decisions relied on each other for optimal care of the patients. Communication between the decision-

makers, the doctors and nurses, was essential for this to be possible. This communication took place daily in morning handover meetings but, as described above, also took place throughout the day as doctors and nurses negotiated the best way to manage a patient's symptoms or distress-behaviours with sedation. Concerns were expressed when there was disparity between the decisions about regular and p.r.n. use of sedation. This arose especially in situations in which there was uncertainty about whether or not a patient was dying. Luke was a 48 year old man with an oesophageal carcinoma. He was transferred to the hospice from hospital for pain control and possibly end-of-life care. He had been treated with chemotherapy and radiotherapy but despite this his cancer had progressed. He had severe pain and even on admission one of the registrars, Belinda, felt that there were some unanswered questions about his expected prognosis when she first assessed him.

> *5:18 Belinda* [registrar]… *came back in to the MDT office and sighed. Mollie* [staff nurse] *and Sophie* [staff nurse] *came in after her and sat down, waiting to hear about the man who had just been admitted – as an informal handover. Belinda said Luke was 48 years old, had 'presented' in 2007 with abdominal pain. It had been thought that it might have been gallstones but on doing some more investigations he was found to have a widespread 'upper GI' malignancy. He had had chemotherapy twice and had responded to this treatment. More recently he had, however, had difficulties swallowing and started vomiting in the past few weeks. A gastroscopy[2] had revealed thickening of the lining of his stomach and almost complete obstruction. He was still vomiting and had been transferred to the hospice for end of life care. Belinda sounded worried as she then said 'I don't think he's end of life yet'. He had pinpoint pupils and was twitching a lot. Ann said he hadn't had any bloods taken for 5 days, but he hadn't been 'peeing' more than a 'trickle' for the last few days either. She said to Mollie and Sophie she thought he was opioid-toxic and she was going to reduce his opioid and send some urgent bloods. She was concerned about his renal function and that it might be reduced and causing accumulation of the opioid.... She then*

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[2] A gastroscopy is an investigation in which a fibre-optic instrument is inserted into the stomach to look for any ulcers, damage to the lining of the stomach, or tumours.

*said that maybe he was 'just dying', but she wasn't convinced he was yet. She
said there were too many unanswered questions about his drugs and what was
going on to say he was dying yet.*

[FN 25/02/10, line 112]

Belinda seemed to feel that there was too much uncertainty about whether or not Luke
was dying to treat him as such without doing further tests. The potential for a reversible
cause for Luke's deterioration was to be explored first, she felt. The following day,
however, in the morning handover, the nurses felt that he was indeed dying.

*5:19 overnight [he] had really been in pain and agitated. He had required 3
extras of fentanyl with midazolam to try to settle him. He had also had lorazepam
at 0200. He was unable to get comfortable in bed, Jane said, he doesn't know
where to put himself. She said he looked like he was dying and needed to be
settled. She asked Michael [consultant] to see him first.*

[FN 26/02/10, line 44]

The consultant, Michael, reviewed Luke with Di, one of the registrars. He spent a long
time outlining to Di what had happened and what he expected to do, before going in to
see him.

*5:20 Michael felt one of the problems was that he was probably dying and yet
there were some elements of his condition which could possibly still be reversed.
His renal function was still poor and may improve further, and there was possibly
that there was still a bit of opiate toxicity… We then all went in to see him. He
looked very pale, with sunken eyes and heavy, audible breathing. His wife was in
tears as she talked about how the night had been – she had found it really
'frightening', he had been in so much pain. The only time he had been
comfortable was when he was 'out of it' and that hadn't lasted for long. She said
he just couldn't settle because he was in so much pain. Michael tried to wake
Luke up to ask him about his pain – he explained to his wife that because it was a
difficult pain he needed to find out if it had changed in any way, so that he could
ensure he gave him the right drugs. Luke was too sleepy, however, to wake for
more than a few seconds… Michael said, while still looking at Luke, that it was
worrying and difficult that he's fluctuating so much and going down so quickly.*

*His wife murmured quietly and agreed. Michael said they would start ketamine[3]
to see if it could help his pain and then he would come back and see him later in
the day. On the way up the corridor Di said to Michael that it looks as though
he's dying. Michael said yes, but that he worries that when someone is on
sedatives they do look as though they are dying and can be mistreated in this way.
He said that when Luke had come in he had looked as though he was dying but
then he improved when the drugs had worn out of his system and was quite alert.
He said that Luke had had quite a lot of midazolam overnight, with the fentanyl,
and it was hard to know if it was just the effect of this or if he was truly dying. He
said they would need to watch and see what happened – and try to avoid
benzodiazepines if they could so they could get a true picture.*

[FN 26/02/10, line 69]

Michael and Di spent several minutes detailing their plan and spoke to Sophie, one of
the nurses, to convey their plan that they did not want Luke to be given more sedative
drugs unless he absolutely needed it, as they felt he may be able to recover a little from
this. Michael's uncertainty was reflected again as he summed up, and said:

> 5:21 *he didn't know if he was dying 'or just drugged from the night before -
> that's the awful thing about benzos'.*

[FN 26/02/10, line 113]

Once again the desire to ensure Luke was settled and comfortable if dying was balanced
by a desire not to use too much sedation 'too early'. The following day I went into the
nurses' office as Di (registrar) was talking to Sophie (S/N) about Luke.

> 5:22 *He had been very distressed and in horrible pain again the night before -
> the ketamine* [change in analgesia] *hadn't been enough. They had given him
> fentanyl and that hadn't worked and in the end they had given him 4 extras of
> midazolam and fentanyl which seemed to settle him. His wife had been distraught
> overnight, too, and they all felt he was dying now. Di said she had just been down
> to see him and thought they should add 20 mg of midazolam into the syringe*

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[3] Ketamine is drug used in this context as an analgesic.

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driver. She felt cautious because Michael had been so keen to avoid midazolam,
but the situation had changed, she felt, and it had to be the right thing to do now.
Sophie agreed, and said 'the girls' overnight had found it very difficult as well -
when he's dying he just has to be settled, not tortured like this.

[FN 27/02/10, line 21]

While Michael had been unsure about whether or not Luke was dying and unwilling to use sedative drugs on a regular basis for his symptoms, the nurses overnight had felt he was dying and used them on an 'as required' basis, which was enough to 'settle him' and render him unconscious. Uncertainty during the process of dying, it seemed, made any decision temporary, and open to change, even within a 24 hour period. Luke was clearly thought to be dying by the time of his second review, and indeed died the following night. One of the potential concerns which the consultant Michael had raised was that the use of sedation may cause patients to look less well and even to look as though dying when not. The transition into 'end of life care mode' was once again made earlier for the nurses than for the doctors. While Michael thought that Luke was 'probably' dying, his uncertainty led him to wish to avoid sedative drugs and not go into 'end of life care mode' quite at that point. While acknowledging that he may be dying, the possibility of him not dying due to his illness was sufficient for Michael to wish to avoid drugs which may make him appear to be closer to death than he was. However the nurses caring for him, it seemed, had already begun to go in to 'end of life care mode', aiming for him to be settled and comfortable while openly saying they felt he was dying. Their priority, from the first extract, could be seen to be to ensure that Luke had a good death; Di, the following day, agreed with this after seeing a further deterioration in his condition. The priority and emphasis of care had changed for Di over 24 hours, while the nurses had appeared to go into this 'end of life care mode' before this point. The use of p.r.n. sedation in this situation was thought with retrospect not to have hastened his death: he died due to his underlying illness. The use of sedation in this way, however, does raise questions about the use of p.r.n. sedation in situations of uncertainty about dying. One of the consultants, Michael, was especially concerned about this: that the use of sedative drugs could make patients appear as though they were dying, resulting in them being treated as they were dying, with a change in focus of care towards ensuring they had a comfortable and 'good' dying and death. He spoke to me about this concern as we walked along a corridor.

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5:23 He [Michael] *said he did think and worry about using sedation - especially when it was used in particular groups of patients like those with dementia. He worried that when they got confused or restless they were sedated and it wasn't questioned - people always looked worse when they were sedated. He used an example of his own, where a patient had been admitted for symptom control of pain but had been agitated and wandered at night. She had been given benzodiazepines to 'treat' this and subsequently became drowsy, looked unwell and was thought to be dying. She then died several days later. He couldn't help wondering how much the benzodiazepines had to do with her death and he'd been very wary since then.*

[FN 06/07/10 line 121]

Once again, getting the diagnosis of dying right was of crucial importance; misinterpreting another process, of an iatrogenic deteriorate on due to sedative drugs, gives rise to the grave concern that sedative drugs in this situation could hasten a patient's death. While any iatrogenic error could in theory result in a patient's death, the familiarity of the process of increasing drowsiness in patients at the end of life, combined with a compelling duty to bring about a comfortable death, makes this a potentially fraught decision-making process. Making the wrong decision in this situation risked either hastening death or failing to achieve comfortable dying and a good death. The obligation to bring about this comfortable dying process was felt so intensely that it drove a sense of failure and even guilt when not achieved. One of the senior nurses, Susan, described in an interview how she felt when realising that a patient whom she felt had been unsettled for several days had not had his sedative medication increased in the week before his death. The interview was interwoven with regret as Susan felt that this patient should have been more comfortable in the days before his death.

5:24 ...I thought I should have like made sure that he was more settled... And it's someone's husband and someone's father and I think all we want is for people to die peacefully and to die comfortable, you know, that's all, with the right amount of medication. Not too much and not not enough, just the right amount to keep them comfortable. And I don't know, I just felt a bit bad at the end of the week when I saw he was still...and when I'd looked at all the extras he'd had. And I just

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thought oh, this is so... And I had to bring it up [at the next MDT meeting] *because I took it away that weekend with me, I felt so bad, I should have done something... I should have like made sure, because I'd been about, do you know what I mean, but doing other things...*

[Susan, senior nurse, interview line 403]

Recognition that this patient was dying bound Susan to strive for him to be settled as he died. She felt she was his advocate in this situation and was relieved when she found out the following week that he had appeared comfortable in the final 24 hours of his life, once his medication had been increased. This compulsion to achieve a comfortable dying process was evident throughout the fieldwork and appeared, for the most part, to be well balanced with concern not to hasten death; a tension between these obligations was only on occasion evident. An awareness of the potential for sedative drugs to at least hasten the *appearance* of dying was, however, more apparent. The consultants interviewed appeared to be particularly aware of this; George described in an interview his reasons for feeling able to use sedation for a patient, having considered the effect that medication could have on the patient's appearance.

5:25 ... it was ... just about being clear that actually, we weren't seeing a physical deterioration due to medication... using medication to sedate him at that stage wasn't going to have any impact on how long he had to live because he was dying quickly at that stage.

[George, consultant, interview line 222]

There was an awareness of the potential for sedative drugs to cause a patient to look as though they had physically deteriorated and concern to ensure patients were not then treated as such, with the emphasis of their care being to ensure a comfortable appearance in dying. As the drive for this 'good dying' was strong, the use of p.r.n. medication frequently led to an increase in the regular background dose of sedatives and this appeared to be unproblematic in most cases. The way in which sedation evolved was a complex series of decisions which frequently culminated in a decision to begin a continuous infusion of sedation. The importance of recognising a distinction between decisions taken to use regular sedation and those taken through the use of p.r.n. sedation is evident when considering those few but significant patients who experience

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overwhelming symptoms for a time and recover. Claire, for example, was a patient first introduced earlier in this Chapter. She had metastatic breast cancer and significant pain related to this. She was said to be deteriorating and was recognised as someone who would stay in the hospice 'for end of life care'. On one occasion over a weekend her pain became so overwhelming in nature that she could no longer tolerate it. She was given a large dose of midazolam to make her sleep for 12 hours. The following week this was discussed in the MDT meeting as the consultant, George, described what he thought was a 'very difficult stage'.

> *5:26* [He] *went on to say that her bad days had increased and her symptoms on the bad days had gone beyond the stage where she could be treated with drugs and maintain her alertness. She had always wanted to be awake and alert and this was no longer possible given the severity of her symptoms. Over the weekend* [he] *had needed to increase her syringe drivers to sedate her as her symptoms were intolerable. She had later (the following day) gone on to tell him that she wanted to be asleep on those bad days. She was said to be 'not-distractible' from her pain at the weekend - but 'yesterday was quite bright'.*
>
> [FN 10/11/09 line 117]

I observed one of the senior doctors, Julia, as she spoke to Claire about this the following day.

> *5:27 Julia reflected back to a few days ago when she'd* [Claire] *had severe pain and she'd had a discussion with George (consultant) about the use of sedatives to help her to 'have a break' from the pain when it was bad. Claire: 'yes I want that… sometimes I need a break'*
>
> [FN 11/11/09 line 109]

After this episode, Claire still had persistent pain but not such that she was unable to participate and enjoy time spent with family

> *5:28 Claire said … she felt quite calm in herself and was able to relax and able to sleep well now. She liked being able to speak to her son when she was well enough and wanted to be alert for as long as possible to 'stay with it' for as long as she could. When the pain was down a bit (like now) she could concentrate on speaking to him and this was good.* [FN 11/11/09 line 201]

Claire died 10 days after this, becoming drowsier in the days before she died and subsequently having a continuous infusion of midazolam to control restlessness in the final days of her life. She was later said to have had a settled and peaceful death. Sedation, in the final days of her life, was used in a routine way and she did not require further episodes of 'respite' sedation. Following the instance of respite sedation Claire recovered and was able to enjoy time with her family. She valued being able to communicate and feel in control for as long as possible; she was someone who wanted to be as awake as possible for as long as possible. She recognised, however, that there were times when this was not possible and her symptoms became so severe that she wanted to be sedated. Claire's pain became intolerable before respite sedation was used. She was unable to cope with her, then overwhelming, symptoms. In a similar way Luke, described earlier, was said to be unable to cope with his pain and was treated with analgesia and ultimately p.r.n. sedation. While Claire was treated decisively through the use of short term planned sedation, Luke was, in effect, sedated through the p.r.n. use of sedative drugs. The situations were different, insofar as Claire was understood to be dying, but not imminently: Luke was 'probably' dying imminently but there was doubt about this and hesitancy to commit to sedation, especially continuous sedation until he died. These two examples raise the potential for there to exist a situation in which a patient who is not in fact dying imminently to be treated with p.r.n. sedation, in a similar manner to Luke, become unconscious and die due to sedation rather than their disease. It should be emphasised that this was not observed during the fieldwork; rather the situation in which this could occur was recognised through the study of different cases in which sedation was used in a variety of ways. The p.r.n. use of sedation in situations of uncertainty about dying appeared to be the least governed of situations, responsive as it was to the fervent desire to bring about good dying for patients who were, indeed, dying.

5.6   Conclusion

This chapter has considered the underlying motivations evident for staff in the hospice as they used sedation. A strong desire to bring about a process of good dying and death was explicit throughout the observations and interviews. Indeed, this was such that not to achieve this state was considered as failure, so integral was this to the work of hospice staff. Using sedation to treat distress or distress-behaviours is a routine part of

practice, underpinned by the desire to ensure a comfortable and peaceful death. This absence of distress-behaviours not only has importance for the perceived comfort of the patient, and as such is seen to be desirable in itself, it also enables other features of good dying, such as allowing family and friends to be present as a patient dies. Moreover, achieving good dying was seen to be important for morale and a sense of job satisfaction for staff in the hospice environment. The way in which sedation was prescribed and administered has allowed further insight into the practice of sedation. The ability to give drugs in a p.r.n. manner has been seen to allow patients who are distressed and thought to be dying to receive sedative drugs even to the point of unconsciousness, even when doctors are not present. This was important in the hospice environment where doctors are on-call but not on site after five 'o' clock in the evening. Furthermore, the 'risk' of not achieving a good death is seen to be abhorrent and contrary to the aim of care in the hospice; the use of p.r.n. sedation may be seen to mitigate against this risk in the out of hours period. This also, however, was seen to lead to the situation where a patient could be sedated to the point of unconsciousness without an assessment by a doctor, or an explicit agreement within the clinical team that a patient was indeed dying. This was unusual, but so familiar were clinical staff with the practice of using sedation and so necessary was achieving a good death, that it became possible that the step of questioning and reversing the reversible could be overlooked. This was an important situation to observe and understand as the p.r.n. use of sedative drugs was so frequent and shaped decision-making so strongly. Underpinning all of the practices of sedation, however, was this desire to bring about the hospice construct of good dying and death. Chapter 6 considers three situations in which achieving good dying and death could be seen to be threatened; the impact of this and influences on decision-making are considered and the ways in which these situations were negotiated provides a deeper conceptual understanding of the practice of sedation and its integral role in end of life care.

Chapter 6 Threats to good dying and death

The last two chapters have explored the routine, everyday use of sedation in a hospice, considering not only what the practice consists of but also the underlying motivations for its use. The different ways in which sedation is used, either in a p.r.n. or continuous manner, have also been outlined and differences between healthcare professionals' interpretation of dying explored. This chapter focuses on situations in which the use of sedative drugs is 'non-routine', explicit and thoroughly considered. Distinct 'threats' to achieving a 'peaceful' and 'comfortable' dying and death are observed. These were seen through the observation of cases in which sedation was used in a way which was out of the norm: this was seen in patients with agitated delirium, uncontrolled symptoms and a form of 'crisis' sedation for massive haemorrhage. These states can all be seen to threaten good dying and death for patients and challenge staff striving for this conception of good dying. The dying process was the focus of this rather than the event of death itself; for this reason the term 'good dying' will be used in preference to a 'good death'. The perceived threats to a good dying process are explored in three case studies, and the use of sedation to 'restore' the process of good dying is discussed. The way in which this was managed through the use of sedative drugs presents an opportunity to consider further the motivations and intentions for using sedation, as the situations drove more difficult decisions to be made. These were exemplified through the situations of agitated delirium, overwhelming symptoms and the situation of a crisis.

6.1   Agitated Delirium

Different symptoms and behaviours appeared to present particular challenges to staff, especially in the case of agitation and aggressive behaviour. These challenges were epitomised in the case of one patient called Bob who had severe symptoms, compounded by difficulty in determining whether or not he was dying. Bob was 72 years old and had been previously very active. He developed urological symptoms for which he had investigations which demonstrated a suspected urological malignancy, later confirmed as metastatic. There was, however, considerable uncertainty in the diagnostic process which caused great distress to Bob and his family. He developed significant problems with pain and reacted strongly against several different types of analgesic drugs, becoming agitated and confused. He was eventually admitted to the

hospice to try to establish an effective analgesic regime. He had episodes of being very confused and agitated, at times even threatening in his behaviour and difficult for the staff to manage. He wanted to be at home, however, and, while remaining confused, his aggression and agitation settled enough to allow his family to feel able to try to look after him at home. He was discharged, with his bed at the hospice kept open for him to return should the discharge be unsuccessful. Once home he rapidly deteriorated and within 48 hours had been commenced on the Liverpool Care Pathway for the dying patient (LCP) by a GP in the community. His daughter, a healthcare professional, described his condition at home:

> *6:1 Mum rang me about quarter past eleven to say she couldn't wake him up. So I went over and he was non-rousable, he was Cheyne-stoking[1]... he was peripherally shutting down. Got the out-of-hours doctor in, put him on the* [Liverpool Care] *pathway… And then all of a sudden when I had the whole family round and I'm sitting there saying to the family it won't be long now, you've picked a bad day dad but that's fine. He woke up. Just woke up. Very, very aggressive. Abusive, physically violent, and punching, kicking, screaming, swearing, he never swore in his life. Don't know what on earth went, we still don't, we don't know what on earth went on there. Why he was so, why he was dying and then woke up… because he had no medication… Had the most horrendous night, took five of us, he was insisting on going to the loo, he was falling, he was hitting the walls, he was hitting us.*
>
> <div align="right">[Joanne, daughter, interview line 157]</div>

He was readmitted to the hospice and found to be very agitated and confused, as his daughter Joanne had described. Alison, the consultant on call established that he could not communicate in any meaningful way.

> *6:2 When he was readmitted he was extremely distressed and unable really to remember or take in information that was offered to him to help him to*

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[1]Cheyne-stoking: Cheyne Stokes respiration; an abnormal pattern of breathing in cycles of taking increasingly deep or rapid breaths followed by periods of apnoea (not breathing) and subsequently more shallow breaths again. This is recognised to occur due to changes in the respiratory centre in the brain and thus in dying patients as well as in other conditions such as heart failure.

understand why he was where he was or to make sense of the symptoms that he

was having.   [Alison, consultant, interview line 14]

Bob was unable to communicate due to his agitated delirium; his family felt they had 'lost him' in the agitation and aggression which was unlike his usual personality and self.

> *6:3 We lost him, yeah, completely, it wasn't my dad. We had, we had lovely*
> *moments where, we had very rare moments where he would, you could see him*
> *popping back through, and they would last sometimes split seconds. And we had a*
> *lovely, my daughter and I had a really, really lovely moment, it was the last words*
> *my dad ever spoke… and I had spent two hours on my own putting his clothes*
> *back on after he'd stripped off, putting his bed clothes back on, walking up and*
> *down corridors when he could hardly walk, you know, he would fall on the floor,*
> *we would have to pick him up again, and Kerry came in and he just adored his*
> *grandchildren, and he gave, he put his arm round her and gave her a really big*
> *cuddle. And I was sitting, thinking God...you know, that's so typical, I'm the one*
> *that's getting hit, she's getting the cuddles, and he was kind of, kind of you know...*
> *and I was thinking please dad don't hit me anymore. And my daughter said to me*
> *mum, duck, and I ducked and he cuddled me, that's what he was trying to do. And*
> *he just said I'm very sorry. That was his last words. So that was the, the...the little*
> *bit of dad coming back through and then of course he went crazy again and*
> *psychotic again. And aggressive.*

                                    [Joanne, daughter, interview line 383]

Bob's agitation and aggression effectively distanced him from his family to the extent that they felt that they had 'lost' him before he had died. The consultant looking after him that day, Alison, was clear that Bob's distress and agitation required management with sedative drugs. His daughter, Joanne, also felt he ought to be sedated, that this was the 'only' way in which he could appear to be himself again. I asked her in an interview what she felt he needed when he was readmitted; she was very clear in her response.

> *6:4 Sedation. Yeah... through the night I was actually begging the nurses to give*
> *him sedation... I knew my dad and I knew that my dad would have hated to be the*
> *way he was and that was what the sad thing about it all, you know, and, and that*
> *was why mum was so distressed, my sister was distressed, you know, because we*

knew dad, it was complete...he was the complete opposite of the guy that he was. He just completely changed. And the decision to use sedation - that was the best decision for him. The only way he could look peaceful and himself again.

<div align="right">[Joanne, daughter, interview line 275]</div>

Joanne and her family had accepted that Bob needed to be sedated and that he was dying. Alison, the consultant, however, felt more uncertain about Bob's diagnosis and his proximity to death. She wanted to be clear about whether or not Bob was dying or whether there was any reversible element which could be treated, as she described in her interview.

> *6:5 ...the guy looked as though he was terminally restless but there was no tissue diagnosis and my concern was whether in fact to just interpret it as terminal restlessness or to ask more questions and have him more fully investigated in hospital. So it was just making sure that there wasn't some other thing, yes it was that distinction that it was, it was appropriate to go into end of life care mode and we weren't missing some opportunity for rescuing him from something.*

<div align="right">[Alison, consultant, interview line 124]</div>

She spoke to George, a consultant colleague who knew Bob from his previous admission, to establish whether there was anything which was likely to be reversible and to clarify how robust the diagnosis of his advanced cancer was. Having been assured that his diagnosis was confirmed as advanced and metastatic urological cancer, Alison assessed Bob over the course of the next few hours and described how she came to form a management plan, as she spoke to Bob's daughter, Joanne.

> *6:6 It was a kind of synthesis as we went through the day. We did talk outside the room about the pros and cons of making him be more asleep. And we talked about how we would find what would be a safe, but helpful, dose of midazolam by using p.r.n. doses until we could work out what the duration of action of individual doses would be and the plan then would be to help him to have a better rested night by using an infusion and then re-group the following day, when in fact I would not have been on call anymore, but George [consultant] would be back in the building to be able to see whether, having had a decent rest ... he was any better, any calmer, any more able to give an account of himself in order to judge which way to go next. Or whether, in fact, following a night of rest, it was*

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becoming apparent that despite that he was physically still more exhausted, in which case we were probably dealing with dying. And either way it was kind of the next 24 hours was going to help us to decide whether what we were doing was best supportive care to get him through some unusual episode or whether what we were doing was best end of life care.

<div align="right">[Alison, consultant, interview line 275]</div>

Alison detailed her plan to give Bob a 'decent rest' and review him the following day. She read from her notes in the interview as she recalled how that was to be achieved.

6:7 'allow regular p.r.n. midazolam 5mg sub-cut[2] today. Aim for subcutaneous infusion to allow full sleep tonight'… And the aims at that point, and these were the agreed aims with Joanne [daughter], *were 'to maintain relief of pain, to reduce his agitation, give midazolam for an overnight sleep and review with the clinical team who knew him after that observation.' During the afternoon we got a phone call, because that was…one o'clock. [At] half past three the SHO[3] who was on call said he'd needed three lots of 5 mg of midazolam. But the last dose seemed to settle him for about an hour. But he was still restless between doses and not fully relaxed ... So she was going to go back again at six to see how many doses he'd had and so her note at six was that he'd needed six doses since one o'clock. So 30 mg since one o'clock. Erm 'still sitting in bed, although sleepy still agitated with a respiratory rate of 16'... So we spoke by phone and she put a driver with 150 mg* [of midazolam] *over 24 hours. And we agreed that we would put in some bigger p.r.n. doses so between 5 and 10* [mg].

<div align="right">[Alison, consultant, interview line 374]</div>

The aims of giving the sedative drugs were documented in the notes and focused on the short term management of Bob's agitation and distress, with a plan to review the situation the following day. The nurses looking after Bob felt similarly, that Bob 'needed' sedative drugs but cited slightly different reasons as Judy (staff nurse) explained:

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[2] Subcutaneous; under the skin.

