The Social Construction of Good and Bad Deaths in Hospice Settings

A multiple embedded case study

AUTHOR:

Dr Stephen J.O'Connor

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Canterbury
Christ Church
University

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ABSTRACT

The activities that health-care professionals perform for the dying on a daily basis contribute in important ways to the experience of death, both for the patient, and those who care for them. Little is known however about the criteria that health-care professionals use when delineating a death as 'good' or 'bad'. The case-study described identifies some of the criteria that health-care professionals working in one South London hospice used when evaluating the quality of deaths occurring in that unit, and demonstrates that hospice workers use a complex system of values when delineating a death as good or bad. Consistent views about the presence or absence of physical symptoms were found, but there was less agreement about the importance of criteria such as spiritual preparedness or acceptance of death. Control and autonomy also featured highly in descriptions of a good death, but these were regarded as problematic when exercised 'to excess' by clients and their families, a position at variance with traditional hospice philosophy. Similarly, there was little construct permanence between hypothetical and literal cases of a 'good' and 'bad' death, which suggests that the criteria which some hospice workers' use are more subjective than the literature suggests.

1.0 INTRODUCTION

Recent developments in pain and symptom management within the hospice movement have done much to ameliorate the discomforts associated with the final stages of terminal illness (Copp, 1997; Zuckerman and Wollner, 1997) and have been credited with the facilitation of an increased number of good deaths within hospices and other palliative care settings (Taylor, 1993b) where health-care professionals are often the first to delineate such deaths as 'good' or 'bad' (Bloch and Parry, 1982). These descriptors impact heavily on survivors' responses to the death of a loved one, but rely heavily upon medical ideas of what constitutes a 'good' or 'bad' death (Lev and McCorkle, 1998). Very little is known however about the criteria which are used when making these judgements (Bradbury, 1993 p. 69), but they are unlikely to be value free. Health-care professionals frequently talk in terms of professionally derived concepts such as 'quality', 'autonomy', 'needs satisfaction', and 'symptom relief' (Copp, 1998; Higginson et al, 1990; Higginson et al, 1989; Hockley, 1988), but personal belief, experience, culture and perception of observed events are equally likely to impact upon these judgements (Mamo, 1999).

Discussions about death and dying are often couched in terms of a good/bad dichotomy (Bloch and Parry, 1982), and it is necessary to identify those factors which make for a 'good' or 'bad' death. The aim of the case-study described in this paper therefore, was to identify the criteria that health-care professionals used when evaluating the quality of a death in one London hospice, and to measure the permanence of these constructs across both hypothetical and literal cases using Yin's (1994) framework. This will be followed by a discussion of the clinical implications of the data, together with recommendations for future practice and research.

2.0 REVIEW OF THE LITERATURE

In reviewing the literature, it was possible to examine the concept of 'good' and 'bad' deaths from three viewpoints. Firstly, the socio-anthropological literature, which demonstrated how 'good' and 'bad' deaths are socially, culturally, and historically derived. Secondly, from the perspective of the growing 'death awareness movement' (Metcalf and Huntingdon, 1991) which has done much to raise awareness about the modern 'death watch' (Kearl, 1989); and finally, empirical studies such as those by Bradbury (1996; 1999) which posit social representation theories of 'good' and 'bad' deaths as an explanation of how and why value judgements about the nature of a death are made by observers during the course of their daily work.

An extensive review of the CINAHL, Cancerlink, MEDLINE and PsychINFO databases between 1990 and 2000 combining the key words 'good' and 'bad' death(s), 'quality of death/dying', 'terminal', 'appropriate', 'timely', 'hospice', 'social', 'natural/un-natural', 'sacred', 'useful', 'nurses'/health-care professionals' perceptions of', and 'nurses'/health-care professionals' evaluation of' rendered several hundred references; but review of the abstracts indicated that the majority of these were ineligible for the review, focusing for the most part on audit, nurses' attitudes, quality of life measures and symptom control. No research papers had been published specifically with 'good' or 'bad' deaths as their focus which was somewhat surprising as the subject had recently been highlighted as a research priority by the NHS National Executive (2000), though the lack of literature highlighted by the review may explain why this is necessary. Fifty-three papers relating to loss, grief and bereavement, patient well-being, outcome measures and health-care professionals' attitudes to death and dying were obtained and reviewed in order to provide background information for the study, but papers relating to euthanasia (literally, 'a good death') were not retrieved, as requests for euthanasia are relatively rare in hospice settings and were not the focus of the study undertaken.

The literature contained many references to, and definitions of, 'good' and 'bad' deaths and provided a 'rich theoretical framework' (Yin, 1994 p.46) for the study which followed. One excellent account of

a participant observation study, Bradbury's (1999) Representations of Death was particularly useful in helping the author understand the nature and workings of social representations theory, which provided a valuable theoretical framework for categorising, understanding, and making sense of the vast data accumulated throughout the course of the study. Her work also provided an interesting counterfoil to the study undertaken, providing as it does, a clear enunciation of post-mortem social representations of 'good' and 'bad' deaths by widows and non-medical death-professionals such as undertakers - as opposed to the pre-mortem work of hospice workers who were the focus of the study reported upon.

2.1   Socio-anthropological and historical Perspectives on Good and Bad Deaths

One problem immediately apparent from the literature was the lack of single operational definitions for each of the key terms 'good' and 'bad' deaths. A number of social anthropologists have attempted to define these concepts in recent years, and their work is worthy of consideration in so far as they provide a theoretical context for the study. The use of socio-anthropological literature is appropriate in so far as nursing and medical care of the dying draws upon an eclectic knowledge base in order to meet the physical, psychological, social, and spiritual needs of dying patients, and given the biopsychosocial context of death and dying in hospice as elsewhere.

Bradbury (1999) suggests that in order to unravel current representations of death it is crucial to place them in an historical context, and describes how, in the pre-industrial age, the notion of a 'good' death was intrinsically linked to social expectations and mores. Death was a personal and a social transition accompanied by complex rites of passage (Van Gennep, 1960) which gave legitimacy to the changed social and legal status of the deceased and those surviving them, and recognised the passing of the deceased from the community or social network – usually a unit of agricultural production - as a whole. For the most part death occurred in the home, and was followed by a series of religious death rites such as the 'laying out' and the 'wake', social occasions which may have lasted for days at a time. Beier (1989) and Richardson (1989) idealise these as 'sacred good deaths' though Elias (1984) points out the historical and economic anomaly in this view when suggesting that, 'rich people perhaps did not always die quickly enough for their heirs whilst poor people may have lain in their filth and starved' (p.75).

Frequent, sudden, and premature death may have been common, but there is little evidence that deaths were any better or less distressing than those in later centuries. Unalleviated pain, non-pain symptoms, and the harshness of daily life are unlikely to have made it any more acceptable. Furthermore, the notion that death was more likely to occur within the bosom of one's own family may have owed more to the fact that, 'in conditions of overcrowding it may have been difficult to find a room in which one could die on one's own' (Bradbury, 1999 p.8). It should also be noted that the underlying assumption that there existed one single, homogenous, universal view of religion and spiritual belief is far from the truth. Schism, persecution and fratricide pervaded European society in the centuries following the reformation, and the medieval view of death and its aftermath were far from comforting – as many of Hieronymus Bosch's drawings demonstrate.

2.2   The Modern Good Death

The modern medicalised good death has been described as, 'a strategy for gaining control through the application of medical scientific knowledge' (Bradbury, 1999 p.149). This enables the physician to control not just the symptoms associated with death, but theoretically, the location and to a certain extent, it's timing as well, particularly when life-prolonging measures such as ventilation and resuscitation are used (Copp, 1998). Walter (1994) suggests that the medicalisation of death may deny individuals a 'good' death as it hides the pain of grief and dying from public view, and may

denude them of dignity so that, 'the death of a patient in the hospital, covered with tubes, is becoming a popular image, more terrifying than the skeleton of macabre rhetoric' (Aries, 1981 p.614).

Illich (1976) has described the 'expropriation' of death by doctors and other health-care professionals and suggests that it has the capacity to alienate an individual from their own mortality. Whilst he can be criticised for holding unrealistically nostalgic views about the nature of pre-twentieth century sacred deaths, he is perhaps correct in asserting that, 'western man has lost the right to preside at his act of dying' (Illich, 1976, p.207), and his criticism, particularly of the dehumanising effect of anonymous deaths in large institutions may have some value. His opposition is based largely however, upon the notion that deaths hidden away in institutions prolong the denial of death more broadly within society, and there may be some truth in this.

2.3   Death Denied

A great deal of debate has taken place concerning the denial of death in contemporary western culture (Aries, 1983; Gorer, 1965), in which the general reaction of lay-people to death and the dying is one of unease and embarrassment. Littlewood (1993) suggests that, 'as living reminders of the unavoidable reality of death, they may be avoided rather than supported' (p.70), whilst Kalish (1977) suggests that, 'for some, the taboo on death is so strong that they dare not refer to the possibility that someone else in the family, most especially the person to whom they are talking, will ever die' (p.217). This may make it difficult for them to reach that degree of honesty regarded as essential to a 'good' death by those in the 'death awareness movement' (Saunders, 1990, 1965; Kubler-Ross, 1991, 1975; Glaser and Strauss, 1968, 1965), and may explain why professional attitudes often reflect little more than, 'a lay response to death' (Kearl, 1989), as demonstrated by avoidance strategies used by health-care professionals in the presence of the dying (Prager, 1987; Redding, 1980).

No wonder then that avoidance, non-communication and the relegation of patients' psychosocial and spiritual needs to the imperatives of physical care are frequently reported in the literature as exemplars of health-care professionals' behaviour towards the dying (Flaming, 2000; Rogers et al, 2000; Prager, 1987; Redding, 1980). Elias (1985) suggests that this may be due to an overconfidence in the ability of the prevailing medical hegemony to cure all ills when he says that, 'closely bound up in our day, with the greatest possible exclusion of death and dying from social life, and with the screening off of dying people from others is a peculiar embarrassment felt by the living in the presence of dying people. Feelings of embarrassment hold words back. While still alive, they are already dead' (p.23).

2.4   Social Death

The idea that social death exists in tandem with, but separate and distinct from biological death processes is not new, though it is primarily a western phenomenon (Goffman, 1961; Sudnow, 1970; Kastenbaum, 1977, 1972), and is without historical precedent according to Sweeting and Gilhooly (1991), who identify the elderly infirm, those with terminal disease, and those who have lost their 'essential personhood' (p.262) such as those with Alzheimer's disease, or in an irreversible comatose state as the likely candidates for such a death. Sudnow's seminal work on the subject defines it as occurring when, 'a patient is treated as a corpse, though perhaps still clinically and biologically alive', a process which causes people to, 'die slow motion deaths from chronic ailments and thereby die socially, as when institutionalised in a nursing home, before expiring biologically' (Kearl, 1989 p.74). It is postulated that this in turn reduces the ability of the individual to achieve a 'good' death since, 'if others are embarrassed about the subject and deny the reality of death for them, they will find it harder to reach a state of preparedness' (Katz and Siddell, 1994 p.21), which many have advocated as being necessary for a good death (Murray-Parkes, 1990; Saunders, 1990, 1965; and Kubler-Ross, 1991, 1975).

There may, however, be very good psychological reasons why denying behaviours persist amongst both lay and professional carers. Disengaging behaviours similar to those seen in the elderly as they approach death may serve a valuable ego-defensive function which protect carers from the worst consequences of a recent death (Flaming, 2000; Mamo, 1999), or the accumulated losses of many years of 'death-work' (Fulton and Fulton, 1971; Lindemann, 1944), but also illustrate how society tends to depersonalise those on the brink of expiry (Mamo, 1999; Kearl, 1989).

2.5 The Natural Good Death

As a consequence of this, many influential clinicians have called for a return to 'naturalistic' (Albery et al, 1993) or 'holistic' approaches to the care of the dying. These have as their basis, a number of 'first principles' namely, the introduction of greater openness or honesty about dying (Rogers et al, 2000), and the adoption of open communication or awareness contexts (Glaser and Strauss, 1965), in which the dying person and their significant others are fully informed about changes in their condition and/or prognosis. Saunders (1970) has described this as, 'the moment of truth', and suggests that this is essential if sense is to be made from the social, psychological and existential suffering of an impending death, and is the only means by which the 'total pain' (Saunders, 1988) can be alleviated and a 'good' death ensue.

The second principle, which derives from the work of the death awareness movement, is the notion of 'timely' as opposed to 'drawn-out' death trajectories (Seale, 1994; Kearl, 1989; Illich, 1976; Glaser and Strauss, 1965). These are age appropriate, naturalistic and unhindered by technological interference, which would otherwise 'require the presence of paid, impersonal professionals instead of family and friends' (White, 1977 p.98). Field and Cassel (1997) therefore add a further four prerequisites which are necessary for a 'good' death, namely;

- Coping with disfigurement and loss of function
- Confronting existential and spiritual questions
- Making decisions about end-of-life care; and
- Planning for survivor's well-being after their death

Walter (1994) describes the work of the 'death awareness movement' as providing a neo-modernist framework for death in opposition to 'traditional' approaches which relied upon religio-social frameworks for the management of death and the care of the bereaved, or 'modernist' (technical-medical, and largely death-denying) approaches where death is subject to intrusive interventions, bureaucratisation and delay (James and Field, 1992). For them, a 'good' death is free from avoidable distress and suffering, comes with reasonable warning, occurs in the company of loved ones, and provides an opportunity for people to be reconciled with family members (Field and Cassel, 1997). It is argued that a naturalistic death enables the individual to achieve a sense of peace, meaning, and transcendence (Byock, 1997, Jennings, 1996, Gavrin and Chapman, 1995), in which dignity and autonomy are maintained (Byock, 1997; Humphrey, 1991) and transcendence or self-actualisation achieved.

Whilst difficult to define, Field and Cassel (1997) probably come closest to a meaningful definition of a naturalistic 'good' death when they suggest that it is one which, 'honours and protects – indeed cherishes - those who are dying, that conveys by word and action that dignity resides in people, not physical attributes, and that helps people preserve their integrity while coping with unavoidable physical insults and losses' (p.25). The concept of 'quality of dying' is less fully developed, but focuses on a person's experience of living while dying (Wallston et al, 1988), and does so within the 'special world of the dying patient' (Field and Cassel, 1997), for whom some physical outcomes may be less realistic, while other outcomes such as spiritual well-being or sense of peace may become more meaningful.

2.6　The Purposeful Death

From the sociologist's perspective however, 'deaths become good when they serve the needs of the dying, their survivors and their social order. They are not necessarily easy deaths, but rather allow individuals to die in character, at their own pace, and in their own style' (Dempsey, 1975 p.231). Weisman (1978) suggests therefore, that 'an appropriate death is one that is timely, such as following the completion of an act, significant, where the death itself stands for something good, for both the dying individual and the survivors-to-be, and wished for' (Weisman, 1973 cited by Kearl, 1989 p.399).

From a socio-anthropological perspective, dying at the right time may be as important as dying in the right way. 'Premature' deaths are almost always perceived in a negative fashion, but that might be equally true in the micro-environment of a hospice setting, where a patient may die before the arrival of a family member, or before achieving 'acceptance' of his or her impending death (Kubler Ross, 1991, 1975,1970, 1969). This brings into question the notion that 'good' deaths do not only serve the needs of patients and their family members, but may, in some way, provide secondary benefits, in terms of carer satisfaction, vocational fulfilment or the ideological aspirations of hospice workers themselves.

2.7　Acceptance and the Appropriate Death

In this case, the needs of 'the social order' (Dempsey, 1975) may well be served by the patient dying in an, 'appropriate manner' which fulfils the social norms and expectations of those working within that culture, and this may affect the way in which the death itself is described. Kubler Ross' (1969) 'stage' of acceptance stands out in particular as a cultural shibboleth within hospice care, which helps to determine health-care professionals' views about the quality of a death since many hospice workers see, 'a move towards acceptance of death as a natural part of the life cycle in a culture that has more and more denied the reality that we are mortal' (Rinaldi and Kearl, 1983 cited in Kearl, 1989 p.439).

However, whilst Kubler Ross is by far the best-known proponent of psychological stage theories of death and dying, and features strongly in the training of health-care professionals (Field, 1984), there are many who refute her ideas (Littlewood, 1992; Kellehear, 1990; Germain, 1980; Kastenbaum, 1975). Certainly, the author has witnessed the distress of many healthcare professionals - nurses in particular - who have berated themselves when patients have failed to achieve acceptance at the point of death when, by any other standard, it may have been described as a 'good' death.

Walter (1994) and Kearl (1989) suggest one possible reason why Kubler Ross' theory has been so uncritically accepted by health-carers, and by hospice and palliative care workers in particular, since it is essentially a description of emotion focused coping which intuitively fits within, 'a female [though interestingly, not a feminist] sponsored movement which developed in reaction to the male dominated medical establishment' (Kearl, 1989 p.440). These coping strategies may have the ring of truth in an environment which values female intuition, care, passivity and human expression above high technology, invasive medical interventions and an ethos of cure, and have certainly been fostered as a component of 'dying well'.

2.8　Perspectives of the 'Death Awareness Movement'

The activities that health-care professionals perform on a day to day basis are important therefore, not only to the physical well-being of the patient as they die, but may also make a positive contribution to the lived-experience, and hence the social construction of good or bad deaths of those who remain (Feifel, 1989). The 'death-work' in which health-care professionals are engaged is vital therefore, not only to the individual facing death, but also to society as a whole since, 'the ability of a society to allocate as many good deaths as possible to its members is a measure of its cultural adequacy' (Dempsey, 1975 p.122).

2.9   The Hospice Movement: A Panacea for Failure within the Mainstream?

The modern hospice movement, started by Cicely Saunders as an implicit criticism of shortcomings in mainstream terminal care provision (Buckley, 1998; Gulland, 1998) has, as its primary purpose, the extension of as many 'good' deaths to its clients as possible. This is achieved by enabling the dying patient to, 'live fully until he dies as himself' (Saunders, 1965 p.4), which Lichter (1991) defines as, 'dying the way that the individual wants', and there can be little doubt that when this occurs, benefits accrue both to the dying patient, and those who care for them, which offers, 'profound opportunities for sharing the experience of living at a depth of personal investment not generally found in human relationships' (Benoliel, 1977 p.139).

