Caring for the person with variant Creutzfeldt-Jakob disease within the hospice service

By

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Abstract

This thesis explores the experience of caring for people with the new diseases of variant Creutzfeldt-Jakob disease (CJD) by hospice services. The experiences of the hospice staff and carers of five people, who had died, or were dying, as a result of variant CJD, at three different hospice sites in the South of England were explored. Data from four focus groups and 11 interviews, with hospice staff (included health care assistants, nurses, doctors and social workers) and family members, plus hospice patient records were analysed. Media material was also examined and used to inform the study.

The thesis offers a theoretical explanation of these experiences developed through grounded theory methodology using an emergent fit design. It describes the event of the admission into the hospice service of a person with a new disease, that of variant CJD, and how the dying experience of these people was managed by both in-house and community hospice teams. ‘Open systems’ theory is used to assist in analysis and interpretation of the participant experiences, and as a means of ‘contextualising’ the hospice service. The hospice is presented as a metaphorical container within which dying is processed, and where the primary task of the organisation had a different emphasis and focus, depending on individual perspectives of participants.

A theory of ‘dealing with the unknown’ was developed to explain the impact of this new disease on system equilibrium. The disease was a novelty and influenced admissions into the service and responses to the disease by others. It engendered the need for staff to use controlling practices to maintain the system balance. There were paradoxes between the practices of in-house and community teams, and between in-house and family member ‘understanding’ of how care was managed. The experience of caring for people with variant CJD was also profoundly humbling for participants. Humility was identified as a response to the realisation of limitations in relieving the suffering of people with variant CJD and their families. The study demonstrated change over time, where hospice staff moved from not knowing to becoming knowledgeable about managing the care of the person with variant CJD. The theory is complimented by and builds on existing theories of hospice practice.
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Introduction to the Thesis

For many years I have had an interest in, and been clinically involved with, end-of-life issues for older people, including people with dementia. This has been both as a practitioner and as an educator in the fields of palliative care and care of older people. The focus of this research developed from these interests. The emergence of variant Creutzfeldt-Jakob disease (CJD) offered the opportunity to explore the experience of providing palliative care for a specific group of people who experience a type of cognitive impairment that is categorised within the dementia syndromes. This thesis documents my journey to explore this experience and develop myself as a researcher.

The literature review comprises Chapter 1 and 2. It begins by providing a background to CJD as a dementia syndrome, the emergence of variant CJD and the scientific and social responses to this emergence. The second part of the literature review addresses literature on hospice practices and theories of hospice care that consider concepts of the ‘good death’, dignity, personhood and the focus on the body of the dying person. Implications of these concepts that relate to dementia care at the end-of-life are considered during this discussion.

Grounded theory, the methodology used to conduct the study, is discussed in detail in Chapter 3. I present a critical discussion of the rationale and justification for my research design and how and why I set out to take a constructivist approach and use open systems theory in the analysis and interpretation of my data. Chapter 4 provides a step by step description of the methods I used to collect and analyse my research data.
In Chapter 5 the findings are presented at the same time as the discussion, in keeping with using grounded theory methodology. A series of figures are presented as each category is described, building up to the complete theoretical explanation of the experiences of my study participants. In Chapter 6 I present a critique of the study and discuss the contribution the thesis makes to an understanding of hospice culture and practice and to research knowledge. This is followed by my conclusion.
Literature Review

Chapter 1 - Creutzfeldt-Jakob disease (CJD)

1.1 Introduction

Chapters 1 and 2 comprise the literature review. Chapter 1 provides a background of the emergence of the new disease of variant CJD, beginning with a short discussion defining the term dementia. This was necessary as dementia is often viewed as a specific disease rather than as symptoms of neurological damage and the cognitive impairment that has ensued from the damage. A description of the four main types of CJD and the mode of transmission of these is given. Responses to the emergence of the new variant of CJD is examined and some discussion on the proof offered by scientists that the disease is directly connected to the outbreak of BSE is provided. A discussion on the clinical progress of variant CJD is then presented, including the diagnosis and care for sufferers, focusing on end-stage issues. The final section of this chapter discusses the social component of variant CJD as a potentially 'dreaded' disease.

1.2 CJD as a dementia syndrome

1.2.1 Neurological diseases and dementia

Brain dysfunction is extremely varied and extensive. It can be caused by brain injury and from a variety of neurological disorders, and may be genetic or environmentally induced. In the event of a neuropathology that leads to the loss of cognitive function, biochemical changes that occur vary, depending on the area of tissue that is affected and the cause of that effect. Mechanisms in this process include tissue destruction, compression, inflammation, and biochemical imbalances. In other words, the process of dementia is one manifestation of some of the many brain disorders (Cheston and
Bender 1999; Wilcock et al 1999; CJD Surveillance Unit 2002). Dementia, therefore, is not a disease in itself but a neuropsychological deficit that has occurred as a result of chronic brain disease or encephalopathy (Neary 1999).

The World Health Organisation (WHO 2003) ICD-10 definition of dementia refers to it as a syndrome due to disease of the brain. It is usually of a chronic or progressive nature. There is a disturbance of multiple higher cortical function, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation. This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

Dementia is used as a specific term indicative of a variety of pathological disorders i.e. dementia is a term related to symptoms rather than to a specific disease. At each stage of history the medical establishment (and the population) accept the textbook definition of their time and the diagnosis depends on an arbitrary dividing line drawn on some point in a continuum of disability and may be viewed as an evolving concept (Berrios and Freeman 1991:1). Berrios and Freeman (1991:1, 2) propose a shift towards the ‘creational’ approach to diagnosis, acknowledging that there is ‘no such thing as the final description of a disease’. Its clinical boundaries, symptom-content, and even anatomical descriptions are no more than temporary scripts, taken from the ongoing medical discourse. That is, the creation of disease can also be viewed as social phenomenon. Once a name is accepted it quickly comes to dominate the social
reality of the disease and the flavour of the name can make a difference to how the disease is perceived and acted on (Shenk 2001).

For the purposes of this thesis, the term dementia refers to the cognitive deterioration that occurs for neurological disorders classified within the dementia syndromes, including CJD. This places my use of the term dementia within a bio-medical frame. Whilst the bio-medical frame will be used to discuss the neurological manifestations of dementia caused by CJD it will not detract from addressing issues such as personhood as this relates to the person with cognitive impairment. That is, throughout the thesis I also consider the psychological and social factors of the experiences of the person with variant CJD. Literature that discusses theories of the social construction of dementia, particularly dementia of the Alzheimer type (see for example; Kitwood 1988, 1989, 1990, 1993, 1997; Kitwood and Bredin 1992; Adams and Bartlett 2003) will not be addressed in any detail.

1.3 Categories of CJD

CJD has historically been classified within the dementia syndromes. Neary (1999) suggests that the traditional definition of dementia, as a global deterioration of intellectual function, is incorrect. He points out that cerebral diseases do not affect the brain uniformly. These diseases preferentially affect certain brain areas. This impacts on psychological and physiological processes that depend on the functioning of specific brain regions.

CJD belongs to a group of diseases known as transmissible spongiform encephalopathies (TSE) that are known to occur in both humans and animals. It is a
The disease is rare, rapidly progressive and fatal. The progress of multifocal encephalopathies is aggressive, it ‘seems not to respect anatomical boundaries or functional systems so that a wide variety of psychological and neurological deficits rapidly emerge’ (Neary 1999:61). Brain damage that occurs is characterised by the spongy appearance of brain tissue seen under a microscope (Lacey 1994; Weihl and Roos 1999; Roberts 2003). It is also referred to as prion disease. Prion is an acronym for a PROteinaceous INfectious agent. The prion theory suggests that the infective agent of CJD is only composed of protein and does not contain nucleic acid, which would be necessary if the agent was a conventional virus. The transmittable agent is either genetic or an abnormal form of prion protein that causes aggregates of cellular protein to accumulate in the brain. The exact process that occurs that leads to brain damage from original inoculation/contamination is incompletely understood (Will et al 1996; Bruce et al 1997; Weihl and Roos 1999; Will et al 2000; Brown et al 2001; Roberts 2003).

Historically three types of CJD have been identified; iatrogenic, inherited and sporadic. Iatrogenic CJD refers to the cases of CJD that have been caused by medical treatment. These comprise a very small number of cases. The causes include: injections of infected growth hormone material, tissue grafts, particularly corneal transplants and human dura mater grafts; and contamination from neurosurgical instruments and depth electrodes (Will 2003). More recently iatrogenic CJD has occurred as a result of a CJD contaminated blood transfusion (Llewelyn et al 2004). Media and medical focus on the iatrogenic risk of contracting CJD substantially increased following the emergence of variant CJD. Inherited CJD occurs where there is a mutation in the prion protein gene that makes conversion into the abnormal form
more likely. Approximately 10% of the cases of CJD are inherited. Sporadic CJD (also referred to as classical CJD) refers to cases of CJD that occur at random throughout the world. They are categorised as sporadic if they have no genetic mutation or any known iatrogenic infection. Sporadic CJD accounts for 85% of all cases of CJD (CJD Surveillance Unit 2004). Other more rare types of spongiform encephalopathies include 'kuru'. Kuru is a TSE that was confined to the Fore social group or tribe, and amongst other groups who intermarried with the Fore group, in the Eastern highlands of Papua New Guinea. It was transmitted through an endocannibalistic ritual associated with mourning. Women and children comprised the majority of kuru victims. During the practice of cannibalism the women carried out autopsies barehanded and did not wash thereafter. Infants and children (of both sexes) appeared to have been contaminated through contact, as children did not ingest kuru-infected tissues. Men, unlike women and children, rarely handled or ate the brain of dead kuru victims and were therefore rarely contaminated (Verdrager 1997; Weihl and Roos 1999; Ironside and Head 2003). Kuru is highlighted here as it provides an example of how contamination can occur from the infectious agent via both contact and ingestion. It is now very rarely found amongst this group due to the cessation of cannibalism in Papua New Guinea (Ironside and Head 2003).

1.3.1 Emergence of variant CJD

In 1996, in the United Kingdom (UK), a new variant of CJD (nvCJD) disease was officially recognised (Will et al 1996; Will et al 2000). What was unusual about this new type of CJD was that those infected were young people and that it closely resembled the spongiform encephalopathy of bovine spongiform encephalopathy (BSE), a prion disease of cattle. This new disease was originally referred to as new
variant CJD and later shortened to variant CJD. The emergence of variant CJD is believed to be linked to the BSE outbreak during the 1980s (Scott et al. 1999). It is widely accepted that the BSE epidemic that occurred in the mid-1980s originated from animals consuming feed that was contaminated with scrapie, a sheep prion disease.

The potential for BSE disease in cattle to cross the species barrier was suggested as early as 1988 (Lacey 1994) and concern about risk to humans was expressed within weeks of the first case of BSE (Britton et al. 1995; Bateman et al. 1995; Brown et al. 2001). However, it was not openly addressed by the UK Government until Will et al. (1996) published a paper confirming the emergence of variant CJD. Emergence of the new form of CJD, and its link to BSE, provoked a world wide interest in all types of CJD. Several countries have carried out surveys to establish the status of all CJD cases and identify any evidence of the presence of the variant type of CJD. Countries that have carried out surveys include the US, France, Italy, Japan and others. These surveys confirmed that variant CJD was initially confined to the UK. However, cases are now emerging in other countries, some with a known connection of possible contamination in the UK, with recently reported cases in Japan in a man who had visited the UK in 1990 (Asia news yahoo 2005) and the Netherlands (Yahoo News 2005a).

To make predictions on the potential variant CJD epidemic it was also important to establish that variant CJD was a new disease entity and not simply the result of better case ascertainment. Hillier et al. (2002) carried out a systematic study of all certified deaths in Wales of individuals between the ages of 15 to 45, between 1985 and 1995.
to detect variant CJD deaths that might have been overlooked. No cases were detected and the researchers conclude that variant CJD was a new disease entity which appeared to predominantly affect younger people (Hillier et al. 2002; Will et al. 2002).

1.4 Mode of transmission and predictions

Since 1996, 156 cases of variant CJD, confirmed or probable (some still living) have been reported in the UK (National CJD Surveillance Unit 2005). This figure is updated monthly. Future predictions have been a matter of debate among scientists within the media and scientific and medical literature, and the implications of the emergence of this new variant continues to be debated. The consequence of the emergence of the variant CJD is as yet unknown. Little notice was taken of Lacey’s (1994) work, yet he provides a comprehensive history of BSE in Britain in which he highlighted the already known risk of contamination by prions, long before the first case of variant CJD was identified. In a summary of what was known by the end of 1988, he points out that diseases caused by agents with similar properties, i.e. the TSEs, later identified as infections caused by the prion protein (prion theory), occurred in several mammalian species, including man. Experimentally the majority of mammalian species challenged with the infective agent would develop the disease, if challenge titres were sufficiently high, i.e. the ‘species barrier’ could be breached. Main routes of natural infection were known to be through ingesting infected food and it was thought that vertical transmission (from mother to foetus) was possible, including contamination of pasture by infected placenta tissue (Lacey 1994; Chesebro 2003). These modes of transmission had occurred in sheep, goats, mink, mule deer and man (kuru) (Lacey 1994; Weihl and Roos 1999; Roberts 2003).
The hypothetical transmission through ingestion of BSE contaminated food has been challenged by a relatively small section of the scientific community. Suggested modes of contamination by organophosphates (McConville 2000) or managanese toxicity, which is related to the organophosphate toxicity theory (Ahuja 2002), have been made. These hypotheses have been refuted by the majority of the scientific community (Garofalo et al 2001). A further suggestion that variant CJD is caused by a bacteria, namely Mycobacterium bovis (bovine tuberculosis), has been made based on the epidemiological maps of the origins and peak incidence of BSE matching England’s areas of highest bovine tuberculosis (Broxmeyer 2004).

As a declared means of provoking debate on the subject of the mode of transmission, Venters (2001) argued that the evidence for variant CJD being a new disease entity is flawed. The argument is made that possibilities other than the BSE connection have not been reviewed and legitimately rejected. Venters (2001) maintained that the numbers are not consistent with possible exposure and incubation, and that the link can only be inferred. These arguments have provoked little debate and Brown (2001a:841) echoes the certainty of other scientists in the field in declaring that ‘there is but one incontestable fact, that BSE is the cause of variant CJD’. However, Will (2003) admits that the evidence supporting the BSE contamination hypothesis remains weak. Although there is no reasonable alternative to the hypothesis, Will (2003) points out that there are major methodological difficulties in establishing risk through past composition of commonly consumed food products.
A cluster of cases in Leicestershire (Allroggen et al. 2000) gave some indication of a hypothetical mode of transmission based on butcher practices where contamination of meat occurred from contact with brain or spinal tissue (Collinge 2001). As a result of this link regular media reports on the subject of variant CJD have identified a range of sources of the contamination through the food chain. These include medication products (BBC 2002a) and baby food (BBC 2002b). A controversial hypothesis that BSE may have entered baby food in the 1970s has been suggested based on the long incubation period from contamination to showing signs of infection (Meikle 2005). Headlines from several newspapers during March 2005 mooted a 'school dinners link' to CJD deaths based on three deaths where the victims had received school dinners using meat that had come from the same local slaughterhouse (Yahoo News 2005; Shipton 2005). These concerns have also been highlighted from a sociological perspective where food risks and the public conception of these have been discussed (Beck 1992, 1995; Shaw 1999; Lupton 1999). Beck (1992:23) particularly highlights how the mass media and scientific and legal professions have the power to change, magnify, dramatise or minimise the knowledge of risk to the extent that these risks are 'particularly open to social definition and construction'.

In 1990 a National Creutzfeldt-Jakob Disease Surveillance Unit was established. The primary aim of the Unit was to monitor the characteristics of all forms of CJD in the UK, to identify trends in incident rates and study risk factors for the development of the disease (Will 2002). The role of the Unit also includes co-ordination of surveillance programmes for CJD throughout the European Union. Their aim is to inform the scientific community, policy makers and the general public of developments as they emerge. The work carried out by the Unit includes attempting
to visit all suspected cases of CJD to collect data on a range of issues, including past diet, occupation, and residence (Will 2002). Since 1996, as a result of the emergence of variant CJD, there have been a number of articles published that discuss risk factors for transmission of all types of CJD (Collins et al 1999; Hansel 1999; Weihl and Roos 1999; Zerr et al 2000; Will 2003). Others have discussed methods of preventing iatrogenic transmission of CJD within the health environment. These included operating theatre practices and the use and sterilisation of surgical instruments and the handling of body fluids (Dyke 1997; Finkelstein et al 1998; Williams 1999; Clarkson 2000; Belkin 2003; Department of Health 2003) with a call for disposable ear nose and throat (ENT) instruments for operating theatres (Bingham 2002). Further concerns were raised regarding risk from contaminated dental instruments (Smith et al 2002), contact lenses and ophthalmic devices (Macalister and Buckley 2002) and cosmetic injections (Laurance 2005). The media and public focus has been on food risk and variant CJD, with more recent concerns expressed regarding possible risks from blood products (Ironside and Head 2003; Roberts 2003; Bird 2004).

Originally the risk of transmission of CJD through blood products was hypothetical, even though experiments on sheep showed that BSE could be transmitted via blood products (Lacey 1994; Collins et al 1999; Brown 2001b). New evidence suggested that transmission through this medium was a very real risk (Houston et al 2000; Roberts 2003; Bird 2004) and led many countries to establish deferral policies for donors who had visited or lived in the UK or continental Europe (Brown 2001b; Brown et al 2001; Wilson and Ricketts 2004). In 1998 transfusion transmission of TSE was clearly demonstrated in animal models and as a result the UK chose to import plasma to manufacture fractionated products. Also, as a result of the
theoretical risk Canada and the US introduced policies to defer blood donations from individuals who had lived in the UK for six months (from 1980 to 1996), a policy that expanded rapidly to other countries (Wilson and Ricketts 2004). By 2002 there was confirmation of sheep to sheep transfusion transmission (Houston et al 2000) and as a result the decision was made in the UK to import fresh frozen plasma for use in patients born after January 1996 (Wilson and Ricketts 2004). The first human case report of variant CJD in a recipient of transfusion from a variant CJD donor occurred in 2004 and resulted in the decision to defer donations from individuals who had received a transfusion since 1980 being made in the UK (Llewelyn et al 2004). A second case linked to blood transfusion has led to concerns that the disease may affect far more people than had been previously thought (Peden 2004; Turner 2004).

Predictions based on contamination and transmission between humans through tissue contamination, as evidenced in iatrogenic CJD and kuru, have been attempted (Croes et al 2002; Verdrager 1997). The recent discovery of a 38-year incubation period for a case of iatrogenic CJD from a low dose of human growth hormone has implications for calculating predictions of further cases (Croes et al 2002). Kuru is discussed here, as some lessons learned from the kuru epidemic have served to inform the transmission of variant CJD through ingestion of contaminated food products. The very small number of kuru sufferers that are still to be found suggest incubation periods of over 40 years (Ironside and Head 2003). Verdrager (1997) used the example of the distribution curve of kuru deaths following the cessation of ritual cannibalism in the Fore group in Papua New Guinea to predict the proportion of a variant CJD epidemic. He suggested that if the cases of variant CJD do reach epidemic levels the peak should be in 2009 and extend to at least 2025 or 2030.
severity of the predicted epidemic has not been realised based on the calculations from Verdrager’s 1997 paper. His suggested doubling effect each year should have brought the number of deaths to several thousand to date.

Predictions on the size of the potential epidemic vary. They range from an upper limit, based on beef ingestion, of 403 cases (Valleron et al. 2001), to 80,000 cases (Cousens et al. 1997), to 150,000 cases, based on concerns of exposure through ingestion of sheep meat (Ferguson et al. 2002). Other predictions have been attempted but owing to the uncertainty of the inoculation period and sources of contamination it has become a matter of attempting to ‘predict the unpredictable’ (Medley 2001). Although the number of people infected with variant CJD peaked in 2000, the possibility of a second peak at a later date cannot be discounted based on possible epidemics in other genetic sub-populations and human-to-human spread (Andrews et al. 2003; Andrews 2005). Other questions have arisen over the potential for BSE contamination to have increased the number of people with sporadic CJD (CJD Newsletter 2003). The evidence for this is based on BSE prion propagating as either variant CJD-like or sporadic CJD-like prion strains in transgenic mice experiments.

Monitoring of the developments of variant CJD is a day-to-day experience in Public Health surveillance. Media hype on the subject of variant CJD and public health has waxed and waned in the manner suggested by Beck (1995:60) where social movements and responses come and go, ‘mostly going’. Beck (1995:60) refers to this as industrial fatalism or organised irresponsibility where public opinion and alarm, stirred by the ‘media circus’, has a ‘half-life’ that fluctuates from a couple of weeks to several months, depending on the type of disaster. This view is demonstrated in the
medical and media discourse that has ensued as knowledge has emerged and evolved
on the subject of variant CJD. Since 1996, when the identification of variant CJD was
at its height, the subject has become integrated into the social fabric of Western life.
Between 1999 and 2004 the subject received little headline attention within the media
as a potential disaster of major proportions. With the confirmation of the first case of
transmission by blood transfusion in 2004 (Llewelyn et al 2004), the subject again
made headlines.

These media responses are consistent with the hype that occurred during the 1980s in
relation to AIDS. As pointed out by Entwistle and Sheldon (1999), during the mid-
1980s statistic about numbers of people dying from AIDS were routinely turned into
news articles. These were rarely reported during the 1990s as journalists became
more interested in diseases such as meningitis and variant CJD (Williams 1999;
Entwistle and Sheldon 1999).

1.5 Clinical progress of CJD

CJD is characterised by a rapidly progressive dementia (of less than two years),
together with at least two of the following symptoms: myoclonus (spasms and
involuntary jerky type movements), visual or cerebellar problems, extrapyramidal or
Initial signs of illness may be non-specific with complaints of dizziness, headache,
sleep disturbances, apathy, mood swings and depression. Neurological symptoms for
sporadic and variant CJD develop and progress extremely quickly. Cognitive
processes, such as memory, concentration and problem-solving are affected and the
individual may become disorientated. Movement is affected, particularly balance and
gait. The individual may become apraxic (unable to perform complex sequential
tasks) and the presence of a tremor and rigidity. Speech becomes slurred and quiet
(dysarthria) and the individual will have word finding difficulties as the content of
language is reduced. Reading and writing deteriorates. Swallowing difficulties occur.
Visual disturbances occur and at later stages there may be cortical blindness. There
may be seizures in the final stages. Iatrogenic CJD has a slightly different clinical
progress where dementia is not a prominent feature (CJD Surveillance Unit 2005).

Variant CJD is distinguished from other types of CJD by the age of onset, symptom
profile, duration of symptoms, histopathology and mode of occurrence. The median
duration of illness from onset of first symptoms to death is 13 months (range six to 36
months) for variant CJD compared to a disease trajectory of four months (range one to
74 months) for sporadic CJD (Hewitt and Llewelyn 2001). The average age of onset
of variant CJD is 28 years (compared to 65 years for the median age at death for
sporadic CJD) with a range of 12 to 74 years reported (Will et al 2000). However,
based on one case of variant CJD diagnosed in a 74 year old some concerns have been
expressed that variant CJD may be misdiagnosed as Alzheimer’s disease in the older
population (Lorains et al 2001; Henry et al 2002). These concerns have not yet been
explored due to processes of accessing autopsy data that would confirm any such
misdiagnoses. It has been reported that the number of post-mortems carried out in the
UK has dropped to an all-time low. That is, less than five percent of deaths in British
hospitals and 25% of deaths in the wider community have autopsies, and the majority
are due to coroners’ requirements (Jha 2005). This has led to a call from the Royal
College of Pathologists to halt the decline in autopsies carried out and deal with the
need to have accurate knowledge of causes of death and contribute to research on
diseases (Jha 2005).

A particular manifestation of variant CJD is the early development of psychiatric
symptoms (Zeidler et al 1997; Douglas et al 1999; Hewitt and Llewelyn 2001;
Spencer et al 2002). However, Bailey et al (2000) found that sufferers of sporadic
CJD were also often referred to psychiatric services in the early stages of the illness.
They report on the distress caused to some family members when the person with
CJD died while still in a psychiatric unit, as the diagnosis of an organic illness had not
been made quickly enough to enable them to move to a medical environment. A
further distinguishing feature of variant CJD is the presence of persistent painful
sensory symptoms such as paraesthesia (pins and needles) and/or dysaesthesia (pain
arising or persisting from innocuous touch) (Zeidler et al 1997).

1.5.1 Diagnosis of CJD

Diagnosis of all forms of CJD is made by clinical and neuropathological examination
and conclusive diagnosis can only be made by microscopic examination of brain
tissue (Poser et al 1999; Will et al 2000; Will 2001). Investigations include
electroencephalogram (EEG), magnetic resonance imaging (MRI) and lumbar
puncture, where 14-3-3 brain protein in cerebral spinal fluid (CSF) has been identified
as a marker for transmissible spongiform encephalopathies. This is indicative of the
more rapidly progressive brain destruction in CJD than that in Alzheimer’s disease
and vascular dementia (Poser et al 1999). A new procedure of tonsil biopsy has been
developed for diagnosis of variant CJD (Hill et al 1999) and a direct gene test is
available for diagnosis of persons who may potentially develop CJD (Will et al 2000).
Not having a clear diagnosis of variant CJD was found to be a major source of distress for some families. Douglas *et al* (1999) found that most of the people with variant CJD were given a psychiatric diagnosis initially and many were angry that a psychiatric label was given. Families reported that the patients denied feeling depressed but were treated for depression. Patients themselves were reluctant to see a psychiatrist or be treated in a psychiatric unit because of the stigma of psychiatric illness and not feeling that this was perceived as a ‘real’ illness. They also report family members’ feelings of guilt at allowing invasive investigations to be carried out. Some families felt that patients were used as guinea pigs, and that some of the procedures were not for the patients benefit.

In one case of sporadic CJD the wife of the person with sporadic CJD described a sense of relief at hearing a final diagnosis (Humphreys 1998). She felt that she was then able to move on, to prepare for the death, but remained distressed by the lack of information about the disease, its treatment and care. Hope of a cure was not an option that was discussed or considered in this case. However, for many families with members who have variant CJD the hope for a cure being found remained until the illness was very advanced (Douglas *et al* 1999).

Early diagnosis is an important aspect in relation to the management of the disease. This was a factor highlighted by Humphreys (1998) where she describes how she was distressed when participating in the bereavement groups. She could not continue to attend because other members of the group had been able to discuss their partner’s
imminent death with them. She felt she had lost her husband many months before he
died and had no opportunity to say good-bye to him.

1.6 Treatment and care for people with variant CJD

Variant CJD also has the added complication that it has been, to date, a disease of
younger people. Dementia in younger people has been identified as requiring
specialist resources, as this group has different needs from the older age group where
much of the dementia research and literature has been focused (Whalley 1997; Harvey
1998; Daker-White et al 2002; Parsons 2003). As yet, research on the end-of-life experiences and issues for this group has not been explored and focus tends to be on
care issues. As pointed out by Woods (1999), despite some success in slowing down the rate of decline in function for the person with dementia through new pharmacological interventions, ‘cures’ are not realistically on the agenda as far as dementia is concerned. To date there is no specific cure for CJD. Palliation has been considered the only treatment. However, since the emergence of variant CJD research has predominantly focused on finding a cure.

The discovery that quinacrine (an anti-malarial agent) inhibited the formation of a disease associated form of the prion protein in mouse brain led to the establishment of a clinical trial of this drug for people with CJD (Department of Health 2001). This trial is ongoing, however Knight (2005) points out that as yet no treatment has been shown to conclusively slow or halt the disease process. In one case, that of 19 year old Jonathan Simms from Belfast, treatment with an experimental drug, pentosan polysulphate (PPS), for which his family had to get High Court approval, has been carried out. After eight months of treatment Jonathan has shown some improvement
in neurological functions, including regaining the ability to swallow. Neurologists have expressed cautious optimism about the improvements that have occurred (Mayor 2003). The most efficacious period for treatment with PPS would be during the incubation period but without a validated pre-symptomatic test and definitive demonstration of safety and efficacy of PPS, treatment at that stage is not an option (Knight 2005). These results have, however, influenced responses of other families with teenagers who have variant CJD (Dyer 2003). Also following High Court action, Holly Mills, an 18 year old girl from Yorkshire began receiving treatment with PPS in October 2003. The result has also been to slow the disease process (Yorkshire Post 2005).

Literature on all types of CJD has flooded medical journals and the popular press since 1996. Only a few articles have specifically addressed the nursing management of these patients, as the focus has been predominantly on disease reporting and cure. There are a small number of published case-studies of the experience of caring for a person with CJD by the community team (Meek 1998), by family members (Humphreys 1998), and in care settings for older people (Wallace 1999). An overview of the role of the CJD Surveillance Unit support for people with CJD in the community (Barnett 2002) and care for people with prion disease (Prout 2000) have provided information on some of the care issues that are encountered in the management of people with CJD. The CJD Surveillance Unit (2005) has also produced an extensive document on the care needs of people with CJD. Few studies have addressed the care of CJD specifically from a hospice perspective (Bailey et al 2000; de Vries 2003a; de Vries et al 2003; de Vries 2004), although Douglas et al
(1999) addressed some of the issues raised in relation to palliative care experiences for people with variant CJD.

Douglas et al. (1999) provide the most comprehensive study of variant CJD cases, where the needs and perceptions of family members and professionals who had been involved in the care of 19 people with variant CJD were identified. The aim of the Douglas et al. (1999) study was to determine the information and care needs of patients with variant CJD, and their relatives. This was in order to inform the planning of services for future patients. They used a qualitative methodology developing a thematic analysis from data collected during face to face interviews with close family members, and semi-structured telephone interviews with a selection of health and social care professionals. The professional participants were predominantly medical. They consisted of 10 neurologists, eight GPs, six psychiatrists, five nurses, two social workers, one physiotherapist and one consultant in palliative medicine. Medical records of the patients were also examined. A comprehensive and detailed report was constructed from the data. The disease trajectory of the 19 cases was mapped, with details that identified and highlighted issues that were encountered, predominantly by family members.

Douglas et al. (1999) found that most of the families were unhappy about the care they received in the acute units. Numerous examples of substandard care are cited. These particularly focused on issues related to urinary incontinence, feeding, poor support, rigid care practices and inflexible visiting times. There is acknowledgement by the families of low staff levels and lack of knowledge about the condition. Nearly all families expressed appreciation of the care they received on units that specialised in
terminal care. However, these were not always accessible, as not all hospices would take patients who did not have cancer. One hospice wanted to discharge the person with variant CJD because the admission was lasting too long and the patient was hallucinating, shouting out and disturbing other patients. Whilst family experiences are detailed and insightful, the experiences of the health care workers, in providing care, is not addressed in detail within this report.

In one of the few studies of the experience of providing care for CJD patients in a palliative care environment Bailey et al (2000) reviewed the issues raised in caring for six people who had died as a result of sporadic CJD in a hospice in Australia over a 12-month period. Using a focus group of relevant nursing staff, the experience of providing care for the patients and their families was discussed. A retrospective chart audit of the cases was conducted and an internet chat-group for people with personal experience of CJD was accessed. Four key issues in caring for the person with CJD were identified. These were physical issues, psychosocial issues, issues in caring for the family, and personal issues experienced by the nurses caring for these people and their families. Douglas et al (1999) identified similar issues in caring for the variant CJD population, plus a number of others. These included: poor communication and co-ordination between different services, issues related to body disposal, dealing with the media, information giving and breaking bad news.

Most families wanted to be able to care for the person with variant CJD in the home, if possible. This was pertinent to making sure a package of care was available (Douglas et al 1999) and comprehensive packages of care for people with CJD are now recommended, including that all CJD patients should be referred to specialist
palliative care services (Douglas et al 1999; Barnett 2002). Some of the issues identified in the Douglas et al (1999) study have been resolved as a result of developments in the support service provided by the CJD Surveillance Unit. Most people with CJD are identified by the Unit and a member of the CJD Unit team liaises with the family and medical and nursing team, giving advice and providing education and support (Barnett 2002). However, as was evident in the Douglas et al (1999) report and identified in brief nursing articles (McVey 2002), there remains a lack of nursing knowledge and facilities that can adequately deal with this type of illness.

The emergence of variant CJD set in place unprecedented levels of care services for carers of people with all types of CJD. Care is now substantially funded and supported and many family members are now closely involved with CJD support groups. Grants are offered to help with the cost of care (Turner 2004) as the following example of a care package demonstrates. The family had nine carers providing 21 hours a day, seven days a week care, including two carers during the day. They had a wheelchair, hospital bed, fully adjustable armchair, hoist and a specially adapted automobile. Also included in the package was counselling for the family and friends, complementary therapies, and a team to help clear the downstairs room ready for adaptations to be made (CJD Support Network 2004). This level of support may be attributed to guilt from the UK Government related to the emergence of variant CJD and also, perhaps more significantly, to the age of the sufferers. The generosity of the support may also have been influenced by the prediction that there would only be a small numbers of cases of variant CJD, as more became known about it.
1.7 Dreaded diseases: The social component of variant CJD*

Epidemics that kill young people have a significant impact on society and as a disease emerges and becomes defined as a 'dreaded disease' irrational fear drives policy (Doka 1997:49). Due to the youth of the people with variant CJD and the distressing nature of the clinical progress, variant CJD could become defined as a 'dreaded disease' in the future (de Vries 2004). The care service provision for this very small group is already extraordinarily elaborate (as outlined above). To those who have had personal experience of the disease it fits within categories of diseases to be dreaded that have been identified by others (Sontag 1978, 1988; Doka 1997). The clinical progress of CJD leads to a state of profound dementia and to death, and dementia, as does death, are terms that provoke fear and dread in the public. Kitwood (1988, 1989) suggests that fear and dread of dementia has a clear basis in reality where 'going senile' is faced with dread, and is seen as experiencing an inevitable path of degrading incapacity to a near-vegetable existence and death. In the event of contracting variant CJD the person becomes progressively cognitively impaired, experiencing dementia type symptoms, leading to death in a relatively short space of time. Variant CJD may come to be regarded as one of the 'dreaded diseases' of the 21\textsuperscript{st} century, not only in relation to the dementia and death component, but also in relation to the youth of those infected, mode of transmission and implications of environmental pollution through the innocent act of eating food that society has been led to assume is safe.

Diseases in this category have occurred throughout history and include the black death or bubonic plague, cholera, typhus, and influenza epidemics (Sontag 1978; Doka 1997; Oldstone 1998) and more recently, since the 1980s, HIV and AIDS.

*"Killer in the shadows" headline referring to new cases of variant CJD. Guardian Unlimited (2004).
(Sontag 1988; Doka 1997). Added to these diseases are the less acute but possibly physically deforming illnesses such as cancer and leprosy (Sontag 1978; Doka 1997). In the early days of HIV and AIDS the uncertainty of the mode of transmission contributed to the dread. This was also applicable to the transmission of variant CJD, demonstrated in the media hype that occurred in relation to eating beef and the fear of taking blood from the UK (Brown 2001b; Brown et al 2001). The believed mode of transmission of the disease speaks of a pollution of a kind that attacks the young through the innocent act of, for example, eating a hamburger. The mode of infection for variant CJD and the age of those infected fits with Sontag’s (1988) premise that some individuals do not necessarily experience stigma, such as ‘innocent victims of HIV’, i.e. haemophiliacs and babies who have acquired HIV through blood produces or maternal transmission. The biotechnology that caused the BSE crisis is an example of the manufactured risk identified in discussions on the political, technological, cultural and economic globalisation (Giddens 1999; Beck 1995, 2000, Rose 2000; van Loon 2000).