[3] Senior House Officer; junior doctor

6:8 ... what can you do? Is he liable to damage himself; is he liable to hurt the family? He's liable to fall 'cause he had a history of falls in the past and I think as an interim measure, the gut instinct's to say right, we'll try and get something to calm him down...

<div align="right">[Judy, staff nurse, interview line 41]</div>

Judy was particularly concerned to prevent further falls due to Bob's agitation and felt an urgency to give him 'something' quickly.

6:9 So eventually erm, I suppose I kind of got a little bit frustrated, which is kind of difficult to say with the medical staff, and went back in and said 'please can I give this gentleman something, I'm frightened he's going to hurt himself and his daughter's really distressed. So eventually I was allowed to give err, a stat dose of 5 [mg] of midazolam…Half an hour, I think it was half an hour later or 40 minutes later, he was up again so it obviously hadn't settled him. Erm, again, I went into the medical staff and I said, you know, 'I'm really upset because this gentleman, this isn't settling him, we need something done fairly quickly'… I felt really, personally, that he was approaching the end stage and that was more important than anything right then, to get him settled. I'm not...you know, I'm not a medic but obviously…. So anyway erm, it was agreed that I could give him another stat but I did, I… asked the SHO would she change the prescription... I know he was still agitated and the medical staff said that basically, just to keep going with p.r.n.s of 5 [mg] of midazolam until he's settled and they wanted to know basically how much it would take to...I won't say knock him out but to keep him settled… I felt it was my...well it was important to get him settled and obviously try and reduce the stress on the family.

<div align="right">[Judy, staff nurse, interview line 55]</div>

Judy expressed her own distress at not being able to 'settle' Bob and felt that because he was '*approaching the end stage'*, it was important to strive towards this goal of getting him '*settled'*.   The pressure to achieve this was felt throughout the interview as she expressed her frustration at not being able to achieve this goal. The nurses caring for Bob overnight too, felt they were looking after someone who was dying. Gail, an auxiliary nurse, felt particularly strongly that Bob ought to have been sedated.

6:10 There was no kind of resting place for him doing – I didn't, well I didn't think there was and it wasn't fair…I think if, if people are agitated and they don't know where they want to be or what they want to do, I think…personally, it [sedation] *should be given because, you know, there's no need for people to be unsettled because there's the right drugs are there, you've just got to make sure that they're written up because to me, you know, it's not fair to them. And if people, you know, aren't on them… you've got to make sure that they are. I think personally 'cause … especially I think if relatives are here … they should have that quality time with them … if somebody's obviously dying, it would be nice to see them settled…*

[Gail, auxiliary nurse, interview line 22]

It appeared that *because* Bob was thought to be dying, the nursing staff in particular believed he ought to be sedated to control his agitation and apparent distress. The consultant responsible for Bob was more guarded about whether or not he was dying, however, and wanted to be clear that there was an option for Bob to recover and wake up from the sedation she initiated, planning for a careful review of his drugs and need the following day. While Judy and Gail felt they were treating a man who was dying, Alison wanted to keep the option open to reduce the sedation, and stay alert to the possibility that Bob might not be dying. The nurses who were looking after Bob were more certain that he was dying at an earlier stage than the doctors involved in his care. The consultant, Alison, acknowledged her own uncertainty as she said in her interview that she wanted to be sure that it was the right time to go '*into end of life mode*'. She said later on in the interview:

6:11 I think the thing that was most interesting to me about it … is how anxious I was about this one. I was far more anxious about this one than I have been about others. And I'm sure it was because of the, the diagnostic uncertainty, as I perceived it

[Alison, consultant, interview line 752]

Alison admitted to feeling wary of going into 'end of life mode' because of this uncertainty about whether or not Bob was indeed dying. Allowing time to assess the effect of an intervention such as sedation was a frequent way in which assessments of this nature were carried out in the hospice. Once the reversible causes for a

deterioration had been reversed, staff would regularly state that they would just have to 'wait and see' how a patient responded, especially for those patients who had just been admitted to the hospice and who were not as yet 'known'. Alison recognised that there was a change required, a different approach to take, if Bob was dying; this was an important and significant decision to make, causing her to feel 'anxious' about it. While in Chapter 4 this change in approach from not dying to dying appeared to occur over a period of time, for Bob this change occurred rapidly and overtly. There was open discussion about whether or not he was dying amongst staff and between the staff and family members. There was a decision to be made, rather than a position at which to arrive. The assessment and subsequent decision was to impact on the way in which Bob was treated and specifically, on the way in which sedative drugs were used. The recognition of dying was seen to influence profoundly the way in which patients in this acute situation were managed clinically and, once dying was diagnosed, appeared once again to enable the acceptance of a reduction in a patient's consciousness.

In Bob's case, the acknowledgement that he was dying was made earlier for the nurses involved than for the doctors: the nurses described him as 'terminally agitated'. Judy, one of the staff nurses, described his behaviour and what she meant by this.

> *6:12 He was just so really restless and he was, you know, as I say, he would twist around on the bed, get up and lay upside down or he'd go on the day bed. ... It's the sort of just constant movement it's, you know, you can't...they can't seem to settle, it's just... they seem as if they just can't settle, they want to be up, they want to be down and they want to be in the bathroom and they want...they just don't know where they want to be. It's a... real restlessness, a real, you know, sort of agitation restlessness and I think knowing the gentleman's history, that he had been potentially aggressive and a danger to both himself and other people ... In his lucid moments [he was a] charming, lovely gentleman, really lovely person but when he went off like that, it was very difficult...*
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> <div align="right">[Judy, staff nurse, interview line 116]</div>

'Terminal agitation', or 'terminal restlessness' were phrases frequently used in the hospice during the fieldwork and interviews as staff described this form of agitation which they saw occurring during dying. Some were very clear that they knew when a patient was 'terminally agitated'; others were less certain. There was a distinction

between the different groups of staff: auxiliary nurses spoke with most conviction about the state of 'terminal agitation' and felt that they recognised this state the most readily. Gwen described this in her interview:

> *6:13 One thing that does get me is people aren't picking up... well I... to me, I'll turn round and say 'that man's got terminal agitation' and they'll say 'well he's just having an off day' or whatever. I say 'no, it's something else' ... and then two days later, you'll get a qualified nurse saying 'I'm sure he's got terminal agitation'. I think, well I said that two days ago. One of the qualifieds[4] now will turn around and say 'I think you're right Gwen'... Well I always say to the qualified 'he's terminally agitated' and they'll either say 'yeah I know, or, are you sure?' I'll say 'well I think I'm right, yeah, yeah'. And then two days later, they'll say ... 'I'll watch him' and then the next day I'll go in, if I've gone off at half past three and come in the next morning and ... she's watched him the rest of the afternoon and when I've come back in she'll say 'I think you're right Gwen' ... and I think the auxiliaries tend to pick up on it more.*
>
> <div align="right">[Gwen, auxiliary nurse, interview line 321]</div>

In contrast, the doctors who were interviewed were less certain about the state of terminal agitation and were more cautious about acknowledging it. John, one of the junior doctors, described how another patient changed as she approached death and his own hesitancy in diagnosing terminal agitation.

> *6:14 the reason I...described her as tortured is that she, she didn't seem to be able to rest, so she would, she might hold one position for seconds and then have to move, sit forward, every time she lay back a little bit in the bed, she became very distressed and sat forward and fidgeted and, and you know was moaning and it was just, just an unpleasant thing to experience really. And looked like an awful thing she was going through. The nurses said they thought she was terminally agitated but until that final day I wasn't so convinced – that day she went home she really was dying, it was awful. It was so important though to get it right and to get her home, because she was so insistent right from the start that that was*

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[4] Qualified nurses; Gwen drew a distinction between 'qualified' staff nurses and 'unqualified' auxiliary nurses.

what she wanted.

John acknowledged that the nurses had thought this patient to be 'terminally agitated' before he was sure that she was imminently dying. This crucial diagnosis, of dying, he considered still to be difficult and one which it was important to 'get right'. The recognition of this state as being an indicator of imminent death was important, it seemed, to ensure that patients were not being misdiagnosed when in fact, they may have had weeks of life left to live. George, a consultant, expressed this concern in an interview.

> *6:15 ... it's not really a term I use much, but people seem to talk about it when they perceive that people are right at the end of life and they're agitated. To my mind the difficulty with the term is that you only really know it either after someone's died, or um, when it's very clear they're dying soon, and I think I sometimes see it being used when people look at though they've probably got some weeks… or longer to live, and they're just agitated and we're still trying to work out what the cause of is, and people start to say 'well maybe it's because they're terminally agitated?', and so I think there's some danger in it, sort of that it means maybe we exclude looking for reasons why people are agitated… so I…I think when people are dying their organs start to shut down and they build up waste products, and various blood abnormalities don't clear their drugs as well, and so they can get agitated and confused, and I guess that could be terminal agitation, but I'm not sure that it's the most helpful term, because it just seems to be, it's almost a lazy label which says that, right, we've made a diagnosis without trying to look at why are they agitated? Because even at the end of life, if somebody is agitated there may be things that you can do, simple things to reverse it.*

Once again, George's concern appeared to be to ensure that a patient was imminently dying before being called terminally agitated rather than having 'some weeks' left to live. The certainty that a patient was indeed dying was important especially to doctors and led to a tension between this need for certainty that a patient was imminently dying and the need to 'get it right', as John said, for a patient who was dying. To delay a diagnosis of dying, it seemed, was to lead to a possibility of not getting it right in dying.

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This was evident in the words especially of the nurses' earlier quotes about Bob, but also in the doctors' attitudes, once dying was diagnosed.

6.2   Overwhelming symptoms

Patients who experienced intolerable and overwhelming symptoms, like those with an agitated delirium, presented a threat to the desired 'good' death in the hospice. A patient with overwhelming symptoms while dying was at risk, it seemed of having a 'bad death'. Similarly to those with agitated delirium, the crucial step in the process of dying and symptom control for a patient was recognition and acknowledgement that they were, indeed, dying. A change in approach occurred once dying was acknowledged, with an associated change identified through the field notes and interviews in the motivation and intentions in using sedative drugs. The need to facilitate good dying was balanced by the need to ensure that death was not hastened: once death was imminent, it appeared, the use of sedation was not thought to affect the speed at which a patient died. George, one of the consultants believed that once a patient was imminently dying, the 'risk' of causing death through the use of drugs became less likely. He said of a patient:

> 6:16 *...using medication to sedate him at that stage wasn't going to have any impact on how long he had to live because he was dying quickly at that stage.*
>
> [George, consultant, interview line 222]

This was frequently the position held: patients were said to be '*dying anyway*' or, as Jen stated;

> 6:17 *The person is going to die, you're not going to bring them back, you're not going to change anything… inevitably they might even die before the… midazolam has time to, time to work.*
>
> *[Jen, staff nurse, interview line 249]*

Having reached a point when death was anticipated imminently, the impact of sedative drugs at an increased dose and with more profoundly sedating effects on hastening this death was thought to be minimal. Relief of suffering and achieving a good dying process was afforded prime importance when a patient was dying.

Sandra was a patient for whom these concerns were prominent. She was a 43 year old woman who had a non-small cell lung cancer. She had been diagnosed only four weeks prior to being transferred to the hospice and had just completed radiotherapy treatment to try to reduce the tumour size. She was described as being a very anxious woman and, on the first consultant ward round, also appeared to be dying. One of the nurses, Judy, reported that she was very anxious during the night in particular and didn't sleep, but then would be drowsy and tired during the day, especially as she had 'needed' several doses of midazolam to treat her anxiety through the night. Judy and the other nurses felt that she was dying, that she 'wasn't a good colour'. Judy emphasised that Sandra was very breathless and anxious and that she 'needed' several extra doses of midazolam to treat this. Sandra was very distressed by her symptoms, especially by breathlessness, and this caused difficulty in communicating. She said that she was not scared of dying, but was 'terrified' by her breathlessness and felt at times that she was suffocating. Her physical appearance conveyed this, as I recorded in field notes:

> *6:18 She was very breathless, leaning forward in bed with oxygen on, looked pale, dusky and drawn. Her eyes were wide and she looked very anxious and on edge, almost panicky. She couldn't speak in sentences and nodded rather than spoke,*
>
> [FN 05/07/10, line 35]

Sandra was very frightened by her symptoms; furthermore she was afraid to go to sleep and initially did not want to accept any sedative drugs for fear that they would make her go to sleep and then she would not wake up again. After a few days, however, Sandra accepted an 'extra' midazolam dose from Mollie, one of the nurses, as my field notes recorded:

> *6:19 I followed Mollie (S/N) as she came out of the drug room and said she was just going to give Sandra 'an extra'. She* [Sandra] *was getting really distressed she said, and it was just awful. As we went in Sandra was leaning forward, holding her knees to her chest and breathing rapidly. She nodded as Mollie said*

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that she had just brought something to make her feel more relaxed. She wasn't able to speak in more than a whisper but as she nodded said; 'give me anything, I can't go on like this'. Mollie nodded and gave her the injection into her arm. She straightened the bed and asked if there was anything else she could do. Sandra's sister said there wasn't and she'd call if there was. As we walked along the corridor again Mollie said again that it was just so awful and that Sandra was terrified.

[FN 05/07/10, line 143]

As Sandra continued to be distressed and breathless throughout the day, she had several 'extras' of midazolam. The following morning as I arrived I met one of the doctors, Julie, who was going to see her as she had been unwell overnight.

6:20   I met David [junior doctor] *who was just going in to see Sandra - he said she had changed markedly. She was even more breathless and David thought she was probably dying. Sandra couldn't say anything more than a few words at a time. She was sitting in bed, knees up, leaning forward, gasping for breath. She felt she was suffocating, she said when David asked her what she was feeling. Her brow was furrowed, eyes were wide and staring and she used all the muscles in his shoulders and chest to breathe. David said he would see what he could do to help and as we walked back up the corridor he said he felt there wasn't anything else he could do except increase the midazolam in the driver. He said Sandra had had 'loads' of extras last night so he'd just put in what was needed and see how she got on overnight. It was awful to watch, he said. Mollie* [staff nurse] *came in to the MDT office at that point and said she had asked Sandra if she wanted to be more sleepy, or whether she wanted her* [Mollie] *to give her something to help her feel 'more relaxed and settled'. Sandra had said yes so Mollie felt her views were maybe changing - from not wanting anything, to accepting things to help. She'd said later to Mollie while she was helping her have a wash: [give me] 'anything, just kill me'.*

[FN 06/07/10, line 3]

Sandra had initially declined any sedative drugs, fearing their effect; as the intensity of her symptoms increased, however, she wished to have anything which might relieve her symptoms, including drugs which would reduce her conscious level. As Sandra's symptoms increased, the staff involved in her care expressed with increasing frequency

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how 'awful' they felt the situation was. Indeed, one of the nurses, Jane, said after giving Sandra an injection of midazolam that she just hoped it 'didn't go on too long for her'. Others expressed similar views, as one of the junior doctors, John, said in his interview:

> *6:21 I wanted her to be asleep. I mean I think you can't help but reflect your own, you know, put yourself in the position or try and imagine yourself in the position of the patient. And she just looked tortured… and I just felt if that was me, I'd just want to be asleep and calm and rested and a bit detached*
>
> [John, doctor, interview line 131]

Some members of staff found it difficult and expressed frustration when symptoms were not brought under control quickly. In the transitional period prior to all members of staff recognising that a patient was dying this was especially evident. Indeed, earlier on that day, one of the nurses, Mollie, came into the MDT office and sat down, having just come out of Sandra's room.

> *6:22 She'd been terrified, Mollie said, asking her to kill her 'now'. She really wanted to be at home to die, and thought she was dying now. Mollie said she thought they'd see if they could get her settled tonight and then get her home - but didn't think they had long to try to settle her - she was going downhill quickly. 'If we get her flattened and settled she might make it home, but she's too up and down just now to get there, Mollie said. She said some people are frightened to put midazolam in the driver - they'd only put 5mg in yesterday. She looked sceptical - as though to say it wasn't enough, I thought. She said that she'd made up for it in extras overnight - she 'needed' 25 mg overnight so 'finally' today she was on 40 mg over 24 hours.*
>
> [FN 06/07/10 line 132]

Later, on the night shift, Annie also expressed relief that Sandra's midazolam dose had been increased from the previous day, as I recorded in my field notes from the handover of day to night staff.

> *6:23 Sandra had had her drivers changed and was now on 40 mg of midazolam over 24 hours.* Annie [staff nurse] *said 'thank God' and raised her eyebrows. She*

looked at me and said they'd only put in '10 or something' last night and she'd needed 'way more' than that.

Mollie and Annie clearly felt that Sandra needed more sedation in order to appear comfortable, Mollie even stating that Sandra needed to be 'flattened' in order to facilitate her wish to be at home. Both Mollie and Annie were also aware of the impact of Sandra's symptoms on her family and wanted to minimise the influence that this would have on their bereavement. In the final stages of dying, staff became increasingly aware of the impact of a patient's distress-behaviours on those around them, especially family members. I observed as Sandra's brother spoke emotively to one of the nurses about how he felt:

> *6:24 He said it was terrible to see her as she was. 'She's fighting it' he said, he wished she would just 'let go'. He couldn't bear watching her suffer like this, he said – 'you wouldn't treat an animal like this'. ... At times he said he wanted to just push the syringe driver to end the suffering –what was happening was inevitable – why should people suffer like this? He said once again that Sandra was 'fighting it'; Annie [staff nurse] agreed and said that the other night she had given her so much midazolam she should have been 'out of it' but she'd kept fighting sleep and trying to keep her eyes open. She would say she wanted to be asleep but look as though she was fighting against the drugs. Annie explained to him that the syringe driver of midazolam had been increased that day, and they did it carefully to incorporate the extras she had had over the previous 24 hours – they couldn't just 'whack it up' or start too high. He nodded and went back into the room again. On the way back up the corridor she said she agreed with him - it was so awful being there and watching suffering.*

Sandra's brother clearly felt that she was suffering and, at least on occasion, wanted her to die rather than continue as she was, such was the impact of watching her 'suffer' on them as a family. While Sandra had initially not wished to have sedative drugs, she later accepted and even requested them. Her brother, watching her 'suffer', felt she should not have to endure dying in this way, a consistent view in the fieldwork considering distress at the end of life. In this way he seemed to mirror Mollie and

Annie's view that it would be 'better' if Sandra was 'flattened' by sedative drugs than continue in a minimally conscious state but with apparent suffering. Sandra was much drowsier the following day and indeed was discharged to die at home. She died the day afterwards and was said to have been 'comfortable in the end'. Her midazolam had been further increased and although there was doubt that she would have been aware of her surroundings in her final 24 hours, nurses reflected the following day in the hospice that 'at least she was where she wanted to be'. There appeared to be an appeal to the wider sense of good dying in this statement as the importance of being in the place of her choice was recognised and balanced against her reduced consciousness which was required, it seemed, to facilitate her being able to die at home. Additionally, she was 'comfortable' in dying through by means of sedation and her suffering, or distress behaviours, had been relieved.

6.3   Crisis sedation

The management of agitated delirium and overwhelming symptoms at the end of life enabled patients to become 'settled in the end'. While the decisions leading to them becoming settled were more acute, requiring large doses of sedation, in the very final hours sedation became 'routine' once again. Once dying was acknowledged as imminent and symptoms brought under control, sedative drugs were used with the acceptance of a reduction in consciousness, in a 'routine', accepted, way. One situation took place during the fieldwork in which this was not possible, however. Richard was a 63 year old man with a laryngeal tumour. He was admitted to the hospice for end of life care; he lived alone and had a large tumour in his neck which bled intermittently. Although his bleeding initially appeared to come under control within a few days, the staff in the hospice felt he was 'deteriorating'. The nurses were concerned about his tumour and the speed with which it was changing, as well as his general physical condition. They, and the doctors involved in his care, felt he was dying within the next few days and it was agreed that he was staying for end of life care. He changed dramatically, however, 2 days later on a Friday evening. Jen, one of the nurses, had been doing a drug round and described what happened in an interview as she went into Richard's room to give him his drugs.

> *6:25 I put the medication down, I was very, very quiet in the room, and the lights were on and everything and he looked very, very peaceful. And I came out of the*

room … and within a couple of seconds of being in that room the auxiliary came running up and said… he's haemorrhaging… and we, we ran back down and basically there was just blood everywhere, coming from his trache[5] site... And it was just pooled, it must have, I must have just left the room and it's happened. He was aware of what was going on, he was tapping on the buzzer, obviously he couldn't vocally shout out for help or anything but he knew what was happening, he was tapping, he had a sensitive buzzer, he was tapping on the buzzer, and there was just like pools in the side of the bed and he had…a carrier bag… the bag was kind of nearly full of blood, there was blood all over the table, it was just absolutely everywhere, it was definitely an arterial bleed… at first I said [to the auxiliary nurse] *grab his Kardex[6] because I knew he was prescribed a crisis pack of midazolam 10* [mg], *so I… grabbed the midazolam and started drawing it up and… I tapped him on the arm to tell him that I was going to give this midazolam, and as he turned I've just got absolutely covered in blood and it was awful and that's my biggest memory, just being covered in blood. And I just remember it, he's kind of, you could see that his breathing was changing, that he was changing facially. His kind of neck just started to relax back, this was kind of in the midst of me giving the midazolam and kind of as I was giving the midazolam, it certainly wasn't the effects of the midazolam. And literally he just kind of...his breathing changed and he just died within ten minutes of it kind of all happening. So I don't even think the midazolam maybe had time to work to be honest.*

<div align="right">[Jen, staff nurse, interview line 25]</div>

Jen described vividly what she witnessed that evening and how she reacted. She wanted to give him the 'crisis pack' of midazolam which was prescribed to be given 'in the case of a crisis'. This situation was anticipated and planned for not infrequently for those considered to be at risk of a 'crisis' event, most frequently of haemorrhage from a large blood vessel. Indeed, at the MDT meeting earlier in the week, Heather, one of the nurses checked that a 'crisis pack' had been prescribed.

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[5] The 'trache' refers to his tracheostomy site; having had a laryngectomy Richard had an incision in his neck, into his trachea (windpipe) through which he breathed.

[6] A file containing the patient's drug prescription chart.

6:26 Heather said she just wanted to check again that there was a crisis pack in place and Izzy [staff nurse] *confirmed there was, adding that it was the first thing she made sure of, when she had come on shift.*

[FN 02/06/10, line 369]

In her interview, Jen described what this 'crisis pack' was:

6:27 Basically… if we have a cancer patient who we know is at risk of a bleed either internal or external and obviously having a bleed external would not only be horrific for the patient but for family and you know I think to see somebody go through that it's…, they probably would die quite quickly anyway depending on the bleed whether it's vascular or arterial but I think we always kind of prepare to make sure that the patient is as comfortable as possible because you're not going to change the inevitable I think once somebody, when the cancer eats away and they end up having a bleed like that anyway well… if we think or the doctors think that somebody is at high risk of having a bleed we would ask them to prescribe midazolam 10 mg that you would give as a stat dose... and it would always be in the room kind of ready. Just because obviously we've got quite a long corridor, where the treatment room is… and if you haven't got the keys at least the drug is in the room ready to give.

[Jen, staff nurse, interview line 117]

Richard was recognised as having had a 'crisis bleed', from which he was expected to die very rapidly. Both the staff nurse, Jen, and Erin, the doctor who was in the hospice at the time, were clear in what their aim was in treating him at that point. Erin described what she wanted for him at this stage.

6:28 I wanted him not to be scared. Erm...and I wanted him to know that he wasn't alone because that was, his two worst fears. And I think that was the same thing I'd wish for any patient who was dying, to not be afraid… to not be agitated. And to know that they were not alone. And I wanted the midazolam to sedate him properly, to make him unaware of what was happening so that he wasn't scared as he had been before.

[Erin, registrar, interview line 149]

Jen, too, described what she wanted for Richard at this point.

6:29 Just to...obviously to sedate him very, very quickly because he was fully aware of what was going on… I think if you know that somebody is having a bleed like this and you know that they're going to die it's to, to me, [the aim is] *to get them out cold if you like, sedate them fully, so that they're not aware of exactly what's going on, and I think you know that the inevitable is going to happen, you know that the person is going to die from this bleed, but you don't want them to be aware that this is happening. He had a massive fear that this would happen and he knew it was a big possibility and it, it had happened to him before… But I think… with a big bleed like that I think you just want to get them out as quickly as possible and fully sedate them*

[Jen, staff nurse, interview line 178]

In this 'crisis' situation, the intention in using the sedation was more overtly to ensure that Richard was 'unaware' of his surroundings and what was happening by using sedation to render him unconscious. The risk of hastening death was considered to be minimal, but still of less importance than enabling him not to be aware of his surroundings and the way in which he was dying. While both Jen and Erin acknowledged that they were unsure of the benefit of giving the midazolam in this situation, as they were not sure it worked 'quickly enough', they felt it was important to 'do something'. They wanted to do what they could to ensure he was 'unconscious as quickly as possible'. This was clearly a case in which sedation was not routine: Jen's intent was brought into focus and was much more urgently to reduce consciousness quickly. The overriding aim, however, was seen by Jen to be the same as for other situations.

6:30 you know just because somebody is dying slowly and you can manage their symptoms and make sure that they have a dignified death, if somebody is at risk of having a massive bleed you've got to have something in place to be able to manage that kind of scenario as well, you know. Erm, so... it's about making sure they have a dignified and a good death whatever happens at the end.

[Jen, staff nurse, interview line 260]

Erin, too, described this, in terms of ensuring a patient had a 'good death', once being clear that a patient was indeed imminently dying;

6:31 I think ultimately you have to know the trajectory, where you are with this patient, if they are on that last few days of life and there is nothing salvageable about this situation then your best care would be to ensure a good death and in so doing you apply sedation, apply analgesia, all those sort of things to get them as comfortable as possible as quick as possible before the end. For both - emergencies or...people terminally agitated at the end of life.