These are acquired through the provision of assistance, 'which is designed to achieve four general purposes; to facilitate normalization of living according to the patient's preferences throughout the process of dying; to maximise opportunities for the patient to participate in decisions affecting living or dying, to foster and encourage open communication between the dying person and those who are important in his or her life; and to help the patient find an appropriate death' (p.135).

The modern hospice movement started by Cicely Saunders is widely acknowledged as pioneering significant improvements in the care of the dying, and has provided a welcome contrast to the care of the terminally ill in hospitals and other institutions, but it could be argued that their primary contribution to the care of the dying has been to demonstrate that a sharp decline in quality of life is neither an inevitable nor a necessary consequence of dying (Field and James, 1993). Many hospices now provide valuable hospice at home services which are highly valued by the dying person and their carers (Field et al, 1992; Higginson et al, 1990), and act as a halfway house between the hospice and the patient's own home. These undoubtedly enable many to die at home rather than in institutions, but the provision of hospice at home services remain woefully inadequate.

2.10   Criticisms of the 'Hospice Death'

Hospices themselves have not been immune to criticism however, and have been accused of institutionalisation, routinization, and bureaucratisation (Aranda, 1999; James and Field, 1992), squeezing patients into a formulaic death ritual as Walters (1994) suggests when noting that, 'in spite of the rhetoric of enabling patients to be themselves, there is overwhelming evidence that hospices also actively teach patients the craft of dying' (p.131). This is in spite of Saunders' assertion that, 'we are not at all concerned that a patient or family should come to think as we do, but that they should find strength in their own inner values' (Saunders, 1992 p.4).

Aranda (1999) suggests that this may be due to a shift from small, charity-based hospices founded by charismatic leaders with a clear ideology of death and dying to broader palliative care services, which are increasingly dependent on mainstream funding. Increased medicalisation, regulation, competition, and a potential loss of patient specificity are the anticipated outcomes of this public-private relationship, and may explain the 'homogeneity' so criticised in hospice deaths. The impact of this ideology, or the culture which springs from it should not be overlooked however, and it is interesting to note that criticism of the 'hospice death' comes primarily from people working within the movement, rather than their clients, who are generally grateful for the perceived advantages which hospice offers (Higginson, 1990).

Criticisms focus primarily around cultural and philosophical issues rather than the physical aspects of care which have been criticised so heavily in other settings (Buckley, 1998). Walters (1994) cites two examples. The first criticises an overt culture of affective passivity that prevents patients from expressing their true feelings in an environment that engenders tranquillity, whilst the second highlights some of the contradictions inherent in nominal adherence to values such as autonomy, individuality and self-actualisation which may not in reality be encouraged:

'Our ethos is chronic niceness. If we allow a patient to be angry, they end up feeling they shouldn't have done it. Our favourites are those who get on with our style… I do wonder whether coldly painted hospital wards may be easier places for patients to say what they really feel' (p.132)

'Nurses talk a lot about autonomy, but there's precious little of it in a hospice. One patient said she'd only come in if she were allowed to sleep in a chair, and the nurses found all sorts of rationalisations why not – risk of pressure sores and so on.' (p.133)

Walter therefore likens hospice patients to a 'society of captives' (Sykes, 1965), a continuously shifting community who have nothing in common save the fact that they are dying and find themselves in the care of a professional elite who, for the most part, are disciples of death 'revivalists' such as Saunders and Kubler-Ross, who regard their mission as, 'enabling people to die a certain version of the good death' (Walter, 1994) which follow a predetermined script (Walter, 1994) which invariably includes:

- Control of physical symptoms
- Open acceptance of diagnosis and prognosis
- Presentation of hope, and desire to 'live whilst dying'
- Keeping mobile, active and 'fighting back'
- Enjoyment of life
- Peaceful death at home

There is, he suggests, a contradiction between the rhetoric of self-determination and autonomy espoused by the hospice movement, and the actions of many hospice staff who, 'see their mission as enabling people to die a certain version of the good death' (p.131). This he argues, means that, 'in spite of the hospice's determination to be more like a home than a hospital, in respect of patient autonomy it remains – ultimately – more like hospital' (p.133).

This contrasts significantly with Bradbury's (1993) definition of a 'good death' in which, 'people exert control over events' (p.69) and may explain why patients' individual wishes are sometimes overlooked (Cohen et al, 1997). Davison and Degner (1998) suggest that the perceived 'professionalism' of the palliative care or hospice nurse may explain why, 'active participation in the final stages of life may be lacking' (p.129), and control continues to rest with, 'paid impersonal professionals instead of family and friends' (White, 1977 p.98).

2.11   Distinguishing Between Process and Outcome in the Evaluation of Death

Byock (1997) supports the view that control and participation are important factors when determining the quality of death when he suggests that, 'good deaths are not random events or matters of luck but represent phenomena which can be understood and, perhaps, fostered' (p. 31). Notwithstanding this, he distinguishes between process ('dying well') and outcome ('good deaths'), when arguing that the term 'good death', 'connotes a formulaic or prescriptive approach to life's end… and tends to blur the distinction between death – the state of non-living, and the preceding time of living' (p.32) – otherwise described as the 'living-dying interval' (Saunders, 1990).

It is apparent from the literature therefore, that professional death-carers must positively anticipate the wide array of needs and concerns which affect the dying and those closest to them prior to, and at the time of death, but some of these needs are still poorly understood or enunciated (Cohen et al, 1997). Process measures such as quality of life tools, whilst useful in assessing the efficacy of care interventions, do not necessarily predict the quality of the outcome in terms of whether a death is considered 'good' or 'bad' by those present at the time of death because of the subjective nature of the values and judgements that shape this assessment.

2.12   Good and Bad Deaths as Value Judgements

Bloch and Parry (1982) suggest that societies, groups, and cultures which adhere to a binary dichotomization of death (as 'good' or 'bad', 'natural' or 'unnatural' etc), make judgements about the nature of a death according to the perceived purpose, regenerative or otherwise, which that death represents. This can take the form of rebirth or release from pain and suffering for the deceased, or socially acceptable and sanctioned qualities modelled by the deceased in the days or weeks prior to death as an example to others. A 'good' death is therefore, 'one which suggests some degree of mastery over the arbitrariness of the biological occurrence by replicating a prototype to which all such deaths conform' (Bloch and Parry, 1982 p.15).

'Bad' deaths on the other hand, are those which are untimely, unanticipated or uncontrolled (Bradbury, 1999). They preclude opportunities for growth, regeneration and healing for either the deceased or their survivors, and fulfil no social, religious or existential purpose. The decision as to whether a death was good or bad however is essentially social (Kearl, 1989), and is frequently the outcome of negotiation and discourse on the part of survivors. Bloch and Parry for instance, point to the example of a positively sanctioned act of self-sacrifice (as in a war for instance), as opposed to a negatively sanctioned act of suicide and notions of purpose or accomplishment are also picked up by many within the 'death awareness movement', such as Byock (1997), who suggests that a 'good' death is one in which, 'in the very shadow of death, one's living experience can yet give rise to accomplishment within one's own, and one's family's system of values' (p.32). It should not be presumed however, that beliefs and values about the nature and quality of death are universal, for it seems likely that social representations of 'good' and 'bad' deaths will vary between lay and professional observers just as much as they would between different social cultures. Death has different personal, symbolic, and social meanings for individual members of the same family, and for professional carers, whose experience, training, values and identification with the deceased may vary enormously.

It would appear therefore, that value judgements about the nature and quality of a death may at one and the same time, be both subjective and objective. They can be intensely personal, and yet they are often constructed within the confines of socially constructed norms, expectations and experiences. The complex judgements made by observers about the nature of a death constitute 'social representations' or 'social constructions' therefore which, 'do not simply represent 'opinions about', 'images of', or 'attitudes towards', but theories or branches of knowledge in their own right for the discovery and organisation of reality' (Moscovici 1973 in the foreword to Herzlich, 1973 p.xiii). These concepts will now be explored further in relation to social representations theory, which is clearly pertinent to the death-work of health-care professionals who care for the biopsychosocial needs of their clients within the social context of a hospice.

2.13   Good and Bad Deaths as Social Representations

The social-psychological theory of 'social representations' (Bradbury, 1999; Farr, 1996; Marková 1987; Harré, 1984) draws upon the work of Mead (1934) and the Chicago School, and more significantly, that of Wilhelm Wundt, who established a distinctive Völkerpsychologie in Central Europe between 1900 and 1920 as a reaction against the reductionist model of psychology advocated by behaviourists such as Allport (1924) in North America at that time.

Wundt and his followers were interested in the study of the internal processes of the mind, 'the conversation held with oneself' (Bradbury, 1999 p.18), though Wundt's followers were swift to point out that the process of 'introspection' was of both social and personal value, arguing that, 'individualisation is the outcome of socialisation and not its antithesis' (Farr, 1996 p.54). Bradbury, (1999) notes that, 'consciousness is an inherently social process' (p.18), and suggests that the study of psychological constructs (such as death) become one-dimensional if they are made without an

understanding of, and sympathy for, the cultural and social significance of the phenomenon under investigation.

The 'theory of social representations' is relatively new however, originating in the work of Moscovici (1993; 1985; 1976; 1973), who argued that social representations serve, 'A twofold function; first, to establish an order which will enable individuals to orientate themselves in their material and social world and to master it; secondly, to enable communication to take place among members of a community by providing them with a code for social exchange and a code for naming and classifying unambiguously the various aspects of their world and their individual and group history' (in Herzlich 1973 p. xiii). Amongst other things, social representations enable individuals within groups to construct reality, aid communication and facilitate socialisation, but both Bradbury (1993) and Purkhardt (1991), suggest that their primary purpose is to make the unfamiliar familiar in order to accommodate and assimilate those events within their life-experience. Moscovici (1984b) suggests that it explains, 'what goes on in people's minds when they are faced with life's great enigmas such as illness, our bodies, our origins, knowledge, death etc' and, 'how these systems come into being and then evolve' (p.941 – emphasis mine).

Bradbury suggests that, 'representations perform these functions by the process of anchoring, in which we use classification and naming to give a new object meaning and objectification, in which we make the unfamiliar familiar by objectifying it' (p.20). In addition, social representations theory may also help to explain 'why' we do this, for the promotion of as many 'good' deaths as possible is not simply a measure of the cultural adequacy of society (Dempsey, 1975), but reflects more importantly the cultural, personal, and professional adequacy of it's 'death-workers'. Cultural values within the 'small-world' (Bradbury, 1999) of the hospice ward may both shape, and be determined by the judgements which health-care professionals make about the deaths they witness, and the social representations of as many deaths as possible as 'good' are important in so far as they legitimise both their labour, and the very existence of the institutions in which they work (Weisman, 1988) and the study described in the next chapter investigated hospice worker's social representations of 'good' and 'bad' deaths and examined the complex relationship between the two. Tentative explanations as to 'how', and 'why' deaths are delineated as 'good' or 'bad' are posited, and a conceptual framework for the social representation of 'good' and 'bad' deaths in hospice settings tentatively offered. Recommendations for practice and suggestions for future research will follow this.

CHAPTER 3: RESEARCH METHODOLOGY

3.1   Rationale for Study

The purpose of the study is to describe the criteria by which doctors, nurses, and other health-care professionals working within a specific environment evaluate the quality or nature of deaths as being 'good' or 'bad'. This can be described as fulfilling the illustrative function (Knafl and Howard, 1984) of research, which is the meaningful characterisation of real-life events such as individual life-cycles, organizational and managerial processes (Yin, 1994), and hence posit explanations as to why some deaths are labelled as 'good' or 'bad' by health-care professionals.

Case study is an appropriate research strategy since, 'the investigator's goal is to expand and generalise theories' (analytic generalisation) rather than the enumeration of frequencies (statistical generalisation). This offers, 'an all encompassing method' which 'copes with the technically distinctive situation in which there will be many more variables of interest than data points, relies on multiple sources of evidence, and benefits from the prior development of theoretical propositions to guide data collection and analysis' (Yin, 1994 p.13) - each of which were relevant to the study undertaken as follows:

- The variables affecting observer's social constructions and representations of death are more numerable than the data or reference point, which may be a single event (death) or process.
- The study makes use of multiple sources of evidence, namely, observation, focus groups, formal and informal interviews and medical and nursing records for descriptions of the death - a process known as data triangulation (Redfern and Norman, 1994) and,
- Prior theoretical propositions, namely 'social representations theory' guided the choice of research methodology, and informed both the data collection and data analysis phases of the study.

This approach was also sympathetic to the exploratory nature of the study, which attempts to, 'represent reality through the eyes of participants' (Hammersley, 1995 p.16). Other qualitative methods might have proven useful, but given that the author was seeking to construct two cases, or exemplars of death (one 'good' and one 'bad'), it seemed logical to adopt this methodological approach. As with other qualitative methods, the case-study approach also allowed for the use of multiple strategies for data collection and analysis so that the contextual richness of complex and multi-factorial value judgments made by health care professionals might best be described, and a greater understanding of the research problem established (Yin, 1989). This is commensurate with the view that case-study approaches are appropriate to the investigation of 'how' and 'why' research questions (Yin, 1989), and are deemed capable of describing a complete scenario without a priori biases.

3.2   Components of the Research Design

Yin (1994 p.20) suggests five components of a research methodology, namely:

- The study question(s)
- The study propositions (if any)
- The unit(s) of analysis
- The logic linking the data to the propositions and,
- The criteria for interpreting the findings

These will now be enunciated with regard to the study undertaken, and the implications of each considered in so far as they guided the research process.

3.3.1 The Study Questions

The study addresses two primary questions in pursuit of its stated objectives, namely:

- How do health-care professionals make judgements about the nature and quality of a patient's death?   And,
- Why do they label some deaths as 'good' or 'bad'?

These questions were influential in determining the study design since how? and why? questions are more amenable to a case-study approach, particularly when the researcher has no control over external events (Yin, 1994), which is likely to be the case when investigating death phenomena as the following figure demonstrates:

Research question	Control over external events	Contemporary focus?	Relevant Research strategy
How, Why?	Yes	Yes	Experiment
Who, What, Where, How many/much?	No	Yes	Survey
How, Why?	No	Yes	Case-Study

Figure 1. Relevant Situations for Different Research Strategies (After Yin, 1994 p.6)

Given that the research questions are clearly enunciated in terms of how? and why? questions, and the researcher was not seeking to control or to manipulate external variables, a case-study approach was clearly indicated. This methodology is particularly appropriate when complex, multi-factorial phenomena, which require a more 'holistic' approach to the research question are being investigated (Yin, 1994).

3.3.2 The Study Propositions

The propositions which underpin the study are as follows:

- Death is a unique and multivariate experience which effects, to a greater or lesser extent all those who come into contact with it (Benoliel, 1977)
- Health-care professionals make complex judgements about the nature of deaths in hospice settings (Copp, 1997; Taylor, 1993b), some of which are capable of being described as 'good' or 'bad'.
- Social, moral, professional and philosophical viewpoints may play a part in these judgements (McNamara et al, 1995; 1994) which,
- Are amenable to study through direct observation and narrative inquiry (Kvale, 1996; Barriball and While, 1994).

3.3.3 Unit(s) of Analysis

A fundamental requirement of case-study research is the definition of the unit of analysis or case under investigation (Bergen and While, 2000). This may be an individual, an organisation, a service, a system, or any other event or entity, but is guided by the research question(s), and should be operationally defined within the context of both the questions, and the propositions which informed the study (Yin, 1994).

The unit of analysis (or cases) within this study are therefore explicit, since individual deaths, or rather, health-care professionals' constructions of those deaths form the focus of the study. These are likely to differ significantly if the first proposition of the study, i.e. that death is a unique and multivariate experience is correct, and form the basis of a comparative analysis between examples of 'good' and 'bad' deaths.

The delineation of 'deaths' as the unit of analysis or case is consistent with the work of others (e.g. Young and Cullen, 1996; Taylor, 1993b; Glaser and Strauss, 1965) and is supported by Yin's assertion that cases should, 'be similar to those previously studied, or should deviate in clear, operationally defined ways' (Yin, 1994 p.25).

3.3.4 Logic Linking Data to Propositions and Criteria for Interpreting the Study's Findings

These last two components have been the least well developed within case-study research (Yin, 1994), but are addressed in sections 3.6, 3.7 and 3.8. They relate primarily to the ways in which the data were examined for pattern matching and analysed according to thematic category in order to make sense of the data (Morse, 1991). Further development and coding enabled relationships between the data to be clarified through diagramming and matrix formation (Miles and Huberman, 1984), which was helpful in establishing the presence of converging (or divergent) data sets (Seale, 1999; Polit and Hungler, 1993).

3.4 Summary of Research Methodology

The study is best described in terms of Yin's (1989) case-study categories as a multiple-case embedded design in that several deaths or cases are described; namely two 'hypothetical' cases (one 'good' and one 'bad' death), garnered from focus group discussions held with doctor's, nurses, and other health-care professionals at the commencement of the study; and two 'literal' cases (Yin, 1989), one 'good' and one 'bad'. These were investigated using after-death interviews with ward staff over a specified period of time (five weeks) supplemented by non-participant observation, informal interviews and examination of nursing/medical records. This facilitated analysis of pattern matching between the different cases, and construct permanence between 'hypothetical' and 'literal' cases in the same informants during the course of the study. A thematic representation of the research methodology is presented in figure 2 on page 29.