The disease caused an unprecedented public response and impact on the beef market that was from the beginning seen as analogous to the HIV and AIDS outbreak (Brookes 1999). The pollution that was equated with HIV and AIDS, of sex, sperm and contagion, was embraced by religious zealots as retribution from God (Doka 1997). Variant CJD pollution has been embraced by environmental zealots (Scott 2000), and as with the early days of (and to date) HIV and AIDS, criticism has been focused on UK and government and policy makers. However, there is some evidence of early policy development as a result of lessons learned from the AIDS experience,
particularly in relation to blood transfusion and tissues donation services (Brown 2001b).

All diseases have a social component and as such they take on metaphoric meanings that are related to the culture of the times and also the particular manifestation of the disease symptoms (Sontag 1978, 1988; Doka 1997). Outcast has been equated to the leper who is seen as dreaded and loathsome, the pox has been metaphorically referred to as a curse, or black death which is dark and evil, and cancer is identified with a crawling and invading crab (Sontag 1978; Doka 1997). HIV and AIDS were equated with sin, shame and sexual pollution (Sontag 1988; Doka 1997). Metaphors have already been created through the media of ‘mad cow disease’ in reference to variant CJD. The public often understand variant CJD easier through the BSE, ‘mad cow’, language. Reports in the media on the subject of variant CJD inevitably include in the headline ‘mad cow disease’.*

Rabies is one disease that comes close to both analogously, ‘mad dog’/’mad cow’, and symptomatically to that of the variant CJD. Rabies is a communicable disease that causes an encephalomylitis and is almost always fatal. The cause of infection is usually as a result of being bitten by an infected mammal but has also been caused by inhalation of rabid virus, inoculation by poorly cleaned vaccine or through corneal grafts (Kaplan et al 1986). Kaplan et al (1986) suggest that, although rabies has never had a major impact on historical events, it has exerted an influence on human imagination out of all proportion to its incidence and regularly captures the

*"The Official Mad Cow Disease Home Page" www.mad-cow.org contains news and science archives, internet links etc and demonstrates how the term ‘Mad Cow’ has become irrevocably linked to variant CJD.
imagination of writers of fiction (see for e.g. ‘Cujo’ by Stephen King 1981). This is due to the mode of infection, classically by a ‘mad dog’ and the terrifying and agonising suffering that occurs in humans before death (Kaplan et al 1986). There are other similarities of rabies to variant CJD where a psychiatric diagnosis may be made due to the bizarre behaviour, altered mood and hallucinations that occur (Kaplan et al 1986; Zeidler et al 1997; Spencer et al 2002).

Variant CJD has become socially equated to dying and young people. The youth of the people with variant CJD and the clinical progress of the disease is particularly distressing, both to the person experiencing the disease and to those who provide care for them (Douglas 1999; de Vries et al 2003, de Vries 2003a). It is these aspects that contribute to the image of variant CJD being a disease to be dreaded.

1.8 Summary

Variant CJD is a dementia syndrome and a terminal illness with a particularly distressing disease trajectory and may become one of the dreaded diseases of the 21st century. The predicted numbers of cases are uncertain and research has primarily focused on pathophysiological and epidemiological aspects of the disease and the search for a cure. There is a growing literature on the mode of transmission, and the global impact this has had, and may have in the future. The National CJD Surveillance Unit has taken a lead in developing support and education, particularly for the families of patients and those closely involved in their care, including palliative care and hospice services. Hospice services have traditionally focused on the cancer death and there is no certainty that they are in a position to accommodate the needs of this patient group. In Chapter 2 I review the literature on hospice
services and care, and the implications of managing people with dementia within the hospice environment.
Chapter 2 – Hospice and end-stage dementia care

2.1 Introduction

In this chapter the literature review is presented in two sections. The first section addresses hospice culture and practice. There is a very large literature addressing hospice practices, the review therefore has been selective, focusing on those aspects that are aligned to the thesis and primarily in the context of UK hospice services. In the first section of this chapter on the evolution of hospice, the literature addressed is drawn only from UK sources, as this is a UK based study. However, the literature that is discussed in following sections of the chapter, on for example more philosophical subjects such as dignity and the ideology of the ‘good death’ have been drawn from an international literature. I begin with a short discussion on the background to the evolution of hospice in the UK that examines definitions of hospice and palliative care and the rhetoric for extended hospice services to non-cancer patients, including a brief review of the debate on the ‘medicalisation’ of hospice care. It has been suggested that what is needed is closer examination of the working of the hospice as an organisation before a full understanding of the field can be achieved. This leads to a critique of four studies that have closely explored aspects of hospice practice using qualitative methodology.

I then consider the subject of dignity within the context of dying and the ethical and philosophical debate on concepts of self and personhood in relation to dignity. This leads on to a discussion on disintegration as a spectacle and how this relates to conceptualising dignity for the person with dementia. These concepts are also discussed in relation to the ideology of the ‘good death’, an ideology that is central to the hospice movement. Dignity and personhood are closely aligned to the ‘good
death’ ideology and implications of these concepts that relate to dementia care at the end of life are considered during this discussion.

The second section of Chapter 2 more specifically addresses literature on dementia and dying. There exists an enormous literature on dementia care in general. As the focus of the study was on end-of-life events the dementia literature has been largely confined to that which addresses end-of-life issues, very little of which is related to the UK context. The hospice model and environment offers an opportunity for sharing in the experience of dying with dying people themselves within an open awareness context and it has been suggested that this model is not congruent with the cognitive state of people with dementia. However, there is a growing body of evidence that people with dementia have awareness of loss and abandonment that may have implications for managing their care at the end of life. I show that the influence of hospice practices is only beginning to infiltrate dementia care practices in the UK, despite recommendations from both specialities. Issues related to introducing people with dementia into the hospice services are also addressed. These include discussion on differences and commonalities in the skills of health care professionals working with the dying or working in dementia care. The implications of managing a person with variant CJD (dementia), within this specialised environment is addressed and concepts related to both hospice and dementia care used to justify my research.

2.2 Hospice culture and practice

2.2.1 Background to hospice in the UK

The beginning of the ‘modern’ hospice movement is attributed to the founding of St Christopher’s Hospice in Sydenham, South London, in 1967 by Cicely Saunders and
developed due to shortcomings in mainstream health services for care of the dying (Stoddard 1978; du Boulay 1984; James and Field 1992; Lattanzi-Licht and Connor 1995; Seale 1998; Clark 2002; Clark et al 2005). The first use of the word ‘hospice’ in the UK was by the Irish Sisters of Charity. They opened their founding hospice near Dublin in 1879 followed by St Joseph’s Hospice in Hackney, East London, in 1905 (Saunders 2000). A number of ‘hospices’ already existed in other European countries that were based on an older medieval tradition, when hospices were wayside places of rest and refuge for pilgrims (Seale 1998:113), i.e. hospice referred to a lodging for travellers, especially one run by a religious order (Oxford Dictionary 1999). As the first modern hospice, St Christopher’s set out to combine three key principles: excellent clinical care, education and research in managing care of the dying person and their families (Saunders et al 1981; du Boulay 1984; Saunders 2000; Clark et al 2005). For Saunders the notion of ‘total pain’ was at the forefront of the drive for conducting research and developing practices in symptom control that involved patient assessment being carried out by a multi-professional team with an understanding of the holistic nature of suffering (Saunders et al 1981; du Boulay 1984; Clark 1999; Saunders 2000; Clark et al 2005). The hospice philosophy also encompassed the principle of giving pain relief to people with terminal cancer regularly and routinely and of developing knowledge and understanding of the range of available drugs and levels of pain upon which they were effective (Clark 1999).

During the 1970s many new hospices were established in the UK, following the St Christopher’s model, and alongside these developments hospice day care and home care team services also began to be established (Clark et al 2005). By the early 1980s there were 58 hospice in-patient units and 32 home care teams in the UK (Clark et al
In 1987 palliative medicine became recognised as a speciality within its own right in the UK and a new journal, *Palliative Medicine*, was established. Help the Hospices, an umbrella organisation for hospices, established in 1984, set out the definitions and qualifications of provision of hospice care which have been modified and extended over the last 15 years as the services evolved. By 1995 there were 250 in-patient hospice units, slightly smaller numbers of day care and hospital support teams, and almost 400 home care support teams and units in the UK and Ireland (Doyle 1997). According to the 2005 Hospice Directory there are now 272 in-patient units in the UK, including Scotland, Wales and Northern Ireland (Help the Hospices 2005), indicating that the growth of these units has remained relatively unchanged since the mid 1990s. Most of the hospices in the UK are independent charities and the sense that the hospice is the property of the supporting community is usually well embedded in the culture of individual hospices (Johnson 1999). This aspect of hospices as organisations has however been little studied. Johnson (1999) shows how the 'vision' of the founders of UK hospices was based on a response to what they perceived as an external demand where founders and trustees gave their lives (or a great part of them) with excitement, energy and enthusiasm with the belief in their power to make a difference. Many of the founding groups incorporated terms such as having a 'religious and medical foundation', and 'showing the love of God' in their vision statements (Johnson 1999).

An underpinning Christian principle, harking from the historical background of hospice, has remained in the provision of care within the modern hospice (Stoddard 1978; Saunders et al 1981; du Boulay 1984; James and Field 1992; Clark et al 2005). This is referred to by James and Field (1992) as the spiritual 'calling', which inspired
many to become involved with hospices. The emphasis of the modern hospice approach has primarily been one of providing care to dying people and their families using a multi-professional team approach, including a Chaplaincy service (Doyle 1993; Hockley 1997; Clark et al 2005). This was promoted as fundamentally humanitarian, with an educational and research focus (Stoddard 1978; Doyle 1993; Lattanzi-Licht and Connor 1995).

In early definitions hospices were seen as providing care over an extended period of the dying trajectory and not just for the terminal stage of dying, in some ways akin to rehabilitation, employing many of its principles; and emphasis was made of the importance of a team approach to care (Doyle 1993). In some documents hospice care is referred to as ‘a philosophy of care rather than a specific building or service’ (Saunders et al 1981; NCHSPCS 1995:5), creating a tension between the terms ‘palliative’ and ‘hospice’ care (Skilbeck and Payne 2005), and apparently completely missing the point that hospices are organisations within which all of the issues of organisational behaviour and activity of those working in the organisation impact on how palliative care is conducted.

Doyle (1993) argues that confusion has ensured due to the range of existing and suggested definitions of hospice and palliative care. These range from emphasising quality of life to a focus on symptoms of the disease rather than the pathology itself, leading, in some instances, to palliative care physicians being described a ‘symptomatologists’, in which case dismissing any association with pathology. Doyle (1993) describes this as a totally unacceptable situation and goes on to outline the extent of the ‘medical’ activities directly related to pathology that are carried out by
palliative care physicians. The National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) was established in 1991 as an umbrella organisation for all those who are involved in providing, commissioning and using hospice and palliative care services in England, Wales and Northern Ireland. The brief was to act as a co-ordinating and representative body for the hospice movement in the UK and to give it a single national voice. The Councils remit was to co-ordinate and develop joint position papers promoting good practice in palliative care and influence health care policy through the Department of Health and Government recommendations and policies (Gaffin 1996).

In 1995 a working party for the NCHSPCS outlined their definition for specialist palliative care, i.e. specialist hospice activity. The characteristics of these were:

Specialist palliative care services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary health care services. They require a high level of professional skills from trained staff and a high staff-patient ratio. They can support the patient wherever the patient may be; at home, in residential or nursing home, in hospital, day centre or a specialist unit. (NCHSPCS 1995)

They were identified as providing:

- Physical, psychological, social and spiritual support through a multi-professional, collaborative team approach
- A lead person who is a trained and acknowledged specialist in palliative care
- Support and involvement of patients/families in management plans
- Encouragement of patients to express their preference about care
- Support for carers and families through the illness into bereavement
• Co-operation and collaboration with primary health care teams, hospitals, and home care services
• Volunteers whose contribution is recognised and valued
• An either directly or indirectly recognised academic external education role
• Standards set for the education and training provided
• Quality assurance programmes that are constantly used to review practice
• Clinical audit and research programmes to evaluate treatment and outcomes
• Staff support arrangements

The NCHSPCS formally changed its title in 2004, to The National Council for Palliative Care (NCPC 2005a), at the same time as making changes to their Constitution. These changes were made to encompass the needs of all dying people regardless of their diagnosis (NCPC 2005a; NCPC 2005b) and to meet the objectives of the Department of Health (DH) End of Life Care initiatives (DH 2003) and the drive to develop palliative care services for people with non-malignant disease is now a Government priority (DH 2005). However, the rhetoric for integrating people with non-malignant diseases into hospice services has been in the literature since 1992 (Addington-Hall et al 1998) and yet there remains limited action in implementing measures to accomplish this.

Whilst, from the outset of the establishment of St Christopher’s Hospice the focus of hospice care has been on the cancer patient, what is often not made explicit within these definitions is acknowledgement of this exclusiveness. Only a small number of people die in hospice in-patient units, approximately 4% of all deaths in the UK whereas approximately 17% of cancer patients in the UK die in a hospice or a
specialist palliative care unit (Tebbit 2004). This has led to criticism that hospices provide 'de luxe' dying (Douglas 1992), 'five star' dying (Field 1994), care for a 'privileged minority' of people with cancer (Doyle 1993), or 'a bit of heaven for the few' (Clark et al 2005). To further compound the elite status of cancer care provision the thrust of the National Institute of Clinical Excellence (NICE) (2004) guidance on improving supportive palliative care is for people with cancer.

Although, from relatively early days of hospice care, people with other diseases were admitted to hospice services, notably people with Motor Neurone disease and Multiple Sclerosis, and in the 1980s people with AIDS (Saunders 2000). The access and equity of the HIV/AIDS population to palliative care has been questioned, however, and evidence suggests that integration has reduced due to antiretroviral therapy and focus has remained only on the terminal stage of the disease (Harding et al 2005).

It wasn't until 1998 that the NCHSPCS outlined the need to extend palliative and hospice care services to people with non-malignant disease (Addington-Hall 1998). Using data from a retrospective, national, population-based, interview survey of relatives or officials of 3,696 people who had died in the last quarter of 1990 from 20 English Health Districts (Addington-Hall and McCarthy 1995b, 1995b) a secondary analysis was carried out to investigate experiences of dying from causes other than cancer (Addington-Hall et al 1998a). The purpose was to investigate what proportion of people who die from non-malignant disease might benefit from input from specialist palliative care services (Addington-Hall et al 1998). The results suggest that 16.8% of people with non-malignant disease and their families were as much in
need of specialist palliative care services, specifically in symptom management, open communication about death and dying and in encouraging autonomy (Addington-Hall et al 1998). These patients also may have suffered the symptoms for longer periods than the cancer group (Addington-Hall and McCarthy 1995a; Skilbeck and Payne 2005).

The case for extending specialist palliative care services to chronic conditions other than cancer has been made based on equity and need, equity implying the right of choice and control over the dying experience for all people (Field and Addington-Hall 1999). The pledge to offer more choice in all areas of medical care for patients has been a government focus since their 2001 Manifesto (DH 2003). Following a national consultation to find out how choices could be extended in ways that would create more personalised care and promote equity, the document 'Building on the Best' was published (DH 2003). Building palliative care services to offer greater choice over care at the end of life was one of the focuses within the document as some of the most powerful consultation responses were as a result of distressing experiences of relatives of people who were dying (DH 2003). The Department of Health proposal is to extend end-of-life services already existing for people with cancer (and HIV/AIDS) and offer these to all, regardless of diagnosis, through formal training programmes across a wide range of health care settings, working in partnership with existing palliative care services. All of this is to be in place by 2007 (DH 2003).

Need however, presents different issues in care provision for people who maybe (slowly) dying from chronic illnesses such as chronic heart failure, end-stage renal disease and rheumatoid arthritis (this literature is not reviewed in the thesis). It has
been proposed that the present palliative care services could meet the needs of the non-cancer group of patients, using support from specialist teams to accomplish this. However, it has also been argued that this would be problematic as specialist fields (such as cardiac, renal, respiratory care) require different specialist knowledge that does not necessarily transfer from cancer care (Field and Addington-Hall 1999). (also see literature reviewed in Addington-Hall and Higginson 2001; Skilbeck and Payne 2005).

Another consideration is just how far the services should be extended, i.e. is the remit for palliative care broad and therefore required to meet the symptom control, psychological and spiritual needs of patients at any stage of their disease, as suggested by Harding et al (2005) in relation to HIV/AIDS; or should the focus of this speciality be on the terminal stage of the illness only? (Field and Addington-Hall 1999). This question is as yet unresolved and there are numerous discussions within the literature of how far the remit of specialist palliative care services should be extended. However, the definition of palliative care offered by the National Institute of Clinical Excellence (NICE) makes the assumption that the services is extended to early stages of terminal illnesses.

Palliative care is the active, holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects are also applicable earlier in the course of the illness in conjunction with other treatments (National Institute of Clinical Excellence (NICE) 2004).

Extending the services of hospice to the non-cancer patient group, including early stages of the illness, presents a number of difficulties and despite the rhetoric very
little integration of people with non-malignant disease into hospice services has occurred. A number of barriers to extending specialist palliative care services to this group have been identified. Of crucial importance are resource implications for specialist palliative care services (Addington-Hall 1998; Skilbeck and Payne 2005), particularly hospices. The resources of existing hospices are already stretched to cope with terminally ill patients with cancer and the small number of neurological patients that are admitted to the service (Field and Addington-Hall 1999). This barrier is closely linked to the method of funding for hospices of which over 50% is through voluntary contributions and there is no certainty that voluntary contributions would be forthcoming to fund the expansion of hospice services to the non-cancer patient group (Field and Addington-Hall 1999). Other barriers to extending palliative care services to non-cancer patients include a potential lack of skills amongst specialist palliative care experts in the care of non-cancer patients, difficulties in identifying suitable non-cancer patients for the palliative care, lack of information on acceptability of these services for non-cancer patients; and vested interest in present arrangements (Field and Addington-Hall 1999; Skilbeck and Payne 2005). An interest in the end-of-life needs of people with dementia also gained momentum in the UK during the 1990s, this work is discussed in more detail in section 2.3 Dementia care at the end-of-life.

2.2.1.1 Medicalisation and hospice

Following palliative medicine becoming a recognised ‘medical’ speciality in 1987 it is suggested that the ‘medical model’ has become dominant in provision of specialist palliative care (James and Field 1992; Clark 1993; Field 1994; Walter 1994; Clark 2002), a position somewhat confirmed by Doyle’s (1993) indignation at palliative care physicians being referred to as ‘symptomatologists’. The concept of
medicalisation refers to the way in which medical jurisdiction has expanded in recent years and the medical model is generally regarded to mean a focus on biomedical research, physical testing and high-technology interventions, with a focus on disease rather than on the person who is ill (Biswas 1993), and control and medicalisation are frequently referred to synonymously (Walter 1994; Sontag 1978). In discussing the definition of this new ‘medical’ speciality, Field (1994) comments that it is noticeable that no reference to the fact of death is made. This comment comes with an emerging criticism of the new hospice ‘medical’ model. According to Clark and Seymour (1999) hospice has developed a form of ‘therapeutic’ culture in which the universal experience of suffering is characterised as a ‘problem’ with a medical solution. This is highlighted in the increasing routinisation and medicalisation of hospice and palliative care that Kastenbaum and Wilson (1997:271) have described as ‘bureaucratic creep’.

The issue, from a sociological perspective, of the ‘prolonged’ dying trajectory (in some illnesses) that has been created by modern Western medicine has been raised by a number of writers on the subject of hospice (Seale 1998; Walter 1994; Copp 1996, 1999; Lawton 1998a, 1998b, 2000). They argue that priority is now being given to patients exhibiting particularly distressing symptoms, especially during the terminal phase of their dying trajectory. This has become the priority of specialist hospice units where definitions of specialist palliative care generally refer to the acuteness of distressing symptoms as in a definition offered by Doyle (1997) where specialist palliative care is deemed an ‘acute’ service.

Specialist palliative care are for specialist needs which can not be met in smaller, non-specialist units and for round-the-clock advice. The specialist units admit and discharge many patients after short lengths of

This definition moved the focus away from that of earlier definitions where providing care over extended periods and making links with principles of rehabilitation was highlighted by Doyle in 1993, just four years earlier. However, in defence of some of the criticism of the medical dominance in hospice care it has been pointed out that medical practices have combined with this some of the most significant developments in symptom management that require the use of technological aids (Ahmedzai 1993, 1994).

Others, such as Bradshaw (1996), have argued for a return to the spiritual dimension of hospice. Using the medicalisation issues identified above as the basis for her concerns about the secularisation of the hospice ideal Bradshaw (1996) argues that the move away from the original charisma of the Christian spiritual elements of hospice care means that these have lost their reality and influence. She suggests that as the original spiritual values diminish so the values become those of the ‘expert’. Skills and techniques offer efficacy in treatment and suppression of conflict, death then is no longer a truth to be confronted, but a process to be managed (Bradshaw 1996). This view is not universally held of contemporary hospice and in a study examining the ‘stories’ of 25 hospice patients and a period of participant observation, Stanworth (2004) constructed an interactive hermeneutic of nine revealed and constructed metaphors that expressed patients’ sources of meaning and sense of self in a non-religious language of spirit. Stanworth (2004) showed that this ‘spiritual’ ‘story making’ exists within contemporary hospice care and may be accessed through the attention of the silent listener.
Seale (1998:117) however, cautions for sociologists not to take sides on the issues of what is essentially 'an interplay of discourse'. He proposes that:

A more analytic approach lies in seeing how these discourses, or grand meta-stories, are appropriated by people as they seek to understand their experience in care settings. That is to say, we need to see how people who work in these settings think about their work, what they do on an everyday basis, and how they, as 'system representatives' seek to mould the subjectivities of the people for whom they care (Seale 1998:117).

Since the early 1990s academics have been asking the question, what do hospices do?, frequently asking this question with particular reference to the cost of the service (Johnson et al 1990, Seale 1991). There are numerous surveys that have collected data on the use of various hospice services. For example, day care (Higginson et al 2000), making comparisons between hospice and hospital or community care (research reviewed in Wilkinson et al 1999), level of need for palliative care (research reviewed in Salisbury et al 1999), and governance, leadership and management of hospice projects (Johnson 1999). There is also a burgeoning literature on aspects of hospice and palliative care, particularly the nursing component, that together construct a 'mosaic' of the hospice service and contribute to a picture of the practices that take place within hospice environments. These studies indicate that definitions of a service do not necessary equate with what actually takes place within a given organisation and offer some of the perspective of 'system representatives', called for by Seale (1998). For the purposes of this discussion I draw on a number of qualitative studies that have been conducted on practices that occur within hospice environments. In relation to my study I draw particularly on theories that consider the hospice service as a type of system, and where organisational behaviour and activity are important
components within the models. These theories are elaborated and drawn on throughout the thesis.

2.2.1.2 Hospice care as a ‘rite of passage’

In a robust and insightful thesis Froggatt (1995) offers a model of ‘rite of passage’, based on the concept of liminality, to explain hospice culture. Using an ethnographic approach Froggatt (1995) explored how the life-death transition was managed in hospice with a focus on the personal bereavement experiences of the nurses. Four types of data collection were carried out in parallel. These were interviews with 32 nurses and six nurse managers from four English hospices, a short period of non-participant observation in one hospice and analysis of the hospice literature that is given to patients and relatives from 113 hospices, plus analysis of contemporary literature on bereavement from Woman’s Own magazine over a period of six months. The data were analysed using the comparative content approach and examination of metaphor use in the language of the participants and written material. van Gennep’s (1960) anthropological ‘rite of passage’ framework was used to provide a theoretical base with which to consider the multiple bereavements experienced by nurses when carrying out hospice work, i.e. the nature of hospice work where staff face repeated losses. The model was applied to the hospice as an institution providing a conceptual framework in which to position the hospice culture’s management of death (Froggatt 1995). An emotional labour framework, a framework closely connected to work on understanding organisational behaviour (Hochschild 2003), was also applied in exploring what kind of emotional labour is undertaken by nurses with patients and family members in dealing with their peers and in relation to their own personal experiences of bereavement.
Froggatt (1995, 1997) presents hospice as a liminal space; a waiting room for the dying. Liminality has two dictionary definitions. One relates it to a transition or initial stage of an event. The second refers to liminal as a boundary or threshold and Froggatt (1995, 1997) uses this threshold metaphor drawing on the work of van Gennep (1960). Froggatt (1997:128) suggests, as does Stanworth (2004), that hospice provides 'a liminal space which is metaphorically structured to manage the process of dying'. According to van Gennep (1960) the transition phase of the 'rite of passage', that is also known as the limen, is a 'space' within which people are cut off from the wider society in a temporary position. The illustrative literature that is provided for patients who are admitted to hospice demonstrated how liminality may be central to hospice culture. Froggatt (1995, 1997) shows how some hospice logos, such as a doorway, symbolically illustrate the liminality of hospice space. The attributes of liminality include: transition, travelling, lodging, equality, absence of status or rank, simplicity, non-violence, totality, sacred institution and reference to mystical powers. These are posited as being features of hospice ideology. Some of the hospice ideological principles that have attributes of liminality are: dying as a journey, bereavement and follow-up care, entry requirements, hospice as family, flattened hierarchy, multidisciplinary team, team nursing, holism and spirituality and physical and social symbolism (Froggatt 1995, 1997).

Within this liminal space nurses become 'ritual specialists' who control the passage of dying in various ways. Rituals are conducted within the context of 'family' and 'holistic' ideals, and work is controlled and managed with respect to emotional expression. Froggatt (1995, 1998) identifies two factors that facilitate the daily work
of hospice ideology by the 'ritual specialist'. These are knowledge and time, i.e.
'possessing knowledge' (specialist hospice knowledge of pain and symptom control)
and 'having time' (to get to know the patient) and are necessary for the establishment
of relationships between nurses, patients and their kin (Foggatt 1995:126). She refers
to these as structures or 'bridges' over which a relationship between a nurse and
patient was established.

Within this model the service is symbolically a 'family system', albeit idealised
family, where staff represent the parent/adult, and the patient and family members the
children. This practice of holistic, family focused care also encompasses the process
of staff personally identifying with the patient and relating this to their own family
members. It is through providing the means of a 'rite of passage', in the organisation
of hospice care, that the service can manage the life-death boundary. In doing so it
can provide 'a space to manage the seemingly disordered process of dying which may
threaten order in society' (Froggatt 1997:134).

This model has much in common with the work of Lawton (1998a, 1998b, 2000),
although Froggatt (1995, 1997) offers a more idealistic model of hospice culture than
does Lawton. She shows how hospices may be construed as communities which
patients enter into as family members, and where the hospice is symbolically shown
to be a protected environment where the specialist knowledge on caring for dying is
used to their benefit. What is also a feature in Froggatt's (1995) thesis is that there is
a need for reciprocity that is allowed due to (the often) long the length of the
admission and to the availability of time for patients and families. Whilst it needs to
be remembered that Froggatt collected data for this study in the early 1990s, when the
norm was for patients to remain in hospice for some time with less pressure for discharge, the rite of passage model is a framework that can explain how order is maintained in the face of potential disorder arising from an individual’s death, recognising that death is more than a medical event, but that it is a process (Froggatt 1995). Lawton (1998a, 1998b, 2000) also presents hospice as a space in which dying is processed but paints a less idealised picture of hospice activity, whilst also drawing on anthropological frameworks.

2.2.1.3 The sequestration of ‘dirty dying’

Lawton’s (1998a, 1998b, 2000) carried out a ten-month, participatory, observational anthropological study within a 19-bedded hospice in South-England, also using detailed case studies of the dying experiences of hospice patients to illustrate her arguments. She identified four major themes that show how dying is controlled and processed within the hospice. These are: day care as a safe retreat; ‘body-subject’ to ‘body-object’ during transmission from day care to in-patient admission; the sequestration of the unbounded body and ‘dirty dying’, during the dying process; and invisible suffering, as the social death.

Lawton (1998a, 1998b, 2000) maintains that the bodily deformation and decay that may occur during the process of dying, is why some patients are now sequestered within hospices whereas others are not. Sequestration is a state of isolation enforced by a social rejection of the unsightly ‘unbounded body’ as proposed by Lawton (1998a, 1998b, 2000) in relation to the in-patient unit at her study site. Particularly powerful images of the ‘unbounded body’ are conjured to demonstrate the level of disintegration:
...incontinence of urine and faeces, uncontrolled vomiting (including faecal vomit), fungating tumours (the rotting away of a tumour site on the surface of the skin) and weeping limbs which resulted from the development of gross oedema in the patient's legs and/or arms (Lawton 1998a:6).

Lawton (1998a, 2000) also goes on to give graphic descriptions of outpourings of blood and sputum and of tumours that grotesquely distorted the faces and bodies of patients, a feature also highlighted by Copp (1996). These descriptions of 'abject embodiment' for cancer patient were also identified by Waskul and van der Riet (2002) in a study using data from participant observation and 72 interviews with 18 cancer patients from a palliative care unit in New South Wales, Australia. All interviews were conducted during a massage sessions and were focussed on feelings about the body of the patient. The authors show how:

Those who experience abject embodiment also know that neither they nor anyone else can easily ignore the appearance and sheer existence of their grotesque and diseased bodies (Waskul and van der Riet (2002:509).

Furthermore, as also described by Lawton 1998a, 1998b, 2000), for these patients 'the "natural" relationships among the self, body, and society have ceased' (Waskul and van der Riet (2002:510).

However, dictionary definitions and the origin of the word sequester, from old French sequestrer, or late Latin sequestrare 'commit for safe keeping', where the Latin meaning of sequester is 'trustee', has more in common with the original philosophy of hospice as a place of safety and hospitality. Lawton sets the scene of pre-entry to the hospice in day care and posits day care as a safe retreat where patients, primarily with
cancer, could meet others in similar situations. In this sense Lawton’s work can be associated with a more idealised ‘rites of passage’ model. For some, day care served as a type of ‘surrogate family’, particularly for those who were socially isolated. The metaphorical ‘family’ was also identified by Froggatt (1995, 1997) as one of the components of liminality. Lawton, as does Froggatt, addresses the complexity of using the ‘family’ metaphor. For example, on how parent/child dependency roles developed within the relationships between staff and patients in day care.

Within the day hospice space Lawton (1998a, 2000) maintains that deterioration and dependency were masked and that discussion about the future was taboo. Essentially death was denied, a ‘conspiracy’ encouraged by day hospice staff (Lawton 2000:47). The depiction of day care as an environment in which death is a taboo subject is contrary to the findings of an ethnographic study by Langley-Evans and Payne (1996). The researchers explored communication processes amongst patients with terminal illnesses in a day care unit over a seven week period of participant observation. They found that patients readily talked about cancer, illness and death, often in a ‘light-hearted’ manner. Lawton (1998a, 2000) however, did find during interviews with some of the patients, that this death denial was not extended to their homes, and patients spoke of reading obituaries and discussing death at home. This does indicate that the patients in day care were able to discuss death and raises the question of why or how Lawton came to suggest that a ‘conspiracy’ of silence about death existed. Lawton’s interpretations of the day care activities were, however, focused on the idea of ‘space’, not as in the Langley-Evans and Payne (1996) study, exploring communication, and this may account for the emphasis she puts on the interactional model of day care as a space for masking deterioration and dependency. That is, day
care was a space or place that could not be understood by others who were not dying, causing the patients to experience a sense of isolation with their diseases.

Lawton (1998a, 2000) then addresses the impact of the move from day care to the in-patient unit. Of particular interest is Lawton's (1998a, 2000) personal response to what she saw in this unit. She expresses the shock and horror of seeing the bodily and psychological deterioration of the people she had met previously in day care. Although she does not address the impact of this in her data interpretation, this appeared to be an emotionally disturbing event for her. This type of response was also a feature of an observational study of hospice care by Ramsay (2000), who reported that she was haunted by the images of a patient's emaciated face. These responses may occur for any person first encountering extreme bodily deterioration and disintegration. Lawton found that on entering the in-patient unit of the hospice the importance of focusing upon the body of the patient and the disease process taking place within it and upon its surfaces became paramount.

The process Lawton (1998a, 2000) describes is one of patients moving from 'body-subject', as in day care, to 'body-object'. Setting the disintegrating body apart from mainstream society, as hospices appear to do, enables certain ideas about 'living', personhood and the hygienic, sanitised, bounded body to be symbolically enforced and maintained (Lawton 1998a, 1998b, 2000). She suggests that conceptualising a hospice as 'no place', that is, a space within which taboo processes of bodily deformation and decay are sequestered allows it to be understood as a central part of contemporary Western culture. In respect to the idea of sequestration, the hiding of 'dirty dying', Lawton (2000) proposes that the hospice could be understood not
simply as a liminal space. It could be understood as 'no place', likening it to that of the 'modern' abattoir (Lawton 2000:144). This proposal is based on the idea of hiding processes and suffering that the general public does not want to see or even know about. Furthermore, she considers the problem of 'living too long' and 'dying too soon' as signifying how social and interpersonal relationships are lost for people who are dying. She refers to this social death as invisible suffering.

Lawton (2000) also draws on van Gennep (1960) in referring to the hospice liminality as a 'fringe/liminal' space where 'non-persons' waver between two worlds, the worlds of the living and the dying. She uses the idea of liminality to emphasise the non-person status of the dying person. Froggatt (1997) also speaks of the threat to the order of society that a disordered process of dying may have, and how the dying are bounded within the space. This liminality is contributed to by the withdrawal of the dying person from social encounters which Lawton (1998a, 2000) suggests starts during the day hospice admission. That is, they experience a social death due to the withdrawal of friends and family. This withdrawal progresses further due to their bodily disintegration. Lawton (2000) argues that the academic rhetoric on hospice is not about fear of death. Neither is it about obsession with death, as suggested by Walter (1994). It is primarily about the question of personhood. Lawton (2000:172) questions; 'When, during the dying trajectory, does one cease to be a person per se, and when does death become a better option to living and suffering?' The work of Copp (1996, 1999) and Lawton (1998a, 1998b, 2000) share some common features where they identify how in hospice care the personhood status of the dying person is in question, particularly as death approaches.
2.2.1.4 Readiness to die – the person-body split during the dying process

Copp (1996, 1999) used prospective case study methodology, combining participant observation, interview data and medical and nursing documentation to explore experiences of patients who were facing impending death in one hospice setting. Comprehensive case reports are presented of 12 individual patients detailing the experiences of both patients in confronting death and nursing experiences of caring for these patients. The study specifically set out to use a symbolic interactionist perspective and the ‘open-awareness’ context (Glaser and Strauss 1965) where it was understood that the patients were living in the knowledge of ‘certain death but at an unknown time’ (Copp 1996:85). I address Glaser and Strauss (1965) awareness-context theory in detail later in this chapter.

Copp constructed a model to describe how both the patients and nurses understood ‘readiness to die’ for this patient group. Three phases of the process were identified, these were: ‘protecting and controlling’, ‘watching and waiting’, and ‘holding on and letting go’. Protecting and controlling was the dominant theme of the model. This involved protecting kin, patient and nurse protecting each other, and protecting self through a number of controlling processes. These themes were both individually distinct but also intertwined. Protecting was about the ‘public’ and ‘private’ fronts, for which Copp (1996) draws on Goffman (1959) to explicate. Everyone protected each other, particularly as physical deterioration accelerated and in the event of the embarrassment of loss of control of continence, memory problems and slurred speech of people with neurological degeneration. These were ‘covered up’ to preserve the dignity of the dying person. As found in Lawton’s work both patients and nurses focused on the bodily deterioration of the process of cancer and this was crucial in
determining quality of life and dignity of patients. Copp’s (1996) participants speak of the body leaking in the same manner as described by Lawton (1998a, 2000) and Waskul and van der Riet (2002).