[Erin, registrar, interview line 397]

Jen marked a distinction between those who die slowly, for whom there was time to manage symptoms and get it right, and those for whom that process was accelerated. Erin drew a comparison between those terminally agitated and those in the 'emergency' situation, wanting the same type of 'good death' for all. In this extreme situation both described their aims to ensure Richard's 'comfort' and ensure he was not alone or frightened: in this situation there appeared to be no alternative to sedation to bring this about. This was not a remediable situation; good dying was not possible. As Erin described the following week at the MDT meeting;

6:32 Erin [registrar] *said how awful Richard's death had been. He had had an arterial bleed and by the time anyone went in to answer his buzzer, seconds after he pressed it, there was blood all over the walls and skirting boards. There had been a crisis pack in his room but Jen* [staff nurse] *had felt he was still too aware. Erin agreed and said while it had been quick and he was 'Cheyne-Stoking' within minutes, he had been frowning too, and she felt he was aware of something.*

[FN 09/07/10, line 179]

'Even' the use of sedation was unable to restore Richard's dying to an acceptable or comfortable process. One of the senior nurses later arranged a reflective practice session for the team; a bad death had such an impact on the staff in the hospice that they needed the opportunity to bring some form of meaning to it. Others have recognised this debriefing and reflection to be a process through which palliative care staff, in particular, can rationalise events which do not go well, or when bad deaths occur

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(Kovan and de Vries, 2010, Kristjanson et al., 2001). In this situation Richard was 'too aware'; he was beyond the reach of even sedation to enable him to be free from distress.

The values which underlie these events and processes will be considered in the next chapter; of note, however, is that while the immediate aims of this acute 'crisis' situation appear to be different to the less acute and routine sedation, the overarching values from which they are derived, may be considered to be similar.

6.4   Conclusion

This chapter has built on Chapter 5 and developed an understanding of the normative foundations of the use of sedation in the hospice context. Sedation has been shown to be linked to the broad concept of good dying and death, primarily through its role in bringing about relief from signs of distress in dying. Staff in the hospice act from a desire to bring about good dying and death and experience a sense of satisfaction when this is achieved. Conversely, feelings of regret and guilt are experienced when a patient is perceived not to have had a good death. These findings are not new; several authors have found and developed the link between achieving a good death and satisfaction among palliative care staff, especially among nurses (Hart et al., 1998, Kehl, 2006). That sedation is used with this purpose is, however, a new finding of this research. This may seem intuitive; the aim of hospice and palliative care may be considered primarily to achieve a good death for a patient (Weisman, 1988) and therefore the aim of the use of sedation at the end of life is, naturally, to bring about that good death. The way in which this is constructed in the hospice may equally appear to be uncontroversial; in the presence of signs indicating distress, sedation is used to remove those signs of distress in the dying patient. Patients are expected to die in a 'settled' and 'peaceful' manner; those whose behaviours and appearance convey distress appear to challenge this expectation and are treated accordingly with sedation. Good dying and death, even in situations which initially threaten the concept, can at times be restored through this approach; this was seen in the first two cases presented in this chapter. The final case, of haemorrhage at the end of life, however, was seen to be different. This death was unquestionably a 'bad' death, though despite this attempts were made through the use of sedation, perhaps to make the death 'less bad', when it could not be restored to a 'good death'. This 'less bad' death may be recognised as reflecting McNamara's 'good enough' death, discussed in Chapter 1 (McNamara, 2004). The desire and need to

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reflect on this death after the event, to derive meaning and to be certain that all that could have been done to restore good dying had been done, suggests, however, that there are instances when 'good enough' is not enough for staff and perhaps what is required is to be able to feel that the death was made 'less bad' through their presence and treatment.

As the use of sedation has been shown to be driven by a desire to bring about good dying and death in the hospice, the next chapter will identify the values which can be seen to underlie these motivations and the clinical practice of sedation in the hospice. These values are fundamental to the palliative care approach in the hospice and, in a culture where autonomy is prized, will be challenged as the specialty of palliative medicine and the palliative care approach is advanced.

Chapter 7 Values

The previous chapters have been concerned with the way in which sedation is given in the hospice and the motivations behind this use. This has shown sedation to be an integral and routine part of end of life care in the hospice, while the motivation for giving sedation arises from a desire to bring about a good dying process for patients. This has been seen both through the use of a routine form of sedation described in Chapter 4 as well as in the more complex cases of sedation when this approach to the control of symptoms appeared to come under threat. The hospice and palliative care approach to dying and death can be seen to inform this practice of sedation as its core values underpin and guide clinical practice. The more testing cases of using sedation found in Chapter 6 demonstrated overtly the values which underpinned the whole decision-making process of using sedation at the end of life. These included the values of the patients and their relatives but predominately represented the values of individual members of staff, the hospice as an organisation and the palliative care 'approach', as it is interpreted in the hospice. This chapter will begin by considering the, predominately shared, values of individual staff, and the relationship of these to the wider values of the palliative care approach. These 'shared' values support the practice of routine sedation and enable staff to carry out an integral part of their daily work. The values of patients and relatives is considered next, before a case study in which values are seen to differ, demonstrating a broader range of values and a process of negotiation and acceptance of alternative views in decision-making. The integral role of values to decision-making has been considered in several different spheres and applied in clinical practice in different ways (Hunink, 2001: 19, Brown et al., 2005). Values-based practice is one approach which seeks to incorporate values into clinical decision-making; alongside evidence-based medicine, values-based practice is seen to redress the balance of facts and values in clinical decision-making (Fulford, 2004a). While evidence based medicine has advanced a scientific, objective process of assessing evidence and making decisions in healthcare, values, too, are inherently seen to form part of decision-making in healthcare (Fulford et al., 2002). 'Decisions require judgements' (Calman, 2010: 277); these judgements are informed and influenced by values. While evidence-based medicine can provide a method of assessing, weighing and deciding about facts, the particular preferences and interpretation of facts depends upon values (Straus, 2005).

Values-based practice is seen to promote a more balanced alliance of values and facts. As healthcare decision-making becomes increasingly complex, the recognition of values and development of skills in negotiating different and conflicting values becomes increasingly important. As palliative care progresses and seeks to deliver an 'ethos' of care in different settings, the values of palliative care and the values of a more diverse patient group may come into conflict. Values-based practice is considered as a way to facilitate decision-making in the context of complex and conflicting values.

7.1 Values in practice: shared values

The previous two chapters have delineated the way in which sedation is used in the hospice in clinical practice and the motivations behind this. Chapter 5 developed the hospice concept of good dying and death, about which there was seen to be a shared understanding; staff knew how they expected and wanted patients to die and in the physical sense this was determined by the extent to which patients were 'comfortable' and 'peaceful' as they died. In practice this was seen when patients died in their sleep, either as a natural or a drug-induced process. The shared understanding of good dying allowed staff to work collectively towards a common aim of achieving this for patients and their families; sedation was seen as a means of achieving this when symptoms or distress-behaviours threatened its 'natural' occurrence. The hospice construct of 'good' dying can be seen to be underpinned by values. The process of good dying and death brought about through sedation can be seen to be motivated, moreover, by shared values of how dying should occur. This was seen at both an individual and collective level. Individually, staff expressed how they thought a patient should be treated and frequently related this to how they would want to be treated, or how they would want a loved one to be treated. For example, Gail, an auxiliary nurse, after saying that she thought patients ought to look comfortable and settled as they were dying, said:

> *7:1 I treat these patients how I would like to be looked after… I just think I would want my… granddad to be settled and, you know...* [I] *can only make people as comfortable as I can*
>
> [Gail, auxiliary nurse, interview line 122]

Similarly, Mollie, one of the staff nurses, considered what she would want if she were to be in the situation of one of her patients.

> *7:2 I just thought if that was me, you know, I would kind of put myself in his position, I would just say.. I really wouldn't want to be aware in that state*
>
> [Mollie, staff nurse, interview line 224]

Mollie felt that this particular patient's suffering was so great that it was better for him to be unaware through the use of sedative drugs. While the values of individual members of staff were conveyed through these terms, staff frequently appeared in practice to draw on a collective sense of values, or of the values of 'palliative care'. These shared values were seen in practice as staff talked about their conceptions of what they expected as a team to achieve for patients, as well as that which was not considered part of their practice, or 'what we do'. This was frequently seen in the field notes and in interviews as staff talked with a clear perspective about what palliative care *is* and what it *does*. In an interview Jen described what she thought one of the key roles of palliative care is:

> *7:3 I really feel that we're good at… making sure people die comfortable and settled like, because we're in such a specialised area for making sure people… have a dignified death and this is what we do and this is what we do well… if a family walks out of here and they're just grateful for the care and* [they sometimes say] *she was lovely and peaceful and she wasn't in pain and things like this, this is what makes us satisfied that we've done our job right.*
>
> [Jen, staff nurse, interview line 307]

Central to Jen's concept of palliative care was ensuring that patients had a good death, and this appeared to define the nature of palliative care as Jen said it is 'what we do'. One of the registrars, too, described the central role of the good death in the hospice and to the way she practiced.

> *7:4 a good death is, is that patients are... comfortable, a settled patient in a place of their choosing, surrounded by people of their choosing. That is a so to speak 'good death'... and I kind of live by that I think. Practice by that.*
>
> [Erin, registrar, interview line 227]

As described in the previous chapter, Erin's motivation for bringing about a comfortable death was motivated by her understanding of the 'good death' concept; furthermore, in stating this as the way in which she chose to practice and 'live', she demonstrates her

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particular value perspective, shared explicitly and implicitly by the majority of staff. While staff conveyed emphatically at times what they felt palliative care 'is' and 'does', that which palliative care did not 'do' was equally expressed by staff. For example, after several weeks of change in the hospice, the introduction of a shorter and more structured MDT meeting caused concern among the nurses about how the hospice was changing in approach and structure. The nurses expressed apprehension that some members of the team would not feel comfortable to speak up these meetings as they currently did, especially the auxiliary nurses. As I recorded in my field notes, one of the senior nurses, Susan, said:

> 7:5 *'it's just not palliative care, we're not like the hospital'. Susan went on to say that she was concerned that some voices would not be heard… in particular Gail's* [auxiliary nurse] *contribution,* [she said] *how important she thought this was and how she doubted Gail would have the confidence in a big meeting to speak up.*
>
> <div align="right">[FN 08/11/09 line 243]</div>

Susan drew a distinction between the hospice and hospital approach, at least in respect of MDT meetings and the inclusion and importance of particular members of the team such as the auxiliary nurses. In drawing a distinction between the hospital and hospice approaches Susan demonstrates her understanding of a conception of what palliative care i*s*, or rather *is not*. The use of the collective pronoun 'we' was common and appeared to convey a shared conception of how those working in the hospice considered themselves to act. For example, Michael, one of the consultants, described in an interview his view about the prolonged use of sedation in palliative care; he can be seen to consider it from a collective perspective as he said:

> 7:6 *I guess some people would argue that we may just be sedating people and just be… performing euthanasia… in a different fashion just by sedating people to death, but… I don't really think that's our intention behind the act in what we're doing anyhow, when we do take that decision to sedate people.*
>
> <div align="right">[Michael, consultant, interview line 311]</div>

Michael's understanding of how sedation is used in palliative care may be seen to be derived from (what he considers to be) a *shared* perspective. In her interview, one of

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the registrars, Grace, also appeared to take on this understanding of the way in which sedation is used, but further, made a distinction between clinical practice within and outwith the hospice.

> *7:7 And so if we do it* [using sedation], *it's not done lightly and it's the decision of the team and even then, it can be a very uncomfortable decision… I suppose outwith hospice practice, then it's difficult to know what's happening and what's going on.*
>
> [Grace, registrar, interview, line 475]

There was an understanding of how sedation was used in the hospice but that which occurred outside the hospice was considered to be different; furthermore, Grace refers to 'hospice practice' in a shared sense, affirming her understanding of sedation as a shared practice in the hospice.

In everyday practice, a shared approach and understanding was assumed as staff demonstrated an implicit trust they had for one another's assessment and management of distress at the end of life with sedation. In a simple, everyday sense, Susan described this in an interview in relation to 'trusting' the assessments and judgements of other nurses:

> *7:8 if I gave oxycodone and they* [the patient] *hadn't really settled but one of the nurses handed over that they had given oxycodone and a little bit of midazolam and they've really settled well, I would be aware of that so I might go with that the next time because the nurse that's told* [me] *I trust.*
>
> [Susan, staff nurse, interview, line 563]

The model of a shared understanding of terms and of appearances or behaviours such as being 'settled' was developed in Chapter 4, however is worth emphasising again here in relation to treatment decisions. Staff acted on the assumption of a shared understanding of distress-behaviours *and* how these should be treated. As Susan described, a patient who had 'settled' in response to an intervention to use a sedative drug (midazolam) would be likely to be given the same drugs again, based on a shared understanding of what the previous effect had been and trust in their understanding of how an 'unsettled' patient *should* be treated. This was implicit every day in handover meetings as nurses 'handed over' information relating to the drugs used and their effect in the same way as

Susan described above. Thus not only the 'good' dying process but the means of achieving this were constructed through a process of shared understanding and based on shared values.

The values evident in the hospice were demonstrated through both a collective assertion of the values of palliative care and through individual statements of the shared value perspective. That there was a shared understanding of the aim and means of achieving good dying in the hospice was considered important to many staff. As one of the social workers, Alice, stated in an interview:

> *7:9   I do feel the team that I work with we all sing to the same tune. I don't think there is...I can't remember working with anybody who didn't have the, the same viewpoint* [about dying in the hospice]… *And I probably would find it very difficult to work with anybody who didn't have that viewpoint. We'd be at loggerheads the whole time. I work with a good team… I think we have to very patient centred. I think we have to...offer holistic systemic care that supports the patient at the centre of everything but also recognise the ripples for everybody, important people in that, that person's life. And we need to look at whatever we can do to support.*

> [Alice, social worker, interview line 298]

Alice describes the values she considers to be central to the care provided by 'the team' in the hospice. Underpinning clinical practice, it seemed, were the values of palliative care.

7.2   Patient values

As discussed in Chapter 4, as patients deteriorated and came closer to dying they frequently became drowsier and less able to communicate. Through the processes described in the preceding chapter, this was often a result of a combination of 'natural' changes associated with dying as well as due to sedative drugs given to treat signs of distress in a 'routine' fashion. These processes evolved slowly over time and while for some patients, seen in Chapter 4, becoming drowsier was something to be railed against; others, in contrast, *desired* to be drowsier as they approached death. For some this was because their symptoms were such that to be less aware was considered desirable in the present; others expressed what they believed they would want in the

future. Barbara, for example, was a patient admitted for a short period of time to treat an infection, but who was very anxious to express her wishes about dying as I recorded in my field notes during a ward round.

> *7:10* [Barbara said] *she didn't really want to know much, she felt she just knew enough and didn't ask questions. She didn't want to be aware when the time comes though. She said she would like to be 'drugged up to the eyeballs' if she could, and be totally unaware when the time comes. She didn't want to be in pain or suffering and wanted just to go - hopefully a long way off now though... [Later] she said again, 'well, it's really simple, I wouldn't want to be aware of dying, I just want it to happen'.*
>
> [FN 02/06/10 line 127]

Similarly Claire, a patient introduced in Chapters 4 and 5, had had a previous experience of requiring sedation for a short period of time to control overwhelming pain. She recovered from that episode and had 'tolerable' pain when she said on a ward round:

> *7:11 she would want to be sedated, she said that she would not want to be 'aware', that she would want to be 'out of it' and... she did not want to suffer.*
>
> [FN11/11/09 line 145]

The avoidance of pain and suffering at the end of life is of course one of the principle aims and values of palliative care. The explicit desire to be 'unaware' in dying, not only as the *means* of ensuring the avoidance of pain or suffering, but also as a desirable state and an *end* in its own right, is important when taking into account the way in which sedation is used at the end of life.   Not only does being unaware prevent the experience of pain and suffering, it may in itself be considered a desirable state. The 'natural' death of dying in sleep, considered by staff in Chapter 4 to be a good death, achieves this through 'natural' process of becoming 'more sleepy for more of the time'. When sedation is used to control symptoms or signs of distress in dying, the associated reduction in consciousness has been so far considered as a *means* to the relief of distress, rather than the *end* aim being to reduce consciousness. Nonetheless, the 'good' dying and death process is characterised by patients who die in their sleep; this is preferable to being 'too aware' in dying. Thus while staff may express their desire to

treat the symptoms and signs of distress with minimal effect on consciousness, the characterisation of good dying in the hospice suggests that being unaware is an attribute which, while present, is not explicitly recognised or acknowledged. The values concerning consciousness in dying of these patients and staff in the previous chapter may be considered in this respect to be shared; concerning good dying and death they may be seen to hold the same perspective of the 'ideal' *mode* of death. In addition to the preferences expressed by patients, family members too, expressed how they wished their loved ones to die, especially in situations when they appeared to be 'suffering'. This was seen in the previous chapter as Sandra's brother emotively stated his desire for her to be 'out of it'.

> *7:12 He said it was terrible to see her as she was. 'She's fighting it' he said, he wished she would just 'let go'. He couldn't bear watching her suffer like this, he said – 'you wouldn't treat an animal like this'. … At times he said he wanted to just push the syringe driver to end the suffering –what was happening was inevitable – why should people suffer like this?*
>
> [FN 06/07/10, line 142]

Another patient's husband, too, felt that it would be better for her to stay asleep and not wake up:

> *7:13 He went on to say he hoped that she didn't suffer. That he almost wished it would be over sooner rather than later, that she wouldn't want to go on as she is now… He imagined… that waking up and realising that you're still here and dying must be frightening. It would be better he felt if she would just go now in her sleep, rather than wake up and be aware of everything all over again.*
>
> [FN 18/11/09, line 197]

Thus being unaware in dying, as developed in previous chapters, was seen as a way of bringing a good dying and death process. Patients were expected to die in their 'sleep', whether a natural sleep or one induced by sedative drugs. It was *because* this was a perspective shared by the vast majority of staff, patients and relatives, that this was considered the *right* way to die, and was rarely questioned or challenged; indeed I saw no challenges to this specific concept of the mode of dying during the observations. In interviews, however, rare cases of challenge were easily recalled. Indeed three

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members of staff cited the same patient who had caused disquiet amongst the team because their relatives had questioned the use of sedation at the end of life. One of the senior nurses, Susan, described the situation where a patient's partner felt that she was being over-sedated by drugs.

> *7:14 ...her partner... didn't want me to give her certain drugs. I mean she did have... a midazolam driver, she had said she wanted that, but then he was fighting that, said the midazolam had over sedated her, so wanted it stopped... So...we did and she was agitated....and he apologised. He said he should never have asked for that...* [When it was stopped] *she just became frightened again, agitated, unsettled. Terrible, like crying, just really distressed again. So we put it back up.*

> [Susan, senior nurse, interview line 737]

In this situation the patient's partner was said to have changed his views about her being over-sedated when witnessing the distress of being less sedated. His apology appeared to vindicate the staff for using sedation in the way in which they had done when the alternative became evident. When presented once again with distress, the patient's partner fell into agreement with the staff in the hospice and sedation was able to treat the distress, through reducing consciousness. In this rare situation in which sedation was challenged, when reintroduced, sedation allowed the patient to approach death without distress-behaviours and enabled her to die in her sleep. The challenge was resolved, it seemed, when the patient was once again 'settled'. Some appeared to consider this mode of dying as the 'right' way to die. One of the auxiliary nurses, Gwen, put it this way in her interview.

> *7:15 I think family sometimes are at a loss and they're trying to tell you what they would do but what they do isn't always right is it?... We had a young woman and her daughter was looking after her quite a lot and if they thought something wasn't right, they were on the buzzer and they were constantly, constantly buzzing saying she'd had too much of this and that, but eventually they started to calm down and they started realising that we were just looking after her mum's best interests... her daughter eventually come around to our way.*

> [Gwen, auxiliary nurse, interview line 219]

Gwen described that patients' families may not always be 'right' in the way they wished for their loved ones to be treated, suggesting that there may indeed be a 'right' way to do things. Interestingly Gwen then used the same phrase as a nurse in McNamara's study some 15 years earlier as she said that the patient's daughter 'come around to our way'. As described in Chapter 1, McNamara conducted an ethnographic study in an Australian hospice in the early 1990s which primarily focused on the 'institutionalization' of the 'good death'. She found that dying was so routinized in the hospice that there was a 'right' way to die; those who were not seen to conform were considered to have 'problems' (McNamara et al., 1994). Indeed, in her study one nurse said she hoped that patients who initially railed against the hospice way of dying and against the acceptance of dying would eventually 'come around to our way of thinking'. Gwen shared this perspective in her interview and an understanding of the aims of caring for dying patients, and 'good' dying has certainly been recognised in practice. What has so far been seen in the fieldwork, however, is that patients and their relatives appeared to *share* this desire for patients to be 'comfortable', 'settled', or even unconscious and unaware in dying. While the data has predominately focused on the values of the staff in the hospice (influenced as they are by palliative care values), these values may be seen to set the context in which the values of others are considered. Thus a patient's values were considered from within the hospice context where values were shared. Patients' wishes appeared to be incorporated into decision-making, or at least this was an expressed intention. For example, Julia, the doctor looking after Barbara, following her earlier plea not to be aware in dying, responded as I recorded in my field notes.

> *7:16 Julia said it was really helpful to know what she thought about these things because, while some people are very peaceful and they just became more sleepy, some do became agitated or distressed and it is good to have an idea of their thoughts about these issues because they always try to make this the most important part of the decision of what to do.*

<div align="right">[FN 02/06/10 line 132]</div>

As the patients' values were predominately seen to be in keeping with those of staff, few concerns were apparent. While this position may appear to be convenient for staff, that these values were predominately shared is not altogether surprising. In studies

concerning good dying and death, to be pain and symptom free is most frequently cited as the most highly regarded 'attribute' by patients (Hales et al., 2010). Many would consider that dying in one's sleep would be a 'good death' and if this ensures the freedom from pain and suffering, it may be quite naturally a 'desirable' death. The avoidance of pain and suffering, on a patient's behalf is also perhaps a 'natural' response for staff witnessing symptoms or signs of distress. The important aspect is that these values are shared; relief of distress behaviours at the end of life with sedative drugs used to achieve a state of being 'comfortable' and 'peaceful', was in keeping with the values of patients, their relatives and staff in the hospice. Developing an understanding of this enables a greater understanding of situations in which these values may be diverse and conflicting.

Thus the practice of sedation at the end of life was integral to end of life symptom management and part of routine practice. Good dying was the motivation for this and was underpinned by the values of staff and the organisation and in practice incorporated the values of patients and their relatives. This section has introduced values and considered their influence on clinical practice, particularly in relation to the organisational values of the palliative care approach, but also in relation to the integration of these with individual values. Values have so far been considered to be predominately shared and to a large extent derived from the palliative care 'approach'. However, values relating to the use of sedation at the end of life were occasionally seen to differ, as one case in particular highlights. While this case appears to be concerned primarily with the reduction of a drug which was thought ostensibly to maintain consciousness, large doses of sedative drugs were also given at the same time. The values relating to consciousness in dying are central to this case. The purpose of this case study is to demonstrate the presence of divergent values but further, to explore the process of negotiation and acceptance of different values which are apparent through the data. This will permit a greater understanding of the relevance of values to palliative care decision-making, particularly concerning the use of sedation, even to unconsciousness in dying.

7.3   Values diversity

Harry was a 42 year old man with a glioblastoma multiforme (brain tumour). He had previously been very active, working full time and playing an active part in local sports events. He was married to Jenny who was a healthcare professional and they had a young child. Harry had been diagnosed 3 years previously and had undergone surgery, radiotherapy and chemotherapy, before being told by his oncologist 3 months prior to admission to the hospice that there were no further treatments available to him. He was admitted to the hospice for a period of respite and assessment as his mobility had been deteriorating at home and his wife had been struggling to manage. Once admitted, Harry's mobility deteriorated significantly and he was quickly unable to weight bear; within 2 weeks was predominately bed-bound. Additionally, Harry's cognitive skills declined and communication became more difficult. He fluctuated between being able to make himself understood reasonably well and not being able to communicate at all. He had an expressive dysphasia which meant that at times his 'yes' meant a 'no' and vice versa. Additionally, Harry's conscious level fluctuated from being conscious and alert one day, to being unconscious for the whole of the following day. Staff explained this fluctuation in consciousness as being related to the dose of steroids he was on (higher doses reduced the swelling around his brain and made him more alert), his tumour growing, and also his relative degree of dehydration (becoming more alert as he became dehydrated and less alert once he started drinking again – related to changes in his intracranial pressure). He had also had several seizures prior to his admission and these continued during his admission. During the times in which he was unable to swallow his anticonvulsant (anti-seizure) medication, an alternative drug to control seizures was administered. Midazolam was then given continuously to prevent seizures from occurring. This, often sedative drug, was given with the intention of preventing seizures from occurring, according to the doctors and nurses who looked after him. After several weeks of Harry's condition steadily declining, but punctuated with spells of improvement and lucidity as well as of deterioration and unconsciousness, Harry was bed-bound and had increasing difficulty in communicating. Several issues arose towards the end of Harry's life. First, Harry's seizures became more frequent, despite being on a continuous infusion of midazolam; his midazolam dose was therefore gradually increased. Second, there was concern that steroids were artificially keeping Harry alive in a situation in which he would not wish to continue to live. Harry was

said to be frustrated and 'too aware', unable to communicate for the majority of the time. Steroids were considered a life prolonging treatment but were also thought to be maintaining consciousness. Harry was thought to be too alert and, as will be seen through the case, for him to be 'asleep' was considered preferable by many members of staff, especially the nurses. This is important when considering changes in his sedative drugs as they were increased to treat and prevent seizures but had an additional effect on reducing his consciousness; helping his family and staff to ultimately be able to consider him 'peaceful'. Harry's frustration was described by one of the nurses, Mollie, in an interview.