3.5 Sample and Setting for Data Collection

Case studies are analogous with replication rather than sampling logic in that each case is considered as a separate research entity and not, as has often been presumed, as a subject within an experiment (Yin, 1994). The cases should serve in a similar manner to multiple experiments, with similar results, (a literal replication) or a contrasting result (a theoretical replication), stated explicitly at the outset of the investigation. There is no 'sample' as such therefore, but separate cases which were selected on a purposeful sampling basis (Bergen and While, 2000). It was hypothesised that if respondents were capable of delineating factors which give rise to a 'good' death in a hypothetical case, the presence of these same variables in a literal case should lead to the death being described in those same terms. One would expect to see convergence between descriptors of 'good' and 'bad' deaths, and the delineation of those deaths as good or bad when those variables were present. For the purposes of this study therefore, four comparative cases (two hypothetical and two literal) were considered sufficient to demonstrate convergence or divergence of these results. Convergence would be sufficient to demonstrate replication logic (Yin, 1994 p.50).
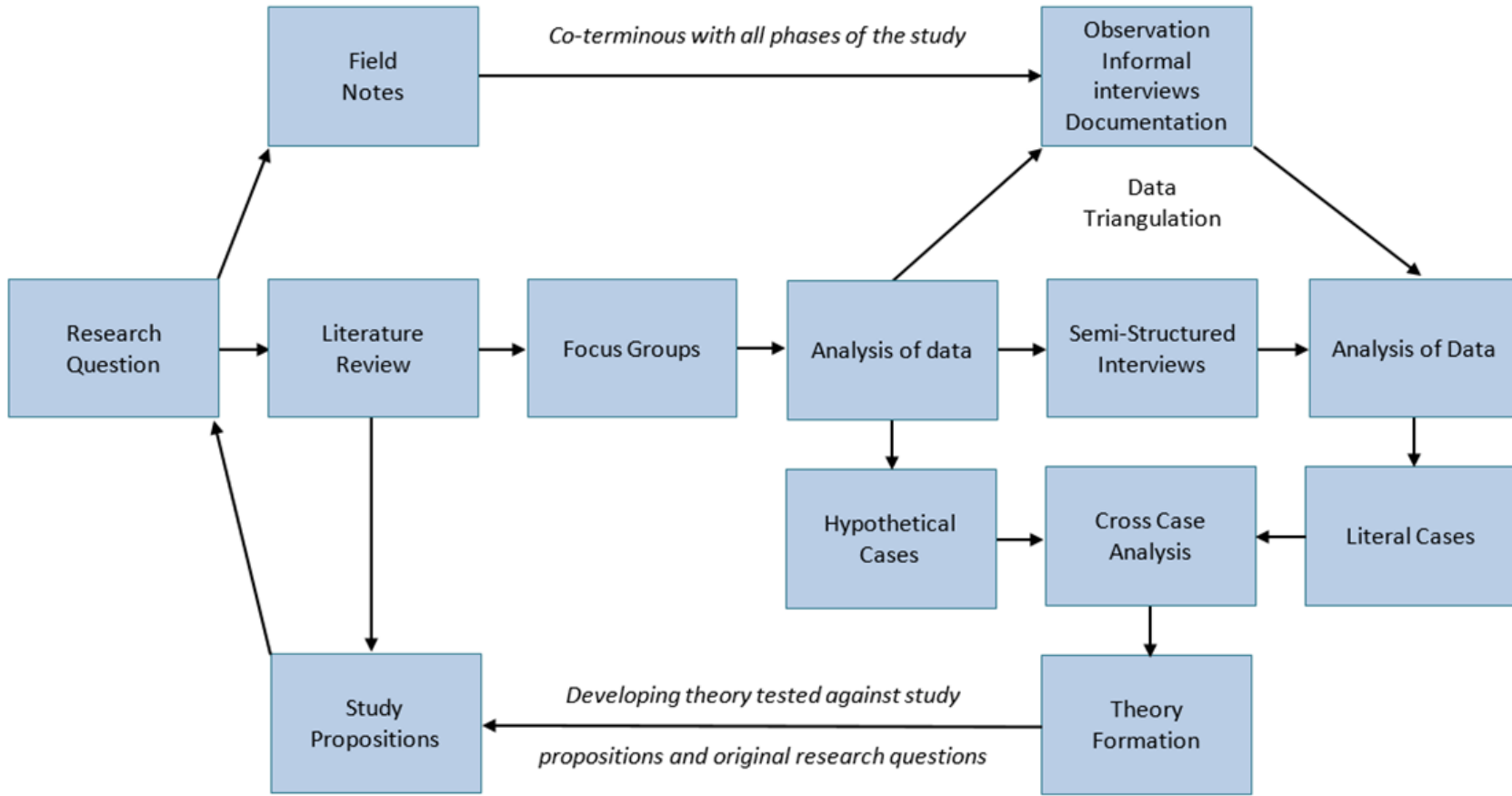
Figure 2: Thematic representation of the study methodology

Cases were drawn from the experiences of health-care professionals working in a South London Hospice, the rationale being that construct permanence within and between cases would be best demonstrated by using the same network of respondents. In doing so, it was hoped that the confounding variables (such as differences in aetiology, speciality, clinical experience and professional socialisation) could be kept to a minimum.

3.6   Data Collection Strategies

A research method such as case-study, which makes use of more than one data collection strategy has both strengths and weaknesses, but has been used by numerous researchers in palliative care to capture the complexity of the issues involved (Higginson and McCarthy 1989; Hockley et al, 1988). It also provides for triangulation (Redfern and Norman, 1994; Denzin, 1989) between data collection methods, data analysis, and the inferences drawn from them; all of which add to the 'robustness' (Yin, 1994) of the research. Data sources are tabulated in Figure 3 (page 32), but data collection methods used in the case study comprised of the following:

- Focus groups
- Semi-structured interviews
- Informal interviews
- Examination of written / recorded records
- Participant observation

The role of focus groups in qualitative research is discussed by Krueger (1994) who states that groups should generate their own descriptors or examples of the phenomenon under investigation without leading questions or the conveying of perceived wisdom or preconceived ideas on the part of the researcher (Krueger, 1994). Similarly, it is important to acknowledge that care of the dying can be a difficult, controversial, and emotive area to discuss which may leave groups or individuals within a group feeling vulnerable and threatened for personal, religious, professional or ethical stances which they hold in common – possibly against a perceived 'outsider', or at variance with the rest of the group. The skill of the researcher as 'tool' in this situation is crucial – in terms of the preparation involved, sensitivity to group and personal agendas, breaking down barriers, and putting people at their ease. Similarly, questions need to be focused, but as open as possible to engender open communication with the researcher.

Open questions such as, 'How would you define a good/bad death?' or 'What circumstances enable a patient to die a good death?' were used to start the focus groups, and probing questions used to clarify concepts as they arose. This had the advantage of being more spontaneous, enabling the researcher to maintain informality whilst incorporating participants' colloquialisms and jargon into the questions. Dichotomous questions answerable by a simple 'yes' or 'no' were avoided as far as possible, and cued questions used to seek further clarification when necessary (Krueger, 1994).

Focus groups took place in a comfortable sitting room within a clearly defined time span during the hand-over period when staff were most plentiful and distractions less likely to occur. Tea and cakes were provided by the researcher so as to enhance the informal but business-like nature of the meeting, and written records in the form of flip charts and respondent notes were retained. It is vital that the views of all participants are elicited (Krueger, 1994), and this was achieved with greater success in the second group by first asking them to brainstorm ideas on paper rather than vocalise them within a large group. This elicited a noticeable increase in descriptors/categories, and a reduction in reiteration by members of the group.

A total of fifteen nurses, two physiotherapists and one social worker took part in the two focus groups (see Figure 2 on page 29). These were recruited by personal invitation from the staff present on the

wards on two predetermined dates, and in each case, all of the nurses who could be spared agreed to take part in the group. The social worker and physiotherapists were recruited on the same basis. The first focus group represented early pilot 'work' (Bradbury, 1999) – as opposed to a pilot 'study', which has been likened to 'free-ranging, open-minded exploration' in which the researcher, 'goes out and visits people and places, interviewing people and listening in on conversations' (Bradbury, 1999 p. 28). Focus groups were essentially 'conversational', the aim being to elicit as many themes as possible, which could be followed up in later interviews. Focus group data were analysed according to Krueger's (1994) considerations for focus group analysis, namely:
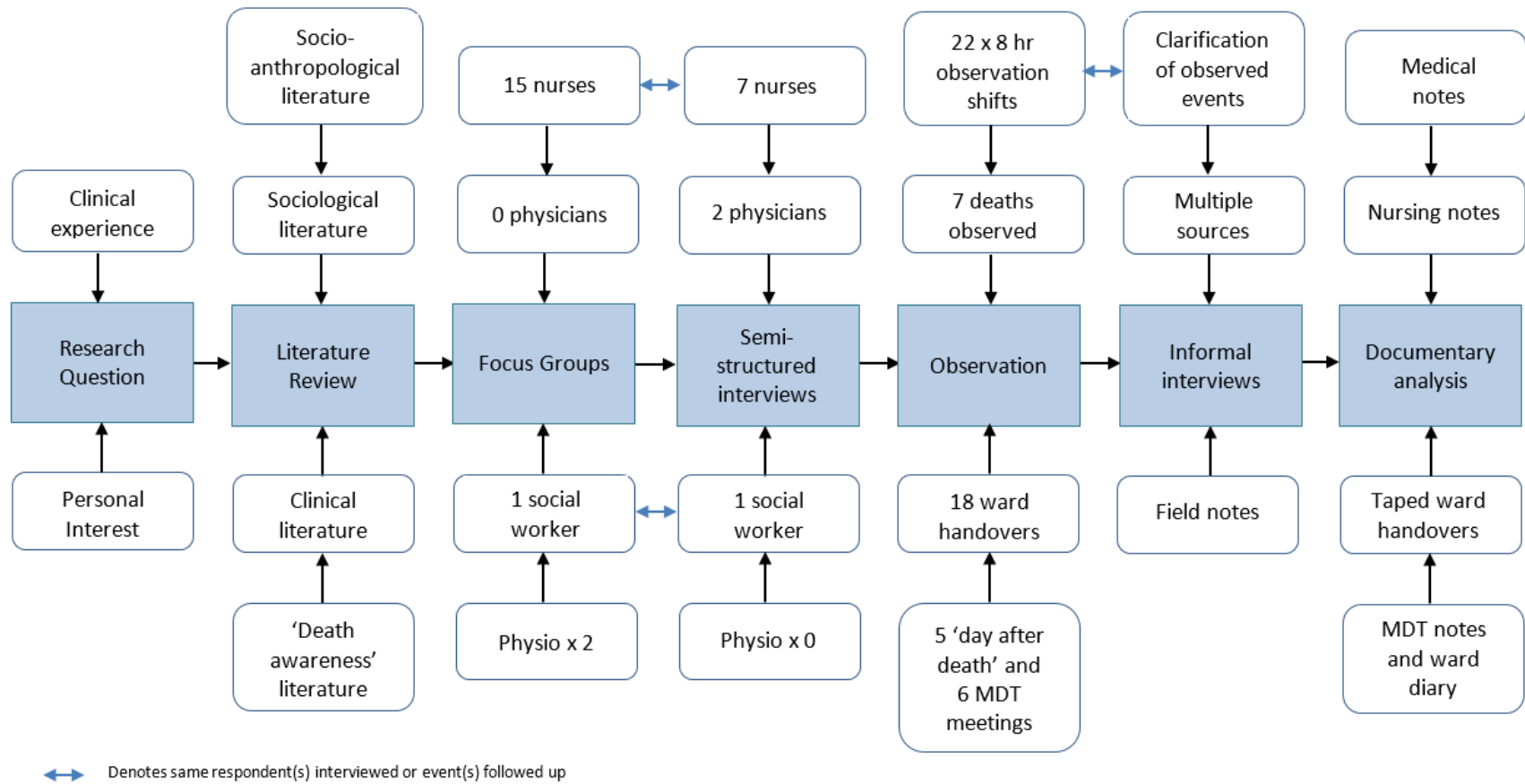
- Consideration of the words
- Consideration of the context
- Consideration of internal consistency
- Consideration of frequency/extensiveness of comments
- Consideration of intensity of the comments
- Consideration of the specificity of responses
- Consideration of the 'Big Ideas'

Semi-structured interviews (Barriball and While, 1994) were then conducted with informants from three disciplines, medicine (n=2), nursing (n=7), and social work (n=1) who had been responsible for the care of the deceased on a purposive sampling basis in relation to the two 'concrete' cases (one 'good' death and one 'bad' death). These elicited detailed descriptions of the circumstances surrounding the deaths themselves in addition to the respondents' appraisal of the death. At times, they also provided insight into the personal cost, professional mores, and attitudes towards death, dying and hospice care which were far from anticipated. No wonder then that interviews have been described as, 'the favoured digging tool of a large army of sociologists (ergo researchers) searching for detailed information' (Kvale, 1996 p.215), as their use is invaluable in eliciting rich data in qualitative research.

Interviews commenced with an invitation to the respondent to talk about the death of a patient for whom they had recently cared, and this was followed up by questions related to the topic of the interview and the theoretical conceptions at the root of an investigation (Kvale, 1996 p.129). For the most part, each interview was spontaneous, but based upon a thematic framework (Sorrell and Redmond, 1995; Barriball and While, 1994) which had been developed in the light of focus group discussions.

Interviews were conducted in a private room on the ward, usually following the 'hand-over' period, when there were ample staff present, the respondent having first agreed to be interviewed, and provided with a respondent information sheet about the study. It was made clear that the tape-recorded data thus derived would be kept in a secure location, and identified through the use of a respondent code known only to the researcher. Respondents were also assured that they could terminate the interview at any time they wished without prejudice to themselves. With the exception of the two doctors, each of the respondents had been present at the second, ward based focus group, and were therefore well known to the researcher.

An unspecified number of informal interviews also took place with these, and other members of the ward staff. These have been described as 'conversations with a purpose' and were undertaken by the researcher throughout the course of participant observation on the ward over a five-week period. They served two main purposes: clarification of observed events, and the elicitation of the nurses' constructions or representations of their client's physical status and comfort levels during the dying phase, which might later affect the way in which the deaths were perceived.

Socio-anthropological literature → Sociological literature

Clinical experience

15 nurses ⟷ 7 nurses

22 x 8 hr observation shifts ⟷ Clarification of observed events

Medical notes

0 physicians

2 physicians

7 deaths observed

Multiple sources

Nursing notes

Research Question → Literature Review → Focus Groups → Semi-structured interviews → Observation → Informal interviews → Documentary analysis

Personal Interest

Clinical literature

1 social worker ⟷ 1 social worker

18 ward handovers

Field notes

Taped ward handovers

'Death awareness' literature

Physio x 2

Physio x 0

5 'day after death' and 6 MDT meetings

MDT notes and ward diary

⟷ Denotes same respondent(s) interviewed or event(s) followed up

Figure 3: Data sources contributing to the study

Tape-recorded and written field notes were maintained after each semi-structured and informal interview in order to supplement the data obtained directly from the interviews themselves, and the observations made by the researcher. These enabled a clear decision trail to be maintained, and enhance auditability (Guba and Lincoln, 1989) and replication logic (Yin, 1989) at each stage of the research process. Similarly, nursing records and tape-recorded descriptions of any deaths occurring on the ward were also examined for convergence and/or divergence from oral representations of the deaths described.

This was fortuitously aided by the ward practice of using taped team handovers once a day, as it was not uncommon for a 'death narrative' to be communicated between nurses on different shifts, or for those returning after nights/days off. Written records often contained value judgements such as 'died peacefully', which could be compared with taped handovers, focus group data, and the data from both types of interviews to examine the consistency and reliability of the broader (hypothetical) themes in addition to the two 'concrete' cases (one 'good' and one 'bad'). Staff were aware, and had agreed that this could take place, but there was no evidence that the way in which verbal reports or written documentation were presented changed over the course of the study. This may have been a factor, but it seems unlikely that overt differences in behaviour could have been maintained over a 5-week observation period.

Participant observation has been defined as the backbone of qualitative methods (Lofland 1985; Lofland and Lofland, 1984) since it can verify the relative 'truth' or validity of the data derived from other data sources (Denzin, 1970), and allows for, 'the separation of theories from observable facts so that the truth of theories can be tested' (Seale, 1999). Observation is the means by which theory can be grounded in the world of observable facts (Seale, 1999), and brings together the positivist and post-positivist traditions in qualitative research.

Yin (1994) notes that participant observation allows for the study of real events in real time, and provides contextual coverage of an event, but notes that it can be time consuming and self-selective. Bradbury (1999) however, suggests that, 'participant observation lends itself to certain research environments, particularly those situations in which the researcher wishes to know more unusual or idiosyncratic 'small worlds' (Bradbury, 1999 p.30), which may outweigh such drawbacks.

The insight into interpersonal behaviour and motivation which participant observation offers may be 'invaluable in producing an accurate portrayal of a case-study phenomenon' (Yin, 1994 p.88), so long as possible manipulation of events by the researcher can be prevented, in this case, by 'working around' the events being observed rather than becoming directly involved in them.

Participant observation was undertaken simultaneously with the other data-collection strategies over a five-week period, the researcher taking on a role commensurate with the hospice 'volunteer' rather than a 'nursing' role with direct patient responsibility. This entailed making tea and undertaking other 'host' duties, answering the telephone, giving out meals and generally being useful without (as far as possible) directly affecting or influencing the care which dying patients received.

3.7   Issues of Reliability and Validity

Bell (1993) defines reliability as, 'the extent to which a test or procedure produces similar results under constant conditions on all occasions' (1993 p.64). This process is more correctly described in case-study designs as replication logic, by which each case would be carefully selected so that it either predicts similar results (a literal replication), or produces contrary results for predictable reasons (a theoretical replication) (Yin, 1989), but each depends upon the development of a rich theoretical framework since the emphasis is on doing the same case, rather than replicating the same results by doing another case-study (Yin, 1989).

One prerequisite for this is the need for an auditable decision trail throughout every part of the research process, a concept known as auditability (Guba and Lincoln, 1989). If the auditability of the research process satisfies other researchers, and is capable of fulfilling the prerequisites of replication logic, then the study is reliable (Yin, 1989). The parallel concept concerns construct validity, which is often problematic in case studies, as researchers have sometimes been accused of using subjective judgements when collecting and analysing the data (Bergen and While, 2000; Yin, 1989). Hence, for many studies there is an, 'intuitive reasonableness to assertions that a certain approach provides an appropriate measure' (Yin, p. 69). Yin advances the notion of generalizability in relation to this problem, suggesting that generalization at the level of theory (rather than empirical data) becomes possible providing that a theoretical framework is first developed (Bergen and While, 2000).