Copp (1996, 1999), as does Lawton (1998a, 2000), also draws on the work of Lawler (1991). Lawler (1991) developed some of the earlier sociological discussions on nursing and embodiment. She refers to ‘the problem of the body’ as a configuration of embodiment that has arisen out of the fragmentation of study of the body. Lawler (1991) was concerned that the emphasis had been on abstract and reductively derived knowledge, and claimed that practical knowledge about the body has not been systematically studied. She saw ‘the problem of the body’ as people not wanting to know about nurses ‘practical’ knowledge of the body. Consequently there was a social pressure to hide the body, some of its functions, and the private nature of work that nurses do in caring for the bodies of patients, i.e. work that is carried out behind closed doors.

Copp (1996, 1999) shows how both patients and nurses consistently separated body from personal self, however, for patients this was related to body distancing in discussions about funeral arrangements. For nurses the split was linked to the process of gauging whether the person’s physical and personal self were in synchrony. The nurses felt ‘rejected’ if the patient chose not to discuss impending death. It appeared to be important that the nurses had formed a relationship with the patient that openly acknowledged the impending death and when this occurred the person-body split was synchronised. An absence of the synchronicity/separation constituted the total annihilation of the person, body and self. Copp (1996, 1999) found that the
establishment of personhood status required a relationship that had developed over time between the nurses and the dying patient and this in turn led to a strong sense of coherence.

This finding correlates with a theoretical framework of hospice work developed by Andershed and Ternestedt (2001). The authors draw together four studies about relatives’ involvement in the care of the dying to provide a useful metaphorical model of hospice work in Sweden. The ‘involvement in the light’ represents meaningful involvement in the dying process for people who have a sufficiently long illness trajectory. This requires time within which relationships can be made between the staff and patient and is depicted as developing a strong sense of coherence. ‘Involvement in the dark’ conceptualised non-meaningful involvement due to a rapid illness trajectory where there was no time to form this relationship. Consequently there ensues a weak sense of coherence.

Of further interest, and in relation to the issue of the capacity of hospices to extend services to a wider group of chronic illnesses, Copp (1996) found that three of her cases did not die during the study, which took place over a number of years. There was lack of conformity to the expected dying trajectory and these patients went through a transition from a dying to a not-dying role. This created tension and conflict for the hospice under study regarding the use of expensive services and the appropriateness of the place of care for the patients with this new role.
2.2.1.5 'Symbiotic niceness'

Li (2002) draws on the work of Lawton (1998a, 2000) and Copp (1996, 1999), although her focus, when drawing on these works, is on the psychosocial discussions within the theses rather than on bodily care. She specifically set out to investigate how palliative care nurses enact psychosocial care in their natural surroundings, with particular reference to their talk and to emotional labour theory. Using an ethnographical approach and conversation analysis of the nurses’ ‘talk’ from two hospices and a general hospital in the South of England, Li (2002) proposed a theory of ‘symbiotic niceness’. The work is underpinned by emotional labour theory, as is Froggatt’s thesis. Li’s (2002) model proposes that through the negotiation and enacting of psychosocial care, both nurses and patients use a number of constructs of ‘niceness’, each one dependent on how patients were categorised by the nurses. The premise is that ‘symbiotic niceness’ is a core component of professional and patient identity which works to maintain social orderliness. It is also posited that this process advances personal, professional and organisational aspirations. She summaries her argument with the equation: nurses’ assets + patient assets = team assets = organisational assets = marketable assets = ‘nice’ organisation (Li 2002:270). This argument, for maintaining orderliness within organisations, will be returned to in the discussion on dementia care within organisations.

The idea of ‘doing niceness’ in hospice is not new. Speck (1994) coined the term ‘chronic niceness’ in describing how staff work at creating an environment in which a ‘good’ or ‘nice’ death can be achieved. ‘There is a collective fantasy that the staff are nice people, who are caring for nice dying people, who are going to have a nice death in a nice place’ (Speck 1994:97). In using this term Speck (1994) refers to a process
where the individual and organisation collude to split off and deny aspects of the stress of caring for dying people, a component of doing niceness also acknowledged by Li (2002) and demonstrated by Froggatt (1995), where the body of the nurse was posited as a metaphorical container for holding emotions which could be released only at appropriate times. Speck (1994) suggests that organisational and work pressure increase ‘not-so-nice’ feelings that are then projected onto management. In this ‘niceness’ relationship it is only the patient who really appreciates what they (staff) are doing in their everyday care practices (Speck 1994). Li (2002) does not examine the impact of ‘symbiotic niceness’ on the wider organisation in any detail. However, Li’s conceptualisation of doing niceness to maintain social order has implications for the maintenance of continuing niceness outside of the nurse/patient interaction relationship, if as Speck (1994) suggests niceness is used as a defence against the fear of death. In which case categorising patients enacting different ‘types’ of niceness supports the proposal that this is a strategy for managing conscious and unconscious defences against the emotional impact of working with dying people, as suggested by Speck (1994).

Although it does serve as a means of managing relations between palliative care nurses and dying patients, ‘symbiotic niceness’ is not easily applicable in the case of people who are demented. At least Li (2002) does not address how ‘symbiotic niceness’ may be enacted with the person who is cognitively impaired. The implication is that the model could not be used as it generally requires the demonstration of ‘niceness’ to be initiated by the patient rather than the nurse.
It is however, a model that may be applied to the relationship between family members (of people with dementia) and hospice nurses. In this case it acts rather as a deceptive mechanism where the underlying feelings and beliefs about how patients should be managed (controlled) may be hidden from family members. Li’s (2002) work is useful in portraying staff acting out organisational roles, displaying the culture and philosophy through actions and words that may not always match practice. The idea of ‘symbiotic niceness’ suggests a somewhat cynical approach to the interactions between nurses and their patients within hospice care. However, Li (2002) is careful to point out that it was not her intention to create such an image of the model. Rather her thesis sets out to show how the symbiotic nature of interactions between patients and nurses is a component of the emotional labour of carrying out psychosocial care.

Within these discussions personhood is implicitly related to concepts of personal dignity and the ideology of the ‘good death’. Lawton and Copp propose theories of hospice care that address the concept of personhood in similar ways. For Lawton (1998a, 2000) personhood was used to consider aspects of self and the place of self during a dying process where self is disintegrating. Lawton is particularly critical of the concept of the ‘good death’ and Copp (1996) is careful not to use the term ‘good death’ but speaks of the ‘model death’. The ‘model death’ is related to a death observed by one patient as to how they would like to die. Copp (1996) later refers to the ‘peaceful death’ as the death whereby the dying person has resolved any issues, where the body-person is synchronised and they have reached a stage of open awareness, i.e. according to the nurses they die ‘at peace’.
In the above four models organisational activity is either implicit or explicit. Froggatt (1995, 1997) presents an idealised concept of hospice work that has commonalities with some of the founding principles of hospice where nurses are depicted as 'ritual specialists' controlling the dying process within a possibly 'sacred space'. Li (2002) presents hospice as a creating an impression of a 'nice', 'marketable' organisation with less of an idealised focus than does Froggatt (1995, 1997), but demonstrates how symbiotic niceness works to maintain social orderliness within the organisation. Controlling is explicit within all of the models albeit with different emphasis. Lawton (1998a, 2000) shows how the dying process is controlled through a state of isolation enforced by a social rejection of the unsightly 'unbounded body', i.e. sequestration. Both Froggatt (1995) and Copp (1996) identify the tension between controlling and protecting, and also identify hospice as place within which dying may be hidden. For Froggatt (1995) this tension between controlling and managing care is related to knowledge and time, i.e. 'possessing knowledge' (specialist hospice knowledge of pain and symptom control) and 'having time' (to get to know the patient). Froggatt (1995, 1998) identifies two factors that facilitate the daily work of hospice ideology by the 'ritual specialist' that are necessary for the establishment of relationships between nurses, patients and their kin. This is depicted as a bridge over which a relationship between a nurse and patient is established, whereas for Copp (1996), this tension relates to protecting self and others through a number of controlling processes. Both Li (2002) and Copp (1996) use the work of Goffman to consider concepts of self, where for Li the self was an 'acted' self, and for Copp (1996), during the dying process, protecting the 'public' and 'private' fronts for patients was of crucial importance. Emotional labour theory, which is closely linked to understanding
organisational behaviour is used to underpin the work of both Froggatt (1995) and Li (2002).

2.2.2 Dignity and dying

The ideology of the 'good death' is central to the hospice movement (Hart et al 1998) and is a subject that has attracted a number of research projects and philosophical dialogue. See for example (Kellehear 1990; McNamara et al 1994, 1995; Low and Payne 1996; Payne et al 1996a, 1996b; Mui Hing Mak and Clinton 1999; Leichtentritt and Rettig 2000; Steinhauser et al 2000; Kristjanson et al 2001; Masson 2002; Seymour et al 2002; Vig et al 2002; Dekkers et al 2002; DelVecchio Tong et al 2003; Walter 2003; Good et al 2004; Walters 2004). However, Lawton (2000) believes that there is an urgent need for more rigorous analysis of such taken-for-granted principles as 'good death' and 'death with dignity'. Within this debate Lawton (2000) points out how the concept of 'dignified death', that is also central to the hospice movement, is articulated principally in terms of a discourse centring on pain, a suggestion that encompasses the debate outlined above on the medicalisation of hospice care. Lawton (1998a, 2000) concludes her thesis with a call for further debate on how and why hospice is promoted as the antithesis of euthanasia when patients admitted to hospice often request assisted death.

Lawton's work is based on an anthropological model and Clark et al (2002:59) points out that it is not the palliative care clinicians who are writing about the 'good death' now, 'but sociologists, anthropologists, historians and ethicists', and these debates are increasingly focusing on the subject of assisted death or euthanasia. This criticism, of distancing the dialogue about the 'good death' between clinicians and scholars,
supports one of the positive elements of the so-called medicalisation of death. That is, clinicians may be more likely to take a pragmatic approach to dying and focus on what patients' really want, in that patients may not fear death but may fear rather the process of dying (Clark et al. 2002).

'Good death', 'dignity' and 'quality of life' are often evoked and used synonymously in end-of-life discussions and debate, and 'dignity has been subsumed into quality-of-life domains, rather than explored for its complex and hidden meanings' (Street and Kissane 2001:95). The concept of dignity is often raised in relation to ideas about the 'good death', by both patients and staff (Payne et al. 1996a, 1996b), in relation to 'death with dignity' (Allmark 2002), in debates on euthanasia (Pullman 2004), and in planning or making decisions about treatments at the end of life (Chochinov 2002; Chochinov et al. 2002; Downie 2004; McClement et al. 2004). Indeed, when Oregon legalised physician-assisted suicide in 1997 the title of the document was the 'Oregon Death with Dignity Act'. A precise conceptualisation of dignity is thought by some scholars to be enigmatic and elusive (Turner et al. 1996; Pullman 2004). Dignity has been referred to as an 'ambiguous euphemism' (Lynch 1982 cited Pullman 2004). Recently it has been referred to as a 'useless concept' (Macklin 2003), a claim that engendered some debate on the British Medical Journal rapid response website (2004). Using measures that were considered relevant to dignity in dying Turner et al. (1996) reported differences in perception between different observers in what makes a dignified death, even with staff using similar parameters in making the judgement.

Radley (2004) presents dignity as both a spectacle and an achievement, a status which is accorded by its appearance. Dignity, as a 'spectacle', refers to suffering (indignity)
that is witnessed. Dignity as ‘achievement’ is seen as the result of an individual’s way of acting. That is, how they may show how they can suffer and yet be dignified (Radley 2004). In this context individual autonomy and personal choice are often seen as synonymous in providing a notion of ‘personal dignity’ (Pullman 2004). In developing an argument on dying, human dignity, and moral meaning Pullman concludes that:

Death with dignity then means dying in a manner that comports with how the dying person understands his or her own personal dignity, rather than according to some one else’s conception of personal dignity, or some externally imposed universal standard of basic dignity (Pullman 2004:174).

Defining dignity as an individual and personal concept brings into question judgements that may be made about care interventions at the end-of-life that use concepts such as dignity that are based on dignity as a ‘spectacle’. Dignity of the patient is always under threat from the way others are involved in constructing a new identity for them (Lupton 1997), particularly when the appearance of the body of the person is rendered grotesque by the disease processes (Waskul and van der Riet 2002). To conceptualise dignity as a ‘spectacle’ requires the spectator to also have a personal concept of dignity. As pointed out by Frank (2004a), dignity may be conceptualised as an ‘event’ happening between persons, rather than a fixed quality. In this case ‘anyone’s loss of dignity threatens everyone; as that other person is treated, so I myself might be treated’ (Frank 2004a:207).

The purpose of developing this argument is to apply concepts of dignity and end-of-life care to people with dementia and perhaps counter the suggestion by Walter (2003) that the ‘bad death’ may be attributed to the death of the person with no autonomy.
That is, according to Walter (2003), the patient with stroke or Alzheimer’s disease, who cannot communicate his or her wishes or whose brain has so deteriorated that there are no wishes left. Models that have been developed that aim at dignity-conserving care approaches (Chochinov 2002; Chochinov et al 2002; McClement et al 2004) require some degree of patient autonomy in their application and are not easily applied to people who are cognitively impaired, except by proxy (spectators). This is due to the fact that it is assumed that little is known about what is taking place within the mind of the person who is severely cognitively impaired and unable to articulate their needs and wishes.

However, there is a growing body of evidence that must lead practitioners to question assumptions about the functioning of the brains (or minds) of people who have severe brain damage. Of note is Bauby’s (1997) personal experience of ‘lock-in syndrome’ following a massive stroke. This enlightening piece of work is witness to the continuing intelligent, humorous and lucid working of the mind in an almost totally paralysed body. The testimony of Bauby (1997) was composed using a specially constructed communicator which he used through the blinking of his left eye. His experience of being ‘locked-in’, and his response to his carers and their individual care practices, demonstrates how important it is not to assume loss of awareness of people with neurological damage, or in their personal experiences of dignity or indignity. Whilst the case of Bauby (1997) is not necessarily comparable to the dementia experience, recent work that draws analogies between coma and dementia (Lidzey 2004; Clarke 2004) allows consideration of the dementia state as one that may resemble the ‘locked-in’ experience.
Studies that have attempted to conceptualise dignity within hospice care have predominately focused on the perceptions of patients (Turner et al 1996; Chochinov 2002; Chochinov et al 2002; McClement et al 2004), where the patient is clearly able to articulate their own experiences of the impact of care and what this means in relation to their personal dignity. One of the characteristics of dignity identified by Chochinov et al (2002) was that dignity was seen by the patients as preservation of cognitive abilities and physical independence. Any major loss of such characteristics was perceived by the patients to be associated with loss of dignity. I return to the discussion by Frank (2004a) and Pullman (2004), where it is posited that concepts of dignity are socially constructed. A socially constructed view allows that assumptions may be made, by others, ‘spectators’, that people with cognitive impairment and loss of physical independence could be seen to be without dignity. I make this argument using Radley’s (2004) position on dignity as a spectacle, where the judgement is based on the ‘observers’ concept of dignity.

There is little empirical research specifically on the concept of the ‘good death’ and its association with ‘dignity’ within the dementia literature. A study using structured telephone interviews with 57 family member care-givers of persons with Alzheimer’s disease who had died whilst a resident in a nursing home in the USA, (Bosek et al 2003) attempted to elicit participants’ understanding of the phenomenon of the ‘good death’ for this group. The researchers found that 89.5% of the participants believed their family member had died with dignity. A significant number (28%), of the caregivers did not believe they had experienced a ‘good death’. Based on the participants’ responses the ‘good death’ was one where the death conformed to the dying person’s preference (as believed by the family member) regarding when and
where to die. It also required that the death occurred without discomfort for the dying person (as observed by caregivers). Bosek et al (2003) conclude that a good death, as proposed in the literature, could not occur when the person is dying from Alzheimer's disease. Having Alzheimer's disease limits the person's capacity to participate in most of the components of a good death (Bosek et al 2003). This supports Walter's (2003) view that such a death may be constructed as a 'bad death'. However, these views are based on constructs about the 'good death' that cognitively impaired people cannot contribute to.

Whilst discussions on the 'good death' are limited within the dementia literature, the term dignity is used frequently, and often as freely and 'loosely' as it is in much of the palliative care literature. Any judgement on the dignity of a person with advanced dementia fits Radley's (2004) concept of dignity as a spectacle, where the dignity status would be determined by the 'spectator(s)'. In this case it is important to develop some shared meaning for dignity within any team providing care for this patient group. In a phenomenological study of nurses' and patients' perceptions of dignity Walsh and Kowanko (2002) found that much of the discussion on dignity revolved around the exposure of the body and the gaze of others, confirming how dignity may be conceptualised as a spectacle.

Enes (2000, 2003) provides a useful conceptualisation of the meaning of dignity in a phenomenological study of eight patients, six relatives, and seven (multidisciplinary) members of a hospice team in a London hospice. What is particularly useful within this study is that the themes are developed from all three groups to form a multidisciplinary conceptualisation of dignity within hospice care. Dignity was found
to be composed of the dimensions, 'being human', 'having control', 'relationship and belonging', and 'maintaining the individual self' (Enes 2000, 2003). These themes confirm the findings of others on conceptualising dignity. Enes (2000, 2003) work also echoes an aspect of Lawton's (1998, 2000) theory on the sequestration of 'dirty dying' in one respect. She identifies that, for all groups, to maintain dignity, certain things should be 'hidden'. That is, there was a sense that certain aspects of the 'self' should not be exposed if dignity is to be possessed confirming the findings of Walsh and Kowanko (2002). This raises an argument against Lawton's (1998a, 1998b, 2000) premise that it is society that has predominantly focused on hiding the 'dirty dying' process. Enes (2000, 2003) correlates with the view held by Storr (1988) that sequestration can also be a chosen by the withdrawing person for a complex range of reasons. Lawton (2000:148) does concede however, that the dying person becomes isolated because, as a response to dying, they were experiencing the world in a way in which family and friends could not and were therefore unable to share in the experience.

2.2.3 Personhood, dying and dementia

Within discussions on dignity also lies the enormous ethical and philosophical debate on concepts of self and personhood. Personhood is a concept that is frequently evoked in both the palliative care and dementia care literature and is often linked to discussions on dignity. There is a large literature on the subject of personhood and dementia which will not be addressed here. I have focused the discussion on discussions on personhood in general and personhood in relation to dying, suffice to say that there is an emerging criticism of the use of the term person-centred care
within the dementia literature (see for example Adams 1999; Nolan et al 2003; McCormack 2004; Adams and Gardiner 2005).

Both Lawton (1998a, 2000) and Copp (1996, 1999) have discussed the concept of personhood in relation to death and dying. For Lawton the inference is that the carers' perception of the dying patient, as they approach death, was that the 'person' had already gone. Descriptions such as: 'slips into a coma', 'switches off mentally' and 'become unaware of their environment' (Lawton 2000:113), were used to denote that the person had gone. A view shared by both staff and family members.

Fu-Chang Tsai (2001) states that deep controversies have developed in Western philosophy in general, and bioethics in particular, on conceptions of personhood. A massive literature exists where debates abound on personhood status of, to list a few: embryos, stillbirths, abortion, childhood, severe disability (including birth defects and accidental damage), mental illness, autism, homelessness, persistent vegetative state, people with profound dementia, and a state of unconsciousness at the end of life. Within these ethical debates argument continues on whether 'persons' are also 'human beings' (Fu-Chang Tsai 2001). It is generally stressed, within this argument, that rationality, self-consciousness, and autonomous moral agency are the key features of being human (Fu-Chang Tsai 2001). Engelhardt (1986) proposes that human beings, such as infants, the profoundly mentally retarded, people in a permanent vegetative state, and individuals with advanced dementia are merely persons in a social sense. However, to be a person in a social sense must, by definition, require some sort of person-to-person interaction. Fu-Chang Tsai (2001) uses this argument to present a Confucian definition of personhood. Within the Confucian model the
boundaries between the self and others is not clear. Personhood is a relational-based state, where becoming fully human is a process that occurs through continuous interaction with other human beings. Much in the manner described by Frank (2004a), where dignity is an ‘event’ happening between persons, the Confucian model proposes that one’s dignity as a person depends as much on communal participation as on one’s own sense of self-respect (Fu-Chang Tsai 2001).

Biomedical ethics do not specifically address the subject of personhood or non-personhood but appear to prefer to use terms such as competency and non-competency (Beauchamp and Childress 2001). Implicit within this however, is that competency equals personhood and non competency equals non-personhood. In the event of a severely cognitively impaired patient’s need for treatment, as is the case for many hospice patients as they near death, the strategy is one of making reasonable medical judgements (medicalisation) (Beauchamp and Childress 2001). These appear to be equated with quality of life judgements (palliative care philosophy) when applied by hospice clinicians. Consent for treatment appears to be grounded in discussions on competence and non competence within hospice settings. Many treatments and interventions are instigated without consent, or with assumed consent, for example the use of sedation. However, little study has been conducted that examines the consent and non consent to the administration of sedation in hospice.

The study by Bosek et al (2003) on the ‘good death’ for people with dementia does highlight that family members have concerns about administration of sedating medication and the possibility of family members raising the issue of assisted suicide or euthanasia and facilitating the death of a person with Alzheimer’s disease was
addressed. Bosek et al (2003) make recommendations that professionals became knowledgeable about the professional standards for assisted suicide or euthanasia in their state or country. This concern was also a factor raised by Seymour et al (2002) in a preliminary exploration of older people’s assessment of morphine and terminal sedation. Seymour et al (2002) highlight the need to find some common ground between patients, family members and healthcare professionals in grasping the implications of sedation at the end of life. Doubts and fears were expressed regarding risk of exclusion from comfort by not adequately representing dying relatives needs. Concerns were also raised about hastening death by use of medications. The possibility of families swaying decision making in a manner that hastened the death are areas in need of further research (Seymour et al 2002). These issues also raise some questions in relation to medications now used in hospice such as, for example, midazolam and ketamine, which have historically been used in anaesthetics, a field of medicine that has a strong focus on consent.

2.2.4 Disintegration as a spectacle

Fear, horror and aversion to the disintegrating body is not new (de Beauvoir 1970; Synnott 1993; Lupton 1994; Williams and Bendelow 1998; Shilling 2003). Nor is it new for an individual to wish to withdraw from the social world for reasons of disintegrating illness (Storr 1980; Mellor 1993; Lupton 1994; Lawton 1998a, 1998b, 2000). However, there have also been periods of history where spectacles of disintegration were on public view as a source of entertainment. There are examples of human dissections of criminals, as a form of punishment, being carried out for public entertainment (Richardson 1988).
Even in the present Western culture the curiosity of the public about death, disintegration, and deformity is identified by the interest that is shown in these subjects. For example, the unprecedented interest in the von Hagens 'Body Worlds' exhibition (2002) which included carrying out a public autopsy. The inclusion of a multitude of public and the media responses in the form of displays of newspaper clippings, also presented at the exhibition, served to further emphasise fascination towards spectacles of disintegration. As pointed out by a contributor to the von Hagen website, 'going to see a plastinate man carrying his own skin draped like a coat over his arm is no different from going to see a travelling freak show in mid twentieth century America' (A804322 2003). The internet displays of beheadings in Iraq and the mixed horror and fascination with these, provide another example of responses to human disintegration, and journalists constantly debate the context, dignity, distance and the nature of the audience in portraying graphic and powerful images of human destruction (Marks 2003). There is a paradox in present Western culture, where there is ambivalence and hypocrisy towards public displays of disintegration with expressions of shock and horror, and also fascination of such displays. This paradox extends to fascination (the need to gaze at) and rejection and disgust (the need to hide or sequestrate) both disintegrating minds and bodies.

2.2.4.1 Sequestration of disintegration

Sequestration of people with dementia is also central to contemporary Western culture. Historically, at least from the Classical Age to the twentieth century, the aged and the insane have been dehumanised and frequently confined to institutions (Goffman 1961; de Beauvoir 1970; Szasz 1975). The disintegrating dying and the demented share a common ground in Western culture in that the bodies and 'minds'
of dementia sufferers have been hidden from society in the same manner as Mellor (1993) and Lawton (1998a, 1998b, 2000) describe the sequestration of the disintegrating dying. Lawton (2000) briefly addresses these commonalities. This sequestration and social rejection has also been identified in institutions for people with severe physical disabilities in long-term care (Miller and Gwynne 1972; Dartington et al 1981; Roberts 1994a). Roberts (1994a:79) describes the crossing of the boundary into such institutions as 'joining the category of non-contributing, non-participants in society', where they were treated as if they were already socially dead. People with dementia are often referred to within the same context as those who are dying, without acknowledgement of the terminal state of the disease, and in some cases referred to as 'already dead' (Gubrium 1986; Orona 1990; Herskovits 1995) while they are quite obviously physically alive.

Much of this debate is echoed in the literature on personhood as discussed earlier. Suggestions have also been made that the person in the advanced stage of Alzheimer's disease may be classified as already 'dead', based on new definitions of death (Blank 2002). Post (1990) draws attention to the ethical debate on the direct killing of newborn (infanticide) and severely demented older people (geronticide) and the implications of this. Because they lack empowering capacities, people with advanced dementia are defined as 'nonpersons' by what Post (2000:247) refers to as 'hypercognitive values of some of the philosophical bioethicists'. Post (2000) proposes that the ultimate hypercognitive assault on Alzheimer disease related forgetfulness is physician-assisted suicide. The justification for physician-assisted death is believed to have arisen from the issue of longer and more agonising dying trajectories (Wolfson 1998). However, in challenging the grounds for euthanasia...
Wolfson (1998) goes on to cite an example of a case in the USA of a 54 year old woman with Alzheimer’s disease who was given a ‘physician-assisted suicide’ death, according to Wolfson (1998), instigated by her husband. She was not terminally ill and had only been diagnosed one year before the assisted death.

I do not intend to develop an ethical debate on dementia and ‘physician-assisted suicide’ but merely to bring to attention the position of people with dementia and their value (and the value they may place on themselves should they become demented) within society. What repeatedly comes to the focus within the above debates is how socially and psychologically important it is to create a sense of ‘order’ within environments of care for these people.

2.2.5 Ordering the disorderly: congruency in dementia and hospice care practices
Dementia renders people vulnerable and dependent upon others for the provision of their care needs and leads to suggestions that they are no longer persons. Mitteness and Barker (1995) and Oliver (1999) suggest that the symptoms that occur in the person with dementia, such as incontinence, unstable mobility and babbling speech symbolise a loss of control that is culturally ‘incompatible with adulthood’ (Mitteness and Barker 1995:191). Of particular interest is a study conducted by Oliver (1999), who analysed attempts by an institution to impose structure and control on the daily lives of residents with Alzheimer’s disease, in a residential setting. Whilst this is a study of old age and dementia it has some congruency with the concept of hospice developed by Lawton (1998a, 2000) in relation to the marginalisation by society of the people who have lost control of bodily functions. Oliver (1999) developed a concept of ‘ordering the disorderly’ and concluded that the need to conceal, contain
and control the disorder of these people is a means of avoiding the risk of exposure of the shortcomings of: '... modernity’s biggest failure; the inability of science to cure the uncontrollable aspects of ageing or to conquer death' (1999:182). Oliver’s (1999) study revealed five ‘imposition of structural controls’ over the lives of the residents. These were: temporally, physically, materially, organisational, and behaviourally and linguistically. Some of these have congruency with hospice practices.

Temporally refers to a strict regime of time structure which tended to create a sense of depersonalisation of residents. This related to the daily activities of people with dementia and there is congruency with hospice care. Whilst the hospice philosophy and practice promotes an environment of granting a high degree of autonomy to patients, Walter (1994), Lawton (1998a, 2000) and Ramsay (2000) make observations about the control of patients that takes place within hospices, albeit subtle control. In an observation study by Ramsay (2000) a state of ‘enforced’ privacy of patients was a focus of the hospice in which the observations took place. This was despite the ‘created’ atmosphere of homeliness (including a cat). Another form of temporal control that is imposed within hospice is that of admission criteria (Hockley 1997). Rigid time limits on the length of stay are imposed in most hospices, with a strict criteria for admission primarily needed to cope with limited bed numbers (Hockley 1997; Eve and Smith 1996; Eagle 2002; Gannon 2002). Douglas et al (1999) report one case where the person with variant CJD was discharged from the hospice because the dying process was taking too long, a situation that caused great distress to the family.
Oliver (1999) found that control and concealment was also physically imposed. This was the manner in which the unit was placed, i.e. beside a medical centre, 'medical gaze' and surrounded by residential areas, 'normality'. An illusion of order is presented behind which were 'decorated' locked doors. There is congruency with this category as identified by Walter (1994) and Lawton (1998a, 2000), in the concept of sequestration, which again is (questionably) more subtle. The hospice environment, the created atmosphere of peacefulness, calm and homeliness (Walter 1994; Lawton 1998a, 2000), serves to provide a front for the process of disintegration and dying (Lawton 1998a, 2000). However, this aspect of the hospice has not been researched in any substantial way. Physical control is imposed through the use of sedation, rather than the locked doors and gates found in the dementia care environment. However, the regimented methods described by Oliver also included sedation.

Materially, the setting and décor of the units are designed to promote an 'image of tranquillity', much in the manner of hospice décor. Oliver (1999) suggests that these serve to conceal the disorder, the bodily degeneration and decay contained within the units. This is a feature of hospices highlighted by both Lawton (1998a, 2000) and Walter (1994) where the peacefulness of the environment is of paramount importance. Organisational and bureaucratic measures were used to take away any time that could be spent with the residents on a personal level (Oliver 1999). Once again a more subtle level of this is present within the hospice and is focused around medication, particularly sedation of people who are agitated and distressed.

Behaviourally and linguistically residents were categorised and stereotyped according to their behaviours and the denial of personhood was perpetuated through
infantilisation and humiliation (Oliver 1999). There is no evidence within the palliative care/hospice literature that indicates congruency of this category within present hospice care. However, in relation to future admission of patients with dementia to hospices, it may be found to be relevant as it is in many other settings where people with dementia are cared for.

2.2.6 Awareness context

The hospice model and environment offers an opportunity for sharing in the experience of dying with dying people themselves within an open awareness context. This sharing of experience within a humanistic or spiritual framework has been the hallmark of the hospice model throughout the history of the hospice movement, from its traditional basis of a place of hospitality, to the present model (Zerwekh 1993; Nebauer et al 1996; Rasmussen et al 1995, 1997; Seale 1998). There is an assumption that nurses who chose to work in this area feel comfortable with the open acknowledgement of death and dying (Payne et al 1998), a factor confirmed in a case study on how role-models influence palliative care nurses in their choice of career (de Vries 2000a, 2000b). The importance of this shared experience is identified by Addington-Hall (2000) as one of the barriers to the integration of people with dementia into the hospice environment.

Awareness-context, in relation to death and loss, is a concept developed by Glaser and Strauss (1965) from their study of dying people in three hospital sites in the USA. Glaser and Strauss proposed four contexts of death awareness between staff and patients. ‘Closed awareness’ is where staff knew the prognosis was poor but did not share this information with the patient. ‘Suspicious awareness’ occurred when the
patient suspected that their condition was serious and attempted to confirm this. In ‘mutual pretence awareness’ both staff and patient knew the patient was dying but chose to pretend that it wasn’t so. ‘Open awareness’ was where all concerned, patient, staff and relatives, knew and acknowledged impending death, and were therefore able to talk about dying. The awareness-context model has been critiqued at length within the palliative care literature (Timmerman 1994; Field 1996; Seale 1999a; Field and Copp 1999) and some further development and extensions of the model have been offered. For example, Timmermans (1994) splits the open awareness context into three different contexts. ‘Suspended open awareness’ refers to a situation where the patient or relative may obstruct staff’s efforts to be open. ‘Uncertain open awareness’ is viewed as a flexible period where death matters can be discussed if they leave a margin of hope. ‘Active open awareness’ suggests the idealised context where patient and family members understand the full implications of impending death and try to come to terms with it. Timmerman (1994) uses his personal experience of the death of his mother in extending the concept of open awareness, pointing out that the importance of the emotional experiences of the patients and relatives is lacking in the Glaser and Strauss (1965) model.

Open awareness context is the model that is fundamental to late modern hospice care and requires human agency, i.e. illness-insight, where patients have the ability to make decisions and discuss the dying process (Seale 1998). Seale (1998) suggests that human agency has a significant place in allowing the patient to enter into the dying role with open awareness. He says that this entrance is culturally shaped and scripted and cannot be applied to the dementia sufferer. A group that could be compared (to some extent) to the dementia sufferer is that of people with brain
tumours, such as malignant glioma. A further challenge to the Glaser and Strauss (1965) awareness categories is made by Salander and Spetz (2002) following a prospective study of 25 patients, with a diagnosis of malignant glioma, on how they talked about death and dying. Patients were not able to share due to cognitive deficiencies, personality characteristics, personality change, deep despair, and the characteristics of their relationships which placed them in the closed awareness context. Salander and Spetz (2002) identified that the couples in their study found ways of making life as meaningful as possible, i.e. through ‘mutual acknowledgement’ context, part of the awareness context theory that the authors believe Glaser and Strauss (1965) did not give due importance to. The idea of a ‘mutual acknowledgement’ context is much more useful in applying awareness context for people with dementia and is in keeping with recent discussions on the importance of capturing the interdependencies and reciprocities that underpin caring relationships within the field of dementia care (Nolan et al 2002; Nolan et al 2003).

A relational approach to palliative care has also been taken up by ethicists using Levinas ethics of the call of the Other’s suffering, a call that ‘commands’ a relational response (Schotsmans 2002).

2.2.6.1 Awareness context and people with dementia

At the heart of dementia is loss (Chesten and Bender 1999) and since the late 1980s there has been a new emerging view in dementia care, where the individual perspective of the dementia sufferer is being stressed. Within this new perspective has come a more developed understanding of both the experiences and emotional needs of the dementia sufferer (Miesen 1993, 1997, 1999; Kitwood 1990, 1993; Kitwood and Bredin 1992; Normann et al 1998, 2002; Oliver 1999). Miesen (1997,
1999) suggests, and offers some proof of, an awareness context for dementia sufferers that exists and could be accessed and scripted in circumstances related to care practices and a concept of loss. Miesen (1997) argues that his clinical observations and research (Miesen 1993), plus the research of others has proven that patients with dementia of the Alzheimer type still respond to their illness, even after their 'illness-insight' has disappeared. He refers to this, using the Glaser and Strauss (1965) awareness-context theory. Miesen (1997, 1999) maintains that the awareness-context causes the dementia sufferer to experience a chronic trauma related to separation, loss, powerlessness, displacement and homelessness. Although Miesen does not suggest that this awareness encompasses death-awareness there is no evidence contrary to the possibility. Miesen (1999) is adamant that for the person with dementia, emotional responses to their experiences remain throughout the dementia process. This is verified in the early research on the variant CJD experience. There is evidence that despite all the apparent symptoms of dementia, many of the people with CJD retained a degree of awareness up to very near the time of death. Family members were distressed by health care professionals' disbelief or disregard of the awareness state of the person with CJD (Douglas et al 1999; Bailey et al 2000; de Vries et al 2003).