> *7:17 sometimes he would be able to nod, sometimes he'd be able to shake his head, sometimes he wouldn't, and it would just be his eyes and he would just shake with frustration sometimes… and when we used to speak to him we used to say 'are you tired Harry?', and he would just look, and I think it was just, just the look, you could just tell that he was just so frustrated, and he just used to shut his eyes sometimes and just really dismiss us, which to me I thought was quite frustrating.*
>
> [Mollie, staff nurse, interview line 133]

Mollie felt that Harry was too aware and Linda, too, felt that his sedative drugs should be increased as he was too aware, as they both described in a morning handover meeting.

> *7:18* [Mollie] *went on to say he is awake and not asleep… Barbara* [Harry's wife] *was getting very tearful, Mollie added, and said Harry was on 100mg of midazolam. Linda [senior nurse] said to John* [junior doctor] *that that was about as much midazolam as you give – and he would need to be reviewed to see if he needed more of the phenobarbitone, or levomepromazine now. She said that he was just not settled just now, he needs to be asleep.*
>
> [FN 22/06/10, line 55]

As Mollie said in the handover meeting, Harry's wife, Barbara, was also becoming increasingly distressed by his frustration and felt he would not have wanted to continue as he was; she therefore asked that any life-prolonging treatments were withdrawn. She asked whether steroids might be prolonging his life at this stage and it was felt by the

doctors and nurses that they probably were. While steroids might have been controlling intra-cerebral oedema[1], thus preventing symptoms such as headaches or seizures, it was felt that these could be controlled, at least in theory, through other drugs such as analgesics and sedative drugs to control seizure activity. So while Harry's sedative drugs were said, particularly in interviews, to be used with the intention of reducing seizures, he was also thought to be 'too aware', and a suggestion made that his sedation be increased, with the acknowledged outcome that he would be less aware and less frustrated. Additionally, a reduction in his steroids ostensibly maintaining his consciousness and controlling symptoms, was recognised to carry a risk of increased seizures and potentially headaches: the proposed response to which was the increase in sedation (to treat seizures) and the use of analgesia (to treat headaches). This was clearly a complex decision and one about which both the consultant and registrar involved felt uneasy. One of the registrars looking after Harry recalled in an interview the process of discussing the reduction in steroids with Harry's wife.

> *7:19 I suppose one of the hardest things I found was… with his steroids and reducing those… well we'd been going through his medications when he'd become more unwell, then we discussed the steroids and what effect would it have reducing them, and that it might… make him more symptomatic… And we discussed the fact that you could consider the steroids a life prolonging treatment in his situation, if it were to be keeping any… oedema at a minimum. And that was a really difficult conversation to have with her, I think because I'm so - steroids are what people with brain tumours are on and you don't think about reducing them down because they'll get all these complications… I could see where they* [the nurses] *were coming from and the idea that the dexamethasone[2] was a life prolonging measure, rather than a symptomatic benefit for him… we were very aware of the consequences but it was just not something I'd seen before I suppose… if there had been any oedema, then it would get worse. As a result, he'd become more drowsy and there would be the potential to shorten his life.*

[Grace, registrar, interview line 72]

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[1] Fluid within the brain tissue, produced in response to inflammation, sometimes reduced by steroids.

[2] A steroid drug.

Grace felt concerned about reducing steroids, partly, it seemed, because 'steroids are what people with brain tumours are on'; this was, for Grace, a previously unquestioned treatment for patients at the end of life in the hospice. She recognised the consequence of this as an increase in Harry's symptoms and drowsiness and also felt there was a risk of 'hastening death'. Michael, the consultant, had similar concerns and stated clearly that he felt this was not something that collectively they would normally 'do'. He went on to reason, however, that in this situation reducing steroids may be the best option for Harry and his family.

> *7:20* [I] *felt uneasy about reducing the steroids… because there was a slight feeling that we were hastening his death which we don't do… but on the other hand if they didn't feel that the quality was there and it was something which we were giving him that was sustaining him that goes along the lines of withdrawing and withholding treatments… But again as I said that was quite an uneasy action, you know, it's just not something we usually do… it's not something which we found very straightforward because on one hand the feeling is that we shouldn't, really be doing any harm, and was continuing the steroids doing harm? Reducing the steroids doing any harm to him in terms of hastening the rate of change potentially, potentially giving him more complications and problems of raised intracranial pressure? But similarly was it harmful to sustain him in that fashion? The family were very, very distressed, also that could affect their bereavement, I guess on one hand we should be focussing on him because our duty and focus is on him really. But there were just a lot of factors which went into it... it wasn't straightforward.*

> [Michael, consultant, interview line 143]

Michael expressly stated that hastening death was something which 'we don't do': this was more than a personal statement, it seemed, and refers to a broader interpretation of what is 'done', or perhaps to what ought to be 'done' in the hospice context. This is also integral to the WHO definition which states that: 'palliative care intends neither to hasten death or [*sic*] prolong life'. Michael and Grace explicitly stated their discomfort that their actions in reducing steroids might, unintentionally, hasten death. Conversely, one of the senior nurses, Heather, stated in an MDT meeting concerning Harry, that it felt as though 'we're keeping people alive'. Implicit in the context of this statement

was that 'keeping people alive' was a deliberate act in the manner of prolonging life, and this was something, in this case, that they ought not to be doing. Grace and Michael appeared uneasy about hastening death (by the reduction in steroids), while Heather was equally concerned, it seemed, about not keeping Harry alive. Both values are conveyed in the WHO definition of palliative care; rather than simply not hastening death, however, the WHO definition importantly states an *intent* not to hasten death. Grace and Michael were both clear in their interviews that their intention was to relieve Harry's distress yet were still concerned about the 'risk' of hastening death. In contrast, Heather was forceful in her view that to keep Harry alive, against his previously held wishes, would have been wrong and was equally not part of 'what we do in palliative care'. The multi-disciplinary team were in agreement that Barbara appeared to speak from a clear understanding of his wishes and his parents, too, were in agreement that continuing to live as he was not in keeping with his previous wishes. While Grace and Michael acknowledged their misgivings, they both reasoned that because this was not something which Harry would have wanted and reducing steroids was a withdrawal of a life-prolonging treatment, although its withdrawal may cause an increase in symptoms, the harm of continuing steroids was greater to Harry (in prolonging a life he didn't or wouldn't have wanted to live) than withdrawing them.

Ultimately, Harry's steroids were reduced and initially his condition did not change. Grace was relieved that Harry's condition did not change rapidly after the dose reduction and that her actions did not seem to directly correspond with a reduction in Harry's consciousness as she said in an interview:

> 7:21 *his conscious level didn't change directly proportionally to how we'd reduced the steroids which I think I found a bit easier, rather than if we had reduced the steroids and the next day, then he'd become a lot more unwell*
>
> [Grace, registrar, interview line 113]

Even though Grace had acknowledged the risks of reducing steroids she felt relieved not to see a direct response to the reduction. Over time, however, he did develop more seizures and the sedative drug phenobarbital[3] was increased in response to this.

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[3] A barbiturate drug used to treat seizures and also used at the end of life to cause sedation

Additionally the phenobarbital was considered by some of the nurses in particular to be necessary to help Harry to be 'less aware' as seen in the earlier extract. In the context of a reduced steroid dose and increased seizures however, Michael and Grace did not consider the addition of phenobarbital to have had a significant impact on Harry's conscious level.

> *7:22 I know it can certainly sedate quite heavily but...hard to know because he was already quite sleepy at that stage... so I'm not necessarily sure it added a great deal more to the level of sedation anyway... I don't think it was necessary in that if he was already sleepy... but certainly the intent there was to try to manage the symptoms which is what we were trying to focus on, even though he was effectively sedated by a combination of the reduced steroids, his disease and of course the midazolam and phenobarb.*
>
> [Michael, consultant interview line 201]

This statement appears in contrast to the earlier accounts from the nurses, Mollie and Linda, as they said that Harry was too aware and ought to be asleep. Grace, too, felt that the sedative drugs contributed little to Harry's level of consciousness, going further as she clearly felt the reduction in steroids was more accountable for his reduced consciousness than the sedative drugs.

> *7:23 I see it as we didn't actively sedate him with medications but we withdrew medications that meant he would become less conscious. Um...but that was a very...conscious decision for us to do that and it had been thought through and discussed with the full team, which I found quite helpful. And although I felt uncomfortable about it, then I think it was the right thing to do.*
>
> [Grace, registrar interview, line 360]

The nurses looking after Harry felt pleased that he was more 'settled' in the final week of his life following the reduction in steroids and increase in midazolam and phenobarbital: they felt that he was no longer as frustrated as he had been, as Mollie described in her interview:

> *7:24 In the last week he woke up very little, but if he opened his eyes he looked really sleepy, he looked really settled, and not like before we increased the*

midazolam and phenobarb [phenobarbital], *you know,* [then] *when he opened his eyes he looked quite distressed… In the last week of his life you could go to him and he'd be peaceful. Sometimes he wasn't rousable but the times that he did open his eyes he looked totally relaxed, really relaxed and yeah, just really peaceful… And his face looked relaxed and kind of prior to that sometimes you could see him scrunching up or biting down and again just kind of being over to one side and really contracted but with the… midazolam and phenobarb.in the driver it really helped just relaxing him, and his wife… said you know 'he looks peaceful' which is something that he hadn't had during the admission.*

<div align="right">[Mollie staff nurse, interview, line 314]</div>

Mollie thought the addition and increase of the sedative drugs enabled him to be 'peaceful' in the last week of life. Indeed, in contrast to Grace and Michael, Mollie concentrated less on the reduction in steroids and more on the contribution of sedation to Harry's care. Mollie also stressed the importance of making decisions as a team and with Harry's wife Barbara. Throughout the course of Harry's stay in the hospice Barbara was involved in the decision-making process, and the staff felt satisfied as a team that she expressed views consistent with Harry's previous wishes. His parents, too, were involved in decision-making, although to a lesser extent. Mollie recalled there being frequent conversations with Barbara and other members of Harry's family and also the 'negotiations' which took place relating to Harry's steroids.

7:25 They [Harry's family] *were actually quite involved, the consultant spoke to them, we kind of always spoke to them to say, you know, 'I'm considering doing this you know, I think I need to do it because' and he would you know, tell them the rationale behind it and you know discuss it, I mean and there was kind of a lot of negotiating between the team and the family about his steroids.*

<div align="right">[Mollie staff nurse, interview, line 194]</div>

Similarly Alice, the social worker involved in Harry's care felt that as far as she was aware, from speaking to Barbara, felt strongly that there had been full and open discussions about the different treatment options, including withdrawal of treatment and likely consequences. She felt this open discussion to be of crucial importance and in an interview said: '*I put my faith in those conversations'*. She went on to describe further her view:

7:26 I think for me the important thing is consultation, working in partnership. It's looking at how best we feel ethically we can support our patient and hopefully by supporting our patient we can support the family. And I think sometimes we have a real struggle because the family's needs come to the forefront so much, because we see how desperate they are about different, you know, all different situations. But the patient's needs at that particular time I feel very strongly have to come first. And we will be around to support the family with whatever while the patient is alive, but also support them after death as well. So I think that's probably my feeling that it needs to be with...everything needs to be done with, with full consultation.

<div align="right">[Alice, social worker, interview line 279]</div>

While there were clear differences in perspectives and values evident through this case, the process of communication and negotiation, it appeared, allowed most staff to reflect on it as a positive experience, having facilitated a process through which, ultimately they 'got it right'. As a senior nurse, Linda, said in an interview:

7:27 So from Harry's point of view I felt that erm it did take us quite a while to get to the place where we felt that steroids could come down and midazolam could increase but I felt as though that was very well thought through. But also we took very much into consideration his wife's feelings. And I think most of the time we get that right and I think that we did on this occasion.

<div align="right">[Linda, senior nurse, interview line 47]</div>

While Grace agreed with this view that 'in the end' they had probably reached the right decision, Michael appeared to question the decisions which were made, concluding however that there were few 'easy options'.

7:28 I think in this case… we weren't genuinely that sure how long he was going to live because… prognosticating in patients with brain tumours and the fluctuating course of their illness most of the time makes it harder to tell… and while sedation was one aspect I think, I think overall the case was… complicated because of the social needs, the psychological support for his relatives as well, being a young man, having a young wife… having parents who were still alive… I

think some of the decisions which we had to make, like relating to the steroids, who, who are we making it for? Was it genuinely in his best interests to reduce them? Making capacity judgements. There were lots of different people who had different points of view and to try to negotiate through that, was difficult as well. I think in terms of… the management of his seizures as I said I don't think there were that many easy options so… I think the midazolam and phenobarb. was probably a necessary step... but again I think it's something which we need to review anyhow because any time we use it we're just conscious, or at least I feel quite conscious I don't want to be sedating people, it can make people look a lot more ill than they actually are once you take that step…

[Michael, consultant, interview line 236]

Uncertainty about finding a 'right' option from a series of difficult options can be seen to pervade Michael's recollection of events. He recognised the different perspectives involved and the need to 'negotiate' these views. In practice, these decisions to reduce steroids and later to increase and add in a second sedative drug occurred as a process which evolved over the course of Harry's admission. There were daily discussions about Harry's condition and reflections on what was happening, as well as decisions about the impact of his symptoms, alertness and communication on his family. Mollie and Alice both stressed the importance of the communication and negotiation which took place while Michael recognised the different 'points of view'. These points of view can be seen to arise from different value perspectives, characterised by the difference in approach between the doctors and nurses in this situation.

While Grace and Michael were anxious about the risk of hastening death through a reducion in steroids, the nurses appeared more concerned with the 'risk' of postponing death for a patient who would not have wished to be kept alive, a view shared in this case by Harry's family. While the WHO definition of palliative care expresses the intent not to hasten death nor prolong life, there is an interesting distinction between the doctors' and nurses' interpretation and emphasis of values. Randall and Downie would assert there to be a tension here, between those influenced by a philosophy which discourages prolonging life and a more modern conception of palliative care in which prolonging life is increasingly part of practice, in keeping with increasing technological

interventions even at the end of life (Randall and Downie, 2006: 102). An active desire to prolong life creates a greater divide between the two perspectives and involves more of a conceptual shift: the change from an active desire to prolong life, to accepting the potential to hasten death, is greater than the conceptual change from simply not prolonging life, to the acceptance of the potential to hasten death. The discomfort experienced by Grace and Michael may be related to a change of this nature; their desires not to hasten death perhaps strengthened by an underlying desire to in fact prolong life. Perhaps the perspective of the nurses and Harry's family is more representative of the traditional palliative care values and especially concerned with the statement that palliative care does not intend to prolong life.

While the value differences explored through Harry's situation have marked particular differences between those of the doctors and nurses, through a process of negotiation, decisions were made as a team. The integrity of both sets of values remained intact and neither was undermined in the final decisions which were made. While this case demonstrates a relatively rare situation of differences in values in the hospice, because of the changing nature of palliative care, the frequency of different and conflicting values may indeed increase. As well as there being diversity of values among staff, this may also exist between staff and patients, as well as their relatives in the hospice; as access to hospice care increases for patients with different, non-malignant diagnoses at different stages in their illness this diversity of values, too, is more likely to increase. An emphasis on choice at the end of life may broaden the concepts of end of life care and lead to the potential for value conflicts. As more interventional techniques are feasible at the end of life in hospices, and as palliative care integrates more into mainstream medicine, conflict may arise between the traditional hospice values-structure and the more science-based 'medical model' perspective of mainstream medicine, with one possible example considered above. This may be particularly evident at the end of life as the traditionally accepted hospice model of using sedation to facilitate the hospice construct of good dying may be challenged. In this context, approaches to facilitate decision-making in the situation of complex and conflicting values, may be considered. Values-based practice is one such approach which may be considered.

7.4   Values and values-based practice

I have shown through the data some of the underpinning values at work when staff were making decisions about sedation at the end of life. These values have been seen to be derived from palliative care values as they have evolved since its inception with the modern hospice movement. These values, embedded within the 'ethos' or 'philosophy' of palliative care were discussed in Chapter 1; their relevance to the practice of sedation in the hospice becomes evident through the data presented in this chapter. In particular, staff have been seen to draw on these values as they make decisions, frequently characterised through the data with reference to 'what we do'. When tested, or in conflict, these values were expressed more explicitly and related to the accepted and known values of palliative care. These values, it seemed, determined the practice of sedation, before ethics. By this I mean that *before* a concern about how sedation *ought* to be used at the end of life, in practice, staff were motivated by values. Values influenced, often in an implicit and unseen way, the reasoning processes of decision-making. For example, in Harry's case described above, an important distinction between the withdrawal of a treatment and the patient's subsequent death, because of his underlying illness, was crucial to the doctors in making decisions: it seemed that the hastening of death would have been contrary to their underlying values. In this way, values may be seen to have a dominant effect on the everyday practice of sedation at the end of life.

An approach which recognises the influence of values on clinical practice has been developed in recent years. 'Values-Based Practice' (VBP), in providing a framework for decision-making in cases of conflicting values, explains the theory of values in practice and how values are involved in everyday clinical decision-making. Though values may be unseen they can still wield significant influence. This holds relevance for all areas of clinical practice, and while developed from psychiatry, VBP can usefully be considered in relation to my data to explain an area of practice, namely the underlying influence of values on the use of sedation at the end of life.

7.4.1 Values-Based Practice

Values-based practice (VBP) has been developed by Fulford and is defined as:

the theory and practice of effective healthcare decision-making for situations in which legitimately different (and hence potentially conflicting) value perspectives are in play (Fulford, 2004a: 204).

The basis for VBP is found in philosophical value theory which is itself concerned with the logical properties of value terms (Fulford et al., 2002). Having developed a theoretical argument for an alternative approach to the 'medical model' of healthcare, Fulford has argued for a:

more whole or complete view of medicine which incorporates both evaluative and descriptive elements of medical practice (Fulford, 1989: 261).

Fulford suggests that the conventional medical model of healthcare is based predominately on facts; he argues, however, that in contrast, its conceptual structure is evaluative (Fulford, 1989: 260). The 'complete view' is found in VBP, combining as it does facts and values in medical decision-making. The ten principles of VBP can be seen in Table 7:1: rather than summarise all principles I will focus only on those which relate directly to and offer an explanation for my data.

No.	The 10 Principles
1	All decisions stand on two feet, on values as well as on facts, including decisions about diagnosis (the "two feet" principle)
2	We tend to notice values only when they are diverse or conflicting and hence are likely to be problematic (the "squeaky wheel" principle)
3	Scientific progress, in opening up choices, is increasingly bringing the full diversity of human values into play in all areas of healthcare (the "science-driven" principle)
4	VBP's "first call" for information is the perspective of the patient or patient group concerned in a given decision (the "patient perspective" principle)
5	In VBP, conflicts of values are resolved primarily not by reference to a rule prescribing a "right" outcome, but by processes designed to support a balance of legitimately different perspectives (the "multi-perspective" principle)
6	Careful attention to language use in a given context is one of a range of powerful methods for raising awareness of values (the "values blindness" principle)
7	A rich resource of both empirical and philosophical methods is available for improving our knowledge of other people's values (the "values myopia" principle)
8	Ethical reasoning is employed in VBP primarily to explore differences of values, not, as in quasi-legal bioethics, to determine "what is right" (the "space of values" principle)
9	In VBP communication skills have a substantive rather than (as in quasi-legal ethics) a merely executive role in clinical decision making (the "how it's done" principle)
10	VBP, although involving a partnership with ethicists and lawyers (equivalent to the partnership with scientists and statisticians in EBM), puts decision making back where it belongs, with users and providers at the clinical coal-face (the "who decides" principle)

Table 7:1: The 10 Principles of VBP

The first principle of VBP is:

> All decisions stand on two feet, on values as well as on facts, including
> decisions about diagnosis (Fulford, 2004a: 208).

This principle relies on acknowledging a distinction between facts and values and the presence of both in all decisions. The role of values has been seen in the first section of this chapter to be fundamental to decision-making about the use of sedation at the end of life. Following an assessment of the 'facts' of a case, values have been seen to guide the actions of staff in making decisions about using sedation at the end of life. For example, while initially appearing to be relatively straightforward, Harry's situation revealed more complexity of values which became evident as decisions about sedation were tested and differing values came to the fore. In a similar way to the development of evidence-based medicine as a response to the increasing complexity of facts, the increasing complexity of values has led to the development of values-based practice; to

deal with the increasing complexity of values in decision-making and situations in which these values conflict.

In developing values-based practice Fulford has taken the perspective of Hare in considering there to be a logical divide between facts and values, or between 'descriptive' and 'evaluative' terms. He therefore considers it to be impossible to 'define a genuinely evaluative notion in purely descriptive terms' (Fulford et al., 1994: 201). Hare's non-descriptivist approach, suggesting a logical divide between facts and values also provides the theoretical basis to explain the relative descriptive or evaluative strength of a term. When there is little variation in understanding of a concept or term, i.e. when there is a shared perspective or understanding, it will hold predominately descriptive properties: when, however, there is wide variation in understanding and perspective, the notion will be considered largely evaluative. In medical terms, decisions about which there is much agreement can be considered relatively value-neutral; while values are present, they are not considered problematic and indeed may be unseen in daily clinical practice. This was seen throughout the data as the predominately shared values regarding the use of sedation at the end of life were relatively hidden in clinical practice. It is only through considering the shared language and behaviours of staff in relation to the practice of sedation that their values become evident. The use of sedation was familiar and understood, and raised no questions in 'routine' practice. The use of 'routine' sedation indeed *relies* on shared values about these distress-behaviours and consciousness in dying. In contrast, when sedation was non-routine and decisions concerning its use became explicit, values became more evident. For example, though not expressed overtly as 'values', staff used value-laden terms to describe how they felt Harry should be treated. The doctors in Harry's case expressed their discomfort about decision-making and the divergence of values became more overt. Thus while the predominately shared values in the hospice led to there being considered a 'right' way to die in the hospice, as long as these values were shared no problems or concerns became evident. It was when there was a difference in values that values became evident. This argument forms the second principle of VBP:

> We tend to notice values only when they are diverse or conflicting and hence are likely to be problematic (Fulford, 2004a: 209).

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The third principle of VBP concerns an anticipated increase in values-diversity as scientific progress continues. As scientific progress is made and more choice is available in all areas of healthcare, including end of life care, there will be more diversity of values and hence the potential for conflicting values is increased. This has been highlighted earlier in this chapter in relation to palliative care; as palliative care develops and expands in context as well as in scope to incorporate patients with any life limiting illness at any stage in disease, the values which are brought alongside this expansion are likely to be more diverse than those contained within the narrow conception of hospice care of the 1960s. Furthermore, as this third principle of VBP suggests, the *scientific* developments likely in the future will also bring further diversity of values. This has been seen in recent years and, VBP would assert, is likely to be the case in the future. In recent years, for example, the use of implantable cardiac defibrillators and domiciliary non-invasive ventilation has brought challenges to palliative care. While switching off a life sustaining treatment is a relatively common decision in intensive care settings, this decision occurs relatively infrequently in a hospice setting (Nambisan and Chao, 2004). Different values are brought into play through this type of intervention, and different approaches to managing decisions have been sought (Mueller et al., 2008). While there is an increasing availability of interventional techniques and procedures for patients approaching the end of their lives, this brings the potential for a host of different decisions to be required to be made; in turn this generates an increased likelihood of divergent values. Further advances such as this can be seen to be likely to present similar challenges, especially of an evaluative nature.

Aside from, or perhaps because of, such medical interventions and developments, changing societal attitudes towards death and dying may also generate more values diversity: as support for a change in legislation regarding physician assisted dying increases, the strength of support in opposition may also increase. Palliative care has traditionally opposed assisted dying and indeed this is held within its WHO definition, or 'philosophy', as it is described by Randall and Downie. Conflicts of values are likely to become increasingly frequent in end of life decision-making; the recognition of this is important if the specialty of palliative care is to be able to support patients, and their values, preferences and wishes, as they approach the end of their lives. If there is an assumption of shared values there is a risk of not being able to identify differing

values if not clearly expressed. This, indeed is a risk captured within the 6th and 7th principles of VBP; the 'values-blindness' and 'values-myopia' principles. As seen throughout the data, values concerning the way in which patients should be cared for at the end of life were overwhelmingly shared by staff in the hospice. In particular, the way in which sedation was used as a patient was imminently dying was accepted to be part of normal clinical practice and at times not acknowledged to *be* sedation, even when causing a reduction in patient consciousness. This implicit understanding of the use of routine sedation, and assumption of shared values concerning its use, could lead to a failure to acknowledge or recognise the values of others when they do in fact differ. Because of its implicit nature there is an, unintentional, risk of suppressing the values of patients. For such a practice to be so implicit as to be unseen is significant in the current medical context where there is strenuous promotion of patient choice at the end of life. Studies which have explored patient wishes at the end of life, and conceptions of a good death, have indeed found wide variations in preferences and values of what it is to have a good death; specifically some have expressed a preference to be aware and alert while others believe they would rather be unaware and sedated (Hales et al., 2010, Vig and Pearlman, 2004). Perhaps preferences change as a patient nears death: to assume that all patients as they die wish to be treated in the same way with sedation is, however, to appear to dismiss the value of an individual in their dying. VBP recognises the risk of the assumption of shared values in causing 'values-blindness' and directs towards the 'skills' of VBP, developed to raise awareness and knowledge of values in clinical practice, develop skills through careful attention to language and seeks to raise awareness of values in this way. Furthermore, understanding of different perspectives is promoted, to avoid 'values-myopia', or a very narrow understanding of patient-perspectives. The development of a broader scope for palliative care over the past decade, and in the future, requires such an understanding, if hospice palliative care is to be able to reach the broadening horizons and perspectives of a palliative care population.