Furthermore, he suggests that three tactics are available to increase construct validity; the use of multiple sources of evidence otherwise known as data triangulation (Redfern and Norman, 1994) in a manner encouraging convergent lines of inquiry, establishing a chain of evidence which Guba and Lincoln (1989) call the auditability trail, and submitting data for review by key informants, all of which were done in the study (see Figure 4 on page 37). This enables the construction of theory development in a tentative or preliminary form, a process known as analytic generalisation (Yin, 1989), in which previously developed theory is used as a template to compare the empirical results of a case study.

Tests	Case-study Tactic	Research Phase
Construct validity	Multiple sources of evidence	Data collection
	Establish chain of evidence	Data collection
	Informant Review	Composition
Internal validity	Pattern matching	Data analysis
	Explanation building	Data analysis
	Time-series analysis	Data analysis
External validity	Replication Logic	Study Design
Reliability	Auditable decision trail	Study Design
	(Guba and Lincoln, 1989)	Data Collection
		Data Analysis
		Composition

Figure 4 – Design Tests for Assessing Reliability and Validity (after Yin, 1989)

3.8   Illustrative Theories

In this respect, it is also important to acknowledge the role of illustrative theories that have impacted upon the study. These include social theories such as symbolic interactionalism (Denzin, 1992), which acknowledge the interactive nature of human relationships and behaviours within a given situation and posit the view that lived experiences of an event (such as a death) are capable of being conveyed through linguistic symbolism and semantic conjunctions (Blumer, 1969). If this were not the case, the process of researching events through dialogue and semantic analysis would be meaningless. Social theories about cultural socialisation, group behaviour and unpopular patients were also drawn upon in addition to organisational theories, such as Harrison's (1987) excellence in organizational performance theory, which seems pertinent given the location of the study within a perceived centre of excellence. Psychological theories of attachment and loss, personality, perception, memory, coping and ego-defensive function also informed the study, and these will be discussed within the context of the data where they were found to inform or enlighten the research process which is illustrated overleaf.
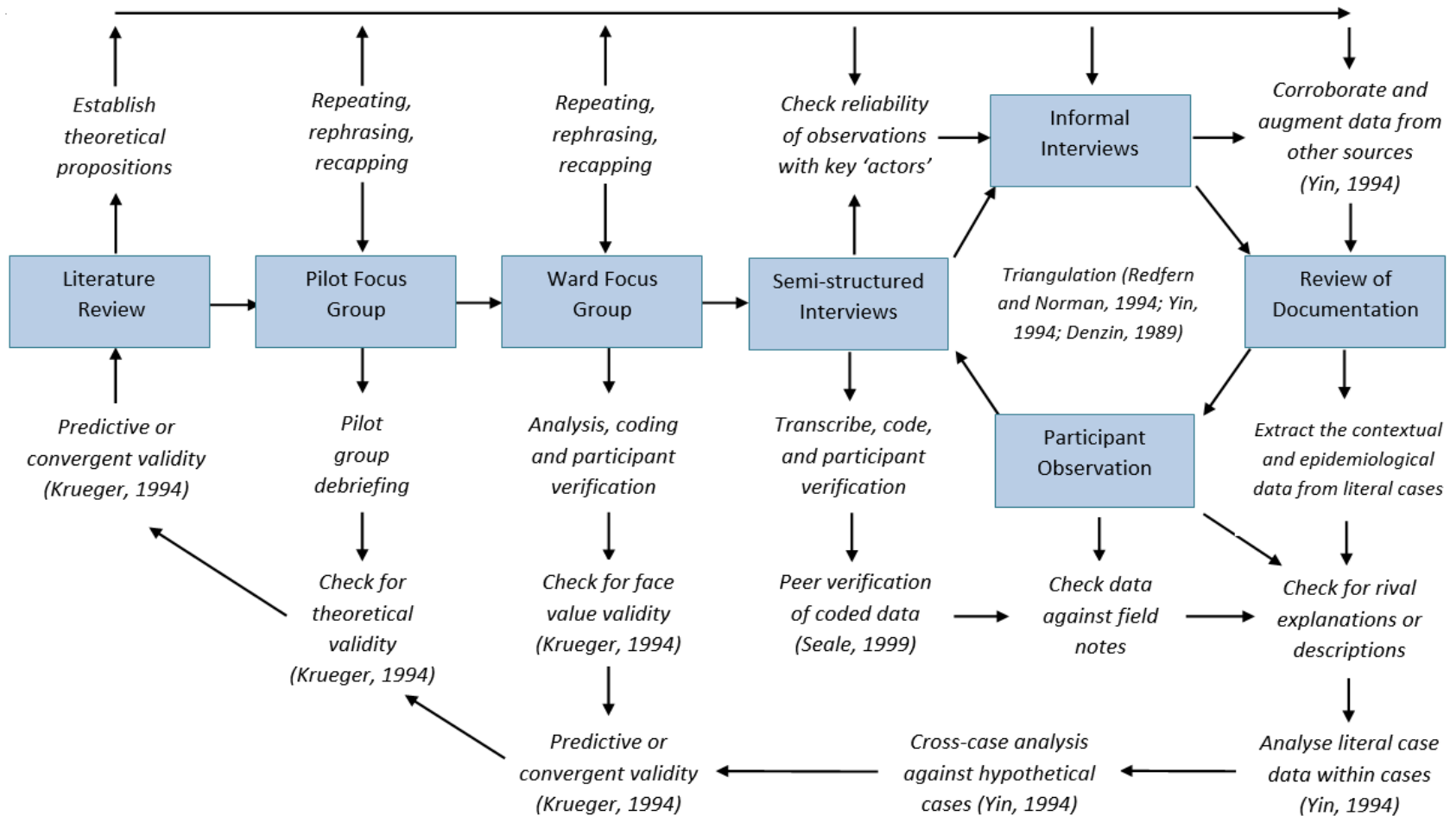
Figure 5: Establishing a chain of evidence: Checks for reliability and validity (Yin, 1994) The Audibility Trail (Guba and Lincoln, 1989)

3.9   Criteria for Assessing the Effectiveness of the Study

The effectiveness of the study was tested in terms of the stated purpose contained in section 3.3(i) and the convergence of any concepts derived from the data (Yin, 1994). Construct validity, internal validity, external validity and reliability (Yin, 1994) was addressed in relation to the strategies developed above, whilst construct consistency will be assessed through participant observation of verbal reports of the quality of the death, informal interview, and comparative analysis of theoretical versus concrete constructs of 'good' and 'bad' deaths (Sandelowski, 1986).

These address the issues of auditability, confirmability, fittingness and credibility described by Guba and Lincoln (1989) which are more normally attributed to the findings of qualitative research, though for the purposes of clarity and consistency within this paper, the author has decided to retain the quantitative nomenclature for those concepts used by Yin (1994).

3.10   Ethical Considerations, Recruitment and Access

Ethical approval for the study was sought and obtained from the Florence Nightingale School of Nursing and Midwifery's Ethics Committee (Appendix 1), and permission to undertake the study negotiated with the chief nurse and medical director of the hospice concerned. Access to the clinical area was then negotiated with the ward manager, who invited the researcher to attend a ward meeting in order to discuss the proposed study, and written information was provided detailing the aims, objectives, and likely duration of the study, including the period of observation (Appendix 2). It was only then, with the verbal agreement of the staff present and/or represented that access for the study was finally achieved. This was considered important if staff were not to feel that the researcher had been imposed on them by an organisational hierarchy, and was vital in gaining their trust (De Raeve, 1992)

Entry to the field was relatively easy in that two members of the ward knew the researcher in his capacity as lecturer at the local School of Nursing and acted as valuable gatekeepers. They were instrumental in overcoming others' anxiety that the researcher was there to 'examine' or in any other way evaluate their practice in a derogatory fashion. It is acknowledged that there is little agreement about which methods of research are most appropriately applied to the complex and sensitive issue of bereavement research, but research with, and on the dying and/or bereaved, and those who care for them is invariably emotive (De Raeve, 1994). It raises a number of ethical dilemmas, but the way in which health-care professionals cope with, and respond to death is an important and legitimate area for study since until such investigations are undertaken, health-care professionals' knowledge, understanding and psychosocial constructions of death and dying will remain unclear (Copp, 1997).

It would have been impossible to predict the effect that such research might have on respondents however, and the ethical requirement to 'do good' and to 'do no harm' therefore underpinned the study, with careful and repeated negotiation of access to respondents, an implicit respect for their views, and empathy and understanding with regards to the emotional costs of such work. Consent for the audiotaping of interviews was sought from all interviewees and tape-recorded interviews were identified with a simple respondent code (e.g. N1, M1 for Nurse 1, Medic 1 etc.) and kept in a locked cupboard. Only one respondent refused to be recorded in this way, but was otherwise happy to be interviewed (and was). On two other occasions, respondents asked that the tape be stopped, and a comment or statement that they had made to be erased, and this was done as requested. Respondent data is contained in figure 6 overleaf.

Attempts were made at each stage of the study to gauge the impact of participation on respondents, and each was offered opportunity to discuss their feelings about the research process on an ongoing basis. On two occasions, interviewees did become tearful when talking about the 'bad' death of a patient whom they had been caring for. On these occasions, the interviewer switched off the

recording equipment and gave some measure of comfort to the respondents, offering to terminate the interview, but in each case respondents were anxious to continue, stating that they found the process of talking about the death to be therapeutic. This may raise questions about the purpose of research, and the interview skills of the researcher, but may also indicate the importance of the research, as each commented that it was the first time anyone had actually asked them about their thoughts and feelings about the death.

Discipline	Unique Identifier	Age	Time at Hospice	Previous Hospice Experience	Specialist Training
Nursing	N1	29	1.5 years	No	Yes
	N2	43	5.0 years	3.5 years	Yes
	N3	51	9.0 years	No	Yes
	N4	42	4.5 years	No	No
	N5	49	7.5 years	2.5 years	Yes
	N6	29	2.0 years	1.5 years	Yes
	N7	34	4.0 years	No	No
	N8	39	8.5 years	No	No
	N9	34	4.0 years	2.5 years	Yes
	N10	NG	6.0 years	No	No
	N11	51	9.0 years	No	Yes
	N12	24	6 months	No	No
	N13	27	2.5 years	No	No
	N14	30	4.0 years	No	Yes
	N15	26	1.0 year	No	No
Medicine	M1	29	1 month	1.5 years	Yes
	M2	37	5 months	4 years	Yes
Physiotherapy	P1	N/G	6.5 years	No	No
	P2	41	4.0 years	2.5 years	No
Social Work	SW	N/G	7.0 years	Yes	Yes

Figure 6 – Demographic Data for Study Respondents

3.11   Data Analysis

Morse (1991) notes that, 'analysis in qualitative research refers to the categorisation and ordering of information to make sense of the data' (p.178) which in this case meant analysing the data firstly within the individual cases (hypothetical 'good' and hypothetical 'bad', literal 'good' and literal 'bad') before doing a cross case-analysis (Yin, 1994) for similar themes and concepts (see figure 2). Data from focus groups, semi-structured interviews and informal interviews were transcribed and subjected to content analysis for concepts or themes which could be categorised as broadly as possible without overlapping (Field and Morse, 1995).

This process was helpful in establishing the presence of converging (or divergent) data sets (Polit and Hungler, 1993) to draw out sub-categories and themes that could be compared against 'hypothetical' data sets drawn from the focus groups. These provide an indication of construct permanence between 'hypothetical' and 'literal' cases – an important consideration in the process of conceptualisation (Knafl and Howard, 1984), or theory development (Yin, 1989) which will now be discussed in relation to the findings themselves.

Data from individual cases will be presented and discussed together before the cross case analysis is considered as divisions between data presentation and data discussion are less apparent within qualitative studies and Yin (1994) himself stresses the need to retain 'context' at every level of the case-study. This equates with his 'Theory-Building Structure' in which, 'the sequence of chapters or sections will follow some theory building logic' in which, 'each chapter or section should unravel a new part of the theoretical argument being made' (p140). It is appropriate therefore to deal with the data and the discussion emanating from it together – in so far as together, they form the basis of theory generation and describe the entirety of the cases described.

CHAPTER 4: DATA PRESENTATION AND DISCUSSION

4.1 Hypothetical Cases

The hypothetical cases were constructed primarily from the two focus groups undertaken at the beginning of the study, although they were also informed by the review of the literature, and in some cases, informal and semi-structured interview data – a process known as data triangulation (Redfern and Norman, 1994) which ensures that the researcher presents a comprehensive picture (Yin, 1994). In all, a total of fifteen nurses, two physiotherapists and one social worker took part in the two focus groups. Open questions such as, 'How would you define a good/bad death?' or 'What circumstances enable a patient to die a good death?' were used to open the groups. Respondents were also asked to list any other words that they would use to describe/convey the quality of a good death, and to evaluate the usefulness and purpose of such descriptions with regard to a) other members of the health-care team, and b) to the deceased's family and social circle.

4.2 Good Deaths

There was unanimity between both groups, and all of the respondents within groups, that they would rarely use the epithet 'good' to describe the death of any of their clients, particularly to the bereaved. One nurse was particularly vociferous, saying, 'I think it's wrong to talk to someone about death being good… how can we? It's not us who've lost someone we love. How can that be good for anybody?' (N9). One physiotherapist however, thought that death could be construed as good when it brought relief to either the patient or family members, but for the most part, reluctance to describe deaths as 'good' seemed to arise from the recognition that every death is unique (Murray-Parkes, 1988; Benoliel, 1977), and cannot readily be reduced to a simple nomenclature which detracted from the personal nature of the loss being described. This appears to be at variance with the suggestions of some authors (Copp, 1997; Young and Cullen, 1996; Bradbury, 1993; Taylor, 1993b), most notably Bloch and Parry (1982), that health-care professionals routinely use binary dichotomizations such as 'good' or 'bad' when making qualitative judgements about the nature of a death. There may have been a reluctance to acknowledge the part that social representations such as 'good' and 'bad' deaths played in their professional work, but respondents may also have been wary not to be seen to be using 'labelling' behaviours in front of the researcher who was largely an unknown quantity at that time. Notwithstanding this, it was evident that such terms were used, even in the focus groups themselves, and it may be that formation of social representations about the nature and quality of a death occurs as a sub-conscious activity on the part of hospice workers, of which they remain unaware.

If Bradbury (1999) is correct in asserting that, 'consciousness is an inherently social process' (p.18), then social representations such as a 'good' or 'bad' death may indeed be socially and culturally constructed within the hospice environment without conscious thought on the part of individuals working there. Certainly, as we shall see in the interview data, there is evidence that 'good deaths' are valued, and their appropriation espoused; so they may have totemic value in the small-world (Bradbury, 1999) of the hospice setting, which is communicated through general value systems and the expectations of the institution, rather than individual cognition. This became apparent when analysing interview data from a senior physician at the hospice who commented that:

'What of course I would argue against is that there should be a perfect hospice death… you have to accept that a number of people are perhaps going to die quite suddenly as well… and that the hospice death isn't the only way to die… asleep and with the curtains drawn… the perception that people dying in their sleep has a beneficial effect on other patients around. I suspect that that idea has been 'handed down' as well – but don't quote me on it! {laughs}.' (emphases mine) (M2)

In spite of this, when asked what constituted a good death, the same doctor said that,

'Generally I suppose, you'd want to die at a good age... generally, you'd want to be comfortable, to maintain quality of life – which is a completely different question until the last minute! Generally, you would want to make sure that family and friends... the closest to you were informed and accepting of that... you'd want to have all of the practical situations sorted, wills... um, I suppose, coming back to trust, that you can trust the people around you that are going to... see you through death.'

The combination of physical comfort and social integration seems broadly consistent with most hospice carers' views, as this quote from one nurse points out:

'Obviously... someone who isn't actually dying in pain – because we have got the analgesia available... nobody should have any pain at all I don't think... and just to have your loved one's around you, and be able to have them near to you.' (N7)

These comments are consistent with data from other interviews and focus group data, members of which were asked to list any words that they would use to describe or convey the quality of a 'good' death. After analysis, fifteen broad themes were generated within the groups that overlap, and are commensurate with other data drawn from interviews and participant observation (Figure 7 overleaf).

Focus groups were limited in size, and one must be wary of generalizing from the results, but the findings are nevertheless quite interesting. One might expect that the relief of physical symptoms, dignity and comfort would rate highly amongst the list of descriptors mentioned by any group of hospice workers (Walter, 1994) given the fact that, 'we have got the analgesia available', and this was indeed the case. There was almost complete unanimity about these 'big ideas' (Krueger, 1994), which might also represent society's expectations of a 'good' death and not just those of hospice-staff, but 'sedated', 'unconscious', 'clean' and 'calm' had not hitherto been noted within the literature. These descriptors may be culturally and socially derived within the hospice – as suggested by the doctor's comments above, but there is little doubt that great importance is placed on calmness, peace and, particularly for the nurses, the value of sedation in managing the dying process. Could this be part of Byock's (1997), 'formulaic or prescriptive approach to life's end... [which] blurs the distinction between death – the state of non-living, and the preceding time of living' (p.32)?

The evidence is scant, but five nurses did feel that it was better, for the benefit of other patients and visitors, that dying patients should be sedated so that, 'they look as though they are sleeping'. Clearly the notions of being asleep, unconscious, or sedated figure highly under Krueger's (1994) 'consideration of frequency and extensiveness of comments' category for focus group analysis, and will be discussed further when discussing the literal case, but it would appear that these nurses placed a high value on the patient being sleepy, asleep, or (perhaps more importantly), having the appearance of sleep in the hours prior to death. Only one nurse argued against this, when she said rather prosaically that the, 'dying process disturbs the disturbed most' i.e. that the tendency to sedate patients may be due more to the discomfort of observers than the needs of the patients themselves; but it is interesting to note that even she said that she would find it easier to tell a relative that their loved one had died 'peacefully in their sleep' than in any other circumstances. Others spoke of this process as 'slipping away', 'passing on peacefully', and 'fading away', and suggested that they would lie to an absent family member if this were not the case in order to help them 'cope better' with the death. The social worker present at one of the focus groups described this as, 'rewriting the script', and whilst not defending the practice, pointed out that the family could be adversely affected by 'our negative perceptions of the death' – a view which is clearly consistent with Lev and McCorkle's (1998) findings.