This ability of dementia sufferers to respond meaningfully to others in some situations has been identified by researchers in the field (Kitwood and Bredin 1992; Sabat and Harré 1992; Normann et al 1998, 2002). Not only through the use of dynamic psychotherapy that has been used in research on this aspect (Hausman 1992) but also through the 'kind care' that may be part of the normal practice of formal care-givers in nursing and residential homes. 'Kind-care' can have an impact on a dementia sufferer in that some lucidity is briefly restored when the person is treated with a high
level of kindness and gentleness (Normann et al. 1998, 2002). Kitwood and Bredin (1992) anecdotally report that people may show ‘rementia’ when a conscious connection is established with a carer. Kitwood (1993) describes these events in relation to care that is centred on the individual.

There are many anecdotal reports of carers relating episodes of the patient unexpectedly speaking or acting in a way that surprises the carer and indicates that the patient may be more aware of his environment and situation than assumed. Such episodes have been referred to as ‘episodes of lucidity’ (Norberg et al. 1986; Aakerlund and Norberg 1986; Normann et al. 1998, 2002). Data from five interviews (over a period of two weeks) with a woman with dementia showed how lucidity is promoted by supporting the person with dementia using concepts of confirmation and communion. Support was given by sharing the person’s view, repeating and reformulating the person’s utterance and not emphasising errors (Normann et al. 2002). Normann et al. (2002) also showed how when the researcher made demands on the person with dementia the response was to go from lucidity to nonlucidity. Using this approach communication can be understood as more than just transmission of information but rather as a certain way of relating to the other (Normann et al. 2002).

Bleathman and Morton (1992) reported experiences similar to those described above when using validation therapy with patients. Examples of the use of reminiscence, where patients have unexpectedly told carers something about their past that was confirmed by their relatives have been described (Bright 1992; Sabat and Harré 1992). Jansson et al. (1993) and Kihlgren et al. (1996) report that dementia sufferers revealed more of themselves to carers who spoke the patient’s native language and provided
patients with calm, loving care. Many of these studies are small but accumulatively they provide evidence that people with dementia retain emotional responses to events that occur in their lives. There is also anecdotal evidence of episodes of complete lucidity immediately prior to death, in the case of profound dementia of long standing. The suggestion that awareness of death is culturally shaped or a sociologically scripted process proposes a narrow focus of human capacity, ignoring much of the biological and functionalist views of human emotion and action.

2.3 Dementia care at the end-of-life

In a review of literature on dementia care, practice and research Nolan et al (2002) raise the question of why and when interventions into dementia care relationships should take place. What is not explicitly acknowledged within this review is that dementia syndromes are, in the majority of cases, caused by terminal illnesses. In which case plans for interventions must begin by addressing the potential disease trajectory with assessment processes that allow preparation for end-of-life care.

Dementia as a terminal illness was not generally acknowledged within the palliative care literature until the 1980s in the USA. Since then a large literature has emerged, predominantly from the USA (Volicer 1986, 1997; Brechling and Kuhn 1989; Luchins and Hanrahan 1993; Hanrahan and Luchins 1995a, 1995b; Luchins et al 1997; Hanrahan et al 1999; Hurley et al 2000; Volicer et al 2001; 2003). A national survey of 400 nursing homes in the USA revealed that carers believed that people dying with dementia had special needs that were primarily reflective of the limitations in communication (Moss et al 2002). Of note was the prominence of discussion on advanced directives, which are a common feature in US healthcare end-of-life planning. These gave staff a clear direction in managing the care and allowed for
substantial agreement between the wishes of the person with dementia, family members and staff, particularly in relation to issues around hydration and tube feeding. Pain control was considered a significant issue by more than half of the nursing homes surveyed (55%), although in practice most of the nursing homes (73%) reported that pain in dementia residents was treated as aggressively as pain in other residents (Moss et al 2002).

There remains a paucity of studies on quality of end-of-life experiences of people with dementia and their carers in care home environments within the UK and it is only in the last decade that palliative care literature in the UK has acknowledged terminal illness status of dementia (Lloyd-Williams 1996; McCarthy et al 1997; Addington-Hall 2000; Lloyd-Williams and Payne 2002). From a secondary analysis of a retrospective, national, population-based, interview survey of relatives or officials of 3,696 people who had died in the last quarter of 1990 from 20 English Health Districts (Addington-Hall et al 1998) 170 people with dementia were identified. These were compared with 1,513 people with cancer (McCarthy et al 1997). The authors concluded that people dying with dementia have symptoms and healthcare needs comparable with those with cancer. This led to recommendations from the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) for specialist palliative care for non-malignant diseases (Addington-Hall 1998) and has extended to psychiatric services, where particular reference is made to end-of-life dementia care, including CJD (Addington-Hall 2000).

An audit of palliative care services in the UK indicated that the majority of palliative care teams do not include people with end-stage dementia in their remit (Lloyd-
Williams 1996). In one small study palliative guidelines were implemented on a number of long-stay psychiatric units and a retrospective evaluation study of all deaths was carried out over 12 months. The study showed that through collaboration and multidisciplinary work between palliative care and psychiatry for older people teams there was a positive impact on the end-of-life care for people with dementia particularly in the management of pain (Lloyd-Williams and Payne 2002).

The effectiveness of a comprehensive home-care package for people with dementia was also demonstrated in a USA study by Volicer et al (2003). The researchers found that care recipients who received psychiatric care, were involved in hospice programmes, and had effective pain relief for chronic conditions that caused chronic pain, particularly arthritis, were more likely to die at home, or stay at home significantly longer than those who did not receive this input. It was recognised that chronic pain worsened behavioural symptoms of the dementia and made it more difficult to keep the person at home. However, this work is significantly underdeveloped in the UK and palliative care services continue to be largely focused on the cancer death.

McCarthy et al (1997) found that the most frequent symptoms reported for dementia patients were mental confusion, urinary incontinence, pain, low mood, constipation and loss of appetite. These were of similar frequency as those reported for cancer patients but people with dementia experienced them for longer. This factor of 'protracted' death was also the conclusion of Black and Jolley (1990) in a review of the characteristics of 97 patients dying during one year while under the care of psychiatry for old age services. Few studies have evaluated prognosis of patients with
advanced dementia or looked at the natural course of end-stage illness of dementia in old age using palliative care principles (Schonwetter et al 2003). This has impacted on the level of service input that is accorded this group at the end of life.

In an earlier interview survey on a random national sample of deaths of people aged 15 and over who died in 10 areas of England Seale (1990) found that those who were the most poorly serviced and supported at the end-of-life were the older cognitively impaired. Most of the group providing care for the dying person with a diagnosis other than cancer and in old age lived alone, or in small family units and resources were general poor. The services for those people dying at home with a non-malignant disease were overall, less than those with a cancer diagnosis, and the burden of care often fell directly onto a frail, elderly spouse (Seale 1990). Whilst these surveys are retrospective carer views, they do provide insight into the problems experienced by this group. They confirm that the progressive neurological and functional decline of the person with dementia may cause a great deal of stress on families and caregivers (Mace et al 1999). This often leads to the need for hospital or nursing home admission, which further impacts on the bereavement experiences of both the person with dementia and their carers, often in a detrimental way (Forbes et al 2000; Nolan and Dellasega 2000; Lundh et al 2000; Gessert et al 2001).

2.3.1 Place of death and dementia care

The issue of where people die, where people should die and where people want to die is an ongoing debate. Also studies of preferences have been in selected populations or in groups receiving a specific service (Higginson et al 1998). Home is often cited as the place that most people would prefer to die (Townsend et al 1990; Thorpe 1993;
Seale and Cartwright 1994; Hinton 1994; Addington-Hall and McCarthy 1995a, 1995b; Karlsen and Addington-Hall 1998; Higginson and Sen-Gupta 2000; Tang 2003), although this preference may change when underlying situations change for the patient (Hinton 1994; Fried et al 1999; Grande et al 2003). Bereaved family members of decedents who receive care at home with hospice services are more likely to report a favourable dying experience (Karlsen and Addington-Hall 1998; Teno et al 2004). However, for various reasons many dying people spend the last days of their life in a hospital, hospice or other care environments such as a nursing home, rather than remaining at home (Hunt 1997; Hinton 1994; Grande et al 1998; Fried et al 1999; Grande et al 2003; Higginson 2003). Reasons for this include family members or significant others not able to maintain care as the illness advances and the person becomes more and more incapacitated (Hinton 1994; Grande et al 2003). Or, that the dying person may not wish to die at home, or may not have been consulted on preferred place of death (Pemberton et al 2003; Storey et al 2003). A further reason for preference for dying in hospital for cancer patients within the USA was that the patients had received their cancer-related treatment in the hospital and had built trusting relationships with hospital staff (Tang 2003). The literature on preferred place of death has also been predominantly focused on the cancer death, and there has been little research on end-of-life wishes of people with dementia.

Specialist palliative care is deemed an 'acute' service within the category and definition of the service. Admission into the service of a person with dementia, who may have a 'long' and unpredictable prognosis, becomes a matter of concern, where 'long term' has a negative connotation for acute areas of healthcare. The less rewarding aspect of dementia care, as opposed to the professional satisfaction from
emotional relationships, that is a feature of hospice care, is considered a barrier to the introduction of dementia care to palliative care environments (Seale 1998; von Gunten and Twaddle 1996; Addington-Hall 2000). Making a prognosis for the progress of dementia to end-stage is problematic due to the variability of the disease trajectory for the different types of dementia and accurate predictions remain one of the difficulties in determining an admission to palliative care services for people with dementia (Luchins et al 1997; Hanrahan et al 1999; Addington-Hall 2000). This is particularly pertinent to the specialist units that base admissions criteria on acuteness or urgency of the needs of the dying person (Gannon 2002; Eagle 2002).

A hospital admission can cause unnecessary discomfort and confusion for the older person with dementia and it is advocated that a conservative or palliative approach should be the mainstay of care. Such an approach weighs the discomfort of the experience of being taken from familiar surroundings to receive what may be invasive technical medical interventions against any likely benefits (Hermans et al 1989; Lyketsos et al 2000). The need for people with dementia to be cared for and supported in a familiar environment has been identified in a number of studies (Forbes et al 2000; Gessert et al 2001; Pickard and Glendinning 2001). In relation to the specific needs of this group the NCHSPCS has recommended that protocols are developed to ensure that individuals admitted to acute units with advanced dementia do not receive aggressive, life-sustaining treatments inappropriately (Addington-Hall 2000). The less rewarding aspect of dementia care, as opposed to the professional satisfaction from emotional relationships that is a feature of hospice care, is also considered a barrier to the introduction of dementia care to palliative care environments (von Gunten and Twaddle 1996; Seale 1998; Addington-Hall 2000).
further barrier identified by Addington-Hall (2000:26), is that older people with dementia may be seen as patients of 'low status'.

Little research has been conducted that directly addresses the wishes of the person with dementia, in relation to approaching death, at a period of the illness trajectory when decision making about end-of-life preferences are able to be articulated. As pointed out by Bow (2002:193), and confirmed in a massive literature on caring for people with dementia, 'ironically, more appears to be known about how to be a caregiver than how to be an Alzheimer's patient'. Surveys on the practice of telling a patient that they have a diagnosis of dementia show a wide variation in practice (Rice and Warner 1994; Maguire et al 1996). Carers are invariably told the diagnosis while there is considerable variation in the practice of informing the person of their diagnosis. At a stage where the dementia is mild or even moderate, the person with dementia is often told the diagnosis, but rarely the prognosis (Rice and Warner 1994), therefore disenchancing any opportunity to discuss death and dying. Potential for the person with dementia to make a will, make an advance directive, arrange Power of Attorney, settle business affairs, and make plans regarding living arrangements may be missed (Pitt 1997) if these discussions do not take place at an early stage of the illness.

This approach is advocated by Bryden (2005) based on her personal experience as a person with dementia. Bryden (2005) maintains that opportunities need to be taken to not only plan for immediate and later care but to also explore more existential issues about life and death, with others, whilst they are still able. Echoing the words and experiences of Bryden, Morris (2003) outlines a vision for dementia survival which he
likens to interventions that would be applied to head injury rehabilitation and use the experience for gaining insight into society and the human condition. He proposes that the person with dementia might actually, for a period of years, become more intelligent in verbal and nonverbal problem-solving by being forced to slow down and simplify and thereby develop new creative and intuitive strengths.

In ‘The Forgetting’, Shenk (2001) reminds us that, in the case of dementia of the Alzheimer type, it is not that the person with dementia forgets what they have learned or experienced, but that they do not form a memory of the event. Consequently the person lives only in the relative now. Bryden (2005) confirms this experience when she moves from her anxious stance, early in her dementia experience, of asking; ‘Who will I be when I die? To, ‘I know who I’ll be when I die’. She bases this on her Christian faith and also the discovery of the Buddhist principle of being in the ‘Now’, a concept that became the most important (and often only) time that could be considered. ‘My spiritual self exists in the ‘now’, with no past or future’ (Bryden 2005:160). This understanding of a fundamental Buddhist concept allowed her to begin to live in a manner that she had never before considered. Her life became more focused on the meaningfulness and sensitivity of relationships moving from the fear and anxiety of loss of control. Shenk (2001) also addresses this manifestation of the dementia process using examples provided by dementia suffers.

With less of a grip on what happened two hours or ten minutes ago, Morris reported feeling dramatically more involved in the present. “I find myself more visually sensitive,” he said. “Everything seems richer: lines, planes, contrast. It is a wonderful compensation.... We [who have Alzheimer’s disease] can appreciate clouds, leaves, flowers as we never did before.... As the poet Theodore Roethke put it, ‘In a dark time the eye begins to see.’ (Shenk 2001:193)
The experiences of people with dementia discussed above supports the Confucian model of dignity where any real meaning or value to being human occurs through continuous interaction with other human beings (Fu-Chang Tsai 2001) or where dignity is an 'event' happening between persons (Frank 2004a). It also has congruency with the recent call for relationship-based dementia care (Nolan et al 2002; Nolan et al 2003) and a relational approach to palliative care (Schotsmans 2002).

Shenk (2001) shows that no matter how long the end has been anticipated by the friends and families of the person with dementia, no one knows quite what to expect. Decisions about end-of-life care being made by family members/carers in late-stage dementia and the need for support in this decision making has been highlighted (Forbes et al 2000; Kramer 2000; Gessert et al 2001). Families were torn between the 'two faces of death', where death was viewed as having opposing faces: tragedy versus blessing, acceptance versus forbidden and acknowledged versus unacknowledged (Forbes et al 2000). The death of a person with dementia may be viewed with relief by the relatives whilst for some it was both a relief and a tragedy. The family may believe that the patient does not have a quality of life and that their misery is prolonged as long as they remain alive (Forbes et al 2000; Gessert et al 2001). Gessert et al (2001) found that many of the participants in their study were ambivalent about the anticipated death of their relatives, and while they believed that death would be a blessing they did not want to appear overly receptive to death or be seen to be unseemly advocating death. Challenges such as these that are faced by families of people with late-stage dementia are complex. They may experience guilt associated with the institutionalisation of the family member, unfamiliarity with death.
in general and death due to advancing dementia, and have limited understanding of
the natural cause of late-stage dementia. In these cases they need support in coming
to terms with some of the events that occur during dying and after death such as
admission to an acute unit or a nursing home or the introduction of artificial feeding
and other end-of-life interventions (Forbes et al 2000; Gessert et al 2001). These
studies emphasis planning and preparing for end-of-life care with families and friends
of people with dementia and in doing so attempts to put more emphasis on the wishes
of the dementia sufferer. However, it cannot be assumed that those who are
considered the 'experts' in providing end-of-life care have the appropriate skills for
the dementia group.

2.3.2 Dementia care skills in hospice
The hospice movement has had a substantial impact on the standard of care provided
for dying people across the health care spectrum and most palliative care is no longer
confined to the hospice environment. As early as 1990, Black and Jolley suggested
that the management of dying of psychogeriatric patients could be improved if lessons
learned from hospice practices were adopted. This call has also emerged as a result of
European studies on the existential issues of death in end-stage dementia (Albinsson
and Strang 2002). The NCHSPCS makes several recommendations for initiatives
aimed at developing partnerships with palliative care services and nursing homes and
psychogeriatric specialists, particularly in relation to education. They recommend
that local care of elderly and palliative care services develop joint training
programmes and promote close collaboration between psychogeriatricians and
palliative care specialists (Addington-Hall 2000). However, changes have been slow
to evolve and these two very different specialities have yet to develop comprehensive
alliances in the educational needs of care staff for people who are dying and have dementia.

There is an assumption that palliative care nurse skills are synonymous with mental health nurse skills (Cutcliffe et al 2001a, 2001b; Black et al 2001). However, there is no evidence to back these assumptions and discussion papers on this subject have not included patients with dementia. Black et al (2001) acknowledge that the common ground between the two specialities is particularly in relation to the psychosocial care approaches that are integral to the palliative care philosophy, rather than to the practice of specialist palliative care, which is the focus of hospice care. The discussions only briefly address the major differences between mental health nursing and general nursing and the physical needs of dying people.

Albinsson and Strang (2003) found major differences between dementia and palliative care staff in providing support, at the time of death, and after. They compared perceptions of good support, between 316 staff working closely with people caring for a person with dementia to 121 staff working with carers of people in palliative cancer care. Dementia care staff placed providing support at time of death of lowest importance on a 10-point item list of categories identified by the researchers, this, despite late-stage dementia clearly meeting WHO criteria for palliative care. There are equally important issues in the ability of palliative care staff to communicate with, and understand the specific needs of people with dementia (de Vries et al 2003). Albinsson and Strang (2003) found that trying to relieve the family’s feelings of guilt was an important factor for dementia care staff but not for palliative care staff. Palliative care staff put more emphasis on availability and bereavement support
(Albinsson and Strang 2003) and propose that one of the reasons for the lack of this from dementia care staff was that they do not feel comfortable discussing existential issues and death (Albinsson and Strang 2002).

The literature on end-of-life dementia care is clearly focused on old-age dementia and the variant CJD population represents a very different dementia group. They are, to date, a younger age group, and the death of a younger person has a different impact on society and on people who are caring for them, as discussed in Chapter one. However, many of the issues discussed above may be applicable to this group.

2.4 Summary

The wider literature of end-of-life care for people with dementia in old-age was explored as a means of considering what capacity hospice environments may have for delivering a service for the variant CJD group. There is a growing literature on end-of-life care for people with dementia that is predominantly from the USA. Whilst hospice services could provide appropriate and sophisticated terminal care for people with variant CJD, there are still areas within the service that are not well developed. These are, particularly, knowledge and understanding of the dementia experience. If hospice services are to embrace the care provision for the variant CJD patient group, and if the predictions of, possibly, many thousands of people becoming infected in the future is realised, there is a need to explore the impact this will have on the services. Research on variant CJD, to date, has had a scientific and medical focus, particularly on issues such as diagnosis, prognosis and cure for the patient group. What is required is the development of some insight into what caring for people with variant CJD will mean to the services and the healthcare professionals who will be supporting
and managing the care at the end-of-life. In Chapter 3 I critically discuss the methodological approach of grounded theory in carrying out this study and how an open systems theory framework was selected to interpret and analyse data.
Chapter 3 – Methodology

3.1 Introduction

This chapter is presented in two sections. In the first section I begin by setting out my research aims. The study design is discussed in detail and a background to the chosen methodological approach of grounded theory is provided and a critical discussion of debates on the use of this methodology is offered. I provide a rationale and justification for the changes that took place to the design as the study developed. This includes discussion on issues and difficulties encountered in developing a constructivist study and how these led to an ‘emergent fit’ design using existing theories of hospice care and open systems theory and the implications of this on development of formal theory. This section also includes a discussion on the implications of considering symbolic interactionism when using grounded theory and how the use of metaphor influenced my analysis. This is followed by a discussion on how the researcher perspective has implications for maintaining rigour and trustworthiness in qualitative research. A brief discussion on the methods of data collection within a grounded theory study is provided. Discussion on these methods is developed in more detail within the Methods Chapter. Analysis processes when using grounded theory are addressed, including theoretical sampling processes that were used. These processes are also discussed in more detail within the Methods Chapter.

In the second section of this chapter I further develop the discussion on open systems theory as it was a significant theory within the emergent fit design. In this section I discuss the hospice as an organisation with a specific culture and ‘space’, as was introduced and implied by Froggatt (1995, 1997), Lawton (1998a, 2000), Copp (1996,
1999) and Li (2002). For the purposes of my analysis and interpretation the open systems model developed by Katz and Khan (1966) was used, in conjunction with concepts of the unconscious at work developed by the Tavistock Institute.

3.1.1 Research aims

1. To explore the issues that arose in caring for people with variant CJD within hospice services.
2. To describe the experience of providing care for people with variant CJD by the hospice team and family members.
3. To identify strategies used by the hospice team and family members in providing care for people with variant CJD.
4. To provide a theoretical explanation of their experiences.

3.2 Study design

Patton (2002) points out that qualitative inquiry designs cannot usually be completely specified in advance of fieldwork. The design for this study was qualitative and was determined by the purpose of the research, which was exploratory, and required the development of research aims in negotiating ethical approval. However, the design also emerged as fieldwork unfolded (Patton 2002). 'Cases' of variant CJD where end-of-life care had been carried out using hospice services were sought. The 'case' construction was based on conducting focus group and individual interviews with hospice staff and family members and examining hospice records relating to care carried out by the service. A case study methodology approach to the research was rejected as this methodology would have required revealing details of the participant experiences in comprehensive case reports and would have compromised
confidentiality and anonymity of the families of people with variant CJD, due to the small numbers of people.

Grounded theory was the methodology of choice as it allows the use of multiple data sources and flexibility in recruitment processes that may evolve as the study progresses. This is recognised as emergent design flexibility within qualitative design strategies where openness to adapting the inquiry occurs as understanding deepens and/or situations change (Patton 2002; Glaser and Strauss 1967; Glaser 1978, 2005; Wuest 2000).

3.2.1 Grounded theory

Grounded theory is a methodology (sometimes referred to as a method) of qualitative research that was developed by Glaser and Strauss (1967). It is considered to be a method of theory generation where the theory, or conceptual framework, develops from, and is firmly ‘grounded’ in empirical data (Glaser and Strauss 1967; Glaser 1978, 2005; Strauss and Corbin 1998). The major difference between grounded theory and other qualitative methodologies rests in the emphasis on theory development, which is the primary aim of the researcher. Theory can assume the form of a narrative statement (Strauss and Corbin 1998), a visual picture (Morrow and Smith 1995) or a series of hypotheses or propositions (Creswell 1998). Also, built into the methodology is a style of extensive interrelated data collection and theoretical analysis that is carried out throughout the course of the research project (Glaser and Strauss 1967; Strauss and Corbin 1998; Charmaz 2003a; Glaser 1978, 2005). The emphasis within the grounded theory approach to research is that the theory is generated from data through a systematic process that is worked out in relation to that
data and not only from flashes of insight obtained from sources outside of the data (Glaser and Strauss 1967; Charmaz 2003a; Glaser 1978, 2005).

The publication of the text on grounded theory procedures and techniques by Strauss and Corbin in 1990 led Glaser (1992) to a vitriolic attack on the way in which they presented the use of this methodology. Glaser's (1992) ‘impassioned’ rebuttal called for the withdrawal or a rewrite of the book, which was refused by Strauss. Glaser (1992) claimed that his intellectual rights to the methodology of grounded theory had been breached and that the text by Strauss and Corbin (1990) provided a method of producing ‘full conceptual description’, but ‘not grounded theory’. According to Glaser (1992:122) full conceptual description represents ‘forcing’ the data, and grounded theory is a process of ‘emergence, discovery and inductive theory generation’. In his text ‘Emergence versus Forcing’ Glaser (1992) dissociated himself from the Strauss and Corbin (1990) ‘Basics of Qualitative Research’ text and sought to ‘correct’ the ‘misconceptions’, that the use of the Strauss and Corbin (1990) approach to the methodology would give readers. A further publication by Glaser (2005), dedicated to Strauss, re-emphasises his stance on the issue of emergence versus forcing data with particular focus on theoretical coding and risks of forcing data when the researcher does not stay open to the process of emergence.

The consequences of the parting of ways of Strauss and Glaser has raised a debate on what are now believed to be two different ‘methods’ of grounded theory (Heath and Cowley 2004). Others have argued that there are more than one (or two) versions of how grounded theory procedures may be implemented (Dey 1999; Chiovitti and Piran 2003; Charmaz 2000, 2003a, 2003b). Charmaz (2003a, 2003b) argues that grounded
theory strategies need not be rigid or prescriptive, as do Glaser and Strauss (1967), Strauss and Corbin (1998) and Glaser (1992; 2005) himself. Charmaz (2003a:256) extends this argument to asking the question: 'who's got the real grounded theory?'. Charmaz's (2000, 2003b) 'take' is that researchers using grounded theory 'tend' to take either a constructivist or objectivist approach.

However, Heath and Cowley (2004) emphasis that there are 'only' two ways of using grounded theory and that these cannot, and should not, be 'mixed'. That is, the original Glaser and Strauss (1967) (purportedly more creative) approach, versus the Strauss and Corbin (1990, 1998) (purportedly more reality-oriented), approach (Patton 2002). This inflexible stance on the use of grounded theory methodology is not helpful. It is highly prescriptive to a paradigm of knowledge construction (qualitative research) that changes daily, and, as pointed out by Patton (2002), emphasises being systematic and creative simultaneously. This debate, I believe, has led many researchers to declare their use of grounded theory with caution, and has led to the frequent use of the term 'grounded theory approach'. The term 'grounded theory approach', means little more than grounding the theory in data, an approach that underpins all inductive, qualitative analysis (see Seale 1999b; Silverman 2000; Patton 2002).

My dilemma was, how do I show that I have used grounded theory, as some scholars say it must be used, or should I declare that I have used a 'grounded theory approach'? My stance was to claim to be carrying out grounded theory, as my strategies met the criteria for a grounded theory study. That is, I carried out simultaneous data collection and analysis; pursued emergent themes through early data
analysis; searched for basic social processes within the data and carried out inductive construction of abstract categories that explained and synthesised social processes (Glaser and Strauss 1967; Glaser 1978, 2005; Strauss and Corbin 1998; Wuest 2000; Charmaz 2003b). Furthermore I carried out sampling to refine the theoretical categories through comparative processes and integrated categories into a theoretical framework through the process of emergent fit (Wuest 2000; Glaser 2005), examining theories from a range of fields of study. Glaser (2005) particularly emphasises exploring theoretical concepts from a wide range of philosophical fields of knowledge in a process he describes as ‘staying open’.

First of all the researcher should study theoretical codes beyond the boundaries of his current discipline and keep studying them. (Glaser 2005:7)

In not confining myself to literature and theory within a specific discipline I was able to provide a broader picture and a new perspective on the subject under study (Glaser 2005).

In keeping with evolving social and academic developments in research, it has been suggested that there have been four periods of grounded theory development (Benoliel 1996). Each period is categorised in relation to knowledge generated within a defined decade. The period from 1960 to 1970 was that of discovery and the move from emphasis on hypothesis testing in qualitative research. Development occurred between from 1970 to 1980 where the language of grounded theory was formalised by Strauss and Corbin (1990, 1998) and it is this more formal language of Strauss and Corbin (1998) that I use in describing the step-by-step process of coding data in the Methods Chapter. From 1980 to 1990 Benoliel (1996) describes a process of
diffusion taking place where collaborative, multi-disciplinary and organisational research evolved. The period from 1990 to the present time is described as a time of diversification where terms such as feminist, constructivist and contemporary have been used to describe methods of conducting grounded theory research. As further pointed out by Dey (1999), the introduction of computer software to assist in manipulation and display analysis processes of qualitative data have added impetus to the debate on the diversification of grounded theory methodology.

I believe my study fits within Benoliel’s (1996) diversification category of grounded theory use, but still meets the requirements of a grounded theory study rather than a grounded theory ‘approach’, as discussed above. Glaser (1992, 2005) has consistently demanded that the researcher remains pure to the process of emergence in conducting a grounded theory study and I believe that I have met this requirement. Another important issue that may lead to the accusation of not staying true to the method is the introduction of the use of computer assisted software in manipulating qualitative data. On this subject Glaser (2005) is adamant that the use of computer software to manage data in a grounded theory is totally inappropriate. Glaser (2005:35) states that ‘hand sorting’, ‘achieves the most flexibility and releases the most creativity’. I discuss my ‘similar’ responses to this in the Methods Chapter (4.3.4 Use of the NUD*IST programme).

The study was originally designed to use a constructivist approach to data collection and analysis based influenced primarily by Charmaz (1991, 2000, 2003a, 2003b, 2004) and on the understanding that realities are captured in the form of socially and experientially based constructions that are local and specific in nature and are arrived
at by consensus between the group under study and the researcher (Guba and Lincoln 1994; Charmaz 2003a). That is, my design intention was to co-construct a theory of the experience of caring for the person with variant CJD at the end-of-life with the study participants.

3.2.2 Constructivist paradigm

Constructivism is a research paradigm that considers reality knowable through people’s mental interpretations or constructions. A constructivist approach is based on a holistic ontology, or world view, where it is postulated that there is no single reality. Any concept of reality is based on perception, is different for all people and changes over time, so that what we know has meaning only within a given situation or context. This approach is based on a world view that knowledge is a perspective that we have created, to make sense of our experiences and the experiences of those participating in the research (Guba and Lincoln 1994; Burns and Grove 2001; Patton 2002; Charmaz 2003a).

It is proposed that the primary assumptions of constructivism are based on several premises. ‘Truth’, is a matter of consensus among the informed and constructors, not of correspondence with objective reality. ‘Facts’, have no meaning except within some value framework, hence there cannot be an ‘objective’ assessment of any proposition. ‘Causes’ and effects do not exist except by imputation, and phenomena can only be understood within the context in which they are studied. Findings from one context cannot be generalised to another; neither problems nor solutions can be generalised from one setting to another. Data derived from constructivist inquiry have
neither special status nor legitimation; they represent simply another construction to be taken into account in the move towards consensus (Patton 2002; Charmaz 2003a).

The difficulties of ensuring consensus was influenced by sampling and access problems in organising focus group interviews at different sites where staff changes had taken place, plus concerns I felt about repeating interviews with family members who were bereaved and had been traumatised by some of their experiences. It became apparent that it would have been ethically inappropriate to repeatedly interview the family members who had already been interviewed by others about their experiences, more than once on some occasions (see Chapter 4, 4.4 Ethical considerations). Consequently, consensus was only achieved following the pilot case analysis, where the preliminary theoretical framework was taken back to some of the participants for discussion and verification.

3.2.3 Emergent fit

In keeping with an emergent qualitative design, what actually occurred as the study progressed was 'emergent fit'. Emergent fit is the process whereby theoretical models, identified within the literature, are constantly compared to the incoming data, i.e. the constant comparative method of analysis (Glaser and Strauss 1967; Glaser 1978, 2005). Existing theory and new data is used to elaborate, extend or develop theoretical construction and this may be used either to develop concepts from theory or theory may be modified to take account of new data (Glaser and Strauss 1967; Glaser 1978, 2005; Wuest 2000; Hellström et al 2005).
Examples of emergent fit can be found in other grounded theory studies. For example, Hutchinson et al (1997) explored the value of awareness context theory in the complexities of social interactions in early Alzheimer’s disease. The researchers show how during data analysis of clients’ experiences of early probable Alzheimer’s disease problems surrounding awareness, or lack thereof, Alzheimer’s disease emerged as an issue that was central to social interaction. The researchers then revisited the Glaser and Strauss (1967) awareness context theory for its potential as a framework for analysing these interactions through the process of emergent fit.

Hellström et al (2005) extend the work of Hutchinson et al (1997) further in constructing an understanding of the dementia experience through awareness context theory plus the theory of the dynamics of dementia, also using an emergent fit design. They discovered, as did Hutchinson et al (1997), that as they systematically carried out the process of constant comparison they found distinct similarities to theories within existing literature with that of the experiences of their study participants. The researchers also do not confine themselves to the original construct of awareness context theory developed by Glaser and Strauss (1965). Emergent fit of constructs developed by other researchers who have extended and elaborated on awareness context theory (for example the work of Timmerman (1994) and Salander and Spetz (2002) – see literature section) were considered. Awareness context theory had previously been confined to the area of dying patients’ knowledge/awareness about their experiences with healthcare professionals and others. The researchers further develop the application of awareness context processes to people with early Alzheimer’s disease and their awareness of disease processes and the implications of these on their relationships with others.
Wuest (2000) describes how she came to the realisation and understanding of the emergent fit process when conducting a second feminist grounded theory study of women’s caring. She particularly emphasises how she came to realise how only the components of pre-existing theory that fit the data could survive. That is,

One does not then code the new data according to the concepts and interrelationships of an existing theory; rather, one compares the conceptual indicators in the new data with similar concepts in the existing theory for fit (Wuest 2000:55).

The theoretical code must ‘earn relevance’ to the emerging fit (Glaser 2005:4), consequently emergent fit is a constant process of moving between a deductive approach of examining theory that seems to explain what is being revealed within data, and an inductive process of interpreting data, checking for fit and modifying accordingly (Glaser 1978, 2005; Wuest 2000). Conceptual indicators from the existing theories developed by Froggatt (1995), Lawton (1998a, 2000), Copp (1996, 1999) and Li (2002) contributed to the emergent fit with data analysis as my study progressed.

The need to control the hospice environment, staff and patients was either explicit or implicit within all theories. This fitted with other discussions on organisational control within health care environments where control and medicalisation are frequently referred to synonymously (Walter 1994; Sontag 1978), and where the conflict between care and control is considered to be endemic to organisational life (Chulow 1994; Hinshelwood and Skogstad 2000). For Li (2002:270) the argument was for maintaining orderliness within the hospice organisation that advances
personal, professional and organisational aspirations using the equation: nurses' assets + patient assets = team assets = organisational assets = marketable assets = 'nice' organisation. The tension between protecting and controlling was the dominant theme of Copp's (1996) model, which I identify as a paradox within my thesis. Protecting was about covering up to preserve the dignity of the dying person, although in none of the four theories is there a developed discussion about the use of medications to facilitate this process of protecting.

Hospice as a 'liminal space' within which people are cut off from the wider society in a temporary position whilst waiting to die, and where dying is processed, was shown to be central to the hospice culture for Froggatt (1995) and Lawton (1998a, 2000). They show how hospice provides a space in which the seemingly disordered process of dying may threaten order in society. The attributes of liminality were posited as being features of hospice ideology; particularly relevant to my thesis was predetermined entry requirements, hospice as family, and physical and social symbolism (Froggatt 1995, 1997). The nurses, as 'ritual specialists' controlled the passage of dying in various ways with particular reference to 'family' and 'holistic' ideals with respect to emotional expression by their possessing specialist hospice knowledge of pain and symptom control, and having time to establish relationships with patients and their kin (Foggatt 1995). The hospice service is depicted symbolically a 'family system' by Froggatt (1995), Lawton (1998a, 2000) and Copp (1996), and as a community by Li (2002). Hospice was construed as community which patients (and in my thesis family members as hospice 'patients') enter into as family members, and where the hospice is symbolically shown to be a protected environment where the specialist knowledge on caring for dying is used to their
benefit. What is also a feature in Froggatt’s (1995) thesis is that there is a need for reciprocity that is allowed due to (the often) long the length of the admission and to the availability of time for patients and families. For both Froggatt (1995) and Copp (1996) it was important that the nurses had formed a relationship with the patient that openly acknowledged the impending death and for Copp (1996, 1999) when this did not occur the existence of personhood for the dying person was in doubt. As the person became closer to death the body as object and the problem of ‘living too long’ were features within the theses of Lawton (1998a, 2000) and Copp (1996, 1999). Nurses focused on the bodily deterioration in determining quality of life and dignity of patients and sequestration due to the social rejection of the unsightly body was central to Lawton’s (1998a, 2000) thesis and implicit within Copp’s (1996, 1999).