This brief overview of VBP allows an exploration of the ways in which its application in an increasingly values-diverse healthcare setting may enhance clinical decision-making. Importantly, VBP is not considered to supplant other forms of decision-making; Fulford rather considers that it will supplement the 'tools' of 'quasi-legal' bioethics (Fulford et al., 2006) and can stand 'side by side' with the principles of EBM

in clinical decision-making (Fulford, 2004b). In the field of palliative medicine the 'space' for values-based practice is clear. Concerned with a patient-centred approach to care since its conception (Saunders, 1978a), the theory and practice of an approach which promotes respect for diversity of values and which may improve clinical decision-making in a complex area is invaluable. Clearly, however, there are challenges. As the data has suggested, the predominately shared values in the hospice regarding end of life care may have led to 'values-blindness' in some quarters. Indeed the palliative care 'approach', in some respects, may be seen to promote this; it advocates a particular version of providing end of life symptom control and care as it has moved out of the hospices into other contexts. This is seen most prominently at a national level through the LCP. In response to initial problems and following reviews of its use in clinical practice, however, it has undergone 11 substantial revisions and in its 12th version promotes a much broader perspective, focused on the individual patient's needs and facilitating a process of inter-disciplinary assessment and care. Hospices, as they care for a more diverse population of patients with different perspectives and needs, may also experience more frequent conflicts of values in the future. Increasing integration with mainstream, medicine is likely to continue and this, as well as the increasingly diverse hospice population, is likely to generate more conflicts of values.   Awareness of the particular values of palliative care and their role in clinical practice is likely to become an important part of decision-making in situations of value conflicts in the future. The theory and skills of values-based practice applied in palliative care may enhance clinical decision-making in situations of complex and conflicting values in the future.

7.5   Conclusion

Throughout this thesis values can be seen to have underpinned the practice of using sedation. Indeed, rather than complex ethical discussions occurring regarding how sedation ought to be used, most frequently an implicit understanding of how sedation ought to be used was observed. This implicit nature was evident when values were shared; differences in values were made explicit through the process of decision-making and this was seen through the case study in this chapter. The recognition of the underpinning values has important implications. First, if decision-making regarding sedation is implicit when values are shared, there is a risk, as explored through VBP

above, of there becoming an assumption of shared values, and the potential to override a patient's values, especially when vulnerable at the end of life.

Second, the values underpinning the practice of sedation in this hospice population may be very different to those outwith this environment. Specialist palliative care in a hospice has developed with a clear link to the hospice movement of the 1960s; mainstream medicine has developed along a separate path. The values of staff in mainstream medicine may differ from those in a hospice and this may impact on patient care. In the absence of an explicit understanding of values which drive end of life practices, conflicts in approaches may exist and this may lead to a smaller, self-selecting group of patients choosing hospice care.

Third, sedation is being debated at an international level. The development of this philosophy and practice of palliative care is unique to the UK. While other countries may have developed palliative care services in a similar way, the underpinning values of palliative care have developed independently, influenced by different cultural and societal norms. This is most apparent perhaps in countries where euthanasia and physician assisted suicide have been legalised. If the practice of sedation is underpinned and driven by values, the practices in different countries will differ accordingly. While there has been a desire to standardise practice through international guidelines, perhaps what is needed first is an explicit understanding of the underpinning values of the practice, which may allow for diversity to be more openly tolerated.

These implications, as well as the wider implications of this study for future practice, are discussed in the final chapter.

Chapter 8 Implications for future practice

8.1   Introduction

This thesis has described the practice of sedation in a UK hospice and generated an understanding of its normative basis. This is bound to an implicit understanding of the process of dying, described fully in Chapter 4. The underlying motivations for this practice may be seen to rest in the desire to bring about a comfortable and peaceful dying process, fulfilling some of the previously described attributes of good dying and death. This is underscored by the values of staff in the hospice; striving to achieve this 'good' dying process, facilitated through the use of sedative drugs to bring about a process of dying which is free from distress.

This thesis has clear implications for UK and international palliative care practice. In this chapter I first examine the implications of the conceptual model of sedation as it relates to the process of dying, and reflect on its contribution to the literature base on this subject. This includes not only the practice of 'routine' sedation, occurring when there is a clear understanding of a patient's dying trajectory, but also 'non-routine' sedation, when the prognosis for a patient is uncertain. I reconsider the case of the controversial 'continuous deep sedation', described in Chapter 2, in light of the results of my study. I turn to focus on two particularly difficult areas of practice which have been highlighted; prolonged dying and the use of p.r.n. medication. I then consider the importance of understanding the values which underlie the practice of sedation in a hospice, especially for patients who lack capacity. In the last section of this chapter I turn to the implications of this research for future clinical practice: I consider the changes occurring in hospices, with a move to increase the care for patients with non-malignant disease and the changes this will mean for decision-making at the end of life. Finally, I consider the implications of these changes for palliative care. Mainstream medicine has become more patient-centred, with patient choice and experience at the forefront of a changing NHS (DH, 2010, McClimans et al., 2011). Within this context, I suggest that palliative care as a specialty must be aware of its values and influence on clinical practice in order to ensure that it continues to offer a 'patient-centred' approach and not simply a 'palliative care-centred' approach. Values-based practice is one framework which supports this and promotes patient-centred care. Palliative care has

already broadened its practice over the past decade to incorporate patients with all life-limiting illnesses; I suggest re-examination of its underlying values may enhance even further the provision of patient centred care.

8.2   Routine and Proportional Sedation

8.2.1   Routine

Sedation has been shown in this study to be a routine and integral part of end of life care. Sedation is routine not only when providing symptom control without a reduction in consciousness but also at the end of life when there is acceptance of a reduction in consciousness. This is an important empirical finding when considering the current literature regarding sedation, as reflected in Chapter 2. This study has shown there is a continuum of decisions about sedation, which relates to the degree of acceptance of a reduction in a patient's consciousness, depending on how imminent death is thought to be. A conceptual model of this has been developed and is seen in Figure 8:1
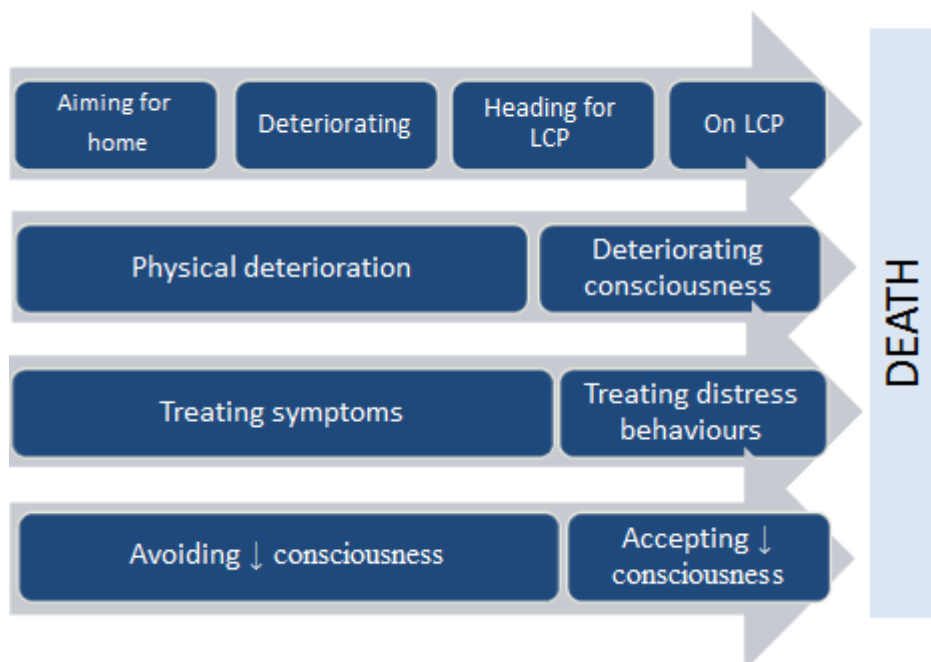
Figure 8:1: Conceptual model of sedation at the end of life

 Decisions to use sedative drugs to control symptoms without acceptance of a reduction in patient consciousness for those who are not dying lie at one end of this continuum; at the other lie decisions to use sedative drugs to control symptoms or signs of distress

with acceptance of a reduction in patient consciousness in an imminently dying patient. The interpretation of dying is of the upmost importance and is recognised as a process rather than being recognised at one specific point in time. There is a process of interpretation as a patient's condition deteriorates and the accumulation of 'cues' culminates in a patient being recognised as dying, often expressed by staff as a patient being 'on the LCP'. This process has been recognised to occur through 'sequences of dying' which are without clear dimensions; thus the point at which a patient progresses through one point in the sequence and reaches another is indistinct, but reflected at some point through a change in the language staff use to describe the patient. This is a recognised, anticipated, sequence of dying which begins with the identification of a patient as 'deteriorating'[1]. While at this point a patient may improve and be treated for a reversible cause for their deterioration, if they do not improve they continue to be described as 'deteriorating', before entering a point at which dying is more openly acknowledged, in the phrase 'heading for the LCP'. This process was recognised initially through changes in a patient's physical condition, such as being less able to mobilise, or transfer out of bed; latterly it was recognised through changes in a patient's alertness, or awareness. This was the *expected* sequence of dying, while not replicated for each patient, it was nonetheless the process which was anticipated, described to patients and witnessed to inform daily practice as patients were discussed and treatments adjusted. By the time a patient is 'on the LCP' their dying is explicitly recognised; even before this point, however, it is often *implicitly* recognised. The boundaries between the sequences of dying are indistinct and the boundaries between acceptance and non-acceptance of a reduction in consciousness due to sedative drugs are equally unclear. So ingrained in the practice of end of life care is the use of sedation that this acceptance of a reduction in consciousness, too, is implicitly understood in practice. This transition from not dying to dying, from non-acceptance to acceptance, occurs on a daily basis, recognised in relation to the accumulation of cues of transition from one status of dying into another.

In this current study the terms 'aiming for home', 'deteriorating', 'heading for the LCP' and 'on the LCP' were the terms familiar to staff and used to convey special meaning to

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[1] As discussed in Chapter 4 this may be considered *within* the final status passage recognised by Glaser and Strauss as 'certain death at known time'.

enable decision-making. These terms may not, however, be the same in other settings or regions, particularly in relation to use of the LCP for the dying patient. For practical reasons I suggest more universal terms embodying a similar meaning could be used beyond this research study and suggest the following: 'not dying', 'deteriorating', 'probably dying' and 'imminently dying'. These terms are important as they reflect an underlying understanding of the process of dying, not bound to a particular period of time. In the past, research and other studies have considered time periods as the markers of dying. These are either used retrospectively, or a patient's prognosis considered prospectively, with a period of two weeks often being considered as representing the end of life. Instead, practice suggests a more dynamic understanding of dying, recognised through the use of these significant phrases.

The conceptual model seen in Figure 8:1 is central to the outcome of the thesis. Sedation is a routine practice, intrinsically part of symptom control in the hospice and understood tacitly to change as a patient approaches death. This contributes to a new understanding of sedation in palliative care. Importantly, decisions regarding sedation may be implicit, based on a shared understanding of the practice of sedation in relation to a patient's dying trajectory. Sedation is used to treat distress-behaviours, rather than to sedate to reduce consciousness. This subtle point was recognised in Chapter 4 but forms a crucial distinction between different types of sedation described in the literature. The use of sedation is proportional, in relation to distress-behaviours, as well as in relation to expected death. Previous literature regarding sedation at the end of life has predominately focused on decisions explicitly made at the end of life, or have used retrospective data to consider decisions as occurring at a single point in time (Broeckaert et al., 2011, Claessens et al., 2008, de Graeff and Dean, 2007). Seeing sedation as a process, evolving implicitly in relation to dying, is crucial if we are to develop an understanding of the underlying motivations in using sedation and the values which underpin the whole process.

8.2.2 Proportional

Routine sedation relies on the *proportional* use of sedation in relation to both the severity of symptoms and to the patient's proximity to death. Dying with uncontrolled symptoms or signs of distress may be considered as a 'threat': in the presence of symptoms or signs of distress, if death is imminent the threat is great and the use of

higher doses of medication to achieve a greater depth of sedation is considered, under these circumstances, to be proportional to the threat of suffering in dying. Similarly, when a patient is not thought to be dying, the 'threat' of dying in this way is small and large doses of sedation to reduce levels of consciousness would be disproportionate to the threat. This has been shown in the previous data chapters and is important in its contribution to the academic literature surrounding 'palliative sedation'. Multiple terms and definitions have been used to describe the practice of using sedative drugs at the end of life, as detailed in Chapter 2. These terms have focused largely on technical aspects of sedation, concentrating as they do on the depth or duration of sedation, for example, continuous deep sedation, intermittent, and mild sedation (Morita et al., 2002b, Rietjens et al., 2009b). Some of the broader terms and definitions are still frequently used, in particular the term 'palliative sedation'. This is usually defined as:

> the use of sedative medications to relieve intolerable and refractory distress by the reduction of patient consciousness (Morita et al., 2002b).

This definition for palliative sedation certainly applies to many of the cases in which sedation was observed in the hospice; it does, however, fail to capture the more nuanced use of sedative drugs throughout a patient's life and dying process. Recently, new terms were proposed by Quill et al (Quill et al., 2009, Reid et al., 2010) and were adopted by the American Academy of Hospice and Palliative Medicine. These were: 'usual' sedation, 'proportionate palliative sedation' and 'palliative sedation to unconsciousness'. 'Usual sedation' is the use of sedation to treat symptoms without a reduction in consciousness; this would equate to the use of sedation to treat symptoms in a patient not thought to be dying, in the model shown in Figure 8:1. Quill defines 'palliative sedation to unconsciousness' (PSU) as the use of sedation with the intent of making a patient unconscious, while 'proportionate palliative sedation' (PPS) involves the continuous use of sedation titrated against its effect on a specific symptom. In PPS, unconsciousness is considered as a side effect of treatment rather than intended, in contrast to this being the explicit aim in using PSU. While this terminology has been endorsed by the American Academy of Hospice and Palliative Medicine (Reid et al., 2010) its use is questioned by some who consider sedation to be part of a single continuum (Cellarius and Henry, 2010, Jansen and Sulmasy, 2002, Reid et al., 2010). Cellarius and Henry argue that the suggestion that the decision to sedate to

unconsciousness is morally different and somehow not proportional may be confusing (Cellarius and Henry, 2010). In practice, my current study suggests, when sedation was considered to be proportional to symptoms and the threat of dying with uncontrolled symptoms or in distress, sedation was a routine and accepted (even implicit) practice. A different set of decisions were made, not in relation to the depth of sedation, or the types of drugs (as these were considered merely the means to the effect), but rather the principle distinction about sedation in practice related to whether or not a patient was dying. Decisions followed from this distinction. Importantly, acceptance of a reduction in consciousness occurred implicitly if a patient was thought to be dying: this was not an explicit, or a different, form of decision-making from that of using sedative drugs to control symptoms without reducing consciousness in those not thought to be dying. The difficulty in decision-making arose, rather, when there was uncertainty about whether or not a patient was dying. This current study supports the view of Cellarius and Henry that using sedation to induce unconsciousness may still be a proportionate response, depending upon the expected imminence of death and the severity of the distress, or distress-behaviours.

While this conceptual model represents the way in which sedation may routinely and implicitly be given at the end of life, clearly there were cases in which the status and sequence of dying was unclear. These were the cases about which there was more discussion, and in which the use of sedative drugs was recognised and explicit. Decision-making was overt and involved a clearer external assessment of reversible features of a patient's condition, alongside the assessment of the risks and benefits of other types of investigation and management. These types of decisions were explored in Chapter 5, which also considered the motivation behind giving sedative drugs at the end of life. In this chapter, the use of sedative drugs was initially time-limited, with review points discussed. Staff explicitly expressed their intent to use sedation with a reduction in patient consciousness to manage symptoms or distress-behaviours only until it became clear that there was not a reversible cause. There was uncertainty and unease about managing such patients, because their dying trajectory was unclear. There was also a heightened awareness of the potential for sedative drugs to cause a patient to appear to be dying; the use of time-limited sedation and clear review points was used to mitigate this risk and decisions were inherently temporary.

The recognition of dying was a process which was recognised by some staff earlier than others. This created tension at times as some staff, who considered a patient to be dying, used sedation in a routine way, while others, considering there to be some doubt, wished to use sedation in a 'non-routine' way. I will return to this important issue later in this chapter. The 'need' for sedation in a patient not previously thought to be dying led to a series of explicit decisions relating to: the intention of using sedation, the duration of sedation and the desired effect of using sedation, as decisions were negotiated and discussed rather than assumed. Sedation was still used proportionately to symptoms, however a more cautious approach was assumed considering the acceptability of a reduction in consciousness until death, relying on approaches which would limit the duration and depth of sedation. Thus sedation in situations of uncertainty about whether or not a patient was dying (i.e. non-routine sedation) was approached differently, with an increased awareness, consultation and a more explicit approach to management.

Based on these research findings I suggest instead of 'palliative sedation', 'sedation at the end of life' is a more appropriate term to encompass a range of a different practices, based on the same underlying process of decision-making and linked to an understanding of dying. Thus I suggest a more accurate definition of the practice of using sedation in palliative care is:

> the process of using sedative medications in a proportional manner to relieve symptoms or distress-behaviours. 'Proportional' relates to the severity of symptoms or distress-behaviours and to the expected imminence of death. This is considered to be a process, as decision-making is dynamic, responding to changes in a patient's condition and the expected imminence of death.

8.3   Continuous Deep Sedation (CDS)

The proportional nature of sedation in relation to symptoms has been described in the literature (Morita, 1999, Morita et al., 2005c, Sykes and Thorns, 2003a): many definitions of sedation in palliative care refer to the proportional use of sedation in relation to symptoms, with either an assumption or explicit statement that it is used in patients who are close to death (Cherny, 2009, de Graeff and Dean, 2007, Morita et al., 2005c). While it has been emphasised by several authors that sedation is a 'last resort'

for *dying* patients (Claessens et al., 2008, de Graeff and Dean, 2007, Quill et al., 2000b, Quill et al., 2009), the ways in which this is recognised and bound to implicit decisions has not been recognised previously in empirical data. The acceptance of sedation with a reduction in consciousness only once a patient was thought to be dying addresses at least some of the concerns about the use of sedation at the end of life. As seen in the literature review, the principal concerns about sedation relate to its potential to hasten death. This may be thought to occur through the use of sedation which reduces consciousness without giving hydration or nutrition in a patient who would otherwise be able to eat and drink. A patient may therefore dehydrate to death. This study suggests that this concern is not a feature of decision-making regarding sedation when a patient is thought to be imminently dying. In this case their ability to drink and eat is considered to be 'naturally' reduced, as part of the dying process. Sedation in this circumstance, therefore, is not responsible for *causing* the inability to drink and eat and thus the risk of hastening death is minimal and not related to the deprivation of hydration caused by sedation. This is, however, the principal concern in connection with the use of continuous deep sedation (CDS), which has been described particularly in the Netherlands and Belgium (Chambaere et al., 2010, Rietjens, 2008). Patients are sedated to unconsciousness and maintained in this state until death (Rietjens, 2008). This practice was not seen in this study.

While patients were unconscious as they died, and many were on sedative drugs, the decision-making process prior to that point was not concerned with the depth of sedation or level of consciousness, rather was concerned with the titration of sedative drugs to achieve the required effect of relieving distress. This distinction is important. While much has been written about the use of CDS in several countries, this data has predominately relied on physician recall and individual interpretation (Deliens et al., 2000, Kuhse, 1997, Mitchell and Owens, 2003, Onwuteaka-Philipsen et al., 2003, van der Heide et al., 2003). Indeed in a UK study based on the original Dutch methodology, physicians were sent questionnaires and asked to consider the most recently deceased patient they cared for. One of the questions asked concerning sedation read:

> was the patient continuously and deeply sedated or kept in a coma before
> death? (Seale, 2010)

While this may lead to important data about how physicians regarded their actions, my study challenges what is actually addressed by this question especially in relation to the debate about continuous deep sedation. Many patients were sedated continuously in this study; a continuous infusion of a sedative drug was frequently administered while a patient was dying to treat symptoms or distress-behaviours. Many patients were also unconscious; this has indeed been seen to be an expectation of 'normal' dying. The extent to which drugs cause sedation alongside a 'natural' process of becoming more sedated while dying is, however, unclear. The intention to sedate a patient deeply (to unconsciousness) until they died was not part of routine practice in this study. The literature regarding CDS, however, suggests this is precisely how this practice is understood – that a patient is 'kept in' an unconscious state until death. Thus the intent in using CDS is to maintain unconsciousness regardless of changes in distress behaviours. This appears to be contrary to what I have observed in practice where sedation is, rather, regarded as a proportional response to symptoms and distress-behaviours. Depending on the imminence of death, it may even be that CDS with the intention of maintaining unconsciousness, regardless of changes in distress-behaviours, is not a proportional response to the 'threat' of dying in distress.

Sedation was seen to be given with the explicit intent to cause unconsciousness only once in this study. When Richard, in Chapter 6, was sedated following his massive haemorrhage, both the doctor and nurse wanted him to be unaware and unconscious. This could be regarded as a form of CDS, or indeed PSU according to Quill's terminology. He was sedated with the aim of making him unconscious until he died. His death was considered to be imminent, in minutes as he was exsanguinating, and the threat of dying in distress was great. Sedation, in this case, could be considered as proportional to the severity of symptoms and threat of (imminent) dying in distress. While the manner of his death was terrible, the use of sedation in this situation could be regarded as routine in its proportional sense. This research suggests that rather than focus on the outcome or depth of sedation, what matters in clinical practice is the manner in which sedation is used. The intention and underlying motivation in using sedation hinges on proportionality; this was tested, however, in situations of prolonged dying and when drugs were used on a p.r.n basis.

8.4 Prolonged Dying

This study has delineated the decisions which are involved in using sedative drugs at the end of life, and the way in which this is justified in the hospice context. The strength of this process of decision-making may be tested particularly when considering the possibilities of misdiagnosing dying and the potential problems associated with using drugs on a p.r.n. basis. That dying could be misdiagnosed when a patient is sedated was considered by one of the consultants in Chapter 5 as Michael considered the risk that sedative drugs could make patients look as though they were dying when in fact they were not. Sedation may be used in the expectation that a patient is imminently dying, and used proportionally to treat distress-behaviours, even to unconsciousness. In this situation if a patient did not die quickly there would be an increased concern that the sedative drugs could contribute to their dying process. While initially used proportionally, a retrospective view may consider the sedation to be disproportionate, if death occurred some weeks after the initial decision to use sedation. This was a situation recognised by staff in the hospice as being particularly difficult. Unintentional hastening of death is often justified in the literature through appeal to the doctrine of double effect, discussed in Chapter 2. In this situation, however, the doctrine of double effect (DDE) cannot be applied. If a patient died as a result of the use of sedative drugs within a matter of days as an anticipated, or foreseen, side effect, it may be possible to consider the DDE as justification for using sedation in such a way. In the situation outlined above, however, the prolonged dying with sedation would not be foreseen and yet could contribute to the patient's death. The fact that this would not have been a foreseen side effect would mean the DDE would not be valid. I would suggest, rather, in this situation the two crucial components to decision-making rest on the intent in using sedative drugs and the use of drugs in a proportional manner: proportional to both the severity of symptoms or distress-behaviours and the *expected* imminence of death. Thus if a patient was reviewed daily and continued to require sedative drugs to treat distress-behaviours, and was thought to be imminently dying due to a process independent of the effect of the sedative drugs, the use of sedation may still be considered proportional. This relies on decision-making being a process, reviewed and adapted according to changes in a patient's condition. Critically, it relies on good decision-making at the time at which dying is diagnosed. This decision-making falls

into question when the decision to use sedative drugs, even to the point of unconsciousness, is made through the use of p.r.n. medication.

The effect of using p.r.n. sedative drugs was seen most clearly in Chapter 6 as one patient, Luke, was given extra sedation overnight by nurses who thought that he was dying. The consultant looking after him, however, felt that there was still some doubt about whether or not he was dying, or indeed if he looked more unwell because of the use of sedative drugs. That sedation to unconsciousness can occur through the p.r.n. use of sedative drugs, as in this case, and instigated by one member of staff, is concerning. The strength of decision-making throughout the data chapters stems from the involvement of the multi-disciplinary team. In this individual decision, the explicit request from the consultant not to use sedative drugs (unless absolutely necessary), because there was doubt about whether or not he was actually dying, was not adhered to because others, overnight, thought that he was in fact dying. While there may have been doubt about how quickly he was dying, the distress of the patient was considered to require treatment with sedation, even to unconsciousness. This flexibility is a feature of palliative care decisions: they change regularly depending on an interpretation of a patient's condition. This is an expected part of practice. The consultant in this case could have stopped all p.r.n. use of sedative drugs, if he had been certain that Luke was not dying, but the consultant was not and the same doubt which led to caution about the use of sedative drugs led to caution about making them unavailable if he *was* in fact dying.

While the current study has described a practice of using sedative drugs at the end of life to treat distress in a way which is proportional, there remain situations which are particularly challenging. This is seen in the situation in which a patient does not die as expected but remains sedated for longer than anticipated, raising the risk of sedative drugs in fact hastening death. This is of most concern if the original decision to use sedative drugs, with a reduction in patient consciousness, was made by an individual, or through the accumulation of p.r.n. sedation. The prescription of sedative drugs to be used in a p.r.n. way may be justified for those patients recognised to be dying; for those not dying, however, I would suggest, such a prescription creates the potential risk of causing a patient's deterioration and misinterpreting their condition as dying. As a result of this study I suggest the routine prescription of sedative drugs to a dose which

may reduce consciousness ought to be reserved for those patients 'probably dying' and 'imminently dying'. If a patient not previously identified as dying was to require sedative drugs with the reduction in consciousness, they ought to be reassessed and the prescription of sedative drugs written only if they were indeed thought to be dying. In this way the use of p.r.n. sedative drugs would be restricted to ensure that decision-making which could lead to a patient becoming unconscious until they die involved more than one member of the healthcare team. While most often routine, these are nonetheless significant decisions which impact on a patient's consciousness and therefore on their mental capacity; this will be discussed in the next part of the chapter.