Descriptor / theme	Number of Respondents Agreeing with Descriptors		
	Nurses	Physiotherapists	Social Worker
	(n=15)	(n=2)	(n=1)
Pain-free	15	2	1
Peaceful	14	2	1
Symptom-free	14	1	1
Dignified	13	2	1
Comfortable	13	2	1
Whilst asleep	12	1	0
Not alone	11	2	1
Anticipated	9	2	1
Sedated	8	1	0
'Old age'	8	1	0
Sudden	7	1	0
Calm	6	1	1
Clean	5	0	0
Unconscious	4	0	0
Socially integrated	0	0	1

Figure 7 – Focus Group Descriptors of 'Good' Deaths – Hypothetical Cases.

One other nurse admitted to, 'making up endings' for family members on the basis that they would, 'believe what they want to anyway', and there was a widespread consensus that families, if absent, should be spared the truth about a death when this was considered to have been 'bad', though one physiotherapist argued against the wholesale use of such strategies on the basis that apparent lies often told cease to be believed. The idea that deaths should be portrayed as 'calm', 'dignified' and 'peaceful' (McNamara et al, 1995; Walters, 1994) was also held by some respondents.

The notion of a 'clean' death was equally interesting, as at first the researcher took it to mean 'clean and swift' – a pseudonym for 'quick' or 'easy' death; but it became apparent when probing the meaning of the word within the group that this was not the case. It was clear that the nurses describing this phenomenon meant exactly that, a death without blood, gore, or any other detritus at the time of death which might render it unpleasant or horrifying to observers and / or the nursing staff present. More importantly for some however, was the sense that the dying person should remain 'intact' so that he might, 'look just like he was when he was asleep'.

Again the juxtaposition of 'sleep' and 'death' are apparent, and vividly so in the minds of two of the nurses who felt that it was important that, 'everything should be as normal in appearance as possible'. They had in their mind the fact that they spent a large proportion of time preparing the body for viewing by relatives, not only on the ward, but whilst it remained in the hospice's mortuary, and regarded this 'cosmetic' part of their work as being of vital importance in helping the bereaved come to terms with the death (Copp, 1998; Byock, 1997; Jennings, 1996, Gavrin and Chapman, 1995). In this respect they may be said to be engaging in the death-work of the Victorian and early twentieth century 'tidy ladies' described by Adams (1993), experienced helpers for the most part, who made the body presentable for the family prior to the funeral, in which case physical intactness and 'clean-ness' would be of paramount importance (Byock, 1997; Humphrey, 1991).

4.3   Bad Deaths

'Bad' deaths on the other hand were perceived as being more memorable, and were invariably associated with pain and uncontrolled symptoms by all of the focus group respondents and all of the

interviewees, as one quote from a senior house-officer at the hospice demonstrates when asked to describe a 'bad' death:

'Painful… someone who's scared, umm… someone maybe who's alone when they die… I think that must be horrible.' (M1)

'Reluctance to die' was also considered to presage a 'bad' death, particularly when young people, small children, and unfulfilled business were involved. Reluctance, lack of acceptance and un-preparedness were strongly associated with 'bad' deaths, which were more likely to be attributed to younger patients rather than the elderly, who were generally considered more likely to be *'ready to go'*. The attainment of a 'good' or 'bad' death was attributed to pre-morbid personality by one nurse of strong religious convictions, who said that a patient's death was a reflection of, 'how well they lived their life', an interesting (if unorthodox) view which was vigorously opposed however by the majority in the group.

Not knowing, or not having a definitive prognosis was also regarded by some as propagating 'bad' deaths, in addition to the length of time people had to assimilate the information and accept the fact that they were dying. Denial (Kubler-Ross, 1991:1975) was always attributed with a 'bad' death, and acceptance with a good one, though when challenging the veracity of acceptance in their patients, nine of the nurses, both physiotherapists and the social worker agreed that exhaustion and capitulation might better reflect the behaviours evident in some dying patients. Similarly, it was felt that sudden, unexpected, and untimely deaths, as for instance, among patients being admitted for respite, rather than terminal care were more likely to be considered 'bad' by the nurses, and to be equated with a poor psychological prognosis for family members by the social worker. One nurse, citing an actual patient scenario explained it thus, *'It was terrible… he'd been told it was an ulcer for years and when he finally came in here he… they were all devastated. It made it difficult for them to trust us'* (N2).

With the exception of poorly controlled physical symptoms, the most important example cited as a factor in determining whether a death was 'good' or 'bad' by the focus group respondents was whether or not friends and family members were present at the time of death. Thirteen nurses and all three of the other professionals represented felt that this was important, whilst two nurses suggested that it may not be an issue. One of these said, *'I really don't think it's always important… I mean, we tell the relatives that the patient can hear them right up to the end, but most of them sit there and say nothing anyway'* (N5). Again, there was a presumption that the dying person would be asleep or sedated as death approached, although the same nurse agreed that it was likely to be very important to family members that they should be present before, or at the time of death in order to say their goodbyes.

The importance of death as a social event (Murray-Parkes, 1988; Feifel, 1989; Kearl, 1989) is clearly outlined in the above comments, and perhaps, rescinds White's (1977) assertion that modern death 'requires the presence of paid, impersonal professionals instead of family and friends' (p.98). He was of course, talking about the modern-medical (i.e. acute hospital) death rather than deaths in a hospice, but it is clear from the above that these health-care professionals would, for the most part, rather have family and friends present at the time of death than not; and that hospice workers, far from being 'disabling professions' (Illich, 1977), appear to pride themselves as being 'enabling professions' in so far as cultivating and facilitating the social activities of the dying person to the very end (Benoliel, 1977).

This is broadly consistent with prevailing philosophy of the hospice and palliative care movement, but may also reflect a socio-utilitarian view on the part of some hospice nurses who have realised that 'good' deaths which are not hidden away may have positive social purpose (Saunders, 1965), as one

member of a focus group suggested when stating that, *'reality is often less frightening than people's fears about death… some of them lose their fear as they watch those around them die – it can be a healing process'* (N7). This nurse was clearly illustrating Weisman's (1973) point that death can stand for something positive when it serves the purposes of both the dying and those who survive them.

Focus group data enabled the researcher to construct a theoretical or hypothetical case for both 'good' and 'bad' deaths, which could then be tested against the concrete or literal cases of each which were derived from the participant observation and interview data (Yin, 1994). Convergence (Seale, 1999) between the two would support the robustness of the study, and confirm the theoretical propositions which guided it (Yin, 1994). The hypothetical cases would also help the researcher to develop sharper and more insightful questions about the study phenomena – a purpose which Knafl and Howard (1984) have described as the sensitisation process. As the focus group data were analysed, it became apparent to the researcher that the descriptors or themes noted in Figure 4 fell into four broad domains:

- Physical or biological
- Psychological
- Social, and
- Existential / Spiritual

These suggested to the researcher that earlier perspectives on death and dying – particularly those of Colin Murray-Parkes (1988) which describe death as a 'psychosocial transition' may be too restrictive. It may be fair to say that his theory was a reaction against the prevailing biomedical view of death as the extinction of physiological life or activity, but in espousing a psychosocial transition theory of death and dying, he may inadvertently have 'thrown the baby out with the bathwater'.

Hospice workers clearly see death as a psychosocial transition, and hence support the validity of his theory, but they are also acutely aware of its physical repercussions. In so far as judging the quality of a death was concerned, physical rather than psychosocial considerations were more frequently enumerated as deciding factors in describing it as 'good' or 'bad', and it seems likely that these occupy the pinnacle of a hierarchical value system, in that failure to manage physical symptoms effectively makes it difficult for other 'domain' needs to be satisfied. These domains may have been anticipated by Benoliel (1977), who notes that, 'assistance to the patient facing death is designed to achieve four general purposes; to facilitate normalization of living according to the patient's preferences throughout the process of dying (Physical); to maximise opportunities for the patient to participate in decisions affecting living or dying (Psychological); to foster and encourage open communication between the dying person and those who are important in his or her life (Social); and to help the patient find an appropriate death (Spiritual/existential)' (p.135). Hypothetical case-data relating to these domains are presented in Figure 8 below.

It is worth noting that while an obvious hierarchy existed in so far as physical needs were concerned, and these were considered as first order priorities, other needs seemed to have equal importance to focus group members. It may be that distinctions between psychosocial and existential needs are not as clearly delineated as one might presume. This may explain the obvious overlap in some areas (such as meaning for example), which may have social, psychological and existential significance. Similarly, it should likewise be noted that there was general unanimity about some descriptors, whilst others were not universally held. Most said that sedation or unconsciousness was more likely to contribute towards a good death, but a number did not support this view. Depending upon the variable therefore, distinctions between 'good' and 'bad' deaths may be less dichotomous than these data suggest, and may be better understood as representing a point along a continuum, rather than as equal but contrary opposites. The reasons for this however, will be discussed later.

Domain	Good Deaths	Bad Deaths
Physical or Biological	Pain is managed	Pain not managed
(First order priority)	Symptoms managed	Symptoms not managed
	Patient made comfortable	Patient uncomfortable
	Patient asleep/unconscious	Patient awake/conscious
	Death is 'clean'	Death is not 'clean'
Psychological	Death is anticipated	Death is not anticipated
(second order priority)	Death is accepted	Death is not accepted
	Death is timely	Death is untimely
	Death is meaningful	Death has no meaning
Social	Patient dies in company	Patient dies alone
(second order priority)	Patient known	Patient unknown
	Patient socially integrated	Patient socially isolated
	Death brings cohesion	Death brings division
Existential/Spiritual	Death is peaceful	Death is not peaceful
(second order priority)	Death is dignified	Death is undignified
	Death is transcendent	Death marks the end
	Death teaches something	Death teaches nothing

Figure 8 – 'Good' and 'Bad' Deaths According to Domain

4.4 Evaluation of Hypothetical Cases

The development of hypothetical cases was useful in two respects. Firstly, they enabled the researcher to clarify some of the concepts previously noted in the literature and thus construct an analytical framework for both 'good' and 'bad' deaths that could be tested against real cases on the ward. Secondly, the data itself identified a number of themes that were not immediately apparent in the literature, and which may – or may not, have had specific relevance for the setting in which the case-study was being conducted (the 'mortuary' work for example of nurses at the hospice, which was an extension of their pre-death caring role). This helped inform the researcher of contextual issues that he may have remained unaware of had this work not been done.

On the whole, when considering the usefulness of hypothetical cases in relation to Krueger's (1994) analytical considerations, it may be said that semantic considerations were dealt with through the seeking and clarification of insight into the words which respondents used during the discussions. These were, for the most part (barring occasional humourous – but valuable 'stress-relieving' interjections), serious if informal affairs. Respondents evidently thought a great deal about their responses, particularly when challenged to defend or to explain a viewpoint that they had expressed, and there was a strong degree of consensus about the vocabulary of 'good' and 'bad' deaths as the data illustrate. The overall impression was that each of the group members, and all of the disciplines represented shared a common-coin of communication when talking about 'good' and 'bad' deaths, and in spite of their stated reluctance to use such terms in the hearing of patient's families, did so extensively and fluently when talking together.

In terms of contextual considerations, the researcher was careful to be as balanced as possible in the discussion, allowing respondents free rein to discuss issues around the locus of the exercise (death) whilst being careful to retain the focus ('good' and 'bad' deaths). The experience of all was validated, and valuable contributions were made by everyone – irrespective of their discipline or training. Internal consistency was generally quite good, in that there were no sudden or unexpected swings of opinion as a result of group interaction, and as far as Krueger's concept of big ideas were concerned,

there was consistent unanimity both between and within the two groups about the social importance of death, control of symptoms, comfort, dignity and patient consciousness - ideas that were to be replicated later as the interview phase of the case-study was conducted and literal cases (Yin, 1994) considered.

Frequency and extensiveness of the comments were consonant with both the expectations of the researcher, and broad themes within the published literature – with the exception of the 'cleanliness' theme, which was entirely new to the researcher and may not have been anticipated from the literature. Most respondents talked knowledgeably about the big ideas that one might imagine any hospice worker to have an interest in, and sympathy for - though these views were held with varying degrees of consistency (as the literal cases will demonstrate). Likewise, the frequency with which ideas were expressed was broadly predictable. One would have expected for instance, that a social-worker would place high value on social integrity – and name it as such, but the theme was touched upon by others under a different, though no less appropriate nomenclature, namely the notion of 'dying with' or 'dying alone' that has already been described.

It is unfortunate however, that greater numbers, and a better representation of professional disciplines were not represented in the two focus groups – particularly medical staff, but in retrospect this could perhaps have been anticipated. In-spite of the lip-service paid to multi-professional working, hospice doctors were still a culturally distinct professional group as the author's field notes demonstrate. These note that medical staff tended not to avail themselves of social or informal opportunities to share experiences or discuss individual cases outside formal arrangements (i.e. the general ward or case-meeting). A separate focus group for the medical staff was considered, but the numbers being so few, it proved impossible to get sufficient of them together at any one time. The researcher did avail himself of two opportunities however, when interviewing doctors in relation to deaths on the ward, to cover the broader aspects of 'good' and 'bad' deaths with them, and their comments in relation to hypothetical deaths have been assimilated with focus groups data.

4.5 Literal Cases

The literal cases (Yin, 1994) were constructed primarily from semi-structured interviews with informants from three disciplines, medicine (n=2), nursing (n=7), and social work (n=1) who had been responsible for the care of the deceased on a purposive sampling basis in relation to two deaths on the ward. Practitioners were asked to suggest suitable examples of 'good' and 'bad' deaths which had occurred during the period of observation (five weeks). Data were transcribed and subjected to content analysis for concepts or themes which could be categorised as broadly as possible without overlapping (Field and Morse, 1995).

Description is the first stage by which interview data is made amenable to analysis by the researcher and is achieved, the most part, by faithfully representing the 'lived world' (Kvale 1996 p. 189) of the respondent in a reported format. A sample of interview data is provided in Appendices 3 and 4, and others will be used elsewhere throughout the course of the following discussion. The reliability of transcribed data, and the inferences drawn from these need to be tested however, and this was done both by submitting a specimen transcript and recorded interview to an experienced colleague (JMC) so that the trustworthiness of the representation, and the consistency of any interpretations drawn from it could be scrutinised. A second transcribed interview was also returned to an original respondent, and the respondent asked to verify its reliability (Yin, 1989). It should be remembered however, that interview data represent but one version of an event, hence the importance of drawing upon multiple sources of evidence (Yin, 1989).

4.6 Criteria for Selection of Literal Cases

It had originally been anticipated that there would be general agreement amongst the informants about those deaths that might be described as 'good' or 'bad' during the study period, but in regard to 'good' deaths this was surprisingly not the case. Respondents had difficulty singling out one death that they could describe as good, not (it should be said) because there were none, but rather because these were regarded as 'the norm' on the ward, and they found it hard to specify a single 'good' death that they regarded as exceptional. Often, they would select specific features from different scenarios to present hypothetical examples of a good death.

When asked about bad deaths however, every respondent drew to mind the example of a death which had occurred three weeks before, not long after the second focus group was conducted, and there is little doubt that this had made an enormous impact on the staff as a whole. One very experienced nurse went so far as to state, *'of all the deaths I've actually seen… I would say that his was one of the worst'* (N2)

The field notes, which contain a comment from the ward manager that the death had been fairly 'traumatic' broadly support this, and there is little doubt that an air of 'failure' (researcher's observations) pervaded the ward whenever the death was mentioned, but it soon became apparent that far from being a universally 'bad' death, there were elements of this death that were both very 'good' and very 'bad'. Respondents frequently contradicted themselves when describing the death, and it became clear that this case was much more complex than had first appeared, boding the question, 'Is it possible for a death to be both good and bad at the same time?'

Having discussed data from the case with the research supervisor (AR) and another experienced case-study researcher (SC), it was decided that this death might actually represent a revelatory case (Yin, 1994), which provides insight into something which has previously been only obscurely understood, namely, that the good/bad dichotomy may be far too simplistic, and it was decided, for the purposes of this thesis at least, to focus upon this one case in so far as it illuminates many of the problems inherent in trying to describe a death according to these criteria.

4.7 Case-History

'Marty' (an assumed name) a forty-four-year-old West Indian man was admitted to the hospice with terminal stomach cancer which had remained undiagnosed over a long period in spite of frequent visits to his GP who had been treating him for an ulcer. When finally referred to an oncologist after an emergency admission to the local A&E department, the tumour was found to be inoperable and Marty was referred for supportive care to the community palliative care team at the hospice, who had been caring for him for two and a half months prior to his admission.

During this time, suspicions had been raised in relation to the safe storage and administration of controlled analgesics in the patient's home when diamorphine ampoules were said to have gone missing, and when admitted, the patient had been reluctant to accept a syringe driver, preferring instead to self-administer IM boluses of diamorphine, after an earlier trial with a diamorphine pump at home had left him with unalleviated pain. Marty lived with his long-term partner and her two children by a previous relationship, and had a wide circle of friends and family members – nieces for the most part, who visited him regularly.

He was admitted to the ward with an exacerbation of his pain, but on admission was verbally aggressive and reluctant to take advice on the management of his symptoms. As these increased, he was taking ever increasing boluses of diamorphine, but went into respiratory depression during the first night, and had been given naloxone by the house-officer to reverse these effects. After this, he wouldn't even let the staff insert a sub-cutaneous cannula for analgesic administration, and was

generally regarded as a 'difficult' patient. He was also prescribed buscopan and octreotide, which he had greater faith in to control his symptoms, but it was evident to the staff working with him that these were insufficient to control his pain. When eventually, he allowed them to commence a syringe driver, he experienced some relief of his symptoms, but died on his third night from a huge gastro-intestinal haemorrhage with his partner, her children, and other family members at the bedside.