3.2.3.1 Theory construction, emergent fit and the place of grand theory

It had been my intention to develop grounded theory within a constructivist paradigm, in which case substantive theory rather than formal theory would be the outcome of the study. Substantive theory is grounded in research on one particular area, specific to a particular group or situation (Glaser and Strauss 1967; Glaser 1978, 2005; Strauss and Corbin 1998; Patton 2002). However, Glaser and Strauss (1967) propose that substantive theory is a strategic link to the formulation and generation of formal theory and the substantive theory may have been developed previously by the author, as demonstrated by Wuest (2000), or another writer (Glaser and Strauss 1967; Glaser 1978, 2005). Glaser and Strauss (1967) maintain that connections between the constant comparative method of analysis and theory generation with regard to both substantive and formal theory need to be made explicit.
Comparative analysis can be used to generate two basic kinds of theory: substantive and formal. By substantive theory, we mean that development for a substantive, or empirical, area of sociological inquiry, such as patient care, race relations, professional education, delinquency, or research organisations. By formal theory, we mean that developed for a formal, or conceptual, area of sociological inquiry, such as stigma, deviant behaviour, formal organization, socialization, status congruency, authority and power, reward systems, or social mobility. Both types of theory may be considered as “middle-range”. That is, they fall between the “minor working hypothesis” of everyday life and the “all-inclusive” grand theories (Glaser and Strauss 1997:32, 33).

What was emerging as I carried out constant comparison were data that revealed organisational behaviour that fitted with the theories on hospice activity and where participants were trying to fit a new event into an organisation that had firmly established boundaries of practice and activities. These interactions, practices and behaviours fitted with theories from the literature on organisational activity, i.e. from grand theory.

My decision to use open systems and organisational theory as part of the emergent fit design, was an evolving process. As discussed above, emergent fit can be used to develop concepts using formal theory as well as modifying substantive theory to take account of new data (Glaser and Strauss 1967; Glaser 1978, 2005; Wuest 2000; Hellström et al 2005). Open systems theory is, however, grand theory, and how grand theory is used in the process of emergent fit is not well elaborated within the grounded theory literature. The grand theory (or basic social process) of symbolic interactionism is frequently associated with using grounded theory methodology, however, Glaser (2005) is adamant that grounded theory does not have an epistemology with an attached theoretical perspective that provides one set of theoretical codes to the exclusion of others. In challenging the place of symbolic
interactionism as the foundation theoretical perspective of grounded theory and theory construction Glaser (2005) affirms that:

Sure, GT (grounded theory) can use SI (symbolic interact) type data and its perspectives, but as a general method it can use any other type data, even other types of qualitative data, as well as quantitative, visual, document, journalistic and in any combination, and any other theoretical perspective, such as systems theory, social structural theory, structural functional theory, social organization theory, cultural theory etc. (Glaser 2005:141).

The main benefit yielded by grand theories is their use of abstract models and the integration of formal theory often requires more guidance from explicit models (grand theories) because of a greater level of abstraction (Glaser and Strauss 1967). It was with this understanding that I approached the use of open systems theory in my theory development. My decision was influenced by the conceptual categories that emerged from my data, the similar concepts that related to organisational activity found within existing theories of hospice care that ‘fitted’ the data, my reflexive processes in conducting the research, discussions with academics on the subject of organisational behaviour, and reading other literature that examined organisational activity. It is the abstract language of open systems theory that I have used to frame my theory and it was this component of the emergent fit process that led me to tentatively claim to have developed the beginnings of formal theory that explains organisational activity in the event of managing a new situation that may have broader application than to the hospice service.

According to Haslam (2004) understanding the psychology underpinning the behaviour of people within organisations belongs in two subdisciplines. These are organisational psychology and social psychology. The imperative to consider using a
A systems perspective is becoming increasingly important in dealing with and understanding real-world complexities, viewing things as whole entities embedded in context and still larger wholes; (2) some approaches to systems research lead directly to and depend heavily on qualitative inquiry; (3) a systems orientation can be very helpful in framing questions and, later, making sense out of qualitative data. (Patton 2002:120)

The seed was planted in influencing my move toward using systems theory following a presentation of the findings of my pilot study at a conference on prion disease (de Vries 2003b). During the conference I was approached by an academic from the audience. He suggested that the material lent itself to using the work of Bion and the approaches used by the Tavistock Institute in interpreting the responses of my study participants. I then embarked on an exploration of the fascinating literature on this subject of which previously I had only a superficial knowledge.

My firm decision to use open systems theory stemmed from my assumptions and experiences of hospice practices which were echoed in the models describing hospice care developed by Froggatt (1995, 1997, 1998), Lawton (1998a, 2000), Copp (1996, 1999) and Li (2002). These models demonstrated how ideologies are very much inscribed in the materiality of social and institutional practices (Kincheloe and McLaren 1994). I was also ‘inspired’ by a meeting with an acquaintance who I had not seen for some years, who greeted me with; “Are you still working in that death
factory?" This comment served me with the idea of the hospice as a metaphorical factory for processing dying. It fitted the conceptualisation of the hospice as a 'container' for people who are dying and as a place where very specialised and specific care practices are performed and where death is 'processed' (Lawton 2000). This fit emerged as the study progressed in the manner stated by Glaser and Strauss (1967:41) where a formal-theory model should never be applied to the emerging theory 'until one is sure it will fit, and will not force the data'. What is strategically important in developing grounded formal theory is that both laymen and academics 'can readily see how its predictions and explanations fit the realities of the situation' (Glaser and Strauss 1967:98).

A detailed discussed on how the abstract language of systems and organisational theory helped to frame my theoretical construct is given in section 3.3, Open systems and organisation theory

Symbolic interactionism is understood to be closely associated with grounded theory methodology, a suggestion challenged by Glaser (2005) who maintains that it is just one of any theory that can be used to underpin grounded theory research studies. However, interactions are an important consideration particularly when examining organisational behaviour and activity.

3.2.3.2 Symbolic interactionism

Symbolic interactionism was brought to the Glaser and Strauss partnership by Strauss from the Chicago school, where the perspective was developed. Although symbolic interactionism had undergone considerable 'fragmentation' and expansion since its
heyday at the University of Chicago in the 1920s and 1930s (Ritzer and Goodman 2003:371), it remains a perspective of social psychology that puts particular emphasis on social interaction (Rock 1979; Charon 2001; Atkinson and Housley 2003; Ritzer and Goodman 2003). Mead (1934) and Blumer (1969) are considered to be the leaders in the development of symbolic interactionist theory as applied by Glaser and Strauss (1967). Blumer (1969) maintained that symbolic interactionism rests on three premises. The first premise is that human beings act towards things on the basis of symbolic meanings that the things have for them, i.e. they identify common sets of symbols that they use to describe that meaning. This includes everything that the human being may note in his or her world; i.e. physical objects, other human beings, categories of human beings, institutions, activities of others. Second, the meaning of such things is derived from, or arises out of, the social interaction that one has with other humans. Third these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he or she encounters. In this process of interactive socialisation a sense of the 'generalised other' is developed that is closely aligned to the social location in which the group is placed (Atkinson and Housley 2003).

Symbolic interactionism assumes that these shared meanings become 'reality', however, Rock (1979) points out that symbolic interactionism pretends neither to absolute truth, nor to an exhaustive interpretation of society. Within the paradigm there is acceptance of uncertainty and modest scope. It is a paradigm within which my personal way of thinking and seeing the world has congruency, as Rock (1979) also claims that it requires an innocence of mind that has often been schooled out of the sociologist. It was important for me to consider what type of data may be used in
analysis that could be interpreted through symbolic interactionist concepts. The question I asked myself repeatedly was how do I demonstrate and justify the use of symbolic interactionism in the interpretation of my data. Particularly when historically this approach has been closely allied to ethnographic studies, where observation of ‘naturally occurring’ interactions were the focus of analysis. It was the importance of the use of forms of language that is the foundation of symbolic interactionist thinking, where interaction within society uses symbolisation and metaphors to frame their activity (Rock 1979). I discuss how metaphors are used in my analysis in more detail in Chapter 4, 4.3.3.1 Metaphors. Rock (1979) claims that symbolic interactionism portrays knowledge as a jointly active process rather than a state. These are: that multiple realities exist, data reflect the researcher’s and participants’ mutual constructions, and that the researcher enters and is affected by participants’ worlds (Charmaz 2003a). In other words, the focus of research that uses a symbolic interactionist approach is on how people define their world and how that definition shapes their actions (Charon 2001).

3.2.4 Researcher perspective

In using grounded theory care needed to be taken that I did not lose sight of the need to maintain the systematic rigour that is the hallmark of the approach (Strauss and Corbin 1998). Indeed, all research should be systematically and rigorously conducted (Mason 2002). Of importance in the use of grounded theory is the emphasis that Glaser and Strauss (1967) put on practical action, as a basis for achieving ‘credible’ interpretations of social interaction. This practical action is related to the process or state of ‘being inside’ and understanding the social world in which the research is taking place. It requires a reflexive approach to the research and refers to the
researcher perspective and how this must be acknowledged as an integral part of the research. Personal critical self-scrutiny as well as critical scrutiny of data is required, a process Mason (2002:7) refers to as 'active reflexivity'.

Within the grounded theory approach the researcher perspective (personal experience) is recognised and represents part of 'theoretical sensitivity'. This is regarded as one of the major challenges for the researcher using grounded theory (Strauss and Corbin 1998; Creswell 1998; Charmaz 2003a, 2003b). Theoretical sensitivity refers to the personal quality of the researcher who, as an insider, would have an awareness of the subtleties of meaning of the social interactions identified within the data (Glaser and Strauss 1967; Glaser 1978; Strauss and Corbin 1998; Charmaz 2003a, 2003b). This sensitivity also comes from reading the literature and documents which provide a background of information that 'sensitises' the researcher to the topic under study. It comes from personal and professional exposure as well as from the analytic process experienced during the research.

It is unquestionable that experienced researchers are sensitised by the very process of involvement in multiple and varied research projects (Strauss and Corbin 1998). Theoretical sensitivity was already present based on my hospice practice and education background. This was further developed during the literature review stage. This sensitivity is acknowledged throughout the study as having a substantial impact on my interpretations of data. Burns and Grove (2001) caution that as the qualitative researcher tends to work alone, personal influences on the subject may go undetected and researchers need to be alert and take action to expose subjectivity. As a means of monitoring my effect upon the research I kept detailed research journals where I
reflected on and recorded my responses to the data and the literature in the context of my interpretations and clinical experience.

Glaser and Strauss (1967) suggest that the researcher may become insensitive or defensive to questions that cast doubt on any preconceived theory that they have become attached to. This is particularly important in the early stages of a study as the researcher can unconsciously fall into accepting what is written due to unrecognised assumptions. However, as the study proceeds, and theory begins to develop, the danger of latching onto an idea, concept, or theory may be decreased (Glaser and Strauss 1967; Chenitz and Swanson 1986; Strauss and Corbin 1998). A crucial aspect of qualitative research is that it must not be assumed that the final representation of the research is totally objective and value-free. In recognising this I needed to take care that the participants in the study were represented. That is, that the end result provided an adequate depiction of their experiences, and the environment within which the study was conducted, and that the claims depicted provide responsible and not misleading knowledge (Sandelowski 1995; Denzin 1998).

3.2.5 Interviews

In the original grounded theory research the ethnographic approach using observational data as a primary source was the method used by Glaser and Strauss (1965), as did other early users of this methodology. However, interviews have become a common form of data source for researchers using grounded theory (Charmaz 2003a, 2003b). In understanding semi-structured interviews several factors are identified by Fontana and Frey (1994) as important in relation to obtaining a rich data from participants. These are, accessing the setting, understanding the language
and culture, deciding how to present oneself, locating informants and establishing rapport. I did not have to ‘get in’ (Fontana and Frey 1994:366) as an insider researcher with a background in hospice care philosophy and practice an understanding of the culture and language of the participants already existed. The use of language and specific terms is important for creating ‘shared meaning’ in which both interviewer and participant understand the contextual nature of the interview (Fontana and Frey 1994; Charmaz 2003a, 2003b 2004). Charmaz (2004) emphasises that to gain a deep understanding of the studied life means entering it. ‘Entering the phenomenon means being fully present during the interview and deep inside the content afterward’ (Charmaz 2004:981).

3.2.6 Focus groups

Focus group interviews generate a type of evidence that is not found in the single interviews. Data from focus groups is complex. Analysis, not only at the individual level, but also of the group interaction, group dynamics and the context within which statements are made, are critical aspects of the process (Morgan 1998). They help to tap into the many different forms of communication that people use in everyday interaction, including jokes, anecdotes, teasing, arguing which may reveal much more about what people know or experience. Focus groups can provide a type of ‘naturally’ occurring data, particularly when a free-flowing conversation is established. They can also facilitate the discussion of taboo subjects that may not be so readily discussed using the single interview process (Krueger1994; Kitzinger 1994, 1996; Morgan 1998; Burns and Grove 2001).
One of the advantages of the focus group interview method is that the group can generate their own questions and pursue their own priorities that lead to a more diverse and comprehensive understanding of the culture from which they have come (Kitzinger 1994, 1996). The interactions were particularly important in the context of this study, as I wanted to understand how the team worked together in providing care for the person with variant CJD, and to set this within the context of the hospice culture. Webb and Kevern (2001) identified that few research articles, within the nursing research literature, reported specifically on the interactions when using a focus group as a data collection method. This, despite interaction identified as a key component in analysing focus group data (Krueger 1994; Kitzinger 1994, 1996; Morgan 1998). My analysis of interactions particularly followed the symbolic interactionist approach where meanings were interpreted through symbolic and metaphorical use of language (Rock 1979).

3.2.7 Hospice patient records
The hospice patient records were used to crosscheck oral accounts and to provide a descriptive and historical context (Atkinson and Coffey 1997). Data from this source provided a version of reality as they represent ‘official’ records and were used as ‘proof’ of events. This does not mean that documents are firm evidence of what they report. However, documents need to be examined in relation to their place within the organisational setting, the cultural values attached to them and the form that they take (Atkinson and Coffey 1997). They also require an understanding of the language and other sign systems from the field (Silverman 2000). This is particularly pertinent to healthcare research where patient documentation is used in various forms as
'evidence', both at a judiciary level and at a practice level, such as through audit reviews (Prior 1997).

3.2.8 Analysis processes

The coding system devised by Strauss and Corbin (1998) provided the focus of using grounded theory for the study. However, the earlier work of Glaser and Strauss (1967) is also referred to in relation to using this methodology. It has been argued by Charmaz (2003a, 2003b) and Heath and Cowley (2004) that the methods used to conduct grounded theory proposed by Strauss and Corbin (1998), as opposed to Glaser and Strauss (1967), are based on a somewhat rigid and objectivist approach. However, Strauss and Corbin (1998) themselves emphasise that the step by step description of grounded theory analysis should not be regarded as a rigid tool for the research process, but rather used flexibly and creatively. Whilst keeping this premise in mind I felt it was important to maintain a structured approach to the coding process. The step by step process of data collection and analysis is discussed in detail in the methods chapter, as is the specific terminology for grounded theory analysis processes.

Computer assistance in qualitative research has become an accepted strategy for the management of qualitative data, particularly the 'code-based theory builders' for researchers working towards theory building (Seale 2000). More and more frequently qualitative researchers are encouraged and expected to use computer generated software in the manipulation of the large volumes of data that is collected when using qualitative research methods (Fielding and Lee 1991, 1998; Creswell 1998; Seale
I did not access computer software for qualitative data analysis in the early stages of the study and the pilot (first data set) was manually coded.

3.2.9 Theoretical sampling – search for deviant cases

Theoretical sampling is a flexible and dialectic process of determining data collection in the light of the developing theory (Glaser and Strauss 1967; Glaser 1978, 2005; Strauss and Corbin 1998; Creswell 1998; Dey 1999; Charmaz 2003a, 2003b). Concept development is the basis of theoretical sampling and gave direction for focus of each new data set collection. Throughout the process of collecting and analysing data in grounded theory is the process of ‘constant comparison’ (Glaser 1978, 2005; Strauss and Corbin 1998; Charmaz 2003a). This involved comparing incident with incident and category with category. It also involved comparing data with incidents from my experience, from my media data and from the literature. Theoretical comparison was used extensively in categorising data, where existing theories of hospice practice informed my interpretations through the process of emergent fit. Constant comparison, in various forms, took place throughout the research process.

The study was designed to collect data from a number of hospices until data saturation was achieved. It is through this process that an attempt to saturate the categories is made. Saturation refers to a process of collecting data or information that continues to add to the categories until repetition from multiple sources is obtained (Morse 1994). This requires researchers repeatedly returning to the field to seek new cases to develop theoretical categories (Glaser and Strauss 1967; Strauss and Corbin 1998; Creswell 1998; Charmaz 2003a, 2003b). Strauss and Corbin (1998:136) refer to saturation as, not only saturation of sources, but also saturation during coding. That
is, ‘when no new properties, dimensions, conditions, actions/interactions, or consequences are seen in the data’. According to Patton (2002), the question of saturation leaves the question of sample size open. Patton points out that there are a number of practical problems related to budget and resources, time and specific design of the research, a stance that is supported by Strauss and Corbin (1998).

Searching for extreme cases or ‘deviant’ cases is a method advocated by many qualitative researchers as a means of establishing trustworthiness. It is also a means of overcoming a tendency to select cases which are likely to support the arguments (Silverman 2000). The ‘deviant’ case may be able to be integrated into the theory construction, or a reconceptualised focus will be required (Perakyla 1997). Streubert and Carpenter (1999) refer to the search for deviant cases as selective sampling. Selective sampling is appropriate as new factors emerge and there is a need to either, increase the sample, focus on a small part of the sample, or seek out deviant cases (Silverman 2000).

3.2.10 Maintaining trustworthiness

Patton (2002) maintains that to demonstrate credibility in qualitative research depends on three distinct but related inquiry elements. These are, rigorous techniques and methods for gathering high-quality data, researcher training, experience, track record, status, presentation of self, and philosophical belief in the paradigm underpinning the methodology being used. Guba and Lincoln (1994) have identified several terms that have been used to describe the processes that contribute to rigour in carrying out qualitative research. These are credibility, dependability, confirmability, and transferability.
Dependability is similar to validity as identified in quantitative research (Guba and Lincoln 1994). It relates to the extent to which an account accurately represents the social phenomena to which it refers (Hammersley 1990; Guba and Lincoln 1994; Burns and Grove 2001). Confirmability, or auditability, refers to the use of the audit trail, or a decision rule, where the reasoning for making any decision is documented and the reader is able to clearly follow the logic that is used throughout the progress and development of the study (Burns and Grove 2001). It represents the detailed reflections and notes which I kept during the research process that were used to illustrate, as far as possible, the evidence and thought processes that led to the conclusions and in presenting the findings (Streubert and Carpenter 1999). Transferability, within qualitative research, lies with those who read the results and determine whether the results accurately describe experiences from similar populations (Glaser and Strauss 1967; Stake 1995).

A further strategy believed to strengthen a study is that of participant confirmation/validation (Silverman 2000). This is where findings are taken back to the participants being studied, and are agreed. This process is also referred to as 'member checking' (Sandelowski 1993; Stake 1995). Participant confirmation is a recognised approach when using a focus group method of data collection, where ownership of data by participants is acknowledged (Kitzinger 1996). However, this approach needs to be used with caution. The risks inherent in using this process are that the participant may correct (perceived) errors in the transcription, depending on their recollection. They may also attempt to clarify, justify or even revoke or alter aspects of what they said during the interview (Hoffart 1991). Sandelowski (1993:7)
also criticises this approach suggesting that participants may agree to do so only to meet the expectations of the researcher, i.e. 'to be good subjects', they may want to minimise conflict and be reluctant to disagree with the researcher's interpretation, and different participants may have different views of the interpretation. Further, the considerations about using this approach are that the participants may choose to withdraw, causing data to be lost to the research, or that the responses of a participant, in reading a transcription or case vignette in which they are portrayed, could be construed as a new experience, and need to be analysed as new data (Silverman 2000). Seale (1999b) suggests that this approach has more strength when the full report of the study is reported back to participants and their responses are monitored.

Successful examples of using participant validation have been demonstrated where the focus group members became co-researchers (Morrow and Smith 1995; Charmaz 2003b). This is when a number of the focus group participants assist in the analysis of videotapes of the groups in which they participated, suggesting categories and revising the developing theory and model. Construction of knowledge, on an issue of concern, should be a joint act of inquiry and closely involve both the researcher and the researched (Denzin and Lincoln 1994). It is an approach that may dispel some concerns raised in ethical arguments. It is of particular relevance to the issue of participants not knowing what theoretical assumptions the researcher will use when analysing and presenting the research (de Raeve 1994). However, the ability of the participant to offer insightful input into the interpretations of data is an unknown risk.

Inter-rater reliability is a process that is generally associated with quantitative research where data is independently coded and the codings are compared for agreement.
(Armstrong et al 1997; Burns and Grove 2001). There is some evidence that it can be used as a strategy for maintaining rigour and trustworthiness of qualitative studies although this has been challenged (Armstrong et al 1997). As a means of testing the viability if using an inter-rater reliability process for qualitative data, Armstrong et al (1997) used six researchers to analyse the same data set. These analysts were very experienced researchers from different countries and different disciplines. Armstrong et al (1997) concluded that there was a degree of consensus in the identification of themes between the different analysts but that the ‘packaging’ of these themes showed a number of different configurations. The analysts chose to embed the themes they identified in a wider context of other themes. These were influenced by the discipline, geography and personal experiences and views of the analyst, an unsurprising outcome as ‘when confronted with the same qualitative task, no two researchers will produce the same result; there will inevitably be differences in their philosophical and theoretical commitments and styles’ (Sandelowski 1993:3). Armstrong et al (1997) concede that the number was too small to draw definite conclusions but they did not find completely divergent interpretations but agreement at a level of situating themes within a wider framework.

A further strategy for establishing trustworthiness proposed by Silverman (2000) is that of comprehensive data treatment, where every single item of data is analysed. This is an important aspect of qualitative research analysis and a strategy for defending the study against ‘anecdotalism’ (Silverman 2000; Burns and Grove 2001). According to Seale (personal correspondence – cited Silverman 2000:147) a good coding scheme should reflect a search for un categorised activities, using all data. In the coding of my data I endeavoured to take this approach. There are sections
(categories) within the data that were 'available' but not used in the final analysis or writing up. One example of these categories is the detailed data on specific medical and nursing interventions and medications used in managing the care of the person with variant CJD in the hospice. These have been used for teaching purposes and in an earlier publication (de Vries 2003a) that specifically addresses treatments for variant CJD.

The following section provides a detailed discussion on how open systems and organisation theory was be applied to other theories of hospice activity in the emergent fit design.

3.3. Open systems and organisation theory

Open systems theory has been used extensively in the analysis of organisations and activities that take place within these, usually with a focus on organisational change and management. Systems theory is based on the sociological premise that human society is a series of systems and originated in conjunction with the founding of sociology. Human biology, and methods and models from the natural sciences, formed the basis of systems theory, where analogical similarities between society and living organisms were made (Hassard 1993). Early systems theories were based on a 'closed system' concept. This model was believed to fit with the biological model where a closed system is deemed to be unaffected by factors external to the organisation. The 'open systems' approach is an approach to organisational theory and practice that builds on human relations theory by suggesting that work behaviour is shaped by the flexible system of relations between social groups that exist within and outside an organisation (Haslam 2004).
Systems theory is orientated in a functionalist paradigm and Parsons' (1951) work is considered central to the development of systems in sociological theory (Silverman 1970; Burrell and Morgan 1979; Hassard 1993). Parsons (1951) posits systems as goal setting and that organisations are both systems in their own right and constitute parts of larger systems. In the case of hospice, hospice is a system within the wider healthcare system. Miller and Rice (1967) take a similar view but refer to goals as 'primary tasks'. The work of Miller and Rice is firmly associated with the establishment of the Tavistock Institute and the terminology I have adopted in using these models is that of systems carrying out the processes of input, throughput and output (Katz and Khan 1966), and defining activities in terms of tasks (Miller and Rice 1967).

Katz and Khan (1966:16) point out that organisations have classically been defined as: 'social device(s) for efficiently accomplishing through group means some stated purpose'. This definition has been extensively challenged within organisation literature and many complex discussions and debates have ensued on what constitutes an organisation, the processes that take place within, and how these may be analysed or how they may be referred to as systems (for extensive critiques of organisations as systems see Silverman 1970; Burrell and Morgan 1979; Hassard 1993; Morgan 1997). This debate varies depending on the particular approach the writer is taking on the subject of organisational behaviour/activity and the way in which they are using a systems or organisational theory.
What is generally agreed is that organisations are a relatively recent phenomenon, and are a product of modernity (Gabriel 1999). Within this is the recognition that Western society is an organisational society. Most of the daily activity of people takes place within organisations, such as companies, schools, hospitals, universities and so on (Gabriel 1999). One of the common ways of defining an organisation has been based on the specific goal of the organisation. Silverman (1970) points out that defining an organisation by its ‘goal’ is problematic in that we can ask an individual about his or her goal and purpose but it is difficult to approach an organisation in the same way. Regardless of this difficulty in co-ordinating individual goals with organisational goals it is fundamental to all definitions that organisations have a system of roles, norms and values that exist for some purpose (Haslam 2004).

Equally important in establishing a definition of organisational functioning is consideration of internal differentiation. That is, there exist different groups within organisations, who will have their own shared roles, norms, values, priorities, preoccupations and culture, plus different power and status (Stokes 1994a; Haslam 2004). These team members are also often accountable to different superiors (Stokes 1994a). I refer here to the multi-professional/multidisciplinary composition of hospice teams. Most hospices have complex teams of nurses, healthcare assistants, doctors, social workers, Chaplains, complementary therapists and volunteers. Team authority can also be complex, however, as in most healthcare settings authority often rests with the doctors. Medical authority appears to be predominant within hospices, especially those that consider themselves specialist units (James and Field 1992; Field 1994) and admission into the service have been shown to be predominantly medically determined (Eagle 2002; Eagle and de Vries 2005). Eagle’s (2002) ethnographic
study of the decision making processes of hospice teams from three hospice sites in the South of England did demonstrate that a large component of achieving a hospice admission required negotiation between nurses and doctors. Seale (1998) has argued that before accepting the medicalisation of hospice argument a more analytic approach is needed where the way in which the people who work in the hospice settings and how they think about their work and how, 'they as 'system representatives' seek to mould the subjectivities of the people for whom they care' (1998:117).

3.3.1 Katz and Khan open systems theory

The seminal work of Katz and Khan (1966), on open systems theory, has been one of the most influential within the field of systems theory research (Silverman 1970; Burrell and Morgan 1979; Kolb 1984; Hassard 1993; Haslam 2004), and continues to influence research and discussion on organisations. In using an open systems approach to critically interpret my data I have proposed that the organisation (hospice) is a social system that coordinates the behaviour of the members by means of roles, norms and values that are embedded in hospice culture. Culture includes all the material and spiritual heritage of the organisation, its myths and stories, artistic and craft artefacts, buildings, tools, laws, rituals and customs (Gabriel 1999). Hofstede (1991) offers a metaphor of culture as ‘the software of the mind’, indicating that it is not only the physical substance of cultural materials but the meanings attached to them and how these give meaning to peoples’ lives. The model of the hospice as a ‘rite of passage’ (Froggatt 1995, 1997) provides one example of how the attributes of hospice may be culturally defined. One of the functions of culture is that of social control that ensures that people behave in accordance with specific social norms and
values. Roles relate to the particular place and functions of the individual within the system and are defined within the system. These roles are internally differentiated in ways relevant to the system's operation (Katz and Khan 1966). A schematic representation of an open system is shown in Figure 2.

![Schematic representation of an organisation as an open system](image)

**Figure 2.** Schematic representation of an organisation as an open system. (Adapted from Katz and Khan 1966; Miller and Rice 1967; Kolb et al 1984)

Systems are considered to be dynamic in nature and with cycles of events occurring over time (Katz and Kahn 1966; Miller and Rice 1967; Kolb et al 1984). Events tend to occur in natural repetitive cycles of input, throughput and output, with events in sequence occurring over and over again. The feedback loop is a part of the evaluation process of system function. It involves taking feedback from the environment. This feedback is reflected on, and judgements are made about future choices and adaptation to the environment. This feedback loop requires a willingness and ability to make changes within the system (Katz and Kahn 1966; Miller and Rice 1967;
Leiper 1994; Morgan 1997). In the case of the hospice service (Figure 3) I propose that the input is the admission of a person with a terminal illness (generally cancer) and their family members.

Figure 3. A schematic depiction of the hospice service as an open system.

The throughput and conversion process is all that is involved in the complexities of caring for a person with a terminal illness, such as symptom management, and bereavement work with both patients and families. Output is the death or discharge of the dying person and includes both in-house and community deaths and discharges, bearing in mind that 'discharge' from hospice is generally a 'temporary' event and that the most common output is that of the death of the patient. This also includes discharge of bereaved family members and significant others, also bearing in mind that bereavement support provided by hospice may extend to a year, sometimes
longer. This is similar to models that have been used to schematically present institutions such as hospitals as 'containers of social anxieties', particularly in relation to fear of death. Obholzer (1994:171) proposes that health care services are 'keep-death-at-bay' services. This idea of keeping death at bay is the opposite end of the spectrum to hospices, where, as proposed by Lawton (1998a, 2000), death is 'processed'.

Feedback through evaluation from service users can constitute a challenge and create a sense of threat to organisations, and it is never easy to get the balance right between attaining a degree of objectivity and taking actions to make changes (Leiper 1994; Morgan 1997). Evaluation studies of health care have traditionally used experimental and quasi-experimental methodologies that include randomized controlled trials, as these are believed to provide the gold-standards for treatments and provision of 'evidence' for practice. The difficulty with hospice care evaluation lies in the complexity of the dying process. Palliative care evaluation of, for example, patient satisfaction (an important element in the feedback loop) has evolved through a combination of quantitative and qualitative studies. Hospice evaluations that have been carried out in specific settings have demonstrated that hospice patients and their families have better symptom control and are more satisfied with the service than with non-specialist palliative care (Seale 1990; Goddard 1993; Hinton 1994; Addington-Hall and McCarthy 1995a; Higginson 1993; Johnston and Abraham 1995; Robbins 1996, 1997; Grande et al 1996; Fakhoury et al 1997; Seymour et al 2003). However, Seymour et al (2003) point out that that there are problems in enabling a synthesis of service outcomes due to the diversity of research methodologies that are used.
Much of the hospice practice is based on ‘best practice’ that has evolved through ‘case study’ of individual patients. This is a process referred to as ‘therapeutic research’ (Illhardt and ten Have 2002), where the goal is to treat the ill person and whilst doing so gather information about the efficacy of the treatment. This ‘best practice’ is often influenced by the varied and individual interests of the palliative care consultants, medical directors and specialist nurses who manage the care of dying people within the hospice services. Warnings against complacency and assumptions that hospices provide a system of care that is beyond criticism have been expressed, with calls for more developed evaluation of hospice practices and the implications of these to the wider social environment (Clark 1993; Walter 1994; Jennings 1997; Lawton 2000).

3.3.2 Tavistock Institute and open systems

The Tavistock Institute of Human Relations was founded in London in 1946. It was set up for the specific purpose of actively relating the psychological and social sciences to the needs and concerns of society (Trist 1990). Through research and consultancy activities the Institute has built an international reputation and publication collection that is both innovative and challenging. Systems theory was one of the first inputs from the social sciences that underpinned socio-psychological thinking and the psychoanalytical approach to understanding organisations, used by the Tavistock Institute, draws heavily on systems theory (Mosse 1994). Research developed by the Tavistock Institute drew on psychoanalytical theory of Freud and Klein. These theories were used to interpret how individuals in large bureaucratic organisations, faced with uncertainty and anxiety, set up psychological boundaries which seriously
distorted organisational rationality and task, and where the system is then identified as suffering (Trist and Murray 1990).

The Tavistock approach involves using ideas developed in the context of individual therapy and applying these to institutions in terms of unconscious emotional processes (Halton 1994). Within this is the view that ideas which have a valid meaning at a conscious level, may, at the same time carry an unconscious hidden meaning, that may be interpreted through symbolic expressions from the unconscious (Halton 1994).

Various strategies were identified that are used by individuals to manage both themselves and the organisation, for example through organisational ritual (Menzies Lyth 1988, 1990). These rituals are proposed as depersonalized routines which create distance between individuals and their roles, screening out threatening emotional involvements and replacing them with a set of mechanical actions (Menzies Lyth 1988, 1990). Menzies Lyth (1988, 1990) found that, within the hospital in which she conducted her research, nursing patients with incurable diseases was one of the nurse’s most distressing tasks. However, this study was confined to hospital nurses’ experiences. Contrary to this, studies with hospice nurses have suggested that hospice nursing provides the opportunity to share in the dying experience in an intimate and meaningful way and can be far from distressing (Zerwekh 1993; Rasmussen et al 1995, 1997; Nebauer et al 1996; de Vries 2000a, 2000b). Payne (2001) showed that despite the difficult nature of hospice work, levels of burnout among hospice nursing staff are low. She attributes this to the supportive interdisciplinary team and a positive environment that is considered the cornerstone of hospice, although she does
not address this from an organisational perspective. However, Vachon (1995, 1997) has shown that hospice nursing provides both a high level of job satisfaction and can also be stressful.

Using emotional labour theory, Froggatt (1995, 1998) and Li (2002) argue that hospice nurses experience anxiety when nursing dying patients and use a number of strategies to deal with this anxiety that are not merely demonstrated through mechanical task actions. Froggatt (1995, 1998) provides an insightful model of how nurses’ bodies are metaphorical containers of emotion. These emotions are contained and expressed only at ‘appropriate’ times, and in ways that do not disturb nurse/patient relationships. Both the work of Froggatt (1995), and Li’s (2002) ‘symbiotic niceness’ model, have congruency with the concepts used by Menzies Lyth (1988, 1990) in demonstrating processes that are used as a defence against anxiety by hospice nurses. Menzies Lyth (1990:443) points out that a social defence system develops over time through collusive interaction and agreement between members of the organization as to what form it shall take. This is often unconscious as verified by Froggatt (1995). The socially structured defence mechanisms then tend to become an aspect of external reality with which old and new members of the institution must come to terms (Menzies Lyth 1988, 1990).

Based on the psychoanalytical model it is posited that institutions (organisations) pursue unconscious tasks alongside their conscious ones, and these affect both the efficiency and the degree of stress experienced by staff (Mosse 1994). These are closely linked to the primary task of the organisation (Roberts 1994b). The identification of the primary task of the organisation is a complex process. A useful
way of viewing these was developed by Lawrence (1977- cited Roberts 1994b) where the tasks are considered at three different levels of consciousness. The ‘normative primary task’ is the formal or official task (Roberts 1994b). These are the operational broad aims of the organisation. In the case of hospice this is the care and management of the dying person and their families, using the philosophical values and principles of palliative care. This task is expressed by Stokes (1994b:121) as ‘what they say they are doing’.