Routine sedation involves the proportionate response to symptoms (of any origin), crucially determined by a patient's proximity to death. Non-routine sedation occurs in situations in which there is uncertainty about whether or not a patient is dying and the 'proportionality' of the response thus comes into question. Reasons for acting to use sedation proportionately in this way are thoroughly ingrained in hospice practice and are underpinned by values, strongly influenced in turn by the values of palliative care. These determine the ways in which care is provided and provide the motivation for acting. Before considering the implications of this study for the future, I will consider the particular issues concerned with treating patients who lack capacity.

8.5   Patient values at the end of life: a challenge for decision-making

While studies have been conducted in palliative care concerning patient involvement in decision-making (Bakitas et al., 2011, Bélanger et al., 2011, Frank, 2009), significant decisions about sedation are frequently made for patients who lack capacity. As patients approach the end of life, their consciousness is frequently reduced, either through the use of sedative drugs or through the 'natural' processes of dying. Treating distress at the end of life may require the reduction of a patient's consciousness to the point at which he or she loses capacity. In this situation there may be a tension between the need to reduce suffering and distress, and to preserve a patient's capacity until they die. A focus on the individual and their wishes, values and beliefs has always been central to an understanding of palliative care, especially in dying. This is captured in Saunders's frequently quoted statement:

> You matter because you are you and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die. (Saunders, 1976)

There may, however, be a tension between enabling the 'peaceful' death and not reducing a patient's capacity through sedation. If the use of sedation reduces consciousness such that the patient loses capacity, the ability to preserve his or her values may be diminished. Treating patients who lack capacity requires particular consideration, in keeping with the principles and guidance set out in the Mental Capacity Act (MCA) as well as in the GMC framework for making decisions about patients who lack capacity and are dying (GMC, 2010, 2005). A summary of the MCA 'checklist' for making a best interests decision is seen in Table 8:1.

Table 1: Best Interests 'Checklist' (Mental Capacity Act 2005) Section 4 (6) &(7)

(6) He must consider, so far as is reasonably ascertainable —
 	
   (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
 	
   (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
 	
   (c) the other factors that he would be likely to consider if he were able to do so.
 	
 (7) He must take into account, if it is practicable and appropriate to consult them, the views of —
 	
   (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
 	
   (b) anyone engaged in caring for the person or interested in his welfare,
 	
   (c) any donee of a lasting power of attorney granted by the person, and
 	
   (d) any deputy appointed for the person by the court,
 	
 as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

Table 8:1: MCA Best Interests Checklist

It was not possible to establish in this research the extent to which the decisions to use sedative drugs were made explicitly with reference to the MCA. The phrase 'best interests' was often used when there was a discussion about patients who lacked capacity. In cases of 'routine sedation' however, because this was an accepted and implicit practice, most often by definition involving patients who lacked capacity, the

decision-making regarding their best interests was unclear. Best interests decisions are rarely straightforward as they require a patient to have lost capacity and not to have an advance decision to refuse treatment or an advance statement. As seen in Table 8:1, The MCA checklist for making best interests decisions suggests that the past and present wishes of a patient ought to be considered, as well as the 'likely' influences of beliefs and values as well as any other factors, on decision-making, 'if he were able to do so'. This requires an approximation of what would influence a patient's decision-making, if they were able to be in the same situation, but with capacity. Hope et al have furthered a discussion about the nature of this type of decision-making, suggesting that rather than rely on a hypothetical choice (i.e. the decision a patient may have made, and what would influence his or her decision in the present situation), valid guidance can only come from considering what is known (Hope et al., 2009). This requires a judgement regarding the relative weighting of a patient's previously held wishes and values, and his or her current wishes and values, based also upon an understanding of the situation and future impact of any decision made. Hope et al expand the MCA 'checklist' for best interests decisions, to incorporate more of an understanding of the strengths of the previous and present wishes and values of the patient who lacks capacity (ibid).

Even this process, however, of best interests decision-making, is not independent of the values of those making the decision, which may also be contextual. In the hospice context, for example, a decision regarding sedation at the end of life may be regarded differently to a similar decision in another context, such as in the patient's own home. The values of an organisation and of the healthcare professionals caring for a patient who lacks capacity play a role in interpreting what constitutes best interests for an individual. The assumption of shared values in this situation may allow the contextual values (e.g. of staff in palliative care) to override the values of the patient, unless actively considered. In this state of incapacity an awareness and understanding of the values which may influence decision-making is of heightened importance. McClimans considers this forcefully:

> If we are serious about providing personalized and responsive care, we should be serious about engaging with the values that shape what counts as health; what counts as harm; what counts as illness and so on. This engagement

requires not simply asking patients what they want, but rather considering the unspecified and undefended values that underpin our healthcare policies and practices (McClimans et al., 2011).

This study has revealed the influence of values on decision-making about sedation at the end of life, and identified the prominent values within the hospice. The potentially vulnerable nature of patients' values in dying, especially having lost capacity, is identified to be of particular significance. While there are models of decision-making which expressly incorporate patient values in the process (e.g. shared decision-making) the first step in considering patient values at the end of life lies in the recognition and awareness of values in play. Values-based practice (VBP), introduced in the previous chapter, is expressly concerned with raising the awareness of values, in order to be able to make decisions which are centred on the patient when values come into conflict (Fulford, 2004a). The 'practice-skills' of VBP are concerned with awareness, knowledge, ethical reasoning and communication. The VBP approach was developed to support decision-making in situations in which values are in conflict: raising awareness of values is the first step in this process (ibid). Raising awareness of values may not only be important when considering individual decisions in a hospice context but also when considering the influence of palliative care values on mainstream medicine in a variety of contexts.

8.6   Future for Hospices: Changing Decisions

This study has shown that decisions about sedation in both the routine and non-routine situations are underpinned by values. This has clear implications for decision-making about sedation at the end of life. If the values of staff in a hospice influence so strongly the way in which sedation is used, it must be of importance that these values are made explicit and overt, if the values of patients and their relatives are not to be compromised. Concern for patients' values, and those of their relatives, has long been considered central to the practice of palliative care: the influence of this and the other values of the palliative care approach is important when considering decision-making at the end of life. These values were described in Chapter 1 through the discussion concerning the changing 'philosophy' or values of palliative care. A summary of the two principal approaches considered in Chapter 1 are seen in Table 8:2. These are the components of

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Saunders's 'philosophy of terminal care' (Saunders, 1978a), and the WHO definition of palliative care, deemed a 'philosophy' by Randall and Downie in 2006 (Randall and Downie, 2006). They appear very different; the former contains a list of the services required to run a successful programme for 'terminal care', with the values underlying this evident only in a few statements; the other is more ideological, containing statements of what palliative care ought to do. While the WHO definition of palliative care is more instantly recognisable, it is important to recognise the earlier, broader approach. While Saunders wrote of the 'philosophy of terminal care', in a period in which the term 'palliative care' was not yet well recognised, the statements which comprise her philosophy are broad in scope and not discordant with the wider definition of palliative care.

Saunders (Saunders, 1978a)	WHO (Sepúlveda et al., 2002)
Terminal Care has: • As its primary concern the family and patient as a 'unit of care' • An experienced clinical team; with expertise in symptom control • A holistic approach which embodies the 'total pain' model of care • Skilled and experienced nurses and good inter-professional team working • A home care programme • Bereavement follow up • A methodical approach to recording and analysis and the development of research • A teaching strategy • Skilled use of architecture to provide an appropriate environment for care of the dying • A mixed group of patients in context and diseases • An administration sensitive to the needs of staff in an emotive environment • An understanding of the importance of the search for meaning at the end of life	Palliative care: • is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. Palliative care: • Provides relief from pain and other distressing symptoms • Affirms life and regards dying as a normal process • Intends neither to hasten nor to postpone death • Integrates the psychological and spiritual aspects of patient care • Offers a support system to help patients live as actively as possible until death • Offers a support system to help the family cope during the patient's illness and in their own bereavement • Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated • Will enhance quality of life, and may also positively influence the course of illness • Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Table 8:2: Palliative Care Values

While values in the hospice concerning the use of sedation were predominately shared, situations of non-routine sedation revealed some values-diversity. This diversity is important. If diversity is present and revealed in situations of non-routine sedation it may also be present but not expressed in cases of routine sedation. When a dying patient exhibits distress-behaviours, sedation is so routinely given that only in the presence of a clear objection would this be questioned, so integral is it to end of life care. Thus, being so ingrained in practice and in the underlying values of the hospice, values may be assumed to be shared. This follows the principles of VBP, outlined in Chapter 7, which state that while values *are* present in all decisions, it is only when values come into conflict that they become evident. Where values are shared by staff

there is a risk that this becomes the only perspective recognised, and the values of patients and their relatives are, even unintentionally, diminished in importance. The ability to recognise and understand a practice such as sedation, enables a more open process to decision-making but also a more open perspective to consider the values of others. As palliative care changes and develops and there is an increase in patients with different conditions at different stages in their illness, their desired approach to care may also differ. The importance of having an overt understanding of practices which are routine and embedded is heightened in this context. The nature of the changes in palliative care are discussed next; I suggest the response to change ought to be a more overt awareness of the underpinning values which drive clinical practice.

Palliative care is changing in a number of ways. Changes in palliative care were discussed in Chapter 1 and focused primarily on: (i) extending services to care for patients with non-malignant disease; (ii) changes in the contexts in which palliative care is provided, extending into community and hospitals; (iii) funding for services and; (iv) a move towards (re)integration into mainstream medicine approaches.

With the publication of the National End of Life Care Strategy (NELCS) has come the explicit intention to provide palliative care to those with any life limiting illness; many new initiatives have resulted from this drive (DH, 2008, Fallon and O'Leary, 2010). Developments in palliative care provision for patients with chronic neurological, cardiovascular, respiratory and renal disease have expanded palliative care service provision; these services, as well as those for other non-malignant conditions, is set to continue to expand (Hanks et al., 2010).

The last decade has seen a significant increase in the literature concerning palliative care for patients with non-malignant disease (Fallon and O'Leary, 2010, Fallon and Foley, 2012, Griffin and Conway, 2008, Murtagh et al., 2004). A number of challenges have been identified in attempting to meet the needs of patients with non-malignant conditions, including developing an understanding of: (i) when palliative care is needed for patients with non-malignant conditions; (ii) how palliative care should be delivered; (iii) what is required of palliative care in terms of symptom control and support; (iv) who should deliver the care and (v) the impact of differences in the dying trajectories for these patients, compared to patients with malignant disease (Murtagh et al., 2004). Among these challenges lies the role of hospices in the provision of care for patients

with non-malignant disease. While there has been a significant change in the literature and in policy to augment care at the end of life for this group of patients, there remains a paucity of published data to show an increase in hospice provision for this group (Griffin and Conway, 2008, Fallon and Foley, 2012, Murtagh et al., 2004). Studies do, however, suggest a trend towards an increase in admissions to hospices for patients with non-malignant conditions (Eve and Higginson, 2000, Griffin and Conway, 2008). The challenge of recognising dying in this group has been recognised, with a different predicted dying trajectory identified, punctuated by acute, sometimes reversible episodes of deterioration (Fallon and O'Leary, 2010, Fallon and Foley, 2012, Murtagh et al., 2004). The challenge of recognising the final, irreversible episode has been considered one of the most significant challenges for palliative care (Fallon and Foley, 2012). Yet if the trend for hospices to care for more patients with non-malignant disease continues to rise, hospice staff will need to develop different skills in recognising dying in this group of patients. In the current study only 4% of patients had a non-malignant diagnosis; this is similar to that reported elsewhere (Eve and Higginson, 2000, Griffin and Conway, 2008). The recognition of dying in this study appeared to be based on an expectation of a dying process which mirrored most strongly the trajectory of a patient with cancer. If the numbers of patients with non-malignant illnesses is to significantly increase, the hospice will need to develop skills in the recognition of dying in this different patient group. This has been recognised in the literature previously; the results of this study provide empirical evidence to support this view of the need for change in approach to meet the different needs of patients with conditions other than cancer (Fallon and Foley, 2012, Griffin and Conway, 2008, Murtagh et al., 2004). As the recognition of dying was most often implicitly understood rather than being explicit, there is a potential danger that patients with non-malignant conditions could, implicitly, be treated according to an understanding of malignant conditions rather than, as their trajectory would suggest, patients with the potential to have an acute reversible deterioration.

This is a challenge for palliative care, especially in traditional hospices familiar with promoting end of life care for those who have malignant disease and a reasonably predictable dying trajectory. In patients who have chronic illnesses, such as Chronic Obstructive Pulmonary Disease (COPD) or heart failure, the relapsing-remitting nature of their condition is such that their end of life care is much less predictable (Fallon and

O'Leary, 2010). This is likely to change the approach to dying in hospices as those who 'relapse' and recover to discharge may challenge the model of managing symptom control in relation to the recognition of a dying trajectory.

More complex decisions relating to the interpretation of dying will have potentially significant impact on the way in which staff interpret and respond to symptoms and signs of distress. A measure of how significant this change has been can be found in a quote from Eric Wilkes in 1994. Responding to Craig's paper regarding the use of sedation for terminally ill patients without hydration or nutrition (Craig, 1994), Wilkes stated:

> Accurate diagnosis in hospice patients is usually straightforward… A hospice is no place for solving diagnostic problems, but so long as over ninety-five per cent of admissions are to do with disseminated and inoperable malignant disease, this presents few difficulties. (Wilkes, 1994)

Hospices *are* now places in which diagnostic problems are considered and in which patients with any life limiting illness may be treated. The need to solve diagnostic problems leads to uncertainty about managing patients' care at the end of life. With an increase in patients with non-malignant disease is likely to come a change in the understanding of the processes of dying with the likely consequence of more uncertainty about dying and hence about the use of sedation. Changes in palliative care provision have led to precisely the converse of what Wilkes stated just under 20 years ago.

This research has shown the interpretation of dying to be crucial to decision-making regarding sedation at the end of life: patients with non-malignant conditions present a challenge to this process of decision-making. This process of decision-making is described in relation to sedation for the first time here; I suggest that this process should be explicit and understood by practitioners in order to be able to meet and address the challenges of changes in hospice and palliative care provision which will make recognition of dying more complex.

8.7   Palliative care future

This study has been concerned with the practices of sedation at the end of life in a hospice. It has recognised a 'philosophy in practice', a set of values strongly held and shared by staff in this context. This philosophy is recognised to form the basis of the transfer of good practice into other settings, exemplified through documents such as the Liverpool Care Pathway for the dying patient (LCP) (DH, 2008, Ellershaw and Wilkinson, 2011). As discussed in the introduction, palliative care has evolved from the 1960s 'movement' into an approach which encompasses a medical specialty, nurse practitioners and clinical nurse specialists as well as specialists from a wide range of allied healthcare professions (Hanks et al., 2010, Saunders, 2006). Its original concepts centred on the provision of holistic care, or 'whole person' care for individuals and their families and friends (Doyle, 1992). It is developing to provide care to patients with any life-limiting illness in a variety of contexts and is also developing a more substantial research and evidence base (Addington-Hall, 2002, Duke and Bennett, 2010). Palliative care is also incorporated into the undergraduate and postgraduate curricula of the majority of medical and surgical specialities and of allied healthcare professions such as physiotherapy and occupational therapy. Saunders stated explicitly in 1981 that:

> We moved out [of the NHS] so that attitudes and knowledge could move back in (Saunders et al., 1981: 4).

Palliative care may be seen to have moved 'back in', bringing with it the attitudes and knowledge which have developed since its origins. Just as palliative care has changed, so too has mainstream medicine. From predominately a paternalistic approach to providing care in the 1950s, increased choice, a focus on patient autonomy and an increasingly consumerist and individualistic society have led to significant changes in the provision of care within mainstream medicine. Multi-disciplinary decision-making and patient-centred care have become the dominant forces in decision-making over the past 20 years and have marked a move away from the approach which Saunders encountered in the 1950s as she began 'the movement'(McClimans et al., 2011, Saunders et al., 1981 :4). Furthermore, following the rise of evidence-based medicine, there have developed models of decision-making which incorporate patient values and preferences (Charles et al., 1997, Edwards and Elwyn, 2009). These changes in both

palliative care, as it has evolved from the hospice movement, and modern medicine, as it has faced overwhelming societal change and a drive towards autonomy and choice, have resulted in a much closer alliance of values between two, previously opposing, values approaches.

Despite these changes and the much closer alliance between palliative care and mainstream medicine, certain distinctions still exist. Throughout the literature those who have focused on what palliative care values *are*, have forged a distinction between the problem-solving (Ellershaw, 2011: xix), perhaps Hippocratic (Randall and Downie, 2006), traditions, most closely aligned with mainstream medicine, and the 'journeying' (Ellershaw, 2011: xix), Asklepian notions (Randall and Downie, 2006), which focus on the importance of being at times a 'wordless presence' (Saunders, 2011: xii), available to listen to the 'whole person'. Kearney, writing in 1994, identified this as a 'deeper level' of care (Kearney, 1992). Writing about the creation of the specialty of palliative medicine, he expressed concern that it may become 'just another specialty'. Kearney, like Ellershaw (Ellershaw and Wilkinson, 2011) and Randall and Downie (Randall and Downie, 2006), considered this deeper level of care to be the principal feature distinguishing palliative care from mainstream medicine specialties. It seems it is in this area of care for the individual that attention to what motivates and gives meaning, is found. This is important when considering the impact of this study as it brings into focus the value which palliative care appears to attribute to the patients' perspective, at least in principle; this study suggests a way in which this could be embodied more firmly in practice. In order to understand and interpret values and thus ultimately what it is which makes a patient a person, this aspect of care, of 'journeying' and being the 'wordless presence', must be retained. Respect for and attention to the values of the person therefore appeals to the heart of the palliative care philosophy. It is this distinctive feature which distinguishes it, Kearney argues, from the 'superficial' (but equally important) care of other specialties. Of course, the superficial and deep, Hippocratic and Asklepian, journeying and problem-solving approaches are important to varying degrees for different patients. Attendance to the deeper levels of care is perhaps more frequently required in specialties such as palliative care given the depths of despair, anxiety and fear which facing death may bring. I would argue, however, that rather than consider this to be solely the domain of those working within palliative care, boundaries ought to become less distinct.

Increased integration of care, of palliative care provision within a mainstream medicine context, and more opportunities for interdisciplinary working may present a way in which the values approaches of mainstream medicine and palliative care could meet. While attendance to the deeper levels of care have been regarded as the domain of palliative care, attendance to patients' values are increasingly considered the domain of all healthcare practitioners (DH, 2010, McClimans et al., 2011). Developing interdisciplinary working with values may allow the 'deeper levels of care', to be recognised in other areas of medicine. Thus, journeying with a patient may become integrated within the problem-solving base of mainstream medicine approaches. This would be in keeping with policies which are directed at incorporating values into practice and the extension of palliative care into broader areas of practice. This is also underpinned in the recent Health and Social Care Act (2012) as the quality of healthcare services is to be measured in part through patient experience and as well as other measures of outcomes. As palliative care develops, interdisciplinary working will become increasingly important in order to provide appropriate care for patients with different diseases. Fundamentally, an understanding of values will be of importance in enabling and facilitating interdisciplinary working in the future. At the very least recognition of that which is inherent to the practice of palliative care but not to mainstream medicine may allow enhanced interdisciplinary working and understanding.

The values of palliative care may also need to be re-evaluated. In Chapter 1 I suggested that the original approach, or values, of palliative care had not been significantly changed by reintegration into mainstream medicine and the 'medicalization' of dying. Attention to areas of spiritual and psychological care has not, I argued, been significantly diminished by the process of integration. My research suggests there is a strong sense of palliative care values in practice, which underpin and guide decision-making. I now suggest that in order to continue to be responsive to change in practice, the values which have been asserted as forming a palliative care philosophy in 2002 need to be reconsidered, while maintaining the original philosophy, more broadly expressed by Saunders in 1978 (Saunders, 1978a). Saunders's original 'philosophy' focused on the individual and family and a way of providing care with an emphasis on the need to develop a local response to meet local need. The WHO statement went further than this to detail what that care ought to entail and I suggest this needs to be reconsidered in view of a change in clinical practice (Sepúlveda et al., 2002). The

conflict of values seen in Chapter 7 was in part related to the value of 'not postponing death', with nurses concerned to promote this point and doctors more concerned with 'not hastening death'. When dying is uncertain, there is a 'risk' of prolonging life in an effort not to hasten death. As discussed earlier in this chapter, the increase in patients with non-malignant conditions cared for in hospices or within palliative care is likely to create particular tensions in this regard. In cases of uncertainty about dying, lives may indeed be prolonged. Furthermore, patients are now cared for in hospices throughout their illnesses, while having life prolonging or even curative treatments. I would suggest that maintaining this value of 'not postponing death' is no longer valid for all patients using palliative care services. Current palliative care *practice* is disconnected from this, embracing as it does, care for individual patients at all stages of their illnesses. This care may be considered to be proportionate to the patient's prognosis, with more interventional management in earlier stages. More importantly, however, is providing care according to the way in which a patient wishes to be treated. For some patients this may include relatively interventional treatments even at the end the end of life; for others it may mean not giving potentially life prolonging treatments even if relatively early in a patient's illness. Not to postpone death enshrines a particular value perhaps more appropriate for the provision of what was known as 'terminal care', which may now be recognised as care for the patients who are 'imminently dying'. As palliative care has progressed, those who may have appeared to be a homogenous group, the 'terminally ill', have become more and more defined as different patterns, or sequences, of dying have been recognised. Thus the group 'imminently dying' now appear to be a more defined group than those who may be considered to be approaching the end of their lives. The recognition of this is important for decision-making at the end of life. If palliative care is to embrace the changes associated with integration and expanding to provide care for all patients with a life limiting illness, it must reconsider the value of 'not postponing death. Importantly, this does not mean that the joining statement of not hastening death ought to be reconsidered too; these decisions are distinct[2]. Palliative care, in progressing alongside societal and mainstream medicine

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[2] This is not uncontested. The distinction between the withholding and withdrawing of treatments which may hasten death and the deliberate and intentional hastening of death is, however, extensively discussed in the literature. A discussion of this nature is beyond the scope of this thesis; the argument, rather, is concerned with the disconnect between clinical practice and the values expressed.

changes, I suggest, needs once again to become more patient–centred and broaden its values in keeping with its already broadening practice. Palliative care must adapt if it is to maintain its core value of patient-centred care.

In addition to the specific proposal for a change in what palliative care does, the awareness of these underpinning values is important in the changing context described above. The first 3 principles of VBP were outlined in Chapter 7 and provided an explanation for what was seen in practice regarding the influence and presence of values in decision-making. The changing context of palliative care service provision described above is also relevant when considering how values ought to be considered in the future. If values diversity increases, the ability to recognise this diversity is of importance in clinical decision-making. When values are shared, and there is a limitation of scope for contact with alternative values, as it could be argued may occur in a hospice, there is a heightened risk of 'values-blindness' and 'values-myopia'. The former relates to a lack of awareness of diversity of values while the latter to a lack of knowledge about the breadth of values which may exist. A hospice may perhaps be considered at an increased risk of this given a relatively stable workforce and low levels of staff turnover. In addition to providing a theoretical background for the presence and influence of values on medical decision-making, VBP incorporates a skill-set which, through developing an understanding of how values are involved in decisions and how they may be expressed, supports the process of decision-making when values come into conflict. I would suggest the primary need for hospice palliative care is to develop an understanding of its practice and the values which underlie these, in order to avoid falling into values-blindness. One way in which this could be developed is through the application of VBP.

8.8   Conclusion

This chapter has described the implications of this research for clinical practice. It has addressed the particular concern of the use of sedation in palliative care. This detailed understanding of sedation in practice is important as it is the first empirical study to describe the intricate relationship of sedation to an understanding of dying. The acceptance of otherwise undesirable side effects, such as sedation, in proportion to symptom severity and to the threat of dying with uncontrolled symptoms or distress is an important model to arise from the study. Furthermore, this research has highlighted

the role of values in clinical practice. In a specialty such as palliative care, which has developed its own distinctive 'philosophy' within which a patient's values are promoted as centrally important, this has particular impact. Recognition of the influence of 'palliative care values' on practice, especially concerning potentially vulnerable patients lacking capacity, is important in order to be aware of that which could restrict a patient's expression of values. An assumption of shared values is the norm: explicit recognition and awareness of palliative care values in practice may allow the otherwise unrecognised values of patients to be expressed. This would be consistent with the 'primary' value of the palliative care approach (Saunders, 1978a). Values-based practice has been proposed as the way in which skills in recognising and negotiating with values may be developed. Finally, this recognition of values in practice may have an impact on the integration of palliative care into mainstream medicine. As the values of patients assume a more central position in healthcare in the UK, this may provide an opportunity for enhanced interdisciplinary working with increased palliative care integration into mainstream medicine. This is of fundamental importance in developing a more patient-centred model of care.

Chapter 9 Conclusion

This thesis has drawn together the medical, philosophical and sociological literature in a study concerning the use of sedation at the end of life. Primarily concerned with how sedation is used and the implications of this for clinical practice in the UK, this study extends further to consider the underlying values influencing practice and suggests that these ought to become explicit, if palliative care is to maintain its focus on patient-centred care. A detailed history of the evolution of palliative care provides the background for a commentary on the broader changes affecting palliative care, including changes in government policy and funding, which in turn influence the direction of palliative care in the future.

In conclusion I suggest a number of outcomes from this research.

- I suggest the two crucial components to decision-making about sedation at the end of life are: (i) the intent in using sedative drugs and; (ii) the use of drugs in a proportional manner: proportional to both the severity of symptoms or distress-behaviours and the expected imminence of death.

- I therefore propose that 'sedation at the end of life' ought to be defined as:

  The process of using sedative medications in a proportional manner to relieve symptoms or distress-behaviours. 'Proportional' relates to the severity of symptoms or distress-behaviours *and* to the expected imminence of death. This is a *process* as decision-making is recognised to be dynamic, responding to changes in a patient's condition and the expected imminence of death.