4.8   The Illustrative Bad Death

Many of the themes emerging from the interview data in relation to Marty's death could perhaps, have been anticipated from the hypothetical cases generated from to the focus groups, and this was indeed the case, with three exceptions. The main categories to emerge from interview data in relation to his death were:

- Unalleviated pain
- Unalleviated non-pain symptoms
- Denial of prognosis / unrealistic expectations
- An undignified / untimely death

In addition to this, two broader themes that could not have been anticipated from the earlier focus group work were also identified, namely:

- Lack of trust / suspicion of staff and,
- Conflicts between patient autonomy and
- Professional control

4.9   Unalleviated Pain

One medical officer described Marty's pain on admission to the hospice thus:

'He was having terrible pain, and when he had the pain, it was extremely clear that, well… his reaction to it was very extreme, in that he would roll around the bed in agony, under the bed, screaming, and was… inconsolable I suppose.' (M1)

This assessment was matched by at least three of the nurses who cared for Marty in the three days that he remained in the hospice prior to his death as one nurse (N1) comments:

'You could see that he was in agony, not knowing what to do with himself, very terminally restless, up and down all night, umm… sitting, crouching, walking, umm…wrinkling his whole face, but refusing to have morphine.'

There is a sense however, that what made this death particularly bad was the fact that Marty was actually refusing analgesia for his pain, which most of the staff found very difficult to cope with. A second nurse put it thus:

'It really is not a nice way to feel, I mean… when I went off duty I was feeling that there was heaps more that I would have been able to do had he let me, but he wouldn't let us… it was really frustrating and upsetting and… (long pause) … yeah… it was horrible.' (N2)

Marty's main non-pain symptoms were stomach cramps and nausea and vomiting from an obstructed stomach. These again seemed to contribute towards the death being described as 'bad', although they were mentioned less frequently.

4.10   Denial

Denial featured heavily in the assessment of Marty's death since this was seen to be holding both he and his partner back from accepting the fact that he was dying. One nurse (N2) notes that:

'On the few occasions when he was in extreme discomfort he would be screaming 'What's happening to me? Why am I feeling like this…' and we really wanted to say, 'It's because you are dying honey, you're VERY (respondent emphasis) unwell – let us help you' - but I didn't think that he wanted to hear that… and even his common-law wife, when I spoke to her, she looked at me like I was speaking a different language.'

This was not universally felt however. Another nurse – one who was actually present at the time of death said, 'when he came in he didn't want to discuss at all about dying – although perhaps this isn't such a bad thing' (N1), though most felt that he had rather unrealistic expectations, *'still very much talking about cure, and going back to (name of cancer centre), and treating the tumour, treating the obstruction, having operations'* (M2).

This lead one nurse (N4) to conclude that, *'he was VERY unrealistic I feel… I mean, he actually wanted to go to the Notting Hill Carnival on the day before he died…wanted us to give him a diamorphine syringe to take with him for the pain'*, an unrealism which extended to Marty's partner who had wanted him to be resuscitated if he died.

4.11   Lack of Dignity

The death when it came was sudden, unanticipated, and far from dignified:

'It wasn't very pleasant – although M. wasn't in any distress himself, it was VERY unpleasant visually. That is the word that I would actually use… to die surrounded by blood… pretty ghastly for anybody… but there wasn't any warning that this was going to happen… it did happen very, very suddenly… My priorities were actually to comfort Marty's family, so we just had to put material on the floor so that we could walk over it.' (N5)

The presence of family members – including his two stepchildren under such circumstances were regarded as particularly distressing by the same nurse:

'It was his poor family that my main concern was for, because it must have been absolutely horrendous for them, watching a loved one… I mean there were a lot of women in there… and just to see him actually vomiting blood was really awful for them to watch… his partner was saying, 'Don't do this to us Marty. Don't do this to us… don't leave us like this'… and his children were there, and it was very, very… [sighs] Hard.'

This may have been made worse by the fact that another nurse had not long said to the family that Marty, who by this time, had consented to a single syringe driver containing diamorphine, buscopan, nozinan, midazolam and an anti-emetic, was most likely to die in his sleep. She concluded*, 'It's a bit of a shame that he had that massive bleed at the very end…I'd find that quite horrific and… distressing'* (N1).

4.12   Lack of Trust

However, one got the sense from talking to staff members that other issues were perhaps more significant when defining the death as 'bad' than the purely physical events surrounding Marty's death. These lay primarily within two broad categories, firstly, that Marty and his partner did not trust them to manage his care appropriately and secondly, that attempts to manage his death had been met with resistance – largely due to his desire to retain control over what was happening to him.

'A lot of the issues came down to sort of control. He wanted to be very much in control, and that was going against what the hospice rules and regulations would allow… the nurses were extremely concerned about him doing that.' (M2)

These comments were supported by one of the nurses:

'I sometimes felt that he didn't trust us – which wasn't easy, and we certainly didn't want him taking full syringes off of us because he might have injected himself in a site that wasn't appropriate… umm… and I think that as professional practitioners we would have been responsible for that.' (N5)

This, together perhaps, with the earlier issues of missing diamorphine phials in the home had evidently affected Marty's relationship with the hospice staff as one doctor noted:

'I think that a lot of the nurses found him extremely difficult to deal with, umm…and that had led to a certain element of animosity.' (M2)

Clearly this was the case, as one nurse (N2) vividly remembered:

'When I went into him to say that the next lot of injections were due he said, 'YOU put that abocath in me didn't you… and I asked you not to' – and I said, 'I did, but I had to… you weren't able to voice that at the time', so he said, 'Well I'm voicing it now… you take it out!'

This issue came up in each of the interviews, and the social worker felt that Marty had been labelled as untrustworthy and unreliable by some of the staff in response to the community palliative care team's anxieties about the missing phials of diamorphine. Certainly, one nurse (N1) described him as a, *'manipulative man'* and a second (N2) described him as *'angry'*, and yet the admitting doctor remembers that, *'when I talked to him about diamorphine he was very concerned that he was going to become a junkie – like people in the streets.'* (M1)

There seemed to be little appreciation however, of the fact that Marty might have good cause to be suspicious or angry – apart from one nurse who said, 'he felt it (the syringe driver) was useless… it wasn't controlling his symptoms, it was just something else for him to carry around… to worry about' (N2). Similarly, she noted that he had, *'lost faith in doctors and nurses in general, not anybody in particular… because of the time it took to diagnose his cancer – which for years he'd been told it was just an ulcer'*. His reticence to relinquish control should not have come as a surprise therefore, but may have been difficult for hospice staff to accept when, *'the majority of our patients DO trust us… it's very seldom that we come up against patients who don't'* (N5).

4.13   Autonomy and Control

These issues led Marty to retain rather more control than the hospice staff were used to in their other patients. This sometimes caused problems, and one nurse acknowledged that, *'he was quite a difficult patient to manage, particularly umm… when you've got seventeen other patients on the ward. He took up a lot of time'* (N1).

His desire to control events was often seen as the greatest factor preventing him from obtaining a 'good' death. One nurse commenting that, *'it hadn't been easy with Marty because he'd had resistance to accepting medication that we felt would actually have helped him'* (N4), whilst one doctor put it more strongly when he said that, *'patients should know that we as healthcare professional also have OUR own autonomy… that they should respect OUR autonomy as well as theirs… because otherwise… well, you can see why people say that we are just giving into anything that anyone wants.'* (M1)

It is interesting to note that autonomy was mentioned 46 times in relation to the patient's right to control the circumstances of their dying during the interviews – and was a feature of focus group data

as well, but control was mentioned slightly more often, 52 times, suggesting that contradictory paradigms may be at work within the scenario being described. It is perhaps noteworthy that the same doctor made the following comment:

'The thing is… you know that we need to give people their autonomy… and actually, when someone tries to be completely autonomous… and their ideas are completely different to ours… that's actually very difficult to cope with.' (M1)

This issue in particular will be dealt with in relation to the cross case analysis, but prior to this, it is necessary to establish which elements of the same death were construed as good.

4.14   The Good Death

In spite of Marty's death being described as a 'bad' death, there was general recognition that many aspects of it had been good – most notably the period immediately prior to death, when drugs within the syringe driver had eventually overcome his pain and other symptoms. Respondents also noted that there had been attempts at reconciliation between Marty and various staff members, and that he had eventually come to accept the limitations which his condition placed upon him. More importantly however, there was a growing recognition by some respondents of Marty's ownership over his dying, and the sense that he died 'in character'. One person summed it up thus:

'He was such a strong character… and that's the way he wanted it…and, umm… you know, we are meant to try and go with the patient's wishes as far as possible.' (N1)

On reflection, some doubted whether he could have died any other way. After the initial problems surrounding his care on admission, he did eventually agree to a syringe driver being set up, and his last hours were actually quite comfortable. One doctor said, *'it was wonderful to see someone who had been SO worked up and in pain, umm… and now he was just completely at peace, and he was really, really thankful, and apologised for how he'd been and said, 'I'd been completely shitty to you yesterday'* (M1) He went on to describe that, *'I think for his last few hours his pain had been quite well controlled. I think he was quite sleepy, but wasn't completely asleep, and in that case, I think we… hopefully controlled his symptoms and make him at peace before he died.'*

Attempts at reconciliation were also made towards some of the nursing staff, one nurse (N2) commenting that, *'at one point when I went into him he says, 'I want to give you a cuddle, I'm sorry the way I spoke to you' and I thought that… you know, had he let us look after him the day he arrived he would have saved himself all that discomfort and all that distress… so I think that was when he accepted it… and of course, he only lived a few hours after that.'*

Another nurse (N1) who said that he died *'reasonably peacefully'* after his haemorrhage corroborates this, as does a second, who notes that apart from the bleed – of which he was not conscious, *'he wasn't in any pain during his actual dying process'* (N5).

Nurse 1 – who had described the death as *'quite hard to manage'* conceded that, *'there were some lovely parts of it, umm… so I am reluctant to say that it was a bad death… it was just the whole situation I think'*, and went on to describe how Marty and his partner had been able to spend time holding hands together and sitting quietly just prior to his death. Eventually she concluded, *'it was quite rewarding in the end… that you could see a change in him… the fact that he knew that the time was coming'*.

Interestingly, those who had been present for those last few hours were marginally less traumatised than those who hadn't, and most distinguished between the 'process' – the difficult days following his admission, and the outcome of that process – the physiological extinction of life which, in spite of it's unpleasantness, was portrayed as being quite peaceful.

4.15   Conclusions Drawn from a Cross-Case Analysis

Hypothetical cases drawn from the focus groups together with the literature review helped to provide the analytical framework (Yin, 1994) against which the literal good and bad death exemplars could be compared. For the most part, there was a fair degree of replication across the two types of case, in that the relief of pain and non-pain symptoms, the social context of dying, acceptance and dignity were all considered important criteria by which the quality of a death could be measured.

Bloch and Parry's (1982) dichotomization of 'good' and 'bad' deaths into two distinct entities was not, however, entirely supported in this case, as respondents readily acknowledged that there were several meaningful – indeed, 'lovely' aspects surrounding Marty's death, and yet they had all delineated it as a bad one in the first instance. This may be due to respondents making a subtle distinction between the 'process', generally regarded as a difficult or unpleasant experience, and it's 'outcome' (Byock, 1997), which those who were present could see in a more positive light.

To these same carers, it seemed more important that Marty had died 'in characteristic fashion' (Dempsey, 1975) or in circumstances (with regard to his not being sedated, and still relatively in control of his death) which he 'would have wished for' (Weisman, 1973 p.399), although it is impossible to gauge whether this represents an attempt at rationalisation on their part. If this is indeed the case, it must be a common phenomenon, since both of the doctors and at least two of the nurses who had cared for him most intensively prior to his death mentioned it.

However, there is something of a paradox here, for it was also they who found it hardest to cope with Marty's attempts to retain control, and were often the most vociferous in stating how difficult they found this to be, one (N1) arguing that clearer boundaries should have been established on his right to dictate the circumstances of his care, and another (M1) vigorously challenging his own right as an autonomous professional not to have his expertise questioned.

Interestingly however, it appeared that these same respondents held to the shibboleths of the death awareness movement, i.e. the notion that denial should be replaced by acceptance (Kubler-Ross, 1975), or that patients should die the 'hospice version' of a good death, least emphatically, and may, in spite of feeling challenged by Marty's attempts to control the circumstances of his dying, have been most flexible in allowing him the space to do so. There was also some suggestion that he actively sought out those that he wanted to care for him, and documentary evidence that he refused the care of others. If this was indeed the case, he may have chosen wisely. Certainly, the 'gut' feeling of the researcher was that Marty's behaviour gave others an excuse to avoid direct care for him, and this may have been expedient under the circumstances.

Lay-professional conflicts about the nature and control of the dying process (Walter, 1994) seem very much in evidence in this case, particularly in so far as professional and/or hierarchical constraints on allowing Marty to control his dying are concerned. The researcher's field-notes contain many references to 'acceptable' modes of behaviour that were encouraged in the patients on the ward – namely passivity, gratitude, contemplation, acceptance – 'actively teaching the patient the craft of dying' (Walters, 1994), but never anger. And yet this perhaps is an unfair conclusion to draw. Cicely Saunders herself defends the right of the terminally ill to, 'live fully until he dies as himself' (1965 p.4), whilst Lichter (1991) talks about the good death as one in which the individual dies in the way that he wants. However, like most converts to a cause, it would appear that some disciples of the death awareness movement find it harder to break free from dogmatic assumptions about what a 'good' hospice death (Davison and Degner, 1998; Byock, 1997) should, or should not entail than those they follow.

The case study also demonstrates that whilst hospice workers in a hypothetical case uphold notions of patient autonomy, involvement and control, many find it harder to support these notions when

they come into conflict with their professional opinion or the prevailing culture of the working environment. The construct permanence of these criteria were weaker than pain and non-pain symptom control for instance, and possibly less strong than notions of social integration and a dignified death, but this may be due to the genuine distress of watching the patient suffer needless pain, which implies that physical considerations override existential concepts in their priorities.

'Quality of life' rarely entered into the conversations, interviews, or focus group data gathered as part of the study, and it was gratifying to see that practitioners were much more concerned about the quality of a patient's death experience (Flaming, 2000). This is hopeful, for it suggests that they have jettisoned the concept in so far as dying patients are concerned, and may be ahead of their academic counterparts in doing so (Hardy et al, 1999; Hearn and Higginson, 1997), but there was no evidence that this concept had been replaced by anything else – let alone a well-enunciated and comprehensive framework for assessing patient experiences of dying.

The study does demonstrate however, that hospice workers construct complex and sophisticated social representations, which help them to classify this important aspect of their social world (Moscovici, 1993; 1973). The criteria that they use to do this appear to have both objective and subjective components. Observable indices, such as pain and non-pain symptom management, the presence of family members, and the physical circumstances surrounding a death are balanced against existential values, that they, or in the second instance, the patient holds dear. The reasons for this are less certain, but appear to have professional as well as personal implications.

It appears that these are shaped in part, by individual's perceptions of death, but they may also be constructed through dialogue in negotiation with others, and there is, it would appear, a desire to see positive outcomes – even in situations which might otherwise be construed as bad or unpleasant (Bradbury, 1999). Cultural norms appear to shape the social representations which hospice workers make (Copp, 1997), or at least provide a measure for their attainment – as is the case with the 'normative' hospice death (McNamara et al, 1995) that one respondent articulated so clearly. They do not however, appear to override the personal values of the subject however, and when these are in conflict with hierarchical views or institutional mores, they seem to be amenable to change over time, and in differing circumstances.

4.16   Critique of Methods Used

Case-study is an intensive methodology which is time consuming and makes great demands upon the researcher – particularly when different methods of data collection are used in a process of triangulation (Redfern and Norman, 1994). It does however, elicit enormous volumes of rich data (Yin, 1994), but this is not without its problems, most notably knowing how to categorise and handle different types of data, and being selective in their use. There is a tendency at the beginning of a study to regard everything as significant, and this was indeed the case, but the researcher eventually learned to apply methodological and theoretical filters when collecting and handling the data. It was, nevertheless, an ambitious project to undertake in so short a time, and the analysis of data was far more demanding than anticipated.

The adoption of a participant observer role was also more difficult than at first assumed. The researcher had constantly to hold back from making his views about the care of individual patients known which was sometimes difficult, as the medical staff in particular would often invite an opinion on such matters given their knowledge of the researcher's career and research interests. Under different circumstances, it might have been possible to have 'blinded' likely respondents to the expertise and interests of the researcher, but this was not possible in an environment in which he was so well known.

Similarly, the researcher found himself to be neither a member of the nursing staff nor a member of the medical team, hovering somewhere in the middle, which was a lonely position to occupy given the nature of the work in which he was involved, and there were a number of occasions when reservations about the quality of care being given caused the researcher to make a series of frustrated field-notes relating to the relative powerlessness of this role. Interviewing others, be they patients or professionals about issues of death and dying is an incredibly sensitive business (Kelly et al, 2000; Mamo, 1999), and the emotional costs to respondents have been well documented (Johnson and Plant, 1996) but there is little published literature on the effects of such research on researchers themselves. In other circumstances, the author would have arranged a formal system of supervision for the duration of the study.

4.17   Implications for Health-Care Practice

The research demonstrates that health-care professionals make complex and sophisticated social representations about the nature of death, both in order to make sense of the emotional labour in which they are involved, and to communicate the positive outcomes of their work. It identifies some – though not all of the criteria that are considered necessary to the facilitation of 'good' deaths in dying patients, but also points to the inadequacy of relying upon a single theoretical framework or conception of what constitutes a 'good' or 'bad' death when caring for the terminally ill.

The study also demonstrates that no single individual has a monopoly of understanding on the subject of death in all its complexity, and likewise, that the needs of individual patients are equally diverse. Respect for the individual, rather than the attainment of cultural, philosophical or professional 'norms' should guide the care of the dying, and health-care professionals, wherever they are working, should reflect upon the importance they place on autonomy, advocacy and the right of individual patients to manage the circumstances of their dying if anything more than lip-service is to be paid to these constructs.