The ‘existential primary task’ is the task people within the organisation believe they are carrying out, which includes the meaning or interpretation they put on their roles and activities (Roberts 1994b). Or what they really believe they are doing (Stokes 1994b). In the case of hospice care I propose that the staff believe that they are providing the ‘good death’. The ‘phenomenal primary task’ is the task that can be inferred from people’s behaviour, and of which they may not be consciously aware (Roberts 1994b:30), i.e. ‘what is actually going on’ (Stokes 1994b). Roberts (1994b:31) cites Turquet (1974) who warned that when a group does not seek to know the definition or feasibility of its primary task, there is likely to emerge either dismemberment of the group, or the emergence of some other primary task. The other primary task may be unrelated to the one for which the organisation was originally called into being.

The above discussion is significant in relation to the evolution of the hospice service from the original foundations of monastic influence to the suggested ‘medical’ model. Whilst no comprehensive studies of hospice as a sociological system have been conducted, there are a number of studies that have conceptualised the behaviours that
take place within the hospice. These offer some insight into the organisational framework of the hospice service and were discussed earlier in the literature chapter. I refer to the mosaic of studies that between them have built up a picture of the hospice as an organisational system.

Criticism of the hospice, as addressed within the literature chapter, has suggested that the original foundation of hospice care has been lost in the process of medicalisation. This does not negate the validity of the emergence of another primary task as an organisation evolves. That is, there is capacity for integration of the old with the new and the 'rite of passage' model (Froggatt 1995, 1997) suggests that some of the founding values and culture of hospice still remain. Also, within the discussions on the medicalisation of hospice, there has arisen criticism of the loss of focus on psychosocial needs of dying people which has been superseded by concentration on symptom control. This has resulted in the emergence of another primary task, i.e. a focusing on the body of the dying person (Lawton 1998a, 1998b, 2000; Copp 1996, 1999). However, the suggestion that hospice care has become body focused is not totally proven and represents one way of viewing the practices within the system, and may vary considerably between individual hospice environments.

3.3.3 System boundaries
Many of the difficulties faced by organisations can be traced to defining the primary task and to managing the system boundaries (Mosse 1994). System boundaries are complex and yet have a fundamental psychological reality (Gabriel 1999). For the purposes of my study I use a simple definition of boundaries. I propose system boundaries are the demarcation lines for the definition of appropriate system activity.
This relates to the admission into and out of the system of both members and other inputs that are necessary for organisational functioning (Katz and Khan 1966). I propose admission of people who are terminally ill as inputs (see Figure 3) necessary for the organisational functioning of the hospice, in fact for the very existence of the hospice. Froggatt (1995, 1997) describes crossing the boundary into the liminal space of hospice marks the move from secular to the sacred space. This, she says, is crossing the threshold from getting better to not getting better.

Boundaries may have both psychological and physical symbolic characteristics, such as uniforms, dress or other insignia, or more subtle characteristic may determine the boundary, such as speech patterns and specialised knowledge (Katz and Khan 1966). In the concept of open systems offered by Katz and Kahn (1966), all members of an organization are considered to be affected by the fact that they occupy a common organizational space, in contrast to those who are not members. Once within the boundaries and becoming a functioning member of the organization, the person takes on some of the coding system of the organization. This requires accepting some of its norms and values, absorbing some of its subculture, and developing shared expectations and values with other members. This boundary condition is responsible for the dilemma that the person within the system cannot perceive things and communicate about them in the same way that an outsider would (Katz and Kahn 1966).

This boundary condition implies potential for individuals within a system to become insular and cocooned within their organisation and in doing so may they be at risk of losing the ability to stand back from their activities (practices) and take a strategic
view of these. It has been suggested that this may be the case of hospice organisations where the emotiveness of the ‘haloed’ practice of caring for dying people causes practitioners to believe that they are beyond criticism (Clark 1993; Walter 1994).

I conceptualise the goals and aims of the hospice system as a philosophical consensus of the members (of the system) and a ‘defined’ way of working that is rich with rituals and routines, in the practice of caring for dying people. Provision of care within hospice is based on philosophical principles of palliative care that are held within a specialist literature. They are reproduced by the primary influential members of the organisation and imposed on other less influential members of the organisation. This is notwithstanding the complexity of the various goals of individuals and sub-groups that comprise the individual hospices that were involved in the study.

Little study has been conducted on how hospices manage their boundaries, i.e. judgements made on admission criteria and power within the teams on making these judgements. Hospices are able to maintain relatively strict boundary controls as opposed to hospitals. For example, hospitals, by their very nature have difficulty in maintaining strict boundary controls as they cannot easily control emergency admissions (Miller and Rice 1990). It has been suggested that hospice boundaries within UK hospices are predominantly managed by medical team members and that terminal ill acuteness is a primary criteria for admission to specialist hospice units (Gannon 2002; Eagle 2002). Eagle (2002) identified that if the patient was known personally to any of the clinicians present during referral discussions the patient had more chance of being admitted, as an emotive argument would be made for the admission.
The cultural and philosophical values and principles that underpin hospice care have evolved since the 1960s, and residual traditional influences and variation exist between hospices. Some hospices have retained large components of the traditional values and philosophies of hospice care whilst others have moved towards the medicalised model and claim to be providers of 'specialist' palliative care. They all have the common purpose of providing end-of-life care for dying people, predominantly people with cancer. This restrictive entry criteria ensures homogeneity of care needs and should reduce the potential for differences and tension within the liminal space (Froggatt 1995, 1997). This potential for minimal tension represents equilibrium within the system.

3.3.4 Equilibrium in systems

Systems tend to move toward the state where components are in equilibrium, i.e. where a steady state exists and when changes in the system result in imbalance, system components move to restore balance (Katz and Khan 1966; Kolb et al 1984). The confined criteria for input (people with cancer), the limited capacity of hospices (bed numbers ranging from eight to 48) plus a clearly defined philosophy of care, allows hospice to maintain a state of relative equilibrium. The philosophy of palliative care defines the central values of hospice and the central values define the goal of an organisation, as well as the basis for forms of legitimate authority exercised within (Hassard 1993). Any change in the system stems from two sets of processes. These are from the demands of the environment and from within the system itself. Demands of the environment influences movement in central values. This process
represents the dynamic nature of systems activity with cycles of events occurring over time (Katz and Kahn 1966; Kolb et al 1984).

The idea of an institute maintaining shape is developed by Mary Douglas (1986) when considering 'how institutions think'. She proposes that for an institution to become stable means settling into some recognisable shape. Institutions fall into stable types that can be recognised in different times and different circumstances. In this instance I refer to the hospice services in general. The different shape of the hospice service as it has moved through evolutionary processes has been mapped by others (see for example Clark 2002; Clark et al 2005). This evolution was influenced by pioneers in the field of death and dying such as Kübler-Ross (1969), Glaser and Strauss (1965, 1968) and Saunders (Saunders et al 1981). According to Douglas (1986:112), any institution that is going to keep its shape 'needs to gain legitimacy by distinctive grounding in nature and in reason'. Douglas (1986) further proposes that the institution then affords its members a set of analogies with which to explore the world. These analogies are then used to justify the naturalness and reasonableness of the instituted rules. It further allows the institution to keep its identifiable continuing form.

The legitimacy of the hospices was grounded in a distinctive and newly recognised need to care for dying people that gained popularity at a phenomenal speed, based on the literature on death and dying that grew from the 1960s. It was a reasonable evolution and matched the scientific and medical development of palliative care (primarily a nursing occupation), to palliative medicine (medically led palliative care) in keeping with the premise that as systems get larger they also get more complex.
(Katz and Khan 1966; Kolb et al 1984). The question that is now being asked by some, for example Lawton (2000), is where now?

There has been increasing differentiation occurring within the hospice service (system), particularly in the development of specialist units and increased medicalisation. This has been contained within a cancer service framework, and as such, equilibrium is maintained by confining expertise to this specific patient group. Although lip-service is paid to the integration of non-malignant terminal illnesses into the hospice services, the reality of this is undeveloped. Consequently the service is able to maintain relative equilibrium. Issues related to funding, charity status and other potential for disequilibrium of hospice services are not addressed in this thesis but are acknowledged as areas that are important in a view of the service within a systems framework.

3.4 Summary

The nature of this study required an inductive approach using qualitative research methodology as the purpose of the study was exploratory and was designed to enable theory construction. Grounded theory offered a research approach that required rigorous strategies in the data collection and analysis.

Open systems theory applied to the hospice service enables a view of the functioning of the organisation as a system in which the care of dying people is managed through processes of input, throughput and output. It also offers the opportunity to frame hospice activities (practices) at a macro level where the hospice can be placed within the wider society as a system within systems of health care. I have suggested that
individuals may have become cocooned and complacent within the system, due to the speciality of hospice practices. In Chapter 4 I outline the methods I used to conduct the study.
Chapter 4 – Methods of data collection and analysis

4.1 Introduction

In this chapter I provide a step by step description of the methods I used to collect and analyse my research data, starting with the pilot study. I discuss in detail my strategies for gaining access and my sampling processes and reflect on the problems encountered in recruiting participants and how these were overcome. The chapter outlines my reflexive processes showing how my thinking sharpened and focused through reading, intuiting, analysing and synthesising data. Carrying out research requires personal and professional responsibility that ensures the design of the study is morally and ethically sound. I critically discuss issues about the ethical implications for the sample group that was under study. I also reflect on what I considered an important issue in this study, that of maintaining confidentiality and anonymity for the participants. The methods used to analyse and code data are outlined and discussed in detail. The research aims were repeatedly returned to throughout the study as a means of maintaining focus.

4.1.1 Study sample

Three hospices were accessed by completion of the study due to issues of sampling and access which are discussed in detail in Chapter 4, 4.3.1.1 Overcoming sampling problems. All three hospices met the criteria for providing specialist palliative care, as defined in the literature section. That is, they had a specialist palliative care physician, specialist social work and bereavement services, in-patient, day hospice, and respite and community palliative care facilities. Bed numbers were 15, 18 and 26.
The pilot data set consisted of: a focus group interview with two senior Clinical Nurse Specialists (CNS), two Junior Hospice Nurses (JN) and two Health Care Assistants (HCA): an interview with a hospice Specialist Registrar (DR): interview with, and examination of detailed hospice notes of a hospice Social Worker (SW): individual interviews with two family members (FM): and examination of the hospice records of the person with variant CJD. The number of participants for the complete study and their codes are listed in Table 1. Type of data collected for the complete study is listed in Table 2.

Table 1  Codes for participants

<table>
<thead>
<tr>
<th>CODES</th>
<th>PARTICIPANT TITLE</th>
<th>NUMBER PARTICIPANTS</th>
</tr>
</thead>
</table>
| CNS   | Clinical Nurse Specialist (experienced hospice nurse) | 8  
(2 interviewed twice/focus group)  
(1 interviewed three times/focus group) |
| JN    | Junior Hospice Nurse (new to hospice care) | 3 |
| HCA   | Health Care Assistant  
(all were experienced hospice care practitioners) | 6  
(2 interviewed twice/focus group)  
(1 interviewed three times/focus group) |
| DR    | Doctor (all were Specialist Practice Registrars) | 3 |
| SW    | Social Worker | 2 |
| FM    | Family Member (this does not include family members from television documentaries) | 5 |

Table 2  Type of data collected

<table>
<thead>
<tr>
<th>TYPE OF DATA COLLECTED</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus group interviews conducted</td>
<td>4</td>
</tr>
<tr>
<td>Single interviews conducted</td>
<td>7</td>
</tr>
<tr>
<td>Two person interviews conducted</td>
<td>2</td>
</tr>
<tr>
<td>Sets of hospice records examined</td>
<td>4</td>
</tr>
</tbody>
</table>
Television documentaries transcribed and analysed | 2
---|---
Newspaper interview analysed | 1

Figure 1 provides a flowchart of the data collection process showing; what type of data was collected from each of the hospice sites, how many participants were interviewed and specifies who these participants were.

**Figure 1  Flowchart of data collection sites and processes**

**In-patient admission**
- Focus group interview, comprised of: two CNS, two JN, two HCA
- Individual (single) interviews with two FM
- Individual interview with one SW plus examination of detailed written notes
- Individual interview with one DR
- Examination of patient hospice records
- Repeat focus group interview – two CNS and two HCA (from above group)

**Community admission**
- Two person (joint) interview with one SW and one DR
- Did not gain access to hospice records at this site

**Community and day hospice/respite admission**
- Focus group interview, comprised of: two CNS, one JN (day hospice), two HCA (day hospice and community)
- Examination of patient hospice records

**Community and day hospice/respite admission**
- Individual interview with one CNS (community)
- Individual interview with one CNS (day hospice)
- Individual interview with one FM
- Examination of patient hospice records

**In-Patient admission**
- Focus group interview, comprised of: two CNS and two HCA
- Two person (joint) interview with two FM
- Individual interview with one DR
4.2. Pilot study

4.2.1 Sample and gaining access

In grounded theory the initial sample is determined to examine the phenomena where it is found to exist, i.e. purposive sampling is carried out. Initially I carried out a pilot study, the data from which has been integrated into the findings. Ethical approval was obtained from the Local Research Ethics Committee (LREC) for this (Appendix 1) and from the hospice site. Prior to the interviews meetings were held with potential participants and the Information sheet provided (Appendix 2). Consent was obtained at the time of interview (Appendix 3).

Requirement for inclusion in the study was that participants had been involved in providing care for a person with variant CJD at the end of the illness trajectory. No Chaplains were interviewed, as, to my knowledge none were involved with my study participants. In keeping with the philosophy of hospice care, family members or ‘significant others’, of the people with variant CJD, were considered to also be members of the hospice teams. All significant others were family members, so throughout the study they were always referred to as family members.

4.2.2 Data collection

4.2.2.1 Focus group interviews

The approach I used in conducting the focus group interviews was to create a non-threatening environment (Morgan 1998). I kept a low profile, allowing a free discussion of the care of the person with variant CJD to develop. My input was

- Examination of patient hospice records

   NOTE: One CNS and one HCA were interviewed for this admission and were members of both focus groups for first in-patient admission above
limited to ensuring all of the questions I had on my interview guide (Appendix 4 and 5) were covered at some stage of the interview and to summarise at various points.

4.2.2.2 Single and two person interviews

Close intimate discussion occurred during the interviews with family members, and a friendly relationship was established, by dint of my personal approach. In the context of being a practitioner in the palliative care field, this was natural behaviour and could not be ‘put aside’. I felt confident that this was mutually agreed in all cases. However, the data collected was of a sensitive nature and during the interview process issues of an emotive nature were raised, both in the single and focus group interviews. Even some time following the interview emotive affect may occur as interviews are also interventions. They affect people, and thoughts, feelings, knowledge, and experience are revealed to both the interviewer and the interviewee. As pointed out by Patton (2002), being taken through a directed and reflective process about one’s life during an interview can be change-inducing. Interviews may leave people knowing things about themselves that they didn’t know, or may not have been aware of prior to the interview (Patton 2002).

This was a crucial consideration during the research process and in preparation for this, a system was established to provide support for myself, and any participant who may require this. The person who negotiated my contact with family members agreed to take on this role for family members. In two cases this was a Specialist Palliative Care nurse and in another case it was a social worker. As a means of providing her own support one family member brought her friend with her to the interview (pilot).
As support for myself I approached a social worker who agreed to act as my support system should I need to discuss any issues that arose for myself.

I did have some concerns as, at some stage, in all cases, one of the family members was in tears during the interview. Distress was verbalised in several ways, with family members reporting that ‘... we don’t go to same church now’ and that, ‘God had let us down’. Some of the distress expressed had implications for making decisions about continuing or terminating the interview. Seymour and Ingleton (1999) recommend that in carrying out research with participants in palliative care the principle of process consent should be used. This is a process whereby consent is frequently checked throughout the dialogue. Some of the concerns raised in using this approach is that it may constrain the research design, possibly reduce the sample size, and data may be missed as a result of a half-finished interview (Beaver et al 1999). I felt that the practice of process consent occurs within an interview relationship intuitively, based on responses of the participant during the interview. My experience was that repeatedly saying, ‘Do you want to continue?’ was an impediment to the flow of the interview. The approach I used was to make an intuitive judgement on how often I used the phrase, ‘do you want to continue?’ This phrase could potentially increase distress whereas I found that an empathic silence allowed the person to express the emotion and make their own choice when to move on with the interview.

4.2.3 Data analysis

For the pilot study I transcribed all data verbatim as soon as possible following each interview. I then listened to the tapes repeatedly, until familiarity with the data was established. Analytical memos were made of transcribed data, i.e. notes taken when
listening to the audio-tapes and whilst consulting field notes. From this I created an interpretative commentary while the information and innuendoes remained fresh. [All other data for this study were transcribed by an experienced transcriber after which I listened repeatedly to the audio-tapes. This enabled me to recall unclear pieces of recorded speech and intonation and emphasis of participants and transcriptions were modified until I was certain of the innuendoes, meaning and interaction contained in the interviews.]

4.2.3.1 Manual analysis of interview data

The method which I used to conduct the focus groups meant they provided a form of 'natural' conversation and the tapes were transcribed with particular attention paid to the interactions within the group. For the manual coding of the focus group data, one copy of the transcription was used to analyse the group interaction, using the notes taken during the focus group interview to guide this. Other copies were made for line-by-line coding and tabulation. I address the subject of tabulation later in this chapter. Large margins were retained on the both sides of the transcription sheets of focus group and single interviews to enable writing of notes when analysing the data. Each line of every page was numbered so location of details was made easier. Several copies of the transcriptions were made. Each copy was used in a different way and a system of colour codes was developed in the coding of the focus group and single interview transcripts. From these sets of transcriptions I developed several 'mind maps'. I used a visual depiction in accordance with my way of visualising the world which is largely pictorial. This visual model was an invaluable tool during the research process. As I worked through my analysis and interpretation of data it was reformed repeatedly.
'Mind mapping' has been described as a visual format that represents information systematically so that the user can draw valid conclusions and take action as necessary (Miles and Huberman 1994; Buzan and Buzan 2003; Buzan 2004). It involves a process of what Buzan and Buzan (2003) refers to as 'radiant thinking'. Radiant thinking is a combination of brainstorming and relational associations that proceed from or connect to a central point. These were all hand written. An example of how these 'mind maps' were used was converted to a Power Point display and can be seen in Appendix 6 where I coded the types of interactions that occurred during the focus group interview as conflict, agreement, hierarchy and in-articulation. Appendix 7 provides a 'mind map' of the categories that were developed as a preliminary theoretical framework from the pilot.

4.2.4 Tabulation

On the first reading of the transcripts for the pilot I was immediately struck by the number of time participants referred to 'not knowing' (Appendix 8) and how much focus there was on the subject of 'sedation' (Appendix 9). This had not been as obvious to me on listening to the tapes or even during the interviews. 'Not knowing' was identified as a very important issue for the participants and clearly had potential to become a core category. I decided to use a process of tabulation, reported to be a strategy to establish trustworthiness (Silverman 2000; Scale 2000), and count how frequently a reference to 'not knowing' and 'sedation' was made. Transcription sheets (for both focus group and single interviews) were used to carry out 'appropriate' tabulation, where the number of 'instances' of certain phrases was counted (Silverman 2000).
This is not a matter of counting for the sake of counting, and is a strategy that may be utilised in different ways. For example, the number of times a certain phrase is used may be tabulated as a means of establishing the presence or absence of key interactions within a given context. 'Counting instances' of, for example repeated words or phrases (Silverman 2000; Seale 2000), or 'manifest coding' (Sullivan 2001), particularly when using a coding scheme, is considered to be a means of increasing rigour within a study. I considered this an important contribution to identifying and maintaining the core category. Secondly (based on analysis of a later data set) it was used to make a comparison between the number of expressions of 'not knowing' by hospice teams who were caring for a person with variant CJD for the first time and a hospice team who had previous experience of caring for variant and other types of CJD cases. This led to the development of the category that explains change over time from 'not knowing' to 'becoming knowledgeable'.

Care needs to be taken when using tabulation processes as evidence as it is a process largely associated with quantitative research methods. Denscombe (1998:169) suggests that this type of content analysis refers to the treatment of data rather than research methods and warns that 'the more the text relies on subtle and intricate meanings conveyed by the writer or inferred by the reader, the less valuable content analysis becomes in revealing the meaning of the text'. For example, within data a number of instances of repeated phrases can be attributed to one or two participants whose habit, during the interviews, was to repeat themselves constantly. These instances were also found to be due to my repeating a question to either clarify or summarise an event or situation during the interview. I found that it was essential that
I took this into consideration when using NUD*IST to tabulate. I needed to ensure that I was not merely providing a number of instances of a word or phrase occurring without considering the context in which it was used.

One example was that of the repeated use of the word ‘ignorance’, occurring five times within a very short section of conversation between two health care assistants. This section demonstrated a symbolic interactionist explanation of the process of designating, interpreting and transforming the ways in which the participants were fitting together their lines of action or conceptualisations through symbolic use of language (Blumer 1969). In this case ignorance was contextualised as a negative expression related to ‘gossiping’. It was also ‘counted’ as an expression of ‘not knowing’, and strengthened the core category. The point I am making is that ‘counting’ must be seen as a more complex method within qualitative data than merely providing a table of ‘instances’. These ‘instances’ may be out of context with the event/situation being analysed, particularly in relation to interview data. It is a very useful method within qualitative research but should not be seen as providing ‘objective’ description, and should only be used as long as it can be justified and contextualised by the researcher.

Analysis of the pilot indicated that the sources of data used provided a rich account of the experience of caring for a person with variant CJD. Design principles for the main study were based on those of the pilot. The findings from the pilot are integrated into the main findings.
4.3 Main study

4.3.1 Sampling and recruitment

Five hospice sites initially agreed to participate in the study. Only three of these were accessed, for reasons I discuss later. They were given a copy of the Information sheet for participants (Appendix 2) at the time of inviting their participation (Appendix 10). A reply letter of agreement to participate (Appendix 11) and letters of acknowledgement were sent to those sites that agreed to participate in the study (Appendix 12). The information sheet (Appendix 2) and a letter of confirmation to participate in the study (Appendix 13) was given to identified, potential participants from within the hospice teams and a date to carry out the data collection negotiated. All family member participants were approached by a hospice staff member who I had previously interviewed, either in a focus group or single interview. It was important that this member was known to them and that it was a person with whom they had a relationship such that I could feel confident that their decision to participate in the study was wholly voluntary and that they had been clearly informed about the study aims.

4.3.1.1 Overcoming sampling problems

As the study progressed recruitment became problematic for several reasons. The first problem occurred when I collected the second data set. What was to be a focus group of four, became two members of staff, and some time into the interview it was revealed that the patient had actually died in 1997. This was despite my clear stipulation that I wanted to collect data on cases that had been at the hospice in the last 12 months. (see Appendix 10, letter to hospices). There was no potential access to family members from this case by the time I carried out this interview.
Analysis of the interview data for the second case of variant CJD maintained the core category and strengthened some categories and weakened others already established from the first data set (pilot). Appropriate admission into the hospice service was a major focus at the time of the death of the person with variant CJD (1997) and strengthened this category and gave me the ' beginnings' of conceptualising the data as 'time contextual'. As a result of the unexpected 1997 case, I checked other agreeing hospices to find that in one case the person had died more than two years previous, consequently I did not pursue data collection from this site. I found that a further hospice that had agreed to participate in the research had not had a case of variant CJD. The agreement was made based on potential admission.

The site where I collected my third data set also became problematic. As a condition of my ethical approval, it required that any approach made to family members must be made by a hospice staff member who knew them. Despite several attempts to arrange contact with family members through the staff member, I was not successful. The reasons for this were never revealed. A further person with variant CJD, identified for me by the Prion Centre, was lost due to the interpretation of gaining ethical approval by the hospice Medical Director. She considered that I could not have access to staff or records unless the family agreed to this. The Medical Director approached the family on my behalf and reported that the family were reluctant but said they would consider it. Following several attempts to expedite this, I was not successful.

At the outset of the study, the predictions were that large numbers of people would become 'infected' with variant CJD, and therefore possibly require hospice care. This
meant that the potential for recruiting participants for the study was high. Variant CJD cases "appeared" to peak in 2000 and by 2002 there was a clear lessening of numbers (see literature section). Also, by 2002, funding by Government for people with all types of CJD was such that for many the care-at-home package was so comprehensive that there was little requirement for hospice input. Most did not fit within my MREC ethical approval criteria, which was to approach cases through hospices.

Sampling became even more problematic by the end of 2002. Another case, identified through my networking was met with a refusal to access by the hospice Medical Director. Other cases I identified through networking had no specific hospice care input due to comprehensive funding support that families were, by then, receiving. Hence, by the beginning of 2003, I had a dwindling potential for participants for the study.

An important aspect of the data that I already had, from three sites, was that it covered a five-year span. That is, three people who had died of variant CJD, one each in 1997, 2000 and 2001. It was at this stage that I made several decisions about the direction of the research. I decided to place the study within a time context, i.e. changes over time of the variant CJD experience and relate this to the hospice as an organisation. I also decided to examine material on the subject of variant CJD within the media. I transcribed two television documentaries of the experiences of two young people, Kate and Jonathan and included them in my NUD*IST data base. On CJD internet sites I found a number of detailed interviews with family members of young people who had died of variant CJD. To one of these, the story of Claire (Pearson 2000), I
applied the coding scheme (manually). These cases did not fit into the category of having been cared for by hospice teams, but were useful in examining family experiences, as my field data had only been able to get family experiences from one site at the time. The media cases are presented in the findings chapter as footnotes, where the experiences were relevant and supported my interpretations. I decided that it was not appropriate to include this data within my own field data as the material had been journalistically manipulated. Evidence of this is demonstrated by how the documentary about Kate focuses on the horrific nature of the disease, risk and food. The focus of the documentary about Jonathan was on cure.

At this stage I also decided that, due to reducing numbers of people being identified as having variant CJD, I would broaden my focus and look for deviant cases. In considering what would constitute a deviant case, I decided that a case of CJD of a different type would be appropriate and as, by that stage, almost all cases of CJD were being managed at home, this would have to be a hospice community team case.

Through networking processes I found a person with a diagnosis of CJD, the type of which was uncertain. There was a possibility that it was variant CJD, but due to a number of other factors this had not been confirmed or excluded. Then, unexpectedly, I found a case of variant CJD, who became an in-patient admission to a hospice that had previously provided care for people with other types of CJD, including variant CJD. This offered the opportunity to look for differences between the experiences of a hospice team who were more experienced and knowledgeable about the disease. This was the team from which I had obtained my pilot data (first data set). Not all of the original team members remained at the hospice but two CNSs
and two HCAs were able to be interviewed again and other members of the team had previous experience of caring for a person with variant CJD.

4.3.2 Data analysis

The provisional theoretical framework that resulted from the analysis of the pilot provided a coding scheme for analysis of further data sets when using non-numerical unstructured data indexing, searching, and theorising (NUD*IST) programme software. Appendix 14 provides a chart of the stages of the research process, demonstrating the flow of the grounded theory development from the gathering of the data, coding, category development and formation to the stage of theory development. In practice, when using grounded theory, this process does not occur in the linear form depicted in Appendix 14. It is a systematic and inductive process of entering the field and collecting data. From there an analytic interpretation of the data is developed which focuses further data collection. This is followed by returning to the literature and then re-entering the field. It is an evolving and constantly developing process of reflexivity and theory building (Charmaz 2003a, 2003b).

4.3.3 Categorising the data

Grounded theory begins with 'basic description', moves onto 'conceptual ordering', and then to 'theorising' (Strauss and Corbin 1998; Patton 2002). In coding my data I followed this three-step process, however, based on Charmaz's (2003a:258) premise that 'coding starts the chain of theory development', theorising took place throughout the process.
The first step is where basic description of the raw data is produced through the process of open coding. This is a process of line-by-line coding of raw data. It also involves examining larger sections of conversation/discourse for interactions occurring between participants (see Appendix 15 for an example of [manual] open coding carried out on a section of my data). The process of open coding produced a large number of concepts or codes. Concepts are defined by Straus and Corbin (2004:303) as ‘conceptual labels placed on discrete happenings, event, and other instances of phenomena’. This involved a combination of ‘literal’ and ‘interpretive’ coding of the data. Literally, I was interested in the words, language used, sequences of interactions and the form and structure of the dialogue (Mason 2002). My interpretive coding was based on my inference of what participants interpretations, understandings, versions and accounts of the events were, i.e. I was ‘reading through or beyond the data’ (Mason 2002:149). This included noting metaphors.

At step two these concepts were put into some order. The most frequently appearing initial concepts were used to sort, synthesise, and conceptualise the large amounts of data (Charmaz 2003b). From this process the concepts were then grouped or classified and the number of units reduced. These units then formed a category.

A category is a classification of these concepts. ‘This classification is discovered when concepts are compared one against another and appear to pertain to a similar phenomenon’. (Strauss and Corbin 2004:303) That is, a category represents a unit of information composed of events, happenings and instances (Strauss and Corbin 1998). These categories were given abstract titles based on the relationships within the groups of coded concepts. The name chosen for a category was one that seemed the
most logical descriptor for what was going on. The classification of these categories often ends in an ‘-ing’, to convey action (Strauss and Corbin 1998; Charmaz 2003b). A source of categories can also be from the literature. However, Strauss and Corbin (1998) caution that care needs to be taken when ‘borrowing’ concepts or names for phenomena as they often bring with them commonly held meanings and associations. In the early stages of analysis (pilot) one category was borrowed from the literature as it so succinctly represented the experience of the participants. This was contagion which was ‘borrowed’ from Doka (1997) in relation to the early days of HIV and AIDS. It served as an appropriate ‘early’ category for the concerns about contamination and risk, but was collapsed into other categories as data collection and analysis proceeded.

The third step was that of focusing on a core category or selective coding. This was the integrative process of selecting the core category and systematically relating it to other categories (Strauss and Corbin 1998). It is also the stage of theorising (Strauss and Corbin 1998). Charmaz (2003a) however, sees theorising as starting at the early stage of coding. Strauss and Corbin (1998) put emphasis on showing that the generation of theory occurs around a core category, whereas Charmaz does not make reference to the concept of ‘core category’. According to Strauss and Corbin (1998) categories that are not related to the core category can be excluded from the theory and other categories that are related to the core category can be examined in more depth. I found, as Charmaz (2003a) suggests that theorising began early in the research process and was constantly refined as data collection and analysis proceeded.
Glaser and Strauss (1967) caution that the researcher is inclined to begin to construct theory at a very early stage of the data collection. As analysis is part of the process all the way through the study, in grounded theory, this is an accepted process. However, it needs to be approached carefully to avoid some of the pitfalls that can lead to accusations of bias and lack of trustworthiness. Silverman (2000:179) advises that in practice the researcher should begin analysis on a relatively small part of the data. Then having generated a set of categories, test out the emerging theory by steadily expanding the data corpus. This was the process that I followed, where the preliminary framework developed from the pilot assisted in developing a coding scheme that was used both to guide further interviews and provide a preliminary theoretical framework (Silverman 2000).

A coding scheme is an operational definition of the content of data material and is also an integral part of conceptual development and theory building. There are no clear guidelines on how to establish a coding scheme for qualitative researchers. Sullivan (2001) suggests that they are typically derived from some pre-existing theoretical stance and then an effort is made to see if the data ‘fit’ the coding scheme. The scheme can be created before commencing fieldwork (Miles and Huberman 1994), or it can be developed following analysis of a small section of data (Silverman 2000; Sullivan 2001), which is how I used this.

I became totally absorbed by the data, writing detailed memos and notes on my thoughts and impressions. This was based on the mandate to write what emerges from the data where memos were used to aid the development and formulation of grounded theory. The term memo, in grounded theory, refers to very specialised
types of written records that contain the products of analysis or directions for the analyst. These are 'analytical and conceptual rather than descriptive' (Strauss and Corbin 1998:217). These were used to 'free associate' and write whatever thoughts came to me at any time, often written on scraps of paper and later transferred to my research journals. These memos became the beginnings of conceptualising the raw data. At the same time I was also reading literature on subjects that were identified in the transcripts. Detailed reflections and notes were kept that have been used to illustrate, as far as possible, the evidence and thought processes that led to my conclusions. Data interpretation was influenced by my intellectual ability and my life experiences, particularly my clinical experience within the field of palliative care, and consequently is never wholly objective and dispassionate. This is in keeping with a constructivist paradigm where the attention to participants and the sense of self ultimately leads the researcher to offer a personal view (Stake 1995; Patton 2002; Charmaz 2003a; Mantzoukas 2004).

One of the means I used to show how participants defined their world was by exploring the use of metaphor in the language that was used. Conceptual systems are largely metaphorical (Lakoff and Johnson 1980) and I have used metaphors to aid my interpretation of the data. These were used both at the conceptual level of the hospice service as a 'container', and in presenting my interpretation of some of the experiences of participants. This reflects one of my analysis strategies of working with words through metaphors and analogies (Miles and Huberman 1994). These strategies were based on symbolic interactionist concepts where it is understood that forms of language mediate the workings of consciousness, the self and social interchange. Society is held to emerge from discourse and symbolisation and the
metaphors which phrase that vision borrow heavily from an imagery of everyday speech (Rock 1979).

4.3.3.1 Metaphors

It is important at this stage that the term metaphor, as used in the interpretation of data, is defined. However, attempting to provide a concise definition of metaphor would require an entire chapter on the subject. An issue of debate is the validity of interpretations made of expressed meanings, including metaphors (Czechmeister 1994). Czechmeister (1994) makes the point that the use of metaphor in life, health and nursing is both a rich resource and potential burden. She claims that metaphors used by others must be considered within the context of the researcher's personal frame of reference, and be validated by the 'actors'. The risk in taking this approach is that the context of the researcher's personal frame may be contrary to that of the 'actor's' world view or interpretation of language. This risk may be less when the researcher and participants share a common cultural understanding of the subject under study, as was the case for myself and hospice staff. However, there may not be this commonality between family members and hospice staff. The metaphors I used were not validated by the 'actors' (participants), for reasons discussed in relation to participant confirmation.

I agree with Czechmeister (1994) who maintains that metaphor will always be an imperfect representation. This view is widely held on the use of metaphors and Leary (1990) points out that although all knowledge is ultimately rooted in metaphorical modes of perception and thought, there are considerable difficulties in precisely defining this term.
Metaphor has been likened to a filter, a fusion, a lens, a pretence, a screen, a tension, a displacement, a stereoscopic image, a form of linguistic play, a false identity, a semantic fiction, a contextual shift, a translation of meaning, a twinned vision, and an incongruous perspective, to mention only a few of its common metaphors (Leary 1990:4).

Dictionary definitions are similar to some of the ‘working definitions’ Leary (1990) offers. Metaphor is a figure of speech in which a word or phrase is applied to something to which it is not literally applicable, a thing regarded as symbolic or something else. Leary (1990) also proposes that similarity (or analogy) is the bond between the two things compared in a metaphor. For the purposes of this study I have adopted Leary’s (1990) working definition of a metaphor:

Metaphor consists in giving to one thing a name or description that belongs by convention to something else, on the grounds of some similarity between the two (Leary 1990:4).

4.3.3.2 Analysis of hospice records

The hospice records were primarily used to cross-check data from the other sources. The issue of accuracy proved interesting in that in one case, the focus group participants reported that the person had been on the ward for a month to six weeks, when in fact, as was clearly documented in the records, the person had only been a patient for 18 days. This gave some indication of the impact of the event on their memories. Other inaccuracies were found, but these were more related to types of medications that were given and times these were commenced. The records also provided useful data on the ‘different’ ways that ‘not knowing’ could be recorded and built on the categories that had been developed from the interviews.
4.3.4 Use of the NUD*IST programme

As data collection progressed all data were inserted into the NUD*IST programme. The choice of computer assisted software was made without exploring as thoroughly, as I now believe was required, all possible programmes. NUD*IST was the package that was made available, through my workplace, to assist in the storage and manipulation of data whilst carrying out the analysis. Prior to choosing to use computer software I had not considered my personal style of ‘seeing’ or visualising data, or the world in general, and how this would influence my relationship with data. The programme was purchased and study programmes attended without any investigation of the limitations of NUD*IST or of the potential of other computer software.