- I have identified a sequence of expected dying in a hospice context, implicit and recognised through the use of significant words or phrases. Transition points in the sequence may be recognised as: 'not dying', 'deteriorating', 'probably dying' and 'imminently dying'. These may be used to identify a patient's trajectory and form the basis of decision-making, moving away from a time-based model which may be more difficult to interpret in daily practice.

- I suggest the routine prescription of sedative drugs to a dose which may reduce consciousness ought to be reserved for those patients 'probably dying' and 'imminently dying'; a patient not previously identified as dying, requiring sedative drugs to reduce consciousness ought to be reassessed.

- I suggest that the process of decision-making about sedation at the end of life should be explicit and understood by practitioners in order to be able to meet and address the challenges of changes in hospice and palliative care provision which will make recognition of dying more complex.

In addition to the research findings which are specific to palliative care, this thesis has wider implications relating to the way in which end of life decisions are made. First, decision making has been shown to be implicit, and based upon the values of individual healthcare professionals. While these values are predominately shared, values diversity does exist. If decision making regarding sedation is implicit when values are shared, there is a risk of developing a culture in which there is an assumption of shared values. This may lead to 'values blindness' (discussed in Chapter 7) in which a patient's values may be overlooked, especially at the end of life. Second, values between organisations may differ; as explored throughout this thesis, mainstream medicine and palliative care have developed independently. While now becoming more integrated, differences in values between organisations are important to acknowledge as they may lead to a differences in patients' experiences of care. Patients may wish to choose their treatment by an organisation based upon its approach to care: organisations must understand their own values in order to allow this choice to exist. Finally, international differences and approaches to end of life care exist. This is of particular importance when considering the nature of sedation at the end of life and its association in some countries with assisted dying. It is crucial to acknowledge these differences when considering such value-laden subjects as sedation at the end of life in order to avoid the misinterpretation of international differences in practice.

Chapter 10   Appendices

10.1 Appendix 1: Table of Prospective Research studies

Author(s) and year	Study aim	Methods	Sample size	Definition (if provided)	Prevalence/ Incidence of use of sedation	Indications for sedation	Drugs used	Results/ outcome
Ventafridda *et al* **1990** (**Ventafridda V., 1990**)	To determine how long before death intolerable symptoms requiring sedation appeared	Prospective	N = 120	-	52.5%	Dyspnoea, delirium, vomiting		52.5% of patients required deep sedation before death
Morita *et al* **1999** (**Morita, 1999**)	Do hospice clinicians sedate patients intending to hasten death	Prospective quantitative data collected on aspects designed to determine key aspects of sedation	N = 71	Sedation "a medical procedure to palliate patients' symptoms refractory to standard treatment by intentionally diming their consciousness"	45%	Physical restlessness with or without delirium (42%) Dyspnoea (41%) Pain (13%) Nausea (1.4%) Multifocal myoclonus (1.4%0 Psychological distress (1.4%)	Opioids (37%) Midazolam (31%) Haloperidol (31%) Diazepam (13%) Scopolamine hydrobromide (9.9%) Hydroxyzine (2.8%) Chlorpromazine Levomepromazine Propofol Triazolam	Conclusion that physicians do not sedate patients intending to hasten death. >90% Palliative prognostic index of 10 or 20 Median survival after onset of sedation 3 days 40% artificial hydration before sedation 70% had continued artificial hydration once sedation started >90% of family members involved in decision making
Peruselli *et al* **1999** (**Peruselli et al., 1999**)	Describe the place, circumstances and "quality" of death in patients admitted to	Quantitative, prospective multi centre survey of patients , weekly evaluation until	N = 401 (eligible patients = ≥18 yrs old, referred to PCUs for the management	"total pharmacological sedation" = "the administration of drugs to obtain total loss of consciousness"	25% (range in different unit 0 – 60%)	Pain Dyspnoea Nausea and vomiting		More sedation in hospital than home (32% vs 23%) Wide variation in use of sedation in different centres

	home palliative care units (PCU), particularly focusing on symptom control and the patient's situation at death	death	of terminal stage cancer and living in the PCU's catchment area)				
Fainsinger et al 2000 (Fainsinger et al., 2000a)	To determine prevalence of symptoms requiring sedation at the end of life in acute care, tertiary unit and hospice	Prospective, quantitative daily assessment of patients, collated on data collection form	N = 150 Patients in acute (50), tertiary (50) and hospice care (50)		Acute care 6% Tertiary care 10% Hospice care 2%	Delirium Dyspnoea		80% in all 3 units developed delirium before death. Increased prevalence of use of sedation in tertiary care. Survival range 1-5 days
Morita et al 2001 (Morita et al., 2001b)	Compare the survival of sedated and non sedated patients receiving inpatient care	Reanalysis of data from another study Prospective, quantitative data Additional data from retrospective chart review collected for this study	N = 209	All sedative psychotropics available in practice included	60% received "some sedative medication" in last 48hours		Opioids 82% Midazolam 23% Flunitrazepam 9% Bromazepam 7% Diazepam 4% Haloperidol 43% Hydroxyzine 15% Chlorpromazine 2.9% Levomepromazine 0.96% Propofol 1.4%	Opioids and sedatives showed no significant influence on survival Opioids prescribed in 82% Mean dose midazolam 26mg/24hrs Maximum observed dose 100mg/24hrs
Chiu et al 2001 (Chiu et al., 2001)	To determine frequency of use of sedation, relationship to symptoms, satisfaction of symptom control of	Prospective, quantitative daily assessment of patients	N = 251 Patients in inpatient palliative care unit		27.9%	Agitated delirium (57%), dyspnoea (22.8%), pain (10%), insomnia (7.2%,)	Haloperidol (50%) Midazolam (24.3%) Morphine (12.9%)	Prevalence in keeping with other studies. 52.9% used sedation intermittently, 37.1% intermittently, 10% evolved from intermittent to continuous

	patients, family and health care workers					
Morita _et al_ 2002 (Morita et al., 2002a)	To elucidate which types of palliative sedation therapy are preferred by the Japanese general population, which factors influence these and how they think clinicians should inform patients about sedation	Cross section questionnaire survey using convenience sample	N = 457 (effective response rate 53.5%)	Palliative sedation therapy "the use of sedative medication to relieve intolerable and refractory distress by the reduction of patient consciousness" Also used mild-deep and intermittent-continuous subgroups		Intermittent deep sedation was chosen as "probably want" or "strongly want" for 86% and 76% for intractable physical distress and psychological distress resp. Mild sedation probably want" or "strongly want" for 82% and 68% for intractable physical distress and psychological distress resp. Care without sedation probably want" or "strongly want" for 25% and 32% for intractable physical distress and psychological distress resp. Those not wanting sedation significantly younger, more educated, more likely to perceive importance of dignity and preparing for death
Morita _et al_ 2002 (Morita et al., 2002a)	To clarify the frequency of sedation therapy for terminally ill cancer patients and to identify physicians' attitudes towards sedation	Quantitative cross sectional questionnaire	N = 697 (49.6% response rate)	Palliative sedation therapy "the use of sedative medication to relieve intolerable and refractory distress by the reduction of patient consciousness" Also used mild-deep and intermittent-continuous subgroups		Mild sedation used by 89% and 64% for physical and psychological distress resp. Intermittent-deep sedation used by 70% and 46% for physical and psychological distress resp. Continuous-deep sedation used by 66% and 38% for physical and psychological distress resp.

Morita *et al* 2003 (Morita et al., 2003a)	To investigate the similarities and differences among standard medical care, palliative sedation therapy and euthanasia	Secondary analysis of 2 previous surveys on attitudes towards preferred treatment for refractory distress		Palliative sedation therapy "the use of sedative medication to relieve intolerable and refractory distress by the reduction of patient consciousness" Also used mild-deep and intermittent-continuous subgroups				Physicians and general population differentiated mild and intermittent-deep sedation from standard medical care, without intentional sedation Inconsistency when including or excluding mild and intermittent sedation is a major cause of difficulty in interpreting research findings Physicians matched continuous deep sedation closer to mild and intermittent sedation than the general population (who mapped it closer to euthanasia/PAS)
Cameron *et al* 2004 (Cameron, 2004)	To document the use of sedation for refractory symptoms in patients admitted to an independent palliative care unit	Prospective, quantitative descriptive study	N = 20 (out of 100 consecutive patients admitted)	Included "all patients who received sedating drugs (apart from sleeping tablets)"	20%	Delirium (45%) Nausea and vomiting (25%) Convulsions (15%) Dyspnoea (10%) Pain (5%)	Midazolam Haloperidol Morphine Fentanyl	Survival mean 3.8 days after sedation started 20% had IV or SC fluids when sedation started, not discontinued in any All patients and/or family involved in decision making
Müller-Bush *et al* 2004 (Muller-Busch et al., 2004)	Evaluate attitudes towards different end of life decisions among the German Association for Palliative Medicine	Quantitative, multiple choice questionnaire	N= 251 (61% response)	"The definitions of specific terms used in the German literature and jurisprudence... were included.to ensure that the meaning of terms was clear to all respondents" Terminal sedation was the term used				94.4% supported "so-called TS" 63.3% supported the withdrawal of life-sustaining treatment in cases with poor prognosis without the patient's consent Recommend use of a descriptive definition Support distinction between euthanasia and terminal sedation outlined by EAPC task force
Kaldjian *et al* 2004 (Kaldjian et al., 2004)	To describe the frequency of	Quantitative, prospective,	N = 677 Response rate	Terminal sedation = "diminishing				96% supported use of analgesics to relieve pain accepting risk of

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	support for terminal sedation among internists, determine whether support for terminal sedation is accompanied by support for physician assisted suicide (PAS) and explore characteristics of internists who support terminal sedation but not assisted suicide	cross sectional survey	47% (Connecticut members of American College of Physicians)	consciousness to halt the experience of pain if a terminally ill patient has intractable pain despite aggressive analgesia				hastening death 78% supported use of TS 29% supported use of PAS 47% supported TS but not PAS- more likely if more experience in providing care to terminally ill or more frequent attendance at religious services
Morita _et al_ 2005 (Morita et al., 2005b)	(i)To determine efficacy and safety of palliative sedation therapy and (ii) identify factors contributing to inadequate symptom relief and complications	Multi centre, prospective, observational study. Quantitative data collection on structured questionnaires. Using validated scales, physicians asked to evaluate (i) intensity of patient symptoms, (ii)communication	N = 102 sedated patients from 7 palliative care centres	Continuous deep sedation (CDS) "the continuous use of sedative medications to relieve intolerable and refractory distress by achieving almost or complete unconsciousness until death"	Sedation was part of inclusion criteria	Fatigue 44% Dyspnoea 41% Delirium 34% Psycho-existential distress 1%	Midazolam (76%) Haloperidol (35%) Phenobarbital (34%) Ketamine (15%) Hyoscine hydrobromide (7%) Flunitrazepam (4%) Chlorpromazine (4%) Levomepromazine (2%)	CDS effective in 80% Respiratory and/or circulatory suppression in 20% - 4% fatal

			capacity, and (iii)respiratory rate just before sedation, and 4 and 24 hours after sedation				
Morita et al 2005 (Morita et al., 2005c)	To systematically explore whether empirical evidence supports the ethical validity of palliative sedation therapy	Multi centre, prospective, observational study. Quantitative data collection on structured questionnaires	N = 102 sedated patients from 7 palliative care centres	Continuous deep sedation (CDS) "the continuous use of sedative medications to relieve intolerable and refractory distress by achieving almost or complete unconsciousness until death"	Sedation was part of inclusion criteria	Midazolam (76%) Haloperidol (35%) Phenobarbital (34%) Ketamine (15%) Hyoscine hydrobromide (7%) Flunitrazepam (4%) Chlorpromazine (4%) Levomepromazine (2%)	No rapid IV administration of drugs. ANH administered in 63%. 94% predicted to die within 3 weeks. 67% expressed explicit wish for sedation. "palliative sedation therapy" (defined as CDS) follows principles of double effect, proportionality and autonomy
Simon et al 2007 (Simon et al., 2007)	Determine the views of medical ethics experts on the term and moral acceptance of terminal sedation	Prospective questionnaire sent to German Academy for Ethics in Medicine	N = 281 (59% response rate)				92% knew the term terminal sedation 73% considered terminal sedation to consist only of sedation when sedation until death was intended 45% terminal sedation comprised the complete elimination of consciousness (significantly more of those with a medical background favoured the inclusion of sedation where consciousness clouded but patient still able to have conscious perceptions
Seymour et al 2007 (Seymour et al., 2007)	To learn about clinicians' (both nurses and doctors) and academic researchers understanding	Qualitative interviews, telephone or face to face with "stakeholders" in the UK, Belgium and the	N = 33 11 doctors 14 nurses 10 researchers				UK: little talk about euthanasia, emphasised palliative sedation as a practice of last resort used in rare situations Belgium; the practice of palliative

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	and experience of palliative sedation for managing suffering at the end of life, and their views regarding its clinical, ethical and social implications.	Netherlands – purposively chosen by the authors					sedation appeared more acceptable than euthanasia. The Netherlands; palliative sedation was assuming the status of an 'equal partner' with euthanasia.
Douglas 2008 (Douglas, 2008)	To address the question of intentionality in the context of analgesic and/or sedative infusions in the terminally ill	Qualitative semi structured interviews with general physicians	N = 8				2 dominant themes (i)Uncertainty about intentions with regard to analgesic and sedative infusions (ii) Greater acceptability of analgesic and sedative infusions than using a bolus injection to hasten death
Rietjens *et al* 2009 (Rietjens et al., 2009a)	To gain more insight in the arguments for and against the use of continuous deep sedation (CDS) in several clinical situations	Focus group study of physicians – 3 focus groups held (as part of a larger study aiming to evaluate the Euthanasia Act Semi structured questioning Hypothetical cases	N = 24	(In vignette) "it is decided to alleviate the patient's suffering as much as possible by administering midazolam until death. Artificial nutrition or hydration is not administered because this would only prolong the patient's suffering"			Most participants referred to CDS as "palliative sedation" All agreed CDS was acceptable Difficulties were found in assessing life expectancy Physicians' decision making about CDS was characterized by balancing their own feelings with the best interests of the patients.
Claessens et al 2011 (Claessens et al., 2011)	To describe the characteristics of patients who	Prospective, longitudinal and descriptive	N = 266	Broeckaert's definition of palliative sedation was used with a	7.5%	(symptoms present in patients receiving sedation)	Low incidence of PS may be due to increasing awareness and palliative care services developing

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	are being sedated for refractory symptoms in palliative care units (PCUs) from the time of admission until the day of death.	study. 8 Palliative care units in Flanders. Staff in each PCU were trained and researcher participated in some data collection. Consciousness was assessed 3 times weekly and the time at which PS initiated was documented		descriptive level of sedation identified, all of which were considered in the analysis as 'palliative sedation'. These were: mild-intermittent, mild-continuous, deep-intermittent in non-acute situations, deep-intermittent in acute situations, deep continuous in non-acute situations, and deep-continuous in acute situations.		Pain Loss of well being Anxiety Fatigue Nausea Depression Drowsiness Reduced appetite Shortness of breath Constipation Dry mouth Disturbed sleep	High symptom distress scores associated with a symptom being regarded as refractory No clear distinction between physical and existential suffering In majority of patients palliative sedation starts as a mild sedation and evolves over time to a deep and/or continuous form of sedation. The principle of proportionality is the essential factor in the decision-making process. There is a clear distinction between PS and euthanasia
Claessens et al 2012 (Claessens et al., 2012)	To describe in detail the evolution of the level of consciousness of patients residing in palliative care units (PCUs) from admission until their day of death	Prospective, longitudinal and descriptive study. 8 Palliative care units in Flanders. Staff in each PCU were trained and researcher participated in some data collection. Consciousness was assessed 3 times weekly and the time at which PS initiated was documented	N = 266	Broeckaert's definition of palliative sedation was used with a descriptive level of sedation identified, all of which were considered in the analysis as 'palliative sedation'. These were: mild-intermittent, mild-continuous, deep-intermittent in non-acute situations, deep-intermittent in acute situations, deep continuous in non-acute situations, and deep-continuous in acute situations.	7.5% of patients received 'palliative sedation'		40% of sedated patients started on 'mild-continuous' sedation 40% of sedated patients started on 'deep-continuous' sedation Conscious level dropped to 'comatose' following 'deep continuous' sedation Conscious level dropped only to 'stuporous' with mild-continuous' sedation >45% of patient changed from mild continuous to deep continuous sedation over time PS is recognised to be a process which evolves according to symptoms rather than as an intervention which is intended to hasten death

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Jaspers 2012 (Jaspers et al., 2012)	To present data on sedation-related issues in the framework of a greater prospective survey on ethical matters in palliative care settings undertaken in the years 2005 and 2006	Online databases were amended to include data regarding ethical decisions related to sedation on 2 occasions during a patient's inpatient stay in a hospice or palliative care unit (PCU). Data was then sampled from this database at a census in 2005 and 2006.	No of patients in a PCU with data entered onto the database: PCU 2005: 537 2006:1018 Hospice: 2005: 102 2006: 287	`EAPC definition: "Palliative sedation is the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, Family and health care providers.	PCU 2005: 13% 2006: 11% Hospice 2005: 34% 2006: 30%	Fear/anxiety Restlessness Suffering Pain Dyspnoea	Midazolam Diazepam Lorazepam Haloperidol Promethazine Levomepromazine Propofol Morphine Ketamine	Higher prevalence of PS in hospices likely to be reflected by the differences in the populations in terms of disease extent and complexity of symptoms. Majority of patients were sedated to somnolence but not coma

10.2 Appendix 2: Table of Retrospective Research Studies

Author(s) and year	Study aim	Methods	Sample size	Definition (if provided)	Prevalence/ Incidence of use of sedation	Indications for sedation	Drugs used	Results/ outcome
Greene and Davis 1991 (Greene and Davis, 1991)	To review deaths requiring deep sedation in 17 patients over 14 years	Retrospective review of notes	N = 17 Community urology unit	-	All 17 patients had required sedation (this was integral to study design)	Pain, prolonged vomiting, seizures, restlessness	Barbiturates	Descriptive review of 17 cases requiring sedation, recommend monotherapy with barbiturates
Fainsinger et al 1991 (Fainsinger R, 1991)	To evaluate the finding that 50% of terminal cancer patients have suffering that requires sedation in the last days of life	Quantitative retrospective case note review of those admitted 6 days or more	N = 100		16%	Delirium 39% Pain 6%		2 patients noted to have died with poor pain control without having been sedated,
Van der Maas 1991 (van der Maas et al., 1991)	To provide information about medical end of life decisions in the Netherlands to inform the debate about euthanasia Commissioned by the Dutch government	Detailed interviews with physicians Questionnaires to physicians identified through random sampling of death certificates Prospective survey of deaths following respondents to the interviews	Interviews n = 405 Questionnaires n = 5197 (76% response) Prospective survey n = 2257 (described by 322 physicians = 80% of					1.8% of death due to euthanasia 54% of physicians had practice voluntary euthanasia 99% of euthanasia had taken place with consent 17.5% of deaths were related to the administration of drugs in such doses to alleviate pain and suffering that death might be hastened 17.5% of deaths were related to non-treatment decisions (e.g. withholding or withdrawal of ANH)

			interview sample)					
Morita et al 1996 (Morita et al., 1996)	Report the present circumstances surrounding the use of sedation for symptom control in Japan	Quantitative retrospective case note review	N = 143	Sedation "a medical procedure to palliate patients' symptoms by intentionally making their consciousness unclear. It included an increase in morphine dose resulting in secondary somnolence and the use of sedative drugs"	48.3%	Dyspnoea 49% Pain 39% General malaise 38% Agitation 23% Nausea 10%	Midazolam 55% Morphine 55% Haloperidol 33% Diazepam 15% Scopolamine 13% Bromazepam 6% Chlorpromazine 4% Barbiturates 4%	90% of those sedated -death was expected in days Mean survival 3.9 days 44% intermittent sedation 27% intermittent then continuous 14% continuous 15% died after single use of sedation 7% patient and family fully informed 45% family fully informed and patients partly informed 4% neither informed
Van der Maas 1996 (van der Maas et al., 1996)	To evaluate the reported use of euthanasia and other medical decision at the end of life in the Netherlands following the introduction of a new reporting system in 1991	Interviews with physicians Questionnaires to physicians attending deaths identified through death certificates	Interviews N = 405 (89% response rate) Questionnaires n= 6060 (77% response rate)					Interview and questionnaire produced similar results – euthanasia frequency 2.3% in interviews and 2.4% in questionnaires In 42% of all deaths were preceded by a medical decision at the end of life
Stone et al 1997 (Stone, 1997)	Determine the frequency, indications and doses of sedatives used in hospital and hospice and	Retrospective quantitative case note review	N = 61	Sedation "the prescription of sedative drugs where reducing the level of consciousness was part of a treatment strategy with the aim of relieving distress	43% for symptom control 26% for sedation 12% for both	**Symptom control** Anxiety 37% Nausea and/or vomiting 35% Other – unsettled 22% Mild confusion 10% Myoclonic jerks10%	Midazolam 40% symptom control/80% sedation Methotrimeprazine 12%/33% Haloperidol 46%/37% Other benzodiazepine 26%/0%	No difference between sedated/non sedated patients Sedative drugs for symptom control given to 67% in the hospice vs 21% in the hospital (p0.001)

	determine how long patients survived after being sedated					Fitting or risk of fitting 6% Muscle spasm 2% **Sedation** Agitated delirium 60% Mental anguish 27% Pain 20% Dyspnoea 20%	Chlorpromazine 6%/0% Phenobarbitone 0%/3%	No significant differences in frequency or doses of drugs used between hospital or hospice
Fainsinger et al 1998 (Fainsinger et al., 1998)	To develop an understanding of the local experience and assess the potential for improved patient management	Quantitative retrospective chart review	N = 76	No formal definition	30% (n=23)	Pain 96% Nausea 43% Dyspnoea 39% Delirium 95%	Midazolam Other "benzodiazepines" Chlorpromazine Lorazepam Haloperidol	Mean midazolam dose 29mg/24hrs Sedation duration average 2.5 days before death Mean equivalent daily dose of morphine significantly higher in sedated vs non sedated group (87mg vs 39mg)
Chater et al 1998 (Chater et al., 1998)	To agree definition and terms for terminal sedation	International survey of palliative care experts – retrospective questionnaire	N = 61 Experts in palliative care	Terminal sedation – "the intention of deliberately inducing and maintaining deep sleep, but not deliberately causing death in very specific circumstances"	77% of experts had used terminal sedation in previous 12 months, prevalence amongst patients not determined (background population not known)	(From recall) Pain (32%), anguish (22%), respiratory distress (19%), agitation, delirium, confusion, hallucinations (19%)	(96 patient) Midazolam (63%) Methotrimeprazine (31%) Lorazepam (17%) Phenobarbitone (8%) Haloperidol (7%) Chlormethiazole (5%) Diazepam (5%) Chlorpromazine (4%) Clonazepam (2%) Flunitrazepam (1%) Propofol (1%) Diamorphine (1%)	40% agreed with proposed definition Proposed the term "sedation for intractable distress in the dying"
Deliens et al 2000 (Deliens et al., 2000)	To estimate the frequency of euthanasia (the administration of lethal drugs with the explicit	Questionnaire: 20% sample of deaths where physicians were identified from death certificates	N = 1355 (52% response rate)					Prevalence of euthanasia 1.1% High dose opioids were used to alleviate pain and other symptoms with a potential life threatening effect

	intention of shortening the patient's life at the patient's explicit request), physician-assisted suicide (PAS), and other ELDs in medical practice in Flanders, Belgium							preceded death in 18.5% Non treatment decisions preceded death in 16.5% of all deaths; 5.8% were taken with the explicit intent of hastening death Medical decisions at the end of life were taken in 39.3% of all deaths (vs 64.8% in Australia, 42.6% in the Netherlands
Fainsinger *et al* 2000 (Fainsinger et al., 2000b)	Determine the prevalence of sedation, improve on previous methods of data collection and broaden understanding of circumstances leading to decisions to use sedation	Quantitative retrospective data collection on proforma in 4 centres (3 different countries)	N = 100 in Israel 94 in Durban 93 in Cape Town 100 in Madrid	Sedation "to decrease the patient to an unresponsive condition"	Israel 15% Durban 29% Cape Town 36% Madrid 22%	(Israel/ Durban/ Cape Town/ Madrid) Pain (1%/ 4%/1%/ 1%) Nausea and vomiting (0%/ 6%/3%/ 0%) Dyspnoea (0%/ 12%/11%/2%) Delirium (14%/ 8%/21%/ 16%) Psycho-existential distress (0%/ 1%/ 1%/11%)	(Israel/ Durban/ Cape Town/ Madrid) Midazolam (80%/88%/51%/82%) Chlorpromazine Diazepam Haloperidol Lorazepam Methotrimeprazine Morphine Oxazepam Phenobarbitone	>90% required medical management for a major symptom issue in last week of life Duration of sedation 1 -6 days Sedation for existential distress significantly higher in Madrid
Morita *et al* 2002 (Morita et al., 2002a)	To clarify the frequency of sedation therapy for terminally ill cancer patients and to identify physicians' attitudes toward sedation	Quantitative, questionnaire based study Use of vignettes to indicate possibilities (unthinkable—strong possibility) of treatments with sedation	N = 697 (49.6% response rate)	"palliative sedation therapy" the use of sedative medication to relieve intolerable and refractory distress by the reduction of patient consciousness" Also used mild-deep and intermittent-continuous subgroups				67% of respondents worked in hospices/palliative care units: 43% at cancer centres and general hospitals 89% used mild, intermittent-deep or continuous deep sedation 83% believed patients had the right to receive palliative sedation therapy Refractory physical or psychological distress – 14%