Similarly, it also highlights the potentially disastrous consequences of 'labelling' patients as 'manipulative', 'problematic' or 'troublesome' – a situation which preceded Marty's admission to the ward, and was based upon inaccurate assumptions about opiate abuse. Later events demonstrate that not only was Marty anxious about becoming dependent upon opiates for the control of his pain, but he was also extremely sensitive to the drugs themselves. One has to ask however, if the same conclusion would have been drawn had Marty not been a black Afro-Caribbean male, and there is perhaps, a strong case for hospice practitioners to reassess their cultural competence to care for those of ethnic or other minority groups.

The research also establishes the need for greater understanding of the emotional labour which those involved in the care of the dying face. There is a general presumption that health-care professionals working in hospice settings become used to death, and that the cultural and philosophical environment in which they work makes it easier to deal with, but without exception, many of those interviewed expressed feelings of inadequacy, guilt and frustration about the circumstances of Marty's death, which had left painful and enduring emotional scars on at least two of them, as demonstrated by their becoming tearful as they spoke about it.

Many of those involved in the death (which occurred overnight) had also gone on 'nights-off' on the Monday morning immediately afterwards, and had not had opportunity to de-brief before this time. The effects of this were twofold, firstly, those who had not been present at the time of Marty's death tended to have formed much more negative social representations of these events, formulated for the most part, from the unfortunate early hours of his admission, and the graphic picture of his dying from a massive haemorrhage. For them, the death was seen as a failure, and the overall effect of this on the moral of the staff was tangible from the researcher's first day on the ward.

Secondly, those returning from nights off later felt, (incorrectly as it turned out), that the ward had 'moved on' since the death, and were less likely to address the issues unless invited to do so. Their sense of 'unfinished business' was very pertinent, particularly in view of Marty's tendency to set 'day-staff' against the 'night-staff' when vying with each for control of his circumstances. Similarly, implicit criticisms were made about the community palliative care team, particularly in regard to the early 'labelling' behaviour, which had deleteriously affected the events surrounding his admission, but there was no established framework by which to resolve these issues.

Without exception, all of the respondents, (including the medical staff), said that they had found it immensely helpful to talk about the death as part of the research process, and the manager of the unit was positively enthusiastic about the effect which this had had on helping the ward establish 'closure' on the events surrounding Marty's death, but these issues should not be left to chance (Mamo, 1999; McNamara et al, 1995). The lack of formal counselling or support services for staff dealing with the emotional labour of death in such a setting is both surprising and deplorable, as is the lack of formal mechanisms to deal with differences of opinion or misunderstandings between in-patient and community staff – who see themselves as two distinct entities, often vying for each other over ownership of the patient.

It is the view of the researcher than a 'knowledgeable, skilled, and empathic stranger' might be invaluable in facilitating these outcomes on a one-to-one basis as and when the need arises. It seems unlikely that clinical supervision imposed 'from the top down' would have quite the same effect, given that feelings of 'guilt' and 'failure' emanated from a belief that the organisation had certain expectations of what could, and should be achieved for dying patients in the hospice, which had not been entirely fulfilled in this case. There was also considerable anxiety about not being seen to 'toe-the-party-line' when discussing things such as denial, acceptance, and the value of a 'typical' hospice death, so it seems appropriate that a neutral outsider fulfil this role.

Similarly, it seems unlikely that many of the issues discussed above would be overcome in a wider discussion or support group – unless this was entirely organic in origin, since the focus groups had demonstrated that there was a tendency not to share one's thoughts or feelings as honestly or as deeply as in the privacy of an interview situation. Indeed, in some cases, there was considerable dissonance between what was assented to in the public gaze of a focus group, and what was later confided to the researcher in the privacy of the interview setting. Likewise, given the propensity of some to try and dominate these groups, it seems unlikely that this strategy would benefit all equally.

4.18   Implications for Future Research

The study presents a number of opportunities for further research. Firstly, it describes some of the criteria which health-care professionals working in the hospice use when defining a death as 'good' or 'bad', and offers tentative hypotheses as to why they do this, but the inferences drawn from it are generalizable to the theoretical propositions which informed the study and not to a wider population (Yin, 1994). Others may therefore wish to test the applicability and consistency (Lincoln and Guba, 1989) of the study by replicating it firstly in other hospice settings – and then those other settings where death occurs. This will help to establish whether the social representations presented here are specific to the hospice in which the study took place, or whether they represent a broader consensus of experience and opinion.

Secondly, it would be useful to establish whether the criteria used by professional carers when evaluating the quality of a death are the same as those used by family members or other informal carers. This may help to identify additional criteria which health-care professionals should consider when caring for the dying, and thus ensure that social representations of 'good' and 'bad' deaths are moved from the narrow confines of a medico-technical and legal professional paradigm to one which

is more broadly defined. These need not necessarily follow the case study methodology, but it is assumed that qualitative methods of data collection, such as interview studies would be used in the first instance to extract the richest possible data on this complex phenomenon.

Further research is also indicated into the ways in which the training, experience, and exposure of different health-care professionals to the care of the dying shape individual social representations of 'good' and 'bad' deaths. In so far as training is concerned, this might be done by means of cohort studies, which follow up health-care professionals who have been exposed to different palliative-care curricula in both pre and post-registration courses, whilst the effect of differing clinical experience might be measured through studies which stratify respondents according to experience and the length of time working in this area.

The case-study described above incorporated the views and experience of a great many different health-care professionals, but there may also be value in looking more intently at the beliefs, values, and constructs which shape the views of individual groups of practitioners, such as doctors, nurses, physiotherapists etc. which will determine whether there is general agreement about the 'criteria' necessary to achieve a good death between those working in different disciplines. The numbers included in this study are too small to extrapolate an opinion from the data, but there did appear to be subtle differences of opinion or emphasis between the doctors and nurses interviewed during the study. Finally, it is clear that health-care professionals need to be much better informed about the needs of the dying, particularly those from different ethnic, social or cultural groups. The concept of 'spiritual care' that is assented to by most working within the hospice and palliative care movement is but one expression of terminal care, and goes far beyond an individual's religious affiliation. This case study demonstrates that notions of control, autonomy and respect for the individual should also be consistent with these aims, and greater understanding is required about the values which individual groups within society place upon both the care of the dying, and the death experience itself. This may be carried out by a series of ethnographic studies, or perhaps, by drawing people from different faith and value systems together and asking them to share their views about matters which are common to us all, through focus groups or individual case studies for instance.

4.19   Conclusion

The study described above demonstrates that hospice workers use complex, and to a large extent, predictable criteria, such as the absence of pain and non-pain symptoms, comfort, dignity, and social integration when evaluating whether the death of an individual patient was 'good' or 'bad'. There was less agreement however about other constructs, such as acceptance and spiritual preparedness, which were not universally assented to, and the concept of patient choice and autonomy which, in spite of suggestions to the contrary, was viewed negatively when carried to its logical conclusion.

This demonstrates the effectiveness of the case study method both to investigate a contemporary phenomenon such as 'good' or 'bad' deaths within a real-life context (Yin, 1994), and to establish relationships between theory and research undertaken in the field – whether this is for the purpose of theory testing or theory generation (Bergen and While, 2000). It also highlights several legitimate areas of interest that require further investigation, and suggests some of the ways in which this might be accomplished. Finally, it demonstrates both the tremendous goodwill of those who care for the dying, and the depth of emotional labour which their work often entails. It also shows how a relatively short period of intense exposure to the small world (Bradbury, 1999) of hospice workers can elicit large volumes of powerful and surprisingly painful data which those who strive to care for the dying should find reassuring. Their refreshingly honest admissions of failure and inadequacy, and their sense of achievement in a small task well done should, if nothing else, inspire others to strive officiously towards the same end when caring for the dying.

APPENDIX ONE

SAMPLE INTERVIEW DATA

M2 Specialist Registrar - 5 months in the Hospice,
but had 4 years' experience of hospice / palliative care.

On-call physician on the weekend of M's death.

[Interviewer – 'Thank you for agreeing to talk to me about M's death. To start with, would you like to tell me what you remember about it?]

I remember M. very distinctly – which I suppose says something about him, umm… I'd not met him before that weekend in any way, but I was just on call, sort of covering. Umm… and I think the nurses contacted me quite early on the Saturday morning to get up and to see him. I'd had some information about him handed over, and really I arrived on quite a stressed ward I think… do you want me to carry on?

[Interviewer – *'Yes… if that's OK?'*]

I think that a lot of the nurses found him extremely difficult to deal with, umm… and that had led to a certain element of animosity it seemed, but there were a number of others who seemed to have bonded with him OK. The one's he liked he liked, and the one's he disliked – he had quite a definite dislike for.

A lot of the issues came down to sort of control. He wanted to be very much in control, and that was going against what the hospice rules and regulations would allow. For example, he wanted to take home some diamorphine for the pain, so that if he was having pain he would be able to give it to himself, whereas the nurses were extremely concerned about doing that – quite understandably, as they can't prescribe diamorphine just to inject into himself, umm… so that was one sort of side of it.

The other side of it was the fact that his symptoms were not being controlled. Umm… he was having terrible pain, and when he had the pain, it was extremely clear that, well… his reaction to it was very extreme, in that he would roll around the bed in agony, under the bed, screaming, and was… inconsolable I suppose… though I have to admit that I didn't ever see him like that, it's just a history I've been getting from other people I suppose.

Umm… I think he may have had some diarrhoea, and certainly the pain was the main thing, though he had vomiting, and was vomiting quite a lot. So err… I went to see him and I think that I was quite lucky in that he seemed to get on with me OK, and I listened very carefully to what he said and um… we came to some sort of agreement umm… about what we could do to get him home for an hour or two, umm… fortunately the nurse that was with him for the weekend was equally well in with him, so between the three or four of us that could talk to him, I think that there was quite a good agreement, and that probably helped to build the relationship for later on in the weekend, because he DID go home and had some time with his daughters and family, and from what I understand, that was quite a reasonable time, umm…

…I can't remember whether he used the injection or not, but anyway… he came back later in that afternoon, still in a bad state, umm… but having chewed things over, and very much talking about cure, and going back to (name of local cancer centre), *and treating the tumour, treating the obstruction, having operations, and… again, we talked to him for quite a long period of time about the fact that* (name of hospice) *couldn't offer him a cure, umm… and with the state he was in at the time there was NO way that he could go through an operation, but that there were other various drug measures to try and control his symptoms which might help to make things better… and to look at it from that point of view… you can't cure the disease, but you can help someone feel better.*

Now he said, and I don't know whether to believe it or not, but he said, 'people have never explained it to me in those terms before', umm…he liked the sound of that, he said it sounded beautiful, because we weren't saying that he couldn't go back to (name of local cancer centre), *but he had to feel better than he was…and we made various other adjustments – I can't remember exactly what drugs he was on, to try and improve things, and he stayed that night, that was Saturday night.*

I can't remember what sort of night he had though. I should have had his notes, but I don't think there would have been that much detail I suspect, probably still not a very good one. He was vomiting, still in pain… umm…

…Next day he was looking worse. He was quite evidently badly obstructed – or completely obstructed as he probably was the day before too, the symptoms being worse and… I can't remember in so much detail what happened on the Sunday… I know we talked again for quite long periods of time and it soon became apparent that things weren't getting any better, umm… in the end we used some midazolam, a sedative on the Sunday, and again… that was something that he'd been very against until that point but… umm… we just talked through the fact that we couldn't stop these symptoms from getting any worse, and err… used the midazolam, and he settled initially, quite well… And as far as I'm concerned, I didn't really see him much more after that.

I switched a bit more to (name of partner) … *she'd gone home, and he was looking just a bit more poorly, so we rang her up and said that we were worried things had changed… and she came in, this was at about half-five, six o'clock – maybe a bit later on Sunday, and I don't know if it was that time or a bit later that she brought the girls with her, but at some point the girls had come too…*

She was very tearful, she was very umm… upset, not so much because he was dying, it was more because she hadn't… as I remember, had an opportunity to talk about these things, or to arrange more practical sort of issues – there were problems over, err… with his other wife, because he had a previous wife and things like this, that sort of issue… and his previous wife didn't know… and then umm… the girls came… I can't remember their names, and the older one… it's one of those terrible situations where you meet in the corridor, and you can't go anywhere else, and I just said something very briefly like, 'How do you think he is?' and she said, 'I know he's more poorly' and burst into tears and ran off downstairs…

(name of partner) *followed her, so I went back to* (name of partner) *later, and was asking her about the girls, and she had said that she had found it very difficult to talk to them and they WERE holding back, so* (name of partner) *thought it was beneficial because she could go off and talk to her, and that had helped. And then we talked to the younger one, and she was very much more stoical about it, she* (name of partner) *said, 'Dad's… you know… he's dying', but she didn't have any real reaction to that.*

After that I didn't hear any more. I was on call but I was elsewhere. I assumed that I'd left him quite peacefully, umm… but I heard afterwards that he had died during the night umm… and it was only sort of later, catching up with the ward – this is not my usual ward - that I heard what happened. I heard that they'd had a very bad night. The actual details of that I wasn't really… you know, I wasn't there at the time, but I heard retrospectively from the ward staff that the ward staff that he hadn't died comfortably'

[Interviewer – *'Using your own words, how would you describe M's quality of life in the 48 hours that you had known him?*]

Umm… Looking at it from his point of view I suppose that he would have been desperately unhappy about it because the day before he died, we were sitting outside in the sun. He was talking quite well. He was quite lucid, certainly Saturday… I'm not quite so sure about the Sunday, and then he died quite quickly, in fact he died within the next 24 hours… and he was in control, right up until Sunday morning, Sunday afternoon. He HAD been doing what he wanted up till that stage, umm… so up to a point all right. The downside I suppose… I would have thought he'd say, was that he was here at all…umm… having said that I think that he did accept that the symptoms were that bad that it was fairly impossible to try and deal with them at home, so he would have been accepting… but on the other hand?

As regards the physical state he was in… talking to him when he was alert, the pain interrupted what he wanted to do, and it was unpleasant, he was so worried about it that he wanted to leap into treatment, either… [3 second pause]

So in some ways, with what was an extremely difficult medical condition to handle, I think it probably would have been as good a quality of life as he could have got… even from his perspective.

From OUR perspective, I think it was dire… umm, because his symptoms weren't well controlled, it is horrible to see somebody rolling about in pain, vomiting profusely… and it's horrible to see a situation that hasn't been properly sorted if you like… I don't mean that in a critical way, but it's nice to see the loose ends tied – and they certainly hadn't been… for instance… and I don't mean this in a critical way, and the fact that there was… animosity… the fact that you see a person die when you haven't really got to the root of their problems…I get the feeling, from knowing him for only a short period of time that these things wouldn't have bothered him quite so much

[Interviewer- *'That being the case, if you were to describe his death in qualitative terms, how might you described the experience of death that he had?'*]

From HIS point of view, I think I would have said pretty much what I've just said… but I think that if you look from his point of view, the quality of his death was about as good as we could do in that situation – because he wanted to be very much in control, which we very much stuck to. He didn't want various interventions we offered that might have improved his physical symptoms - a naso-gastric tube for example, and he died quickly. I got the impression that he didn't want to hang around… so I guess I would have described it as, 'he got as good a death as he could have got' … umm…

I don't think you could say that it was a good death… certainly the circumstances wouldn't permit that… but that's a bit contradictory isn't it? It's not a good physical death… he was obviously uncomfortable physically, but because of the condition he had, we couldn't get him any better than that… and he understood that.

I suppose looking at it from OUR point of view, we would say that it was a nasty death in that we were never going to be able to get under control perfectly… even if he was the most compliant of patients… it was always going to be, umm… [five second pause]

… and if we could have made his visit better than it was, but not 100 percent, I suppose he would have been… [eight second pause]

… as far as the taste it leaves in our mouth afterwards…

[Interviewer – *'You described the mood on the ward as being quite stressed, and said that the nursing staff were quite stressed?'*]

Yeah…

[Interviewer – *'Would you have said that M's family were stressed?'*]

I only met (partner's name) *… I spent quite a lot of time speaking to her with M… I think… from what I remember, she was very much happy to be guided by what he wanted, that was the impression I got, in that she listened to what we talked about and she would back up things I said… like the nasogastric tube.*

She said 'why don't you think about that', but he said, 'No, I really don't want that' or, 'No, it's really important for me to get home', then she would be really quite supportive of that. So the only time I saw her stressed in any way was on that Sunday evening when we talked about the possibility of him dying, and she was really very tearful… but it seemed to be the practical side of things that were making her tearful – rather than the physical side…

She was worried about giving him midazolam, because he didn't get to sleep before, but I said, 'Look, I have talked to him about it and he agreed to have it' – but we'd built up enough trust by that stage, so she accepted that and it was OK. In retrospect she might look back on that and say… but at the time she seemed quite accepting. I think that we had built up quite a good relationship… trust is the other point… I think they were quite distrusting of some people…

…the impression I got was that umm… not everybody was willing to respect his wish to be in control… you know… 'We know better and this is what we are going to do' – and he did drop that line on Saturday umm… I think it was about midazolam, but on the Friday night… I think it came about then. He was a very forthright person and he could be a very… insulting person! If he didn't like someone he would let them know. And he said that about the night staff when I started… he didn't like the way they treated him…

[Interviewer – 'Do you think that (name of partner) *trusted them?'*]

I dunno… she would probably have looked on them as individuals, and judged them as individuals… but every patient who comes in here has horror stories about what medical staff have done to people… umm… and she would probably have said the same… I think… I got the feeling she trusted me… but maybe she didn't…

[Interviewer – 'Hmm… And your perception was that to her, what mattered more, even than his physical symptoms, was that his wishes were respected?']

That was the impression I got at the time… she would tolerate some quite distressing symptoms in him, as long as his wishes were respected… that's the impression I got… she was in on all the conversations we had. She KNEW that we were offering other things, but other than suggesting it, it didn't seem to distress her if he said no.

[Interviewer – 'If M. was able to have the best possible death that you could prescribe for him, what features would you say were important?']