Becoming competent at using the package was considerably time consuming and I spent a large part of my research time just learning to use NUD*IST. It soon became clear to me that the data display option within NUD*IST did not allow the complex visualisation of the data that I had when using the manual display system during analysis of the first data set. Engaging with data is a crucial aspect of the research analysis process. It became clear to me that the limitations of NUD*IST did not allow me to ‘see’ the work in its entirety, in a manner that suited my ‘way of looking’ at the world. When using grounded theory each set of data is ‘new’. That is, as part of the process of constant comparison different questions are asked of the participants and specific focuses are developed and new data sources are sought as the theory develops. Following input of a third data set into the programme I became increasingly frustrated by the inability to ‘see’ my analysis development in its entirety. As a widely spatial thinker and an experienced painter I needed to be able to
‘see’ the data in its ‘wholeness’, as one looks at a picture. My research journals bear witness to this, and I covered many pages with diagrams, matrixes and configurations of how the emerging framework could be presented.

While manipulating the data it could only be viewed in segments reading left to right. I began to feel as though I was pursuing in the use of this software, because it was the ‘way to do this’ and was required of me at this level of study. I could not ‘see’ the developing construction of my theoretical framework whilst working at the computer and had to constantly stop and draw diagrams of my insights and how these fitted within the framework.

I had identified immediately with a short discussion by Charmaz (2003a) demonstrating her reservations on the use of computer assisted software in carrying out grounded theory research. Charmaz (2003a:268) quotes Lincoln in a personal communication (1998). Lincoln asks her students, “Why would you want to engage in work that connects you to the deepest part of human existence and then turn it over to a machine to ‘mediate’?” Charmaz (2003a) suggests that the software packages are more suited to objectivist grounded theory rather than constructivist approaches, where objectivist approaches echo positivism. My original analysis of the data for the first data set using mind-mapping processes were more appropriate to both a constructivist approach to grounded theory, and to my personal learning style.

On realising the limitations of NUD*IST for my needs, a decision needed to be made as to whether to purchase a different software programme and once more embark on a learning programme of how to use it. I considered returning to the ‘tradition’ methods
of manual manipulation of data. Finally I chose to return to a mind mapping system of displaying my data, using a wall display of a cut-and-paste process with post-its and a white board to record ideas and make notes on, whilst at the same time continuing to manipulate the data within NUD*IST. Input into NUD*IST was carried out following changes made on the wall display and visa versa. NUD*IST provided the advantage of enabling easy access and manipulation of data and transfer into my word document. Essentially the combined systems were complementary. I did not however, use the memo writing facility in the NUD*IST programme as I found memo writing was an activity that occurred more often away from the computer. Memo writing was confined to my research journals.

Fielding and Lee (1991, 1998), Creswell (1998), and Seale (2000) promote the use of computer software programmes to analyse qualitative data. In doing so I believe there is a danger of returning to the narrow approaches that were the reasons for much of the early development of qualitative research methodologies. Seale himself is a scientific, quantitative researcher by background. It could be assumed that his background, as with many other researchers who have moved from the quantitative school into using qualitative approaches, bring with them the philosophical underpinning of the scientific approach with the use of computerised technology. However, Seale (2000) is careful to point out that it is important that researchers who are using computer software to manipulate qualitative data remember that these programmes do not carry out the analysis or 'build the theory'. Any theory or conclusions that are developed are the work of the researcher’s own thinking, intuiting and insightful development (Seale 2000).
As a means of adding rigour to my study I approached an experienced researcher to carry out manual coding on my first two data sets (included the pilot data). The choice of the person was based on her experience in using grounded theory at PhD level, her experience as a post doctoral researcher and supervisor of PhD students. The background of this person was in sociology and the focus of my research was towards psychosocial frameworks of understanding human activity. Only line-by-line coding was carried out by this researcher so comparison could not be made between more developed themes or categories from the data. However, codes that were congruent with my own were identified with enough concordance to give me confidence in my coding.

4.4 Ethical considerations

Ethical approval was granted from the Multi-centre Research Ethics Committee (MREC) (Appendix 16) and relevant Local Research Ethics Committees (LREC) were informed prior to data collection at each site.

In carrying out research involving clinical situations it is of paramount importance to avoid deception and to protect the autonomy of participants and maintain confidentiality. Lee and Kristjanson (2003) further point out that in relation to the vulnerability of palliative care participants, the first responsibility of the researcher is to ensure that there is potential benefit from the question being answered. This has also been shown to be a primary concern for ethics committee members (Stevens et al 2003). de Raeve (1994) goes so far as to question whether research on dying people should be undertaken at all. de Raeve (1994) raises the question of: what do the participants get out of the experience of participating in a research study. As, in the
case of a dying person, who may not be alive at the end of the research, the
dJudgements made by the researcher would be unchallenged (de Raeve 1994). It was
one of the primary concerns of this study that my judgements and interpretations of
the words of all participants were just and valid and would cause them no harm.

Sensitivity issues potentially affect almost every stage of the research process (Lee
1993). Furthermore this was a sample from whom I was attempting to gain
information about people who were not able to give consent due to cognitive
impairment. As a result of concerns about the protection of vulnerable people in
research studies, accessing participants for research purposes has become very high
profile within the healthcare arena (COREC 2004). Accessing palliative care patients
and families has become problematic and some ethics committees serve as powerful
gatekeepers and may disallow access to this group (Lee and Kristjanson 2003; Ewing
et al 2004). Some areas of research are considered more sensitive than others. The
political stance on which areas are more sensitive than others varies with swings in
political concerns and media interests (Lee 1993). Surveys and research of the variant
CJD population has been politically encouraged and heavily funded. This research
has included detailed and lengthy discussion about intimate and traumatic experiences
of grief and loss for families of people with variant CJD.

Family members of all cases in my study had been interviewed by the CJD
Surveillance Unit at some stage prior to my approach to them. In the earlier cases
family members had been inundated by approaches from journalists. I discovered that
a doctor from the prion centre had embarked on a Medical Doctorate (MD) study of
the hospice experience of people with variant CJD and was accessing the same group
as myself. Network sampling is a useful strategy when sampling rare or deviant populations (Lee 1993). The ‘network’ of hospice and palliative care is such that many people are known to each other and even hospice directors I approached to gain access, informed me about the MD study. The sample for variant CJD was very small, 136 cases at the time of making my application for ethical approval. Hence, I was competing with an array of other researchers and journalists for a very small and very vulnerable group, and my concerns about confidentiality and anonymity were considerable and justified.

Family member participants had also been interviewed by social services regarding social care needs, and two of the families had been interviewed within the same week I interviewed them. One had been interviewed by the CJD Surveillance Unit, the other by Social Services. The family members informed me that these interviews were going to take place. However, when I offered to postpone my interview they were adamant that I should go ahead. Their enthusiasm was based on a strong desire to assist in any way they could in taking forward any research that would benefit other sufferers of variant CJD.

During the collection of data for the pilot study I discussed the subject of confidentiality and anonymity with family members and recorded these discussions on audio-tape. Essentially I pointed out that considering the small number of cases and the detail that I was asking about the events it may be possible to identify the person in future publications. The family members did not consider this to be an impediment to the study. This was not surprising as intimate details of the
experiences of people with variant CJD are to be found on the internet and details of several cases have been televised since the disease was identified.

Research can also potentially empower participants (Hammersley and Atkinson 1995; Osborn 1999). My 'impression' was that family members felt empowered in being part of a study that they saw as advancing the cause of people with variant CJD. Patton (2002) addresses this issue in arguing that there are new directions in informed consent where confidentiality versus people 'owning their own story'. Osborn (1999) also takes this stand in relation to research within psychiatry, including dementia care. He suggests that whilst the protection of research participants must remain a high priority for researchers, the exclusion of some patient groups based on their diagnosis or status is now recognised as counter-productive and disenfranchising. Privacy has remained the dominant presumption of researchers but is being challenged by participants in research who insist on owning their own story as part of healing, empowerment and pride, and in some instances researchers offer this option (Patton 2002). I chose not to take this approach for my study and my stance was to protect participants in every possible way. Patton (2002) poses the question, is this protective or patronising? This question led me to some lengthy reflection on not only the right of families to tell (and own) their stories but also consideration of a collaborative approach to the research with other participants, particularly hospice staff. My preference would have been to allow participant ownership of the data. However, this did not eventuate due to a number of factors that I addressed earlier in participant confirmation.
4.4.1 Consent

Obtaining informed consent from participants in any study is ethically essential. Burns and Grove (2001) cite the Nuremberg Code (1949) in emphasising the importance of ‘informed’ consent. They define informing as: ‘...the transmission of essential ideas and content from the investigator to the prospective subject’. And consent as: ‘...the prospective subject’s agreement to participate in a study as a subject, which is reached after assimilation of essential information’ (Burns and Grove 2001:206). This required rigorous approaches to obtaining consent and required negotiation of a number of ethical processes and committees before actually meeting the participants. Signed consent was obtained from participants prior to both focus group and single interviews (Appendix 3). Participants were informed that they could terminate the interview at any time without giving a reason and that the audio-tapes would be destroyed.

Debates about the requirements for informed consent have been a focus of research throughout the 1990s (Osborn 1999). Much of the ethical discussion on the issue of consent in palliative care has focused on consent from patients. de Raeve (1994) argues that due consideration of the power base of the researcher in transforming the data into an abstract analysis, which will include the personal subjectivity of the researcher, is not information that will be communicated to the participant. They may be unaware of the extent to which the material they have consented to be used will be used. de Raeve’s (1994) focus is on participants who are patients. For the purposes of this study, patients were not involved directly in the data collection process. However, within hospice philosophy and practices family members may be regarded as either patients/clients (for bereavement support) or carers (as part of the hospice
team), often oscillating within these roles. My stance was that family members were members of the team who were providing the care. Although there were issues of bereavement for all family members, this was not the focus of my research.

4.4.2 Confidentiality

Despite the earlier discussion on empowerment of family members through owning their own story and lack of concern about potential loss of confidentiality, one of the important issues for me throughout this study has been how to maintain participant and hospice site confidentiality and anonymity. This is due to the very small variant CJD population and the possibility of identification. As per University regulations, audio-tapes and back-up diskettes of transcribed material are kept in a secure environment and will be destroyed within five years of completion of the study. To further manage maintaining confidentiality and anonymity I have taken care in selecting extracts of raw data that I present in full within the findings. These are presented in a manner that I hope cannot match the material specifically to identifiable incidents or sites. A system of identifying the raw data has been devised that allows me to trace the extract but that does not allow easy identification of a specific case or site. However, within a constructivist paradigm the final presentation should be a conceptually abstract account of the experiences (Charmaz 2003a) and therefore reduces any possibility of identification of participants.

4.5 Summary

In this chapter I have provided a detailed description of the methods that I used in collecting and analysing my data. Sampling difficulties and how these were overcome were addressed. Issues about the use of NUD*IST had implications on
how I managed and analysed my data sets. My methods of overcoming the problems I encountered were elaborate and time consuming and at times frustrating. Much of this difficulty related to my personal reactions to the analysis process and how qualitative data can be managed. However, I believe the procedures I used ensured that data was completely saturated. In the following chapter I present the study findings.
Chapter 5 – Findings and discussion

‘Dealing with the Unknown’
An explanatory theory of managing the care of the person with variant CJD by the hospice service.

5.1 Introduction
In this chapter I present the findings and discussion simultaneously, in keeping with grounded theory methodology. A series of figures will be presented as each category is described, building up to the complete theoretical explanation. I refer to all cases as having variant CJD, as the one case that had an uncertain diagnosis was considered to be a ‘possible’ variant case at the time of interview. Due to concerns about confidentiality and anonymity specific details of the cases of variant CJD are not presented.

The admission of a person with variant CJD into the hospice service and the experiences of staff and family in caring for the person represent a ‘micro’ event within the organisational context of the hospice service. The theoretical explanation presented in this thesis relates to the impact of this micro event on the service. Other theoretical models of hospice care influenced the practices that were used in caring for the person with variant CJD and also influenced my interpretation of data (Figure 4). The models proposed by Froggatt (1995, 1997, 1998), Lawton (1998a, 1998b, 2000), Copp (1996, 1999) and Li (2002) were considered the most influential for my interpretation of hospice practices but not exclusively.
Hospice Service 'Container' (Open system)

System boundary

Inputs

Predominantly people with cancer

New event:
People with variant CJD entering the system

THEORIES OF HOSPICE CARE

'Rites of passage' (Froggatt 1995, 1997)

Readiness to die (Copp 1996, 1999)

Sequestration of 'dirty dying' (Lawton 1998a, 2000)

'Symbiotic niceness' (Li 2002)

'Dealing with the unknown'

Novelty
Fitting in - 'Opening the floodgate'
Did fit / Didn't fit
Gossiping
Ghoulish voyeurism
Ignorant outsiders
'Drawn' to stories
Bullying
Horrifying - 'Worst possible nightmare'
Personhood status

Controlling
Managing care
Restoring dignity
Normalising
Granting autonomy
Maintaining the environment

Humility

Becoming knowledgeable
Bewildered family

Figure 4. Variant CJD as a 'micro' event within the scheme of caring for dying people within the hospice system.
The categories are presented in the following order:

**Core category -- 'Not knowing',**

Not knowing is theoretically presented as ‘Dealing with the unknown’. Not knowing is interlinked with all other categories and is addressed within each of the categories.

The following four categories support the core category of ‘Not knowing’:

‘Novelty’, ‘Controlling’, ‘Humility’ and ‘Becoming knowledgeable’.

Novelty reflects the process of finding a place for the new, curiosity and disturbance of system equilibrium and expresses the entrance of the new disease into the system. Within this category three themes were identified. These were *fitting in*, where people with variant CJD were paradoxically seen to both fit and not fit into the hospice system. *Gossiping* occurred as a result of the novelty of the disease and lead to behaviour that I have conceptualised as ‘ghoulish voyeurism’, where curiosity and fascination about the condition was displayed by ‘others’. This led to participants being ‘drawn to stories’ about the subject of variant CJD. These ‘others’ are described as ‘ignorant outsiders’, and in some cases children of both people with variant CJD and their relatives were subjected to ‘bullying’. *Horrifying* was a theme that emphasised the novelty of the disease and personhood state. It served to identify how people with variant CJD were seen to be without personhood due to the cognitive impairment caused by the disease.

**Controlling** relates to the use of strategies to maintain the equilibrium of the system. Two themes emerged within this category. The first was *managing care*, an activity
that involved ‘restoring dignity’, ‘normalising’ and ‘granting autonomy’, for the person with variant CJD and their families’. A second theme within the category of controlling was that of **maintaining the environment**. This related to the need to maintain the tranquillity of the hospice environment as a means of establishing system equilibrium. **Humility** is a category that posits a concept of experience in caring for people with variant CJD that engendered a sense of helplessness and powerlessness and recognition of limitations in relieving the suffering of others. **Becoming knowledgeable** refers to change over time, of moving from not knowing to gaining knowledge and experience in caring for a person with variant CJD. A theme that was identified within this category was that of the ‘**bewildered family**’.

I propose that the experiences of staff and families reflected the organisational philosophy and culture of the hospice and I present the hospice service (in-house and community) as a metaphorical ‘container’, based on the concept of an open system (Katz and Khan 1966). I have argued that the impact of the admission of people (into the system) with a new disease entity, of which one of the symptoms was dementia, required staff to examine the norms and values embedded in practices and attitudes towards end-of-life care in new ways. Scientific developments within the field of prion disease continued to add information, not only to the literature discussed, but also for the participants over the study period. The results cannot be viewed as a static piece of knowledge or interpretation of the events and experiences, but as experience and knowledge in a state of flux.

The ‘system’ includes all services provided by the organisation, such as day hospice, respite services and community care. There were **similarities and differences**
between the experiences of the staff and families who were admitted into a hospice unit and those who were managed in the community (at home). There were also contradictions, which I refer to as paradoxical situations, within individual cases, that will be addressed, and the significance of these discussed. It is suggested that some systems tend to move towards a state where components are in equilibrium, where a steady state exists and when changes occur this results in an imbalance of the system (Katz and Kahn 1966). Imbalance in the system requires adaptation of the system to return to its state of equilibrium. I have argued that the hospice service (system) was thrown into imbalance by the admission of people with variant CJD.

5.2 Not knowing

A number of terms and phrases that represented not knowing were used repeatedly throughout data. Such as; 'not knowing', 'couldn't tell', 'didn't know', 'hard to tell,' 'uncertain', 'it was the unknown', 'ignorance', 'no one knew', 'going in blind', 'in the dark' and so on. Reference to 'not knowing' was core to the experience of caring for, and having a family member with variant CJD. The term was used and understood in different and sometimes complex ways. For example participants referred to themselves not knowing, 'I don't know', to the group not knowing, '... we didn't know', to it not being generally known, 'nobody had any idea'. I have interpreted the use of not knowing in several ways, firstly, as being without knowledge, i.e. having no knowledge about many aspects of the disease of variant CJD. Within this I include any reference to not knowing and uncertainty related to risk factors for variant CJD. This uncertainty about disease and health is not new and preoccupies many ill people and their friends, families and carers (Seale and Basiro 1996). Secondly, I have interpreted 'not knowing' as not being able to communicate adequately with the
person with variant CJD. This included referring to the person with variant CJD as 'not knowing what was happening to them', and also to staff and family not knowing what the person with variant CJD was experiencing. A further interpretation was the idea of, 'it was not what we were expecting', denoting having some expectation of knowledge that was not realised, or that participants were not prepared for. This 'way' of not knowing added to conceptualising variant CJD symptoms as horrifying. A further interpretation was related to others (members of the public) who did, or did not, know. Not having, but wanting to have knowledge about the disease, and the person with the disease as an object of curiosity. This is addressed under the category of Gossiping. ‘Not knowing’ was also interpreted as a term to express that the participants just 'did not know what to do'. They were left with a sense of helplessness that also related to a more complex expression of ‘The Unknown’, suggesting something more esoteric. I have addressed this within the category of Humility. Becoming knowledgeable is linked to language or expressions about having knowledge. Expressions that indicated moving from not knowing to knowing, such as trying to ‘get to grips with’, ‘sort out’, ‘get to the bottom of’ and ‘work out’, demonstrated how participants attempted to move from not knowing to becoming knowledgeable.

5.3 Novelty – finding a place for the new, curiosity, and disturbance of the system equilibrium

This category addresses the entrance of the new disease into the system and the process that occurred was that of finding a place for, and curiosity about, this new disease and is interlinked with not knowing (Figure 5). The term novelty was chosen for this category based on the very 'newness' of variant CJD, where dictionary
definitions refer to novel as ‘something interestingly new or unusual’, and novelty to a ‘new or unfamiliar thing or experience’. Dictionary definitions of novelty also suggest it may be something intended to be amusing as a result of its originality or unusualness. This definition implies a lightness which was not the position of people with variant CJD or their families. Yet the term novelty conveys my interpretation of responses to this new disease, particularly the interest, curiosity and fascination that people demonstrated. This curiosity was piqued by the very newness and unusualness of the disease and the desire to ‘know’. ‘Not knowing’ served as a stimulus to treating the disease as a novelty. In using the term novelty I propose that it is without any implications of lightness or amusement towards variant CJD.

5.3.1 Fitting in – ‘Opening the flood-gates’
Consideration of whether a person with this new disease of variant CJD was an ‘appropriate admission’ to hospice had a particular focus that served to position the hospice service as a metaphorical container which could be entered through the ‘gate’. This was a container that could be overwhelmed by a metaphoric ‘flood’, with admission to the hospice of a person with variant CJD seen as potentially a ‘major part of our work’ with ‘tens of thousands’ of people about to be diagnosed and requiring hospice services. It ‘could have opened the floodgate’ and ‘filled the whole hospice’.

The ‘floodgate’ was the hospice entrance/admission and the pressure was of a flood of people with variant CJD outside this gate. The hospice service also needed to protect
Figure 5. Novelty – finding a place for the new, curiosity and disturbance of system equilibrium
itself from this potential ‘flood’ of people because it did not have capacity to provide bed numbers for a possible epidemic. The floodgate was symbolically protecting the service capacity. Once the person with variant CJD was admitted into the service the ‘gate’ then became a protection for the person with variant CJD from the media ‘frenzy’. This frenzy represented a metaphorical flood of journalists.

SW. And it was just a huge press frenzy. Terrible, and he is, he was not the sort of man to be able to engage with the media. A part of my role was really to protect him as much as I could from exposure to the media (V1-512, 515)

The idea of a metaphorical flood of people with variant CJD was likened to ‘a dam burst’, implying again floods of people filling the hospice. The reference was again to potential numbers of people with variant CJD, of which there would be implications for hospice services, in the numbers ‘still to come through’¹. The idea of the malevolent and dangerous potential of the numbers of people with variant CJD that were waiting to be diagnosed was also expressed as a potential metaphorical explosion of air, ‘the bubble will burst’, or fiery explosion, that of a ‘time bomb’. The implications of the hospice services being unable to take these people as patients contributed to the metaphor of the hospice as a container with specific boundaries.

¹Newspaper headlines suggested hidden, but potentially large numbers of cases using the ‘tip of the iceberg’ metaphor. The metaphorical iceberg symbolises a hidden mass, a mass that is enormous, malevolent, unseen and unknown, and possibly dangerous. CJD’s 48 victims ‘could be just the tip of the iceberg’ (Daily Telegraph 18/12/1999)

¹Kate’s Fiancée: I’ve even heard hundreds of thousands bandied about. This is just the tip of the iceberg. The public knows so little, and still so much is unknown about this disease. (TVD-295-297)
The management of system boundaries is crucial to effective organisational functioning and boundaries need both to separate and relate what is inside and what is outside. Inside the hospice system very specific activities take place in the management and care of dying people, whilst in the wider healthcare/scientific community a totally new (terminal) disease had been identified. The management of the boundaries, that is, processes by which entry and exit of the system is managed, is complex. In relation to hospice admission this is not managed by one person but (generally) by a multidisciplinary team. Admission criteria to hospice is paradoxically ‘tight’, with a focus on symptom management for people with cancer and a shift of emphasis away from psychosocial care (James and Field 1992; Eagle 2002; Eagle and de Vries 2005; Li 2002; Gannon 2002), and flexible, in that it is variable across hospices and is often based on telling the ‘right story’ (Eagle 2002; Eagle and de Vries 2005), or as termed by Gannon (2002:17), ‘playing the game’. Gannon (2002:53) concludes that ‘the “responsible clinician” deciding a patient’s “best interests” regarding hospice admission is not clear, leaving clinical and ethical queries’.

The flexibility of admission criteria can also be construed as ‘light’ (being made with a level of flippancy or humour) and is reflected in one participant laughingly reporting a comment by the Medical Director. *When I’m away ... don’t be sort of opening the doors to all the waifs and strays*, in relation to taking admissions while he was away. This exchange took place shortly before the hospice took the admission of a person with variant CJD, but before they even knew of the existence of this person. This ‘lightness’, coupled with humour, was also a feature of Eagle’s (2002) descriptions of telling the ‘right story’ to achieve the hospice admission.
Modern hospice care is philosophically an environment where patients have agency, have the ability to make decisions, and are dying within an open awareness context (Walter 1994; Seale 1998). The importance of the shared experience that occurs in open awareness was identified by Addington-Hall (2000) as one of the barriers to the integration of people with dementia to the hospice environment. Admission to the hospice has been determined largely by the cancer death experience, although people with Motor Neurone disease (MND) are a group of patients who are more frequently associated with hospice admissions. People with variant CJD (and by association dementia) were not appropriate because specialist palliative care does not yet have a remit for this group.

Within the system’s characteristics and for the purposes of this study I refer to the admission to hospice as the stage of ‘inputs’ (Katz and Kahn 1966). In this case the input was a ‘new disease’, one that was so new that it had the potential to upset the equilibrium of the system. Participants were comfortable and felt knowledgeable about caring for people with cancer, as a terminal illness, and much of their experience was confined to this area of disease.

**DR I think from a professional aspect it really challenged me because whilst I was responding as if it had been a cancer diagnosis or motor neurone disease, I was concerned professionally about my lack of understanding of the illness, of its origins, and of its ongoing nature. Um and so much of the psychological work with the family really rested on questions being answered about those factors and I didn't have that and people look to professionals to provide those answers. And we're saying well I can't tell you, we don't know, and that's difficult. (V1:640-648)**
The potential for the person with variant CJD to 'fit' into this system was of major concern to the teams. However, fitting in was paradoxical and reflected the diversity and individual nature of the cases and individuals associated with them. The paradox was that they both 'didn’t fit' and 'did fit'.

5.3.1.1 'Didn’t fit'

DR ... she actually at the time didn't fit the criteria for admission, but at the time we only took patients with MND and um AIDS and I think, which again was very unusual. (V1:58-62)

Although (it was believed) there were potential 'floods' or 'explosions' of people with variant CJD about to be diagnosed, people who would be requiring palliative care, hospices did not have a 'criteria' for their admission. They ‘didn’t fit’ into the system for a number of reasons. There is an understanding, within hospice culture, that people who are dying go through established and accepted processes as they move towards death (Walter 1994; Seale 1998; James and Field 1992).

CNS He didn't go through the process that some patients go through. Go through, you know, like a bereavement process, denial and anger and then acceptance. (Z1:359-361)
This process is embedded in the understanding of how people experience death and dying, in this environment. It has become a stereotype of the ‘staging’ of dying and bereavement that many hospice staff adopt (James and Field 1996), that is based on models of the bereavement process such as Kübler-Ross’s (1970) stages. In the hospice environment staff teach dying people how to die; ‘Hospice staff are missionaries who see their mission as enabling people to die a certain version of the good death’ (Walter 1994:131). Participation in this negotiated dying is ‘crafted’ between the staff and dying person (Walter 1994). The idea of ‘crafted’ dying also has congruence with the models developed by Froggatt (1995) and Copp (1996, 1999). It requires the person who is dying to have some degree of agency, that is, to be able to discuss death and dying (Seale 1998). Despite criticism of the assumptions about the ‘staging’ processes that people go through as they move towards death (Walter 1994) much of this thinking still remains amongst hospice staff as demonstrated in my study. Participants made the assumption that the person with dementia could not go through these ‘stages’. The person with variant CJD did not fit into the system because he ‘couldn’t have taken onboard and gone through the angst’, as in a ‘normal’ bereavement process and the teams were not able to navigate the person through the process because they didn’t know enough about the disease and couldn’t communicate with them.

CNS You’ve got the mental deterioration going on alongside, rapidly, very rapidly so even being able to come to terms with them it’s not possible is it. And nobody could tell him what was going to happen, you know, nobody had any idea how it would progress. (21:361-364)
Admission criteria to hospice, although largely confined to people with cancer, is also variable and flexible, but is constrained by a number of factors. Bed numbers are small, so the possibility of ‘bed blocking’ by ‘long stay’ patients is an important consideration. The concern regarding ‘long stay’ and the dementia diagnosis that was attached to variant CJD immediately posed a risk to the system equilibrium, where the potential to ‘block’ a bed arises. ‘Long stay’ and ‘long term’ are constructions of negativity in relation to aspects of health care in many areas of the health services. Most particularly in old age and dementia admissions into acute services, where ‘long’ (time) and ‘dementia’ are equated. Making a prognosis for the progress of dementia to end-stage is problematic due to the variability of the disease trajectory for the different types of dementia. Accurate predictions remain one of the difficulties in determining an admission to palliative care services for people with dementia (Luchins et al 1997; Hanrahan et al 1999; Addington-Hall 2000). People with dementia were referred to as ‘long terms’, by study participants. Specialist (hospice) palliative care is deemed an ‘acute’ service within the category and definition of the service as discussed within the literature.

The ‘acute’ category for admission was the means by which people with variant CJD could enter the system. This was due to the severity and advanced state of the illness that all cases were at. It is a system that does give priority to admissions that are clearly at a terminal stage of an illness, even when it is not cancer (Eagle 2002; Gannon 2002). All of the cases in this study were at an advanced stage of the illness at the time of admission. However, the staff did ‘not know’ that this was going to be the course of events based on the information they were given regarding the prognosis of variant CJD. So there was anxiety and uncertainty about the acceptability of the
admission as, ‘...according to the literature that we had we could have been looking at a couple of years’.

In taking the admissions I posit it as ‘breaking into the container’, where staff ‘broke our rules’ to accommodate the ‘newest of new’ thing, an ‘unknown’ category of patient for whom they believed they would be able to provide appropriate care. However, they only needed to break their rules ‘a little bit’ because of the belief that the person with variant CJD in the advanced stages of the illness ‘needed the sort of care that we were able to provide’.

Or the person with CJD was ‘in’ before the team realised just what the symptoms were that they would be dealing with. They ‘weren’t aware’ of the ‘degree of dementia’, but by that time they were ‘already committed’, they ‘didn’t know’, ‘had nothing to go on’. It was the ‘dementia’ that was focused on, as one of the symptoms they were not expecting, and that was not appropriate for a hospice admission.

‘Not knowing’ and the novelty of the disease also impacted on the challenges of supporting family members with bereavement issues. It was not a new situation that participants had to admit to patients and families that they didn’t have answers to certain questions. However, they were knowledgeable enough about the terminal processes of cancer (and for most hospices motor neurone disease). That is, they generally had confidence in answering questions about end-of-life issues for people with these diseases. It was a new experience to have to say they didn’t know, about almost every aspect of the disease. Many of these questions were related to the risk
posed to other members of the family, particularly the children, and not knowing what the future held for them.

One CNS proposed that for people who die 'normally' 'it was the end'. In this sense she was not referring to 'the end' in relation to the death, grieving and bereavement, but to the unknown implications of genetic types or vertical transmission of variant CJD. It wasn't necessarily the end for the anxieties of the families where the person with variant CJD was a mother (two cases) and had possibly passed the disease to their children during pregnancy, referred to as 'incubating', by participants. It was not publicly acknowledged by the scientific community that this risk was present even though by the end of 1988, it was established that 'species barrier' could be breached and that vertical transmission (from mother to foetus) was possible (Lacey 1994; Chesebro 2003). Participants in the earlier cases were not aware of this possibility as genetic implications were still under investigation. The only response hospice teams could offer family members was that they didn't know.

CNS And that was a question her husband asked (ABOUT THE POSSIBILITY OF THE CHILDREN BEING AT RISK DURING THE PREGNANCY) but the only answer we could give was there wasn't any evidence for that. But that's because there is so little evidence about the disease itself anyway. (W1:584-61)

SW And he did talk a lot to me about her pregnancy and wondering whether, you know, with the last child, that this was going to manifest itself in him later with the incubation period, I mean we didn't know very much about the disease at that stage. (V1:236-240)
Not fitting also related to the experiences of the person with variant CJD (as related by participants) and what they (appeared to feel) about entering the system. My interpretation of the (related experiences) was that they also didn’t fit because they ‘did not want to fit’ or were ‘not able to fit’ and this related to the person with dementia being moved from a familiar environment to an unfamiliar one (from home to hospice).

Hospice, as a concept, does create fear and anxiety for people, based on the connotation of death and dying, and it is understood that it is a place where people go to die. For people with dementia, in this case variant CJD, the possibility of them ‘knowing’ that they were entering a hospice is uncertain. According to family members, the person with variant CJD did know when they were not in a familiar environment. People with dementia often experience fear and anxiety when moved from a familiar environment to an unfamiliar one. They can become distressed when out of familiar environments and surrounded by people who are strangers (Pickard and Glendinning 2001). Although they may not have known it was a hospice, the people with variant CJD would initially have been aware of being in an unfamiliar environment. Fear and anxiety as a result of being out of their environment, experienced by two of the people with variant CJD, during their day hospice and respite admissions, was recognised by the teams and families as a reason for not fitting.

Comparing activities carried out in day care for people with dementia, and hospice day care, suggests that day hospice care does not provide activities that would be appropriate for the dementia group. One CNS from a day hospice described the
environment of the hospice variously as ‘alien’, ‘where on earth’, ‘a prison’, and it was ‘downhill all the way’, in discussing the respite admission of one of the people with variant CJD. All of the components of equilibrium imbalance for the system were demonstrated as a result of the admission. This confirms findings within the dementia literature where it has been shown that the integration of cognitively impaired and lucid individuals is problematic. The agitation of the cognitively impaired individuals caused anxiety, fear and irritation for those who were lucid (Ragneskog et al 2001).

CNS She would slide out of the recliner onto the floor, she caused a lot of distress to the patients that were there and plus the fact, the physical fact of getting her back into the recliner, so we sat her in her wheelchair and fastened her in that. And she rocked and rocked and rocked to try and tip the wheelchair over. We had to have a nurse with her doing one-to-one all the time. And even in the wheelchair she’d try and slide out of that. And she just looked such a frightened lady and I just thought (PAUSE) the other patients were obviously distressed.

INTERVIEWER What sort of way did they show they were distressed?
CNS The conversation, the whispering, there wasn’t, they were just focused on her all the time and they couldn’t PAUSE but I suppose they didn’t want to stare, but they couldn’t help it. And it just, the whole day just was focussing on this lady. And they were scared to move out of their chairs. I think also because with her wriggling and sliding they were scared if they tripped over or she came out and caught them. (Y:5-20)

This person ‘could not be accommodated’ by the system and she ‘did not want to fit’ into the environment of the day hospice, an environment that was not designed to cater for people with dementia and where the staff had no experience with this type of behaviour. She also appeared to be aware enough of the circumstances of her position
to be able to articulate a question (that was also an accusation), to her husband when he came to collect her.

CNS ... when he first came back, she just looked at him, and said 'Why?'
That was really the first word she'd uttered all day. 'Why?' (Y1: 44-46).

The poignancy of the CNS’s expression in repeating the word ‘Why’, during the interview cannot be expressed in the written form. She whispered the word with intense emotion, and repeated the phrase, ‘she just said why’, several more times during the interview. The story the nurse tells is that of a woman who felt betrayed and abandoned by her husband.

The survey of day hospice services by Higginson et al (2000) identified that behavioural problems were one of the common reasons why patients might be excluded from the service, although the survey does not detail what these behaviours might be. It is also suggested that this may reflect the concern that staff had over the group dynamics in day care and a lack of confidence in dealing with behavioural issues (Higginson et al 2000). Both of these reasons appear to have been influential in not being able to accommodate the person with variant CJD in day hospice.

The husband’s expression, in relating the experience of seeing her face when she returned home from a week of respite care at the hospice, also cannot be adequately expressed and he became tearful discussing this experience during the interview. His wife ‘did not fit’ into the system, not only because she didn’t want to (because it was so distressing), but also because he couldn’t bear to let her experience this anguish.

On return from a week of respite care in the local hospice the husband of this person
with variant CJD was adamant that he would not repeat that experience. It was too traumatic for both himself and his wife. Confirming other dementia work where it has been shown that carers will take up services only if they consider them to be of a suitable quality (Pickard and Glendinning 2001).

**FM** ... *when she came back from the hospice, the result was we spent most of the time up there, for the next five days so it wasn't really, I didn't have a rest, that's what, I didn't get anything done. Then when she came back here if you'd seen her face when she saw the house, you'd never (PAUSE – TURNING ASIDE TO CRY) my wife is a home loving woman. (Y3:537-541)*

Her experiences of loss, anguish and betrayal confirm how the person with dementia may experience a trauma related to separation, loss, powerlessness, displacement and homelessness (Miesen 1997, 1999). Her husband likened the experience of the respite admission to *'child abuse'* , and was convinced that she had had a very deep emotional reaction to the experience, as she experienced her first major *'myoclonic'* spasm during this respite admission. To be likened to a site of *'abuse'* goes against the philosophical foundations of hospice care. However, this event indicates that there may be an unacknowledged element to an admission to hospice that can be likened to abuse.

**FM** *I suppose anyone would be if they were in the system, it's like child abuse it's somebody left out in the park by themselves and something. I can only react on her experience in the hospice. She was alright in the hospice, there was no distraught kind of thing. But there must have been a reaction for her to have a deep, to have a first spasm and then to, you know, the facial expression I saw when she came back, so there must have*
been a reaction. And that's why, you know, as long as I can keep going
I'll keep her in the house. (Y2:823-830)

Lawton (1998a, 2000) also showed that the admission to hospice could be constructed as a type of punishment by some patients.

Whilst it is well established that respite and day care services are an important part of a strategy to maintain care of the person with dementia at home, the appropriateness of the use of palliative care respite and day hospice for this group needs to be carefully considered. The services provided are variable and there has been very little systematic evaluation of these (Ingleton et al 2003; Payne et al 2004). It has also been identified that the needs and wishes of carers are not prioritised by specialist palliative care services (Payne et al 2004).

The type of activity that is conducted in day hospice units generally includes review of patients' symptoms, some treatments and a variation of activities such as complementary therapies, art, and music therapy (Higginson et al 2000). Activities are heavily focused on socialising and would explain why there is little expertise on managing the behaviour of a very distressed person with a dementia syndrome. There was no evidence of people with dementia being admitted to this service in the survey carried out by Higginson et al (2000).

The impact of being out of familiar surroundings (not at home) was also recognised by another day hospice team. Participants suggested that the attendance at the day hospice of the person with variant CJD had been not only futile but a traumatic experience and that he 'would have been much happier to have been at home'. Whilst
at the day hospice the presence of familiar people had provided some sense of security and was an important factor in how his care was managed.

\[ \text{HCA Well he didn't like to think that his sister wasn't here either did he.} \]
\[ \text{He didn't like, he didn't like (SISTER) being out of his sight really.} \]
\[ \text{JN In fact it got to the stage that when she had to leave, she had to actually leave her handbag.} \]
\[ \text{HCA Because he, he, that was the only way he could be sure she would come back. It was a real fear that she would abandon him. (X1:45-49)} \]

Even in their own homes the person with variant CJD had a sense and knowledge of who people were and who amongst these people made them feel secure. ‘If somebody else went in and we weren't with them, he wasn't happy’.

Distress can be contagious and participants were upset by the distress of the person with variant CJD in all cases, to the extent that a JN at one Day Hospice found herself ‘dreading’ the days when he attended. The team consoled themselves that ‘he never remembered’ that he had been distressed by the experience. This lack of knowledge about memory capacity of the person with dementia demonstrated how dementia care is not part of the professional knowledge base of hospice teams. Much of the feeling about the experiences of staff in all cases is encompassed in the following exemplar from one of the doctors. The quote also demonstrates the paradoxical situation of both fitting and not fitting into the system.

\[ \text{DR ... it was sort of very challenging, very time consuming. Um, and at times it felt inappropriate because it felt that we were using our skills that we would usually, that we'd gained through normally cancer patients but some other non-malignant, non cancer patients, and we were trying to fit} \]
her into that box and sort her symptoms out in the way that we understand from patients that were normal at that time. So at that level it felt to be inappropriate, but that she had a terminal disease that was progressing rapidly, that was very symptomatic and that the family had extreme psychological needs and we are experts at all of those while not having much experience with CJD. For those reasons it felt appropriate. Um, also of course you'd have to question, where else could possibly cope with her, and um I know the experience from her care at the local district general hospital was that that had been far worse. Um, so although I don't think it felt ideal and we didn't feel we were achieving a good death like a normal good hospice admission, um I think it was appropriate. (W4:147-162)

Within this quote are two of the criteria of fitting into the hospice organisation with its philosophical principles and care practices that focus predominantly on the cancer death. This was seen as fitting the person with variant CJD 'into that box'. 'That box' includes achieving the 'good' death' that is believed to be fundamental to hospice care. Within this was the belief that they did offer an appropriate environment for this group of dying people. Also that they did offer the best that was possible for a person in such an advanced state of disease, even though it was not a disease they were familiar with. The skills that they did have were adaptable to providing care for a person with variant CJD. This reflected a belief in the philosophical principles of hospice care by 'experts' in palliative care practices who could deal with any terminal illness. It represents the systems adaptation potential, of applying specialised cancer care knowledge in providing end-of-life care for any person.
The paradox of ‘fitting in’ was that these were people who did not have cancer so they did not fit some levels of criteria. They displayed ‘dementia behaviour’ which was considered unsuitable for a hospice admission. They also did not fit because the experience was so traumatic (and increased ‘dementia’ behaviour), and family members were equally traumatised by the admissions. The contradiction is the variant CJD cases (technically) fitted the admission criteria, because they were in need of care for ‘acute’ dying, and manifested symptoms that were within the remit of specialist hospice services to manage. The family experience (of the in-house admissions) was that the person with variant CJD ‘did fit’ into the system, that is, that admission was very appropriate.

5.3.1.2 ‘Did fit’

The responses of the family members who experienced in-house hospice care confirm the literature that suggests the public place hospice care in high esteem (Grande et al 1996; Fakhoury et al 1997; Seymour 2003). In this respect I classify family members as both carers and as patients i.e. bereaved persons. As discussed in my ethical section, family members within the hospice may oscillate between patient, relative and team member status.

The symbolic act of providing ‘protection’ is embedded in the hospice philosophy and the definition of palliation as ‘cloaking’, or sequestration, as a place of sanctuary, a ‘safe retreat’ (Lawton 1998a, 2000) further emphasises this view albeit, for Lawton, only in relation to day hospice admissions. It also returns me to the ‘protecting role’, addressed earlier by the social worker who believed it was her role to protect the
family member from the media, that the hospice system 'container' provided, where the person with variant CJD was protected from curious visitors.

FM. They were really good at stopping people coming in. (PATIENT'S HUSBAND) requested that certain people not be allowed to come in. They did that, stuck by if there was somebody new at the desk. Once people got to know it was nice because (PATIENT'S HUSBAND) wanted them to be stopped. So she wasn't shown off to anybody that was what we wanted. (WI-76-80)

The expressions of family members, about patients who were admitted to an in-house hospice unit, of how well they felt they 'fitted in', were repeated throughout the interviews. One family member repeatedly expressed how wonderful the hospice was. Family members made a point of saying that they wanted to have the interview so they could tell me about their experiences of in-house care and one family member referred to the hospice as, 'it was like getting to Shangri La when we got here'. The hospice as a metaphorical Shangri La* was repeated on several occasions. Describing the hospice as Shangri La correlates with the ideology of the model of liminality proposed by Froggatt (1995, 1997). The concept of Shangri La fits within attributes of liminality, where this is applied to sacred places such as monasteries. It is particularly interesting that this family member chose to use this term in relation to hospice which is a place connected to death and dying. 'Shangri La' provided a symbolic metaphor for the hospice, reflecting the origins of hospice and the ideology of liminality. Implicit within the symbol of Shangri La is that a space is created in

* The term Shangri La originates from the novel 'Lost Horizon' by James Hilton (1933), and refers to a 'hidden' valley in the Himalayas where people lived in peace and harmony and had the potential to retain eternal youth, and live for ever.
which people are ‘living’ in peace and harmony and where there is potential for everlasting life. The original philosophy of hospice as a sanctuary, a place of hospitality where dying was ‘cloaked’ is by definition a primary task of hospice. Families (in-house) experienced the hospice as the epitome of what the organisation stands for in the eyes of the public, a place of hospitality and a safe retreat, a sanctuary, being like ‘home’ or ‘family’ (Seymour 2003).

Within this is the ‘rite of passage’ idea of being cared for during the journey to death (van Gennep 1960; Froggatt 1995, 1997). van Gennep (1960) considers these within the complex rites of transition through the funeral rites. Funeral rites, according to van Gennep (1960) are the most extensively elaborated and assigned the greatest importance. In this instance I refer to the dying person with variant CJD as, although not already dead, in a position that may be equated with the transition accorded within a funeral rite of passage.

In trying to express what he meant by ‘Shangri La’, the family member made the connection with the use of aromatherapy massage, and other care practices that the family found difficult to articulate. He struggled to describe how the experience was something that was more than just nursing care, providing descriptions that fit with the level of presence proposed by a number of researchers (Zerwekh 1993; Nebauer et al. 1996). The model of hospice as a liminal space, likened to a family (Froggatt 1995, 1997), is also particularly apt in describing some of the family responses to the admission. Family members described the experience as becoming accepted, being like a family member, even to likening the hospice to a ‘holiday camp’. 
Family members spoke of becoming ‘very “pally” with some of the nurses’, making friends with other families who had relatives dying at the hospice, and that whilst they were unhappy that the person was dying, the experience ‘wasn’t miserable’.

FM-1 I didn’t know anything about aromatherapy but I think it’s extremely good now, seeing it in action, you know (PAUSE) But it was, it was more than that, more than just nursing care, it was ...

FM-2 It was the ambience ...

FM-1 Yes, but it was like um, it might sound corny but it was holistic really in that, there was more, there was, you know the nurses seemed to have some sort of extra thing that they passed on to you without speaking about it ...

FM-2 Absolutely and when we come here now which we do quite regularly for counselling and we come, and we have everything that’s on offer really, and the nurses come out from all corners and throw their arms round us and it’s as if we’re all old friends, you know. It’s wonderful, it is, it’s wonderful. (Z2:59-72)

Another family member reported how she had ‘lived here’ during the admission and that, ‘Everybody was so nice it made you cry’. Family members were able to visit at any time, to stay as long as they wanted and to bring children in. This high degree of support and homeliness of the hospice was frequently compared to the strict visiting
regimes of the NHS hospital ward where the person with variant CJD had previously been a patient.

*FM. I mean you could bring the kids as well and he (YOUNGEST CHILD) used to love coming in, and I think she knew that he was there. I could just come in and out whenever I wanted you know and they offered to give me lunch!* (W3:218-221)

Family members even went so far as to describe the care as *'loving care'* , proposing that they 'couldn't get it more right'.

*FM And it was done with such loving care you know, it was as though, I felt, they all loved (PATIENT) better than they loved anybody else in the hospice and that probably everybody felt that, you know ... and it really, it really was true, I thought, well, you said once if you was a king you couldn't get better treatment (PATIENT), you know.* (Z2:1163-1180)

This is the symbolic and idealised, 'loving' 'family system' that was identified as one of the attributes of liminality that may be found in the hospice environment (Froggatt 1995, 1997). It is the 'love' attributed to the hospice staff that assists the dying through the 'funeral' transition. Nursing without love has been described as empty, cold and technical, whereas love can give meaning to nursing and may enable the nurse to 'care' for the person (Lanara 1991). Love, in nursing, was understood as something qualitatively different from 'caring' and Fitzgerald and van Hooft (2000) concluded that 'love in nursing' was understood as the willingness and commitment of the nurse to want the good of the other before self, without reciprocity. The interpretation by the family member of the nurses' actions as love correlates with the above and also with the theology of 'moderated love' proposed by Campbell (1984).
Campbell refers to the tension between 'being with' and 'doing to' using the metaphor of 'skilled companionship' to suggest a type of moderated love offered by nurses, doctors and social workers in their provision of care for patients.

Li (2002) suggests that these relationships could be construed as a co-performance of 'niceness' occurring between family members and staff. I would argue that something occurred (at least for family members) within the relationships that went deeper than a socially constructed therapeutic interaction that could be termed as 'being nice'. The interactions fit more within the original concept of hospice where the term hospice originates from French from Latin *hospitium*, from *hospes, hospit*, meaning a home providing care for the sick or terminally ill and lodging for travellers, especially one run by a religious order. The medieval concept of hospice was of a place offering a welcome to all those in need, not only the sick and dying but also as an act of hospitality (Stoddard 1978; Lattanzi-Licht and Connor 1995).

These experiences express the components for which hospice has come to be recognised, and represents the hospice in a state of equilibrium. Hospice culture is frequently viewed by members of the public as a place of serenity and tranquillity, with a family atmosphere. Family members highlighted this focus by repeatedly making comparisons between experiences of other healthcare sites and the hospice, a feature also identified by Douglas *et al* (1999). Philosophically the hospice provides a tranquil, safe and ambient environment where the family or significant others are considered integral members of the team. It reflected more than just care and emphasised the importance of developing relationships with people.
The subject of variant CJD, usually prefaced with ‘mad cow disease’, was headline news and the novelty of this new disease was heavily fuelled by the media. Although the hospice was seen by family members as a place where the person with variant CJD was protected from curiosity, there remained a more than usual interest in these patients. This led to people talking about it in a manner that I have categorised as gossiping. Novelty engenders gossip at all levels of the community as people are curious about the new and need to talk about it. Gossiping was a component in all cases and linked to not knowing as a component of novelty and wanting to know about this new disease.

5.3.2 Gossiping

Gossip is considered to be universal because it is psychologically and socially useful (McAndrew and Milenkovic (2002). It has also been pointed out that there may be an equally valid evolutionary argument for gossip as there have been arguments about the social value and construction of gossip (Crawford 1998). McAndrew and Milenkovic (2002) propose that both social comparison and gossip are social strategies and that these have developed in human beings in response to evolutionary pressures experienced throughout human history. I propose that (some of) the gossip that occurred in my study participants fitted with the evolutionary concept where humans need to have this information as a means of adaptation to the environment and for their survival and was a response to sensational news. The appeal of sensational news has been well explored within sociology and journalism (Seale 2002; Aust 2003). Sensational news as having purpose is not addressed in detail in the above literature and when it is addressed it is frequently with a negative connotation, such as the media’s need to ‘acquire, keep and expand their audiences’ (Seale
2002:40) that appeals to the public interest and enjoyment of drama (Aust 2003). There is agreement amongst analysts and critics that the emotional impact of a story or its presentation are what decide whether or not it is afforded valuable space on the front page of a newspaper (Seale 2002). A number of sociologists suggest that sensational news is socially constructed through discourse and journalists also incline to this view (Seale 2002).

Others have argued that sensational news has an important purpose within evolutionary psychology. Davis and McLeod (2003) argue that emotional appeal to sensational news is uncorrelated with frequency of occurrence. They believe that emotional responses are not socially constructed particular to time and place, but reflect human universals. They base this argument on matching determinants of our ancestors’ ability to pass on their genes (environment of evolutionary adaptedness (EEA)), with sensational news items, published between 1700 and 2001. Twelve distinct categories were identified that remained stable over the 300 years and matched those of topics that evolutionary psychology identifies as having greatly influenced the success of humans in evolutionary adaptance. Three of these are relevant to this study; accidental/natural injury/death, harm to child, and taking a stand/fighting back. The authors argue that these topics are not socially constructed on the basis of time or local cultural values but reflect human universals, and that newspapers did not exist in the EEA, but gossiping probably did. This served a higher intellectual function allowing communication about social information.

*The documentary on Jonathan was based on the family’s fight to have treatment using PPS.
Jonathan’s Father: If we have to fight the rest of our lives, we will continue that fight. (TVD:8)

Jonathan’s Father: We had two choices and only one answer. And that was for us to lie down and let this evil consume us. Or get up and fight.
Jonathan’s Mother: We fought from day one, non-stop. (TVD:30-32)
This functionalist conceptualisation of gossip is confirmed by the UK (and global) responses to beef consumption, tissue transplantation and blood transfusion policies and protocols that have emerged following the discovery of variant CJD. The gossip that occurred appeared to encompass components of the above in the anxiety that was expressed about the risks from food and other sources of contamination.

Four themes support the category of gossip. These were ‘ghoulish voyeurism’, ‘outsider ignorance’, ‘drawn to stories’ and ‘bullying’, all of which occurred due to the unknown and novelty factors of variant CJD.

5.3.2.1 Ghoulish voyeurism – ‘a peep show’

Much in the manner in which people are drawn to horror stories and movies (Tamborini 2003), or other displays of the grotesque or unusual (Waskul and van der Riet 2002), fascination with people who are different, particularly who overtly display psychiatric or neurological symptoms, led to the category of ghoulish voyeurism, suggesting a metaphorical ‘peep show’. Voyeurism is defined as obtaining enjoyment at seeing the pain and distress of others and may be seen as taking this interpretation ‘too far’, however, the term fascination proved ‘too light’ to hold my interpretation. Adding ghoulish (being morbidly interested in death and disaster) to voyeurism I believe accurately portrays the experiences described by participants of the type of interest taken in people with variant CJD.

*CNS Her (ESTRANGED FAMILY MEMBER) bringing, as far as (HUSBAND) and her sister were concerned, bringing strangers to observe and see what was happening, a peep show. The ‘mad cow’ title.*
Here's (PATIENT), she's got 'mad cow' disease. They were getting a lot of stick apparently, from neighbours and people. (W1:303-306)

HCA The neighbours who hadn't spoken to him for years, had to come and visit ... the fact that they just said, just coming to have a look. (Z1:667-669)

There is a compulsion to look at anything different, 'they always looked', (people passing the room of one of the people with variant CJD at the hospice). It is reflected in how, for example, motorists slow down on motor-ways to 'look' at an accident, described by Mazairac (2004) as 'a socially accepted horror movie'. One family member likened this type of behaviour to looking at a hanging, emphasising a ghoulish fascination. This fascination is confirmed in historical accounts of public hangings and autopsies (Richardson 1988) and more recently on the autopsy carried out by von Hagens on television and the interest in the internet images of beheadings in Iraq. One family member spoke of this potential when we were discussing the responses of people to his wife. He spoke of how people were fascinated by things/events that were unusual.

FM People are nosey. It's like when you see someone hanging, just a thought, if you went down the street and someone hung themselves, there'd be loads of people staring at it ... (Y2:868-870)

The novelty element was clearly linked to the concept of 'mad cow'. The language to describe BSE and CJD has become symbolically linked to the term 'mad cow'. The information and discussion about variant CJD could not be contained, because it was novel, interesting and fascinating to the public. I include here the participants as also
being ‘members of the public’. The media does not try to contain sensational news, such as the variant CJD stories, and through the media the concept of the awesomeness of the disease was fuelled and variant CJD is repeatedly referred to as ‘Mad Cow Disease, the human form of BSE’.

CNS People don’t associate it with CJD. A lot of people have no idea what that means, but the minute you say mad cow disease they automatically have this total horror picture in their minds. (X1:863-865)

This is the language that the public identifies as variant CJD, and indeed all forms of CJD. This point was made with emphasis and also with irony by one family member in relation to his experience, where the person with CJD was not a certain diagnosis of the variant type.

FM People it’s just, you know, people think, anyone who speaks to you say that they always associate it with mad cow disease you know. It’s just CJD, CJD, mad cow disease. CJD is mad cow disease, when you say it’s CJD, they just say mad cow disease, they think it all comes from meat, everyone you speak to, always one hundred percent. One hundred percent of people associate CJD with mad cow disease (LAUGHS – IRONICAL) (Y2:893-900)

The youth of the people infected with variant CJD and the horror of the disease symptoms were contributing factors to the fascination that led to gossipping. However, being the ‘object’ of fascination changes the orientation to the event or situation. When a person has not had a close personal experience of a traumatic event or situation it is possible to be curious without any feeling of emotional risk, and one family member struggled to put into words how it felt to be the object of people’s
curiosity. ‘You thank God’ that it is not you when you witness others being subjected to curiosity. It is only after personal experience that it makes ‘you look at life differently’. At this stage he was speaking of how some friends and visitors had come to the house after her illness had started, and then did not come back again.

Gossip occurred because people ‘outside’ of the system, were not informed enough about the circumstances of the individuals who had variant CJD. Their behaviour was seen as displaying ignorance. The ‘knowledge’ referred to here is not just about the disease progress but also about the personal lives of the person with variant CJD and their families.

5.3.2.2 Ignorant outsiders

Outsider ignorance was seen as the opposite to insider knowledge (professional knowledge). Knowledge contained within the boundaries of the hospice (system) was seen as accurate knowledge and talk/gossip outside of the boundaries of the professional ‘inside’ knowledge was seen as occurring because they ‘didn’t know, ‘they don’t have all the facts’, ‘don’t have the knowledge’. Gossip and ghoulish voyeurism that occurred ‘outside’ was seen as the result of ‘ignorance’. Making judgements about the curiosity of others is demonstrated in the following extract where the ‘outsider’ is judged as ignorant. The term ignorance served as a symbol of gossip and of ‘not knowing’. Ignorance here was seen as a manifestation of the curiosity and rudeness of people ‘not in the know’ (not insiders). Ignorance and rudeness were also associated with using the term ‘mad cow’. 
HCA-1 I think it's um, people are like that out of ignorance aren't they.
JN Yes, it's the unknown. I think it was good that the other patients didn't
know.
HCA-1 I do think, you know, I mean, we didn't have that problem here did we. Because they didn't know, but if they did we don't know what they
would have been like because it is ignorance.
CNS No.
HCA-1 Some people behave really bizarre because you know they're so
ignorant. But it's curiosity because if you take somebody out into S High
Street in a wheelchair, people stare at you and they have to look, and I
think it's just curiosity.
HCA-2 Yes.
HCA-1 It's rude, it's very rude, because you know if I was in a wheelchair
I wouldn't want to be stared at.
HCA-2 No.
HCA-1 But some people are so, I don't know, but they don't even know
what CJD means. They only know the language of mad cow as well.
(X1:841-858)

In the above extract there is an assumption made that gossip was an 'outsider'
occupation, caused through ignorance. However, gossip also did occur within the
system. The boundaries of the system (professional boundaries) suppose that
confidential medical knowledge and information is (ethically) contained, but the
power of curiosity about the novelty element of the subject caused 'breaches' in the
containment of this information. It was likened to the early days of HIV and AIDS
and how the novelty of that may have also broken through the boundaries of
confidential knowledge.

CNS There were a lot of breaches in confidentiality throughout the
hospice. It was discussed in the staff restaurant and I think this was all
The comparison between the early days of HIV and AIDS is a feature throughout data and literature (Brookes 1999). AIDS set in place the beginnings of the concept of ‘public death’. Not the public deaths identified by Richardson (1988), but that of the globalisation of death (through sensational media stories) where death experiences are shared through the media*. As pointed out by Small (1993) in relation to what he refers to as the paradoxes that defined AIDS, stereotyping the epidemic has made its public face what it is. People with AIDS were able to personalise the epidemic and by doing so make considerable individual achievements, but they also experienced considerable individual grief and crass exploitation.

Despite the small number of variant CJD deaths (compared to the AIDS numbers, even in the earlier days) the interest and fascination about variant CJD disease was initially fuelled by the media. However, the exploitation holds a different position to that of the early days of AIDS. The variant CJD death is about ‘innocent’ victims of ‘biotechnology’, of human manufactured disease within the new risk society (Beck 1995; Lupton 1999; Giddens 1999). This fuelled the media exploitation of variant CJD stories that participants in this study were drawn to.

In the 1997 case it was news that there was a person with variant CJD within the local community and this was ‘leaked out’ to the media. The presence of a person with variant CJD could not be contained within the system. There was

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*Millions watched Zoe’s final hours (Daily Telegraph 29/10/2000).
'constant pressure' to 'get the stories' of family experiences and such a sensational story could not be kept out of the public sphere. The boundaries of the system were breached by the novelty of the disease and this lack of information on potential risk made participants take more than a 'general' interest in the subject of variant CJD.

5.3.2.3 'Drawn' to stories

HCA Certainly if I ever see anything about CJD in the paper I immediately read it. Immediately drawn to it. And sometimes it'll talk about somebody who's ill with it or someone that's just died with it and it brings it all back very, very vividly. (X1:327-330)

Being 'drawn to stories' interlinks with 'ghoulish voyeurism'. Anything on variant CJD that participants had read in the papers, heard on the radio or seen on television was discussed and related to the novelty element of the disease. Being drawn to stories also serves as an indicator of the importance/relevance of Davis and McLeod (2003) concepts of sensational news and Evolutionary Environmental Adaptedness, where participants highlight that the disease was 'caused, technically by humans'. Participants, in all cases, gave examples of 'individuals' they had heard or read of within the media, and appeared fascinated by the subject. The fascination was related to a number of factors. For healthcare workers it was the mode of infection for variant CJD, potential risk to themselves, the potential numbers of people who could become infected, and the age and circumstances of the patient group. Stories in the media brought back vivid recollection of the experience of providing care for the person with variant CJD, and the horror of the impact this had on families and friends and I posit that the 'talk' within the focus group can be construed as gossiping.
CNS And its because its been caused, technically, by humans. That makes it all the worse really. Listening to the news last night and they have compensation and care packages for them. Did you see they showed a family whose 14 year old is dying from it. That was just (PATIENT) all over again. That must be awful for these people. (W1:338-342)

JN And I just kept on thinking to myself, how many cases are there that we don't know of. That is what I kept thinking, and must admit even now I think you know sort of if you do read anything in the newspapers, you know, how many cases are there? (X1:321-326)

Being drawn to stories was not confined to the healthcare participants, and family members compared their experiences with the experiences of others. For families it was a much more personal matter. One family member showed me a poem written by another carer and copies of the CJD newsletters, and they all talked about case numbers and other political and financial issues related to support for people with variant CJD and their carers.

Just as people who have had traumatic experiences do not want to return to the site of the trauma, some family members found it difficult to return to the hospice, where they had agreed to be interviewed, as it brought back too many memories. The visual impact of someone experiencing the disease was ‘unbearable’ for one family member. When a person has direct experience or can relate personally to a situation the impact is more powerful and lasting.
FM I don't like watching things on telly. I can't bear that. I have to turn it over. I don't mind listening to something. To watch someone the same I find that quite hard at the moment. (W2:255-256)

The teams also did not know if they were at any risk in taking the variant CJD admission, a concern that was still present in the 2003 cases. This was contributed to by the ongoing research on the subject of variant CJD and media discussion on risk factors. They were drawn to media stories about potential risk of variant CJD for health care professionals also making links to the early days of HIV and AIDS. There is global uncertainty and anxiety regarding the implications of variant CJD (Giddens 1999; Beck 2000, Rose 2000; van Loon 2000). Lessons learned from the early days of HIV and AIDS were indicated in comments on how someone may say in the future 'well you were at risk'. Participants in the early cases had already identified that information they had been initially given was inaccurate. These concerns have been vindicated by the recent confirmation of transmission by blood transfusion.

JN And the other thing is, you know, I know they say you can't really catch it you know cross-contamination from human to human ...
HCA We don't know ...
JN But we don't know that and will it be in years to come that yes you can.
HCA Especially ...
JN We're actually finding out things now that we were told weren't true, I mean, in another year are they going to be saying that you can catch it through something else.
HCA Droplet infection ...
CNS The girls from the prion unit said they weren't sure whether it could be passed on by body fluids, they didn't know if it was held in the blood,
they weren't able to say that it is. But equally they were not able to say that it isn't. (W1:62-75)

For family members the potential for risk was much more real than for the hospice teams. There was potential risk for their own children and themselves and one family member became very anxious, at any stage that she felt unwell, particularly if it was psychological in nature.

FM. I mean everyday you sit there and think Oh I'm feeling a bit depressed, Oh God, you know, has it happened. That plays on your mind as well, because you think you're going to get the same and I've never really eaten much beef in my life anyway, but I mean, except for baby food, and you worry yourself. You know if you get a little bit upset you worry that you might have got it. (W2:429-436)

The novelty of this disease and the 'mad cow' connotation also led to bullying of the younger children of families. This was not only direct relatives but also nieces and nephews of one of the patients. As no children were interviewed for this study these were not firsthand reports of the bullying but were events related by others.

5.3.2.4 Bullying

Name-calling and other types of verbal harassment represent some of the most prevalent forms of bullying (Crozier and Dimmock 1999:506; Cowie 2004). Being called 'mad cow' or subjected to taunting, such as 'your mother is a mad cow' were the experiences of children of three families of variant CJD patients and their relatives. As none of these children were interviewed for this study this information was reported by others who made assumptions that these experiences were distressing
to the children, as did the social workers who were involved in addressing these issues with the children. The impact of name-calling as a form of bullying in schools is an under researched area and the small existing literature suggests that it is difficult to identify because it is often a hidden type of bullying (Crozier and Dimmock 1999).

Following a study, using a questionnaire measure for 60 pupils, with interviews carried out with 20 children from the junior department of an inner-city primary school in South Wales, Crozier and Dimmock (1999) conclude that name-calling and the assignment of unkind nicknames are prevalent and hurtful features of school life. Although this study is small it was carried out with rigour, sensitivity and ethically sound procedures and I believe allows the assumption to be made that these experiences were hurtful to the children discussed in my study. This form of bullying was closely linked to the novelty aspect of the ‘mad cow’ title.

Bullying implies an element of malice, and ‘taunting’ and ‘teasing’. Where there were children involved social workers dealt with issues about bereavement and the bullying that arose, up to, and more than a year after, the deaths of the family members, in two cases.

*CNS* The boy was told that his mum had ‘mad cow’ disease, in the playground. And (THAT SHE WAS) she was dying. (W1:307-308)

*SW* ... and they weren’t happy because of the ‘Your Mother’s a mad cow’ and all of this in the playground, just bullying going on. (V1:269-271)
Bullying was also attributed to the cruelty and ignorance of others and discussion about bullying engendered considerable emotion within the focus group discussions when this subject arose and was again equated with ignorance.

HCA-2 The son was teased basically. They'd make noises, that sort of thing. Like a cow. Yes, that sort of thing. And there was an occasion in the canteen with the little girl and there were beef-burgers on the menu and they were throwing beef-burgers at her; that kind of taunting.

HCA-1 Isn't that awful.

HCA-2 Yes, terrible, just terrible.

HCA-1 Because children can be so cruel, that's the thing.

HCA-2 Just ignorance. (XI:173-180)

The manifestations of the disease was particularly frightening for the children, so not only were these children bullied in their respective schools, but they also had to deal with seeing their family member go through a rapid deterioration to a person who could no longer speak, walk, eat or behave in a ‘normal’ manner.

There is very little research on responses to horror and these are largely confined to studies on horror within the cinema, that is, horror movies. The number of, and variations on, expressions of horror, made this an important theme within the category of novelty. These same expressions of horror do not appear in data from the team who had previous experience in caring for people with variant CJD, compared to the other cases. I propose that horror was ‘blunted’ by previous exposure. Expressions of horror do, however, appear repeatedly in the experiences of the family members throughout data.
5.3.3 **Horrifying – 'worst possible nightmare'**

The ‘horrific’ nature of the disease was portrayed in many ways and all of the following terms and phrases are found repeatedly within the data, ‘worst thing I’ve ever seen’, ‘worst possible nightmare’, ‘just a nightmare’, ‘horrendous’, ‘the most horrific disease I’ve ever seen’, ‘I’ve never seen anything like it’ and ‘the shock of actually seeing her’.

The abject body is both fascinating and repulsively horrifying (Waskul and van der Riet 2002). To witness a young person displaying all of the neurological symptoms and behaviours that are associated with dementia was profoundly horrifying and disturbing for participants. Horror was expressed about the disease process and symptoms, and at how the people with variant CJD were treated at other sites. The horror expressed by the parents of one of the patients was not about the death, it was about the manifestation of the illness and how closely aligned it was to the horror of psychiatric illness, presented as a metaphorical ‘straightjacket’.

> **FM-1** Well, through all the places we went and all you know, it’s the horror of it, it’s not that (PATIENT) died, it ...

> **FM-2** ... it is incomparable with any other illness.

> **FM-1** It’s the way, I mean I imagine if (PATIENT) were to be taken away and put in a straightjacket, you know it was that horrible, it was nightmarish you know, the illness is so ...

> **FM-2** ... and (PREVIOUS SITE) almost made it that way didn’t it, er the straightjacket bit, it was all but, wasn’t it. (Z2:1230-1239)

*Kate’s Fiancée: Watching somebody actually um, starve to death is the most horrendous, horrendous thing to watch. Someone who had been so vibrant, somebody so young. That last, that last week when everything had been taken away from her. When she couldn’t hear, couldn’t move, couldn’t eat, when she couldn’t drink, she couldn’t laugh, smile, talk, listen, eyes half closed. And just praying she would go soon ... (CRYING) (TVD:270-277)*
People who are so neurologically damaged that they display behaviours described earlier are frequently perceived as without personhood. These were the symptoms that variant CJD people displayed that led participants to use terminology about them that indicated them being attributed a non-personhood status.

5.3.3.1 Personhood status

Issues of underestimating the potential for emotional expression, lucidity and personhood status, specific to dementia care, have been substantially developed within the dementia literature (Kitwood 1990, 1993; Kitwood and Bredin 1992; Miesen 1993, 1997, 1999; Normann et al. 1998, 2002). The status of the person with variant CJD was of one who had lost personhood status, even when they remained fully conscious. In this context they fitted the description of 'total annihilation of the person, body and self', i.e. Copp's (1996, 1999) conceptualisation of person-body split or separation. An absence of a separation, as proposed by Copp (1996, 1999), is a position that is granted to patients by the hospice staff and depends on them having some knowledge and understanding of the person, previous to the state of unconsciousness. If there was no previous knowledge of the person then the person and 'dead' body could not be separated. This was also acknowledged by Kabel and Roberts (2003:286) where one of their participants is quoted as saying ... we have the time to form the special bonds’ (A01) which then allowed the person who was dying to maintain their personhood.

Staff had not had the opportunity to make a relationship with the person with variant CJD during the admission due to their cognitive status. Time has been identified as
essential to forming nurse/patient relationships in hospice (Froggatt 1995; Copp 1996; Andershed and Ternestedt 2001; Li 2002; Kabel and Roberts 2003). This forming of relationships could be instant or it could take time (Froggatt 1995), however, the formulae always required a cognitively intact patient.

Family members believed that the person with variant CJD was aware of them and their surroundings, a finding confirmed by Douglas et al. (1999). Hospice staff participants did not overtly make a connection between demonstrations of awareness by the person and their behaviours. However, there were indications within the data that they did attribute the person with variant CJD some degree of awareness. I also posit that they were not aware that, within their talk, they were presenting these patients as non-persons. Generally family members used analogies that demonstrated a closer personal relationship with the person, such as, 'like a zombie', 'like a ragdoll', 'like a babe again', and 'just an empty shell really'. Although Post (1990:325) suggests, metaphors of 'shell' and 'husk' may lead to an exaggerated view of the extent to which the person with dementia is no longer what he or she once was and establish a 'tyranny of the normal', they did have a quality of endearment that was not always apparent in those used by hospice staff participants. Analogies used by hospice staff likened the person with variant CJD to an animal, a thing or object such as a stick. All participants, at some stage, used analogies of non-personhood. 'Turned into this ... thing', 'howling and screaming like an animal in a corner', 'a little, tiny, curled up stick, 'a puppy dog', or referred to them as 'already gone', no
longer a person', 'had no personality', and 'lost the person'. Seeing a person in these states caused fear and aversion in others, particularly the children.

*S W* ... and the children were very frightened because Mum had turned into this ... ‘thing’ that they didn't recognise. And in such a short space of time, it hadn't happened over years, it was just so rapid and frightening. *(V1:734-737)*

The inability to communicate in a ‘normal’ way was equated to being without personhood. Not being able to communicate appeared to also place the person with variant CJD as one without a face. This offered further evidence of how having agency has become an important aspect of having meaningful communication within