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							and 15% resp. chose continuous deep sedation as a "strong possibility Depression or delirium – 39% and 31% chose psychiatric treatment without intentional sedation as a strong "possibility" (42 and 50% resp. also chose continuous deep sedation as a "possibility" or "strong possibility" Those choosing psychiatric care for delirium and depression had significantly more end of life care experience, specialized in palliative care and greater confidence in symptoms control Independent determinants for decision to choose continuous deep sedation: less confident in psychological care, greater preference for symptomatic care, higher levels emotional exhaustion and depersonalization.
Muller-Bush *et al* 2003 (Muller-Busch et al., 2003)	Critical analysis of 7 years of experience of the use of sedation in the final phase of life in a German palliative care unit	Quantitative retrospective case note review of the last 48 hours of life	N = 548	"Sedation in the final stages of life... defined as the use of sedative drugs (usually benzodiazepines with or without complementary opioids given by the intravenous or by the subcutaneous route) to reduce the consciousness sufficiently deep to provide comfort	14.6% (n=80)	Pain 29.1% Gastrointestinal (nausea, vomiting, constipation, bowel obstruction) 17.4% Dyspnoea 14.6% Psychological distress (anxiety, depression) 2.4% Cachexia/fatigue 9.3% Cognitive disorder/delirium (drowsiness, agitation) 8.5% Bleeding 2.4%	Midazolam	Tendency over more recent 3 year period for sedation for psychological distress to increase 60% continuous sedation 40% intermittent 33.8% had no oral fluid or nutritional supply after sedation, infusions continued

				for the patient until death occurs"		Skin (ulceration/oedema) 5.3% Neurological 8.9%		in all patients Ability to communicate reported in 50%
Sykes and Thorns 2003 (Sykes and Thorns, 2003a)	To determine how sedative doses change at the end of life and how often the doctrine of double effect might be relevant	Quantitative, retrospective case note review	N = 237	"a judgment was made of the dose threshold for each drug beyond which significant sedation was likely to have occurred"	48%		Midazolam 82% Methotrimeprazine 22% Haloperidol 35% (but not above threshold for sedation – only in antiemetic doses)	No difference in survival from admission between group receiving sedation in last 48 hrs and those not\n\nThose receiving sedation throughout last week of life had significantly longer survival than those not sedated\n\nConclusion that sedatives do not hasten death, are safe to use and requirement to invoke the doctrine of double effect is uncommon
Onwuteaka-Philipsen *et al* **2003 (Onwuteaka-Philipsen et al., 2003)**	To present new data on the rate in 2001 of euthanasia, physician-assisted suicide, and other end-of-life decisions in the Netherlands, and a longitudinal analysis of decision-making practices since 1990. Also, to examine physicians' attitudes towards end-of-life	Detailed interviews with physicians\n\nQuestionnaires to physicians identified through random sampling of death certificates	Interviews n = 410 (85% response rate)\n\nQuestionnaire n= 5617 (76% response rate)					Rates of euthanasia rose from 1990-1995-2001 by 1.7%-2.4%-2.6% respectively\n\nDeaths without explicit request to hasten death had fallen\n\nResults in keeping with rise in euthanasia and a fall in other end of life decisions

	decision making during the period 1990–2001.		
Mitchell and Owens 2003 (Mitchell and Owens, 2003)	To investigate the prevalence of physician assisted death in New Zealand within the context of availability of palliative care services.	Questionnaire (English translation of Dutch questionnaire) sent to 2602 general practitioners. Commercially available database used to identify these GPs, representing 87% of GPs in New Zealand in 2000	N = 1302 (50% response rate)	63% had made a medical end of life decision that could hasten death 5.6% attributable to PAS or euthanasia 44% of these involved no discussion with patient 87% had palliative care services available 13.6% were decisions taken partly with intent of hastening death, 53% not discussed with patients 19% withheld or withdrew treatment with explicit intent to hasten death, 48% without discussion with patient 85% had palliative care services available – conclusion that availability of these services does not seem to affect medical end of life decisions
Pomerantz et al 2004 (Pomerantz et al., 2004)	(i) To describe attitudes of physicians regarding terminal sedation (TS) (ii) to explore	Quantitative retrospective questionnaire	N = 135 (mailed to 580 = 23% response rate)	73% had used TS 93% felt there were circumstances in which they would use sedation "Primary deciding factor" was pain in 75% 7% cited this as dyspnoea

	demographic characteristics that might be related to the use of TS and (iii) to compare those who have and have not used TS and their views on its morality							Those with capacity would be the principle decision-maker in 78% of cases Family would be principle in17% Physician in 1%
								In 69% the principle intention was to achieve symptom control Treating intractable symptoms in 27% Hastening death in 4%
								8% expected TS would hasten death
								Regarding views about TS: 55% of those who had used TS and 35% who hadn't disagreed with statements that: TS would be "immoral", "would violate my religious beliefs", "would violate my professional ethics", "is inconsistent with the physician's role of preserving life"
Rietjens et al 2004 (Rietjens et al., 2004b) **Rietjens et al 2006 (Rietjens et al., 2006a)**	Describe the practice of terminal sedation in the Netherlands Comparison of clinical differences and similarities	Face to face interviews about the most recent use of terminal sedation in previous 12 months	N = 410 (stratified sample of clinical specialists, GPs, nursing home physicians)	Terminal sedation = the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration	52% reported having used terminal sedation in the past	Reports in previous 12 months of: Pain 51% Agitation 38% Dyspnoea 38%	Benzodiazepines 21% Benzodiazepines and morphine 35% Benzodiazepines with another drug (other than morphine) 4% Morphine only 31% Morphine with another drug (other than	59% of cases in which terminal sedation used had been discussed with patient 79% discussed with other caregivers 17% not discussed 47% partly used with intention to hasten death

	between terminal sedation and euthanasia					benzodiazepine) 5%	17% with explicit intention to hasten death Comparison of TS and euthanasia: Compared to euthanasia, those receiving TS were more likely to suffer with: anxiety(37%vs16%, p<0.001) Confusion (24%vs2%, p<0.001) Requests for euthanasia more often related to loss of dignity and sense of suffering without improving: TS more often related to severe pain
Morita et al 2004 (Morita, 2004a) **Morita et al 2004 (Morita, 2004b)**	Clarify the physician reported sedation practices and the factors influencing the sedation rates	Quantitative retrospective questionnaire to all palliative care units in Japan	N = 81 80% response rate)	Intermittent-deep and continuous-deep sedation investigated. Intermittent-deep = "the intermittent use of sedative medications to relieve intolerable and refractory distress by achieving almost or complete unconsciousness". Continuous-deep = "the continuous use of sedative medications to relieve intolerable and refractory distress by achieving almost or complete unconsciousness until death"	CDS for physical symptoms <10% in 41% of institutions 10-50% in 54% of institutions >50% in 6.2% of institutions CDS for psycho-existential suffering 0% in 64% of institutions 0.5-5% in 32% of institutions >10% in 3.6% of institutions	Psycho-existential symptoms causing suffering which required sedation Meaningless/ worthlessness 61% Burden on others/ dependency 48% Death anxiety/fear/ panic 33% Wish to control time of death 24% Isolation/ lack of support 22%	36% of physicians reported experience of CDS for psycho - existential suffering All competent patients explicitly requested sedation All family members gave consent "where available" CDS more frequently performed by physicians who did not believe clear consciousness necessary for a good death, did not believe CDS shortened life, worked with nurses specializing in cancer or palliative care, judged symptoms as refractory without treatment

								trials, who used CDS without using intermittent sedation first
Kohara *et al* 2005 (Kohara et al., 2005)	Investigate the influence of sedative drugs on consciousness in a Japanese hospice	Quantitative retrospective case note review Level of consciousness measured on communication capacity scale	N = 124 (consecutive patients Jan to Dec 1999)	Sedation = "medical procedure to decrease the level of consciousness in order to relieve severe physical distress refractory to standard interventions. Excluded drugs like morphine which may have had secondary effect on somnolence	51%	Dyspnoea 63% General malaise/restlessness 40% Pain 25% Agitation 21% Nausea and/or vomiting 6% 54% .1 uncontrollable symptom	Midazolam 98% Haloperidol 84% Scopolamine hydrobromide 10% Chlorpromazine 5% Flunitrazepam 2% Ketamine 2%	Palliative performance scales poor in majority of patients prior to sedation Duration of admission 28.9 days and 39.5 for sedated and non-sedated patients, resp. (no significant difference) Mean midazolam dose in last 7 days 51-66.7mg/ 24 hours 69% continuous sedation 30% intermittent sedation (80% of these went on to have continuous sedation) Patients receiving sedation more likely to receive higher doses of opioids
Rietjens *et al* 2005 (Rietjens et al., 2005) **Rietjens *et al* 2006** (Rietjens et al., 2006b)	To gain insight into the characteristics of a good death for the Dutch population and subsequently to compare this with those of physicians	Questionnaires to sample frame of 1777 members of the Dutch general public Face to face interviews with Dutch physicians	1388 (78% response rate) members of the general public 391 physician interviews (response rate 81%)	In questionnaire sedation referred to in vignette: "bring the patient in a condition of unconsciousness, being unaware of pain and dying within one week"				Items frequently considered important: Possibility of being able to say goodbye to loved ones 94% Dying with dignity 92% Deciding on treatments at the end of life 88% Dying free of pain 87% Acceptance of euthanasia, terminal sedation and increasing morphine was related to wish to have dignified death and concerns

						about becoming a burden
						Acceptance of euthanasia lower among physicians than general public (64% vs 85%)
						Further differences seen in accepting euthanasia for incompetent adult (36% vs 63%), patients without serious disease 11% vs 37%), dementia 6% vs 62%)
						No differences between the groups considering the acceptance of terminal sedation
Miccinesi *et al* 2006 (Miccinesi et al., 2006)	To estimate the frequency and characteristics of continuous deep sedation in six European countries: Belgium, Denmark, Italy, The Netherlands, Sweden, and Switzerland	Quantitative, retrospective questionnaire about medical decisions at the end of life, part of EURELD consortium, results for CDS presented separately here	N = 20,480 total from all countries Response rate reported: Belgium 59% Denmark 62% Italy 44% The Netherlands 75% Sweden 61% Switzerland 67%	"Continuous deep sedation (CDS) with or without artificial nutrition or hydration (ANH) Question of continuous deep sedation: "did the patient receive drugs such as barbiturates or benzodiazepines, to keep him/her continuously in deep sedation or coma until death?" Further question was asked about whether artificial nutrition or hydration were given	Belgium 8.2% Denmark 2.5% Italy 8.5% The Netherlands 5.7% Sweden 3.2% Switzerland 4.2%	Use of CDS without ANH Belgium 3.2% Denmark 1.6% Italy 3.0% The Netherlands 3.7% Sweden 1.8% Switzerland 2.9%
Seale 2006 (Seale, 2006b)	To assess the extent to which UK doctors	Postal survey using questionnaire	N = 857 (response rate 53%)			Rate of voluntary euthanasia 0.16% PAS 0%

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Seale 2006 (Seale, 2006a)	discuss end-of-life decisions (ELDs) with patients, relatives and colleagues, and to assess the degree to which patients' lives are shortened by ELDs and to estimate the frequency of different end-of-life decisions (ELDs) in medical practice in the UK, compare these with other countries and assess doctors' views on the adequacy of current UK law	translated from Dutch into English (same as Australian and New Zealand studies) Physicians identified from commercially available database			Alleviation of symptoms with potentially life shortening effect 32.8% Decisions not to treat (in case of potentially life prolonging treatments) 30.3% Comparison of data with other countries allowed grouping into "permissive" (Netherlands, Belgium, Switzerland) and "non permissive" (Denmark, Sweden, and Italy)countries UK considered non permissive but differed from other non-permissive countries in willingness to discuss end of life decision making with patients and relatives
Van der Heide *et al* 2007 (van der Heide et al., 2007)	To assess the effects of the 2002 Dutch law and changes in end of life care. To assess the reporting rates for euthanasia and PAS and physicians' reasons for non-reporting	Retrospective, quantitative questionnaire based on death certificate sampling to identify (anonymous)patients cared for by physicians who were then contacted to provide details relating to this	N = 6860 questionnaire responses (77.8% response rate)	"was the patient continuously sedated before death"	8.2% reported use of CDS prior to death 7.1% with a decision which may have hastened death (such as the withholding or withdrawal of artificial nutrition or hydration)	Significant fall in reported rates of euthanasia and rise in use of CDS Sedation most common in subgroups in which euthanasia and PAS most common: patient ,80yrs, men, patients with cancer, attended by GPs

		death. Stratified for type of death						
Rietjens *et al* 2007 (Rietjens et al., 2007)	To explore nurses' experience with and attitudes towards palliative sedation (PS), focusing on the reasons why palliative sedation was used, the nurses' perceptions about palliative sedation and their ideas about how palliative sedation affects the dying process.	Qualitative, semi structured interviews, analysed using constant comparative methods	N= 16 nurses from (i) palliative care inpatient unit and (ii) medical admissions unit in a tertiary hospital	"The use of continuous I.V. benzodiazepines, barbiturates, or other medications to bring an imminently dying patient into a state of unresponsiveness to alleviate suffering from symptoms that cannot be controlled with conventional therapies."				Described the most memorable patient who had received palliative sedation All involved PS for a physical symptom +/- Nonphysical symptom Patient wish Family distress about patient's suffering 8/16 included the use of PS for existential distress Nurses found it harder to understand use for existential suffering and this was thought to be out of their range of expertise, but still felt to be necessary Different perceptions on whether PS hastened death
Rietjens *et al* 2008 (Rietjens et al., 2008)	Describe the practice of palliative sedation and compare patients who were sedated prior to death with those not sedated	Systematic retrospective analysis of case notes of patients who had died (medical and nursing) between 2001 and 2005	N = 157	Patients considered to have received PS when there was an annotation in the notes of the use of "continuous deep sedation"	43%	Terminal restlessness 62% Dyspnoea 47% Pain 26% Anxiety 6%	"Midazolam, sometimes combined with propofol, was the most commonly used drug to induce sedation"	68% PS started on last day before death 91% of cases PS was discussed with either patient or family – non competency primary reason not to discuss with the patient No differences in survival after admission between sedated and non-sedated groups

							Sedated patients were younger than non-sedated (55yrs vs 59yrs, p=0.04)
Reuzel et al 2008 (Reuzel et al., 2008)	To examine the practice of end stage palliative sedation in the Netherlands	Questionnaire and interview studies Questionnaire piloted initially Interviews qualitative semi structured	Questionnaire N = 515 (response rate 35%) Interview N = 28 (20 in first round, 22 in second round;14 of those initially interviewed were included in this)	End stage palliative sedation "the continuous reduction of a patient's consciousness by use of drugs when death is imminent"	(Questionnaires) Pain 57% Dyspnoea 51% Anxiety 43% Exhaustion 34% Delirium 20% Loss of dignity 20% Existential suffering 17% Vomiting 7% Nausea 7%	Midazolam 48% Diazepam 19% Clonazepam 1% Opioids 74% Chlorpromazine 1% Haloperidol 20% Levomepromazine 5% Promethazine 3% Ketamine 1% **Opioids alone 22%**	More experienced, GPs and physicians who consulted palliative care experts administered opioids alone significantly less often All of those interviewed stated preference for use of midazolam and non could explain the numbers using opioids alone
Curlin 2008 (Curlin et al., 2008)	To estimate the proportion of physicians who currently object to physician-assisted suicide (PAS), terminal sedation (TS), and withdrawal of artificial life support (WLS), and to examine associations between such objections and physician ethnicity,	Quantitative survey data as part of a national survey	N = 1144 (1820 sent out, 63% response rate)	TS defined as "sedation to unconsciousness in dying patients"			69% of physicians objected to PAS 18% of physicians objected to TS %% of physicians objected to WLS) Highly religious physicians more likely to object than those with low religiosity Asian ethnicity or being of Hindu religion and having more experience of dying patients increased likelihood of objecting to PAS and TS

	religious characteristics, and experience caring for dying patients							
Rietjens et al 2008 (Rietjens, 2008)	To study the practice of continuous deep sedation in 2005 in the Netherlands and compare it with findings from 2001.	Retrospective, quantitative questionnaire based on death certificate sampling to identify (anonymous)pati ents cared for by physicians who were then contacted to provide details relating to this death. Stratified for type of death	N = 6860 questionnai re responses (77.8% response rate)	2001 questionnaire: "Did the patient receive drugs, such as barbiturates or benzodiazepines, to keep him/her continuously in deep sedation or coma until death?" 2005 questionnaire: "Was the patient continuously and deeply sedated or kept in coma until death?"	2001 5.6% 2005 7.1%	Fatigue 55% Dyspnoea 48% Unclear consciousness 47% Pain 42% Confusion 23% Anxiety 21% Vomiting 5% Depression 3%	Benzodiazepines 83% Benzodiazepines and morphine Benzodiazepines and other Drugs Morphine alone 15% Morphine and other drugs	Use of CDS increased from 2001 to 2005, preceding 5.6% to 7.1% of all deaths, respectively For 47% of those receiving CDS it was started in last 24 hours of life 94% sedated for <1 week Almost all GPs and nursing home physicians withheld fluids 9% had previously requested euthanasia but request not granted 9% had sought palliative care consultation
Seale 2009 (Seale, 2009a) **Seale 2009 (Seale, 2009c)**	(i)To estimate the frequency of different medical end-of-life decisions (ELDs) made in the UK in 2007–2008, comparing these with 2004 and (ii) to report UK doctors' opinions about legalisation	Postal survey using questionnaire translated from Dutch into English, with modifications to wording to adjust for the potential to overestimate ELDs. Additional	N = 8857 questionnai res sent out 42.1% response rate (67% palliative medicine specialists, care of the elderly specialists	Questionnaire asked "Was the patient continuously and deeply sedated or kept in a coma before death?"	16.5%			Non treatment decisions in 21.8% of deaths "double effect measures" (where drugs were given with intent of alleviating pain or suffering with possibility of death as a foreseen but unintended side effect) 17.1% CDS more common in UK than other countries, esp. in hospitals, home care settings

	of medically assisted dying (euthanasia and physician-assisted suicide), comparing this with the UK general public.	question about continuous deep sedation added from the 2006 survey. Physicians identified from commercially available database	48.1%, neurologists 42.9%, "other" hospital specialists 40.1%, GPs 39.3%)					and in younger patients Low proportion of doctors in favour of life shortening treatments cf general public (agreement that a doctor should be allowed to end a patient's life if the patient requested it in 8.6% of physicians and 51.3% of the general public) Palliative medicine specialists particularly opposed (73.4% strongly oppose a doctor being allowed to end the life of someone dying from cancer, who explicitly requests the ending of life vs 32.2% of "other" hospital specialists)
Rosengarten 2009 (Rosengarten et al., 2009)	To provide a description of the use of PS as experienced within the Jerusalem Home Hospital Unit	Retrospective review of medical records of the Home Hospital Unit from December 2005 to March 2006	36 patients received sedation, no total no. provided but this represented <5% of all patients	"the use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness."	<5%	Intractable pain Agitation Delirium Vomiting and nausea Existential suffering	Morphine Midazolam Haloperidol Fentanyl Promethazine	Prevalence of sedation is lower than that reported in the literature concerning hospices and hospitals, likely to be a reflection of a different patient population Morphine used as monotherapy 'with due consideration of, and careful adherence to, the limit of the therapeutic window'.
Pautex 2009 (Pautex et al., 2009)	To determine whether recent changes in opioid management for pain has affected the proportion of patient retaining	Retrospective review of medical notes of consecutive hospitalized patients who died in	n = 141		2%		Midazolam	34% of patients retained consciousness until death 2% were intentionally sedated because of refractory symptoms, using midazolam at a mean

	consciousness until death	palliative care wards in 2005, with the calculation of the number of unconscious days before death arising from a series of validated tools				dose of 30 mg/day An impaired level of consciousness in the last days of life is more likely to be due to progression of the underlying disease, leading to metabolic abnormalities, the primary or secondary effect of drugs used for symptomatic treatments
Van der Heide 2010 (van der Heide et al., 2010)	1. To investigate physicians' and bereaved relatives' perspectives on end-of-life decision-making practices during the last three months and the last three days of life of cancer patients 2. To assess the impact of the LCP in hospital, home and nursing home settings.	Questionnaire and review of medical notes. Questionnaire completed by the patient's physician within a week of death; relatives were contacted 2 months after the patient's death Patient data gathered before and after the introduction of the LCP in each setting	N = 311 patients with cancer	"The parenteral administration of benzodiazepines or barbiturates"	27% of hospital Patients 33% of nursing home patients, 11% of patients who died at home	Introduction of the LCP reduced the use of drugs that were estimated to have a potentially life-shortening effect, from 46% to 28%. In last 3 months of life, patients who died in hospital received anticancer therapy and medication to relieve symptoms more often than those in nursing homes or at home. In the last 3 days of life, patients who died in the hospital or nursing home received more medication than those who died at home. The LCP reduced the extent to which physicians used medication that might have hastened death. Relatives of patients who died in the hospital tended to be least positive about the

							patient's and their own participation in the decision-making.
Chambaere 2010 (Chambaere et al., 2010)	To determine the prevalence of continuous deep sedation until death in Flanders, Belgium, between 2001 and 2007 and consider the ethical debate surrounding the practice.	Quantitative, retrospective questionnaire about medical decisions at the end of life, including CDS	n = 3623 (58.4% response rate)	"Continuous deep sedation (CDS) with or without artificial nutrition or hydration (ANH)

Question of continuous deep sedation: "did the patient receive drugs such as barbiturates or benzodiazepines, to keep him/her continuously in deep sedation or coma until death?" Further question was asked about whether artificial nutrition or hydration were given | 14.5% | | Benzodiazepines alone Opioids alone Benzodiazepines and opioids | There was a significant rise in the prevalence of CDS from 2001 to 2007, from 8.3% to 14.5% Opioids were used alone to sedate patients, contrary to international guidelines CDS was used to hasten death as a "co-intention" in 17% of cases There is a need for a national guideline for CDS There is a need for more qualitative research |
| **Babarro 2010 (Alonso-Babarro et al., 2010)** | To determine the incidence and efficacy of PS for patients with cancer and intractable symptoms | Retrospective review of medical notes of patients under care of community palliative care team | N = 370 patients under care of palliative care team: 245 died | "Palliative sedation is the use of specific sedatives to relieve intolerable suffering from refractory symptoms by reducing a patient's level of consciousness." | 12% of patients received palliative sedation | Delirium 62% Dyspnoea 14% Nausea/vomiting 7% Seizures 7% Anxiety/psychoexistential suffering 7% Pain 3% | Midazolam Levomepromazine | Using a decision-making and treatment checklist to facilitate palliative sedation at home, patients were sedated using midazolam and levomepromazine. PS may be used safely and efficaciously to treat intractable symptoms at home |
| **Oosten 2011 (Oosten et al., 2011)** | Determine whether the patient characteristics in terms of their underlying pain problem and its treatment is | Systematic retrospective analysis of case notes of patients who had died (medical and nursing) between 2001 | N = 157 | PS is the monitored use of medication intended to induce varying states of unconsciousness, but not death, in order to relieve refractory and unendurable symptoms in patients in whom death is | 43% | Terminal restlessness 62% Dyspnoea 47% Pain 26% Anxiety 6% | "Midazolam, sometimes combined with propofol, was the most commonly used drug to induce sedation" | Prior to the onset of sedation the opioid dose was higher, more frequently rotated to an alternative opioid and ketamine and spinal medication was used more frequently. 'findings suggest |

	related to the need for sedation	and 2005		imminent.			that…sedated patients had more difficult pain problems'
Buiting 2011 (Buiting et al., 2011)	To investigate: 1. whether and how palliative treatment alternatives come up during or preceding euthanasia consultations and 2. how the availability of possible palliative treatment alternatives are assessed by the independent consultant	Qualitative interviews with euthanasia consultants and physicians	n = 26 (14 euthanasia consultants &12 physicians)				Sedation was considered a different decision to the decision to use euthanasia Physicians did not consider sedation to be an alternative for euthanasia
Anquinet 2011 (Anquinet et al., 2011)	To study The characteristics of continuous deep sedation until death ' , for patients dying at home in Belgium	Qualitative interviews with GPs regarding patients previously identified to have received CDS prior to death	n = 28		Pain Agitation Dyspnoea Fear Restlessness Epilepsy Hopelessness	Benzodiazepines only 32% Benzodiazepines in combination with opioids and/or other drugs 43% Opioids only 14% Opioids and other drugs (excluding benzodiazepines)11%	Patients were still receiving opioids alone for sedation, contrary to international recommendations In 46% of cases GPs used CDS with at least a partial intent to hasten death This study provides evidence of the need for a guideline in Belgium, similar to that in the Netherlands
Swart 2012 (Swart et al., 2012)	To study the practice of continuous	Structured questionnaire sent to 1580	n = 606 (38% response		**Cancer and non-cancer patients**: Pain	Midazolam (used significantly less frequently for non-cancer	Practice of CDS is different in patients with cancer and those with a non-cancer

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	palliative sedation for both cancer and non-cancer patients.	physicians regarding their last patient receiving continuous sedation until death	rate)			Physical exhaustion Dyspnoea Delirium Existential suffering, Psychological exhaustion **Non-cancer >cancer patients** Dyspnoea Muscular Confusion Depression **Cancer patient > non-cancer patients** Nausea and vomiting	patients	diagnosis. This is likely to be due to the less predictable course of illness with non-cancer patients, and less certainty of the imminence of death
Onwuteaka-Philipsen 2012 (Onwuteaka-Philipsen et al., 2012)	To assess the frequency and characteristics of euthanasia, physician-assisted suicide, and other end-of-life practices in 2010, and assess trends since 1990	Retrospective, quantitative questionnaire based on death certificate sampling to identify (anonymous)patients cared for by physicians who were then contacted to provide details relating to this death. Stratified for type of death	n = 6263 (74% response rate)	"was the patient continuously sedated before death"	**Use of sedation**: As a euthanasia or PAS decision: 18.1% To end life without explicit request:52.2% As an intensified alleviation of symptoms decision: 20.3%		Benzodiazepines Opioids	The frequency of the use of intensified alleviation of symptoms has increased since 2005 The frequency of use of CDS has increased. This may be a result of increasing access to palliative care, as was experienced in Belgium

Chapter 11   References

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