A good death… Umm… generally I suppose, you'd want to die at a good age, generally you'd want to be comfortable, to maintain quality of life – which is a completely different question until the last minute! Generally, you would want to make sure that family and friends… the people closest to you were informed and accepting of that, generally, you'd want to have all of the practical situations sorted, wills, umm… that you are spiritually… umm… content with your own life, and that… I suppose… coming back to trust, that you can trust the people around you that are going to, sort of, see you through death… you would have to trust the midwife that brings you into the world, and I guess it's just the same… there's a quote in there somewhere (laughs)

[Interviewer – 'I guess, looking at all of that, that M. had the complete antithesis – in almost every respect…']

Except… one, that he seemed to know what he wanted… and, and, it isn't on my list, but it's your wishes at how things should be… I suppose that's the issue… M. was totally competent to make decisions… he knew exactly what was going on as regards drugs and things, and so you had to respect… because it was there… it was present…

Now… I wonder at an earlier stage if he could have been confronted more… particularly about more long-term views…so I suppose some of those problems could have been dealt with much earlier on… but I wasn't there so I don't know. Control CAN be overcome, but you DO have to go step by step…

… I suppose it's this issue of control isn't it? This balance between how much you respect their control, and how much you want to act to their benefit. You could see it yourself, with the nurses who were dealing with him on Saturday… they are nurses who very much like to respect what people want, that's what they're taught to do, umm… but other, more opportunistic individuals may have seen that

THAT was the time that they HAD to over-ride his control, and that that was perhaps the right time to do it… I didn't quite read it that way, but I wasn't there at the time umm…so I would be critical to override it…

[Interviewer – *'Would you say then, looking at M's death, that he was someone who was never going to have the classical 'hospice' death that one might have 'prescribed'?*]

NO… he was NEVER going to have that… of course, you would need to define that but um… the sort of thing… thinking about sleeping peacefully and then gradually slipping away, then no, he was never going to have that physically, and because of his personality he was always going to be quite a tricky one, but what I would of course argue against is that there should be a perfect hospice death. It depends of course how you define that but if you do, I think that it has to come in… that the aspects of autonomy and control, what a person wants are…

[eight second pause] *… but you have to accept that a number of those people are perhaps going to die quite suddenly as well… and that the hospice death isn't the only way to die… asleep and with the curtains drawn… The perception that people dying in their sleep has a beneficial effect on other patients around… I suspect that that idea has been 'handed down' as well but don't quote me on that one'*

SAMPLE INTERVIEW DATA

N1 – recently qualified staff nurse at the hospice for eighteen months following
fourteen months in oncology. Qualified 3 years. Patient known to nurse for 4 nights. He died on her
last night shift.

She was nurse in charge of the ward on the night of M's death.

[Interviewer – 'Thanks for agreeing to talk to me (Name of Nurse) … *Do you want to start off by telling me what grade you are and how many years experience you have got in caring for the dying?*']

Ok. I'm an E grade staff nurse on (Name of Ward), *umm…and I've been working at* (Name of Hospice) *for eighteen months. Umm… prior to that umm… I was ion oncology for fourteen months, and that was before qualifying, so I'm three years qualified.*

[Interviewer – *'That's great thanks. To start off then, would you like to tell me a little bit about M's death, umm… just the circumstances around it in terms of what happened, and how long you'd known him'*]

Umm… I knew M. for… I think he was admitted, I was doing the night shifts and I looked after him for the four nights. I think he was a new admission on my first night, and he came in for terminal care. I mean… he was in fact dying… umm… and he died on my last night, umm… what I consider really to be a bad death in some respects, in that M. when he came in didn't want to discuss at all about dying, although perhaps this isn't such a bad thing.

Umm, he died on the fourth night, reasonably peacefully, but it was a bit unfortunate that he had a massive oral bleed, um… which distressed his partner and his two nieces that where with him at the time, umm… and he died within seconds of starting to bleed umm, but there was a lot of screaming and going-on on their part because the partner was reluctant to discuss that he was dying, umm… and just HUGE emotional issues, a lot of tears, umm… I mean in some respects it was a good death, but, umm, it's just that M. required a lot of attention during those four nights. He was quite a manipulative man, umm… wanted to be very much in control of giving his own injections, didn't want a syringe driver, didn't want morphine, umm… would rather be in pain and be awake, umm… which is always quite difficult I find for staff nurses to deal with although we have to respect different people's cultures, umm… but I think it's because we feel ourselves that we wouldn't want to be in that pain…

Umm… but he also didn't want sedation for that purpose, umm… but it was quite hard to watch him suffer because… evidently you could see that he was in agony, not knowing what to do with himself, very terminally restless, up and down all night, umm… crouching, sitting, walking umm… wrinkling his whole face, but refusing to have morphine, umm… he became quite manipulative, umm… in the respect that he was demanding that certain nurses weren't to look after him, umm…

I don't know if that was connected with the fact that he was getting quite angry that he was dying umm… demanding in the middle of the night to see a doctor for no apparent reason, umm… demanding to speak to the night sister, umm… to discuss that certain nurses not give him medication, umm… and they needed to set boundaries in the day with the doctor about it. We were happy for him to give himself his own injections but not to actually draw it up. Umm… but then he would still try and manipulate you in the evening although the boundaries had been set.

[Interviewer – *'hmmm'*]

Umm… so he was quite a difficult patient to manage, particularly umm… when you've got seventeen other patients on the ward. He took up a lot of time… umm, in fact I was in the room for hours at a time. He was a VERY, VERY frightened man, umm…… (five second pause)

[Interviewer – *Do you think that the work of establishing boundaries was one of the factors that made it a bad death?*]

Umm… I think that the boundaries should have been set as soon as he came in because it was very apparent as soon as he came in that he was of that character umm… I know he demanded in the middle of the night at one stage that umm… he was going to go home just like that, umm… and one of the main reasons for coming in was that his partner, who has been his partner for many years couldn't

cope with him at home being in that amount of pain. They've also got umm… two youngish daughters as well, umm… so perhaps the boundaries needed to be set earlier.

Even though they were set he was very manipulative with it anyway, and he would test the same thing with different nurses, umm… I still don't know whether I would actually call it a bad death, umm… HARD, one that's going to make you think for a while, 'could I have perhaps handled it differently?'

Umm… It was nice that his partner was there. On the last night he sat up about two hours before he died and err, I helped him sit and they held each other and he was trying desperately to say 'I love you' to her, and she was rocking him, and that was very, very lovely umm… and I knew that he would die that night and that's what I said to her – although she didn't want to hear it. Umm… so there were some lovely parts of it, umm… so I am reluctant to say that it was a BAD death, umm… but err, it was just the whole situation I think.

[Interviewer – *'Are there any other words that you would use to describe it other than good or bad?'*]

Hmm… (ten second pause) *I can't think of a word off-hand really umm … (five second pause) … I mean, I suppose the death itself was a bit… just a bit sad that he had to bleed at the very end, umm… because she [M's partner] did, although she was reluctant to, err, talk about it, and said that it would be quite nice if just slipped away in his sleep and I said that there was a high possibility that that might happen. Umm, and… perhaps it's a bit of a shame that he had that massive bleed at the very end. Umm… I'd say it was distressing for me because I think that if I saw that with a loved one I'd find that quite horrific, and, so, DISTRESSING might be a word.*

[Interviewer – *'A better word?'*]

Yeah.

[Interviewer – *'Had M. ever talked to you about, or given any intimation of how he might like to die?'*]

No, not at all. He didn't, umm, really want to talk in a direct way about Dying. He spoke, umm… in an indirect way about close friends that were ill with cancer, umm… that he'd been, umm… helping with, and he actually, on the second, umm… right before he died, umm… looked through our BACUP books, umm, not of his related cancer, but of his friend's, because he said that he wanted to read them and help them. I mean, in actual fact, umm… when the sister on for the house and myself sat down with him and explained that there were other patients on the ward and it couldn't be just me that looked after him – other nurses would have to answer the call-bell, umm… he actually said, 'Well I could help with other patient's psychological problems because I'm very good at helping people that are very very ill', but he never talked about himself being very ill. You tried to broach the subject and he would change it quickly.

[Interviewer – *Hmmm…. 'How would you describe that behaviour in M?'*]

[Nurse - Forcefully] DENIAL*…umm, which again, isn't always such a bad thing, umm… I think that umm… as nurses some of us want to see acceptance towards the end umm, but umm, I'd say that denial wasn't such a bad thing anyway. And perhaps you shouldn't umm, be trying to bring someone out of denial. I did give him the opportunity to talk about it, and he didn't, so I didn't push it.*

[Interviewer – *'Do you think it's possible to have a good or appropriate death in denial?'*]

I think you can certainly have an appropriate death in denial. Umm, I don't think that necessarily accepting that you are going to die is a good death.

[Interviewer – (agreeing) *Umm… 'M's partner - even though she didn't want to talk about the death… how easy do you think she found it to accept the death?'*]

Umm… she did say, very close to the end, after she had been holding M. – this is about an hour or so before he died, that she wished that she had been there the night before. Umm… to see if he would talk about it. She regretted that they never spoke about the end and umm… and how he felt about it umm…. I know when she was crying after he died that she was saying 'I don't believe it I don't believe it and rocking herself' and just generally quite distressed, but… I mean it's hard to say how anyone might feel, but I'd say that there was almost a bit of relief there as well…

Because she'd seen him in so much distress at home and I think he'd been like that for quite a while at home, being quite a determined man, which would have been distressing for her so, perhaps it could have been a relief for her.

[Interviewer – *Hmm. 'Did she make any comment to you about the manner of the death in terms of value judgements or a subjective comment?'*]

No, umm… not really. Obviously she screamed when he started bleeding, you know, 'Come quick, come quick', umm… but once he'd been cleaned up and when she went and said goodbye she never made any comment that it was horrific or anything like that. She said 'Thank you very much' and stuff. She only stayed for about half an hour umm, with the other two family members that were there umm… she didn't, she didn't really make too many comments, and was very quiet when she left.

[Interviewer – *'When you were handing over the next morning to the day staff can you recall how you described the events of the evening to them, when you where handing over?'*]

Umm… I just gave a very brief handover, umm… because we do taped handovers, umm, just that he had deteriorated during the night, umm, that his partner was with him, and two other family members came in that where there to the very end, umm, I didn't actually say it was a bad death on the tape, umm… I said that umm... that he'd had a bleed at the end, and other than that it was quite peaceful, and that they would be ringing the next week to arrange to come in for the 'day after death' (meeting), *but I certainly didn't say that it was bad or horrific or anything. Just the very basic facts.*

[Interviewer – *'You used the word that there were some aspects of the death, of the evening that were quite nice, that there was a positive element to the events of the night…'*]

(Agreeing – *hmmm*)

['*…can you isolate those aspects that made it positive for you?*]

Just that she was really… was kind of saying 'goodbye' when she was holding him just before he died, umm… and that the niece who was very close to him rang in about one o'clock, and she said, umm, will her uncle be more awake in the morning to chat to, and she actually said, because she would like to say goodbye to him properly and things. She seemed to be accepting that he was going to die but not that imminently, and I actually said to her that in my professional opinion, 'I think that he will die tonight, although you can never tell these things'.

She actually then made the decision to come in, and that was actually quite positive because she badly wanted to be there, and was, and was a great support to the partner, umm… although she had been drinking. She was a bit hysterical when she came in, but that was quite positive… and he was fairly comfortable. Umm... he did have a syringe driver right at the VERY end. I would have liked to have given him a little bit extra at one stage when he seemed to be a bit twitchy and appeared to be in pain, umm… but the partner refused point blank. We had a discussion about it and we agreed to see how it goes – whether he would settle down, because I knew that would have been M's wish too – because he was against having anything himself, and he DID settle of his own accord… so that was quite positive.

I seemed to gain the partner's trust umm…. (seven second pause) … *Umm, I mean, I'd say it was quite good – it's just that it was, it was the whole situation, it was difficult to manage for the whole four*

nights, and was taking up quite a lot of time, umm… when you've got a lot of other patients on the ward.

[Interviewer – 'When he was twitching you felt that it was more important to do what you knew, or had been told of his own wishes as regards treatment rather than the immediate sorting out of his symptoms. That took priority you felt?']

I felt it took priority umm… obviously with symptom control there is the potential to start getting worse, and being in more pain and getting twitchier, but yes, I certainly think that going in there with some sedation and umm… pain control, umm... he was unable to discuss it being unconscious practically. He was unable to discuss it with me so I discussed it with his partner umm… and I felt, from what she said, that he would have said exactly the same thing – with nursing him on the nights before, so I was prepared to see how he went and he settled of his own accord.

[Interviewer – (agreeing) *Hmmm, 'So there was a strong correlation between what you knew of his views and what his girlfriend was expressing on the night. Do you think that made it easier for you?']*

It did make it a lot easier yeah, umm… I felt I had to justify to the other, umm, there was another, fairly umm… new staff nurse on who'd been in the room with me because she (the partner) *buzzed 'cos he'd sat up and was getting twitchy err, and she said, umm, why did I not give him anything, and I had to sort of justify my reasons – about being the patient's advocate, and just as I explained it to you then… and she seemed very happy with that, because you feel that you've got to do something the whole time umm… so that was quite rewarding and, and it was just good to get the trust of the partner.*

[Interviewer – 'Was he on anything other than the diamorphine or morphine?']

In the driver you mean?

[Interviewer – 'Yes']

The driver had um… five drugs in it, umm, it was agreed with him to actually put it up on the day shift, umm, on the day before… no the day he died, in the morning… so he had five drugs in one driver – even though you are only meant to have three, but it was agreed with the doctor. Umm, he had midazolam, nozinan, a VERY small amount of diamorphine, umm… buscopan, and something else, some anti-sickness I think… so a HUGE cocktail in one driver that ran over twelve hours – so I had to change it during the night umm… and also going through with the partner exactly what it had in it umm… she did question me about the diamorphine, you know, 'are you sure that this isn't going to kill him?' – because she was still at that stage of you know, sort of semi-denial like, umm… he wasn't going to die he was going to get better…

[Interviewer – 'This is on the night that he died?']

Yeah…. Umm, but it was quite rewarding in the end, that you could see a change in him… the fact that she knew that the time was coming…

[Interviewer – 'And other than his bleeding, and the short period where he was twitchy, he was otherwise quite comfortable?']

Yeah, very much so, yeah… yeah

[Interviewer – 'And she seemed to be happy with that']

*….. (fifteen second pause) …. Umm [*nodding]

[Interviewer – 'Is there anything else that you would like to say, or ask me about the interview?']

I don't think so

[Interviewer – 'Looking back over the whole experience, would you say that there was anyway that it could have been better? That's not a judgement in any way on your care, but could it have been any different given the situation you were in?']

…. (five second pause) ….

I really don't think so actually…. NO, he was such a strong charactered man… and that's the way he wanted it, umm… and, umm… you know, we are meant to try and go with the patient's wishes as far as possible, umm, so… possibly not. Per…haps… you know, when he was still very chatty the night before, perhaps she, I think that she (the partner) *felt bad that she didn't spend that time with him, but I did, I particularly described to her that we had gone to the kitchen together… he had wanted some weetabix and hot milk, and then he was looking at the BACUP books, and she looked at me and said, 'Oh, I wish that I had been there because I'm not going to get that now' and, umm… but you just don't know these things.*

She (the partner) *felt that she would have wanted to be there, so perhaps that's the only thing different… that maybe, umm…someone could have given her the indication that it was going to happen fairly quickly, so that she could arrange for someone to look after the girls and maybe spend a bit more time with him.*

[Interviewer – 'Do you think that would have been practical?']

Umm… Yes, because there was one… two nights before he died umm… that was when he said that he wanted to leave the hospice umm… and I was actually on my break and the nurses called her in at about six o'clock in the morning and she actually calmed him down and he said that he wanted a bath at six o'clock in the morning, so the girls (other nurses) *ran a bath and she spent an hour with him, umm… just holding his hand while he relaxed in the bath. It helped his pain a bit as well. Umm… so she was quite good. I don't think that she would have aggravated the situation.*

[Interviewer – 'So you think that it was important from M's point of view that it was important that she was there with him on the night that he died?]

Umm… I'm NOT sure about that because I know, umm, the night before when he was very frightened, he never actually asked for his partner to be 'rung' in – and I DID ask him at one point 'would you like her to be here now?' umm, because he squeezed my hand at one point and didn't say he was frightened, but non-verbally he looked frightened, and I said umm, 'would you like me to call her in so she can sit with you – because I'm sure that she would be more than happy, umm…but he declined the offer, so I don't know whether he would have wanted her in there at the last moment or not.

[Interviewer – 'You can only go by what happened can't you']

Yeah…

[Interviewer – 'Well thank you. I think that we have probably got through everything. Is there anything that you would like to ask me?']

No… I don't think so.

[Interviewer- 'Have you found it helpful?']

Yes, DEFINITELY!

[Interviewer – 'Really, I'm just looking to draw out the strands that make a death good and bad, and words you've used, like umm… 'advocacy' which you've used have obviously made a difference in M's case']

(Agreeing) *Huh-huh!*

[Interviewer – *'control, the human contact – the fact that he was able to embrace his partner…and I'm trying to draw out the things that make a death good or bad. You know… the fact that even though he hadn't communicated necessarily how he would have wanted to die, there was a sense in which he died in character…'*]

(Agreeing) *Huh-huh!*

[Interviewer – *'… and there is a sense in which you were really tuned into his character, and what he would have wanted, which I think, umm… it suggests to me that it was very much the sort of death under the circumstances that he would have…'*]

(Agreeing emphatically) *Oh Yeah!*

[Interviewer – *'… and there is a sense in which you were really tuned into his character, and what he would have wanted, which I think, umm… suggests to me that it was very much the sort of death under the circumstances that he would have wanted…'*]

(Again, agreeing emphatically) *Oh Yeah!*

[Interviewer – *'… because it sounds as though he was in control'*]

(Agreeing) *Yeah*

[Interviewer – *'right up to the very end almost…''*]

Yeah

[Interviewer – *'which was quite good. OK… thank you (Name of nurse).'*]

'OK! Thank you…'

[Interviewer – *'Not too traumatic?'*]

(emphatically) *NO!* (laughs)

[Interviewer – *'OK… Thanks very much'*]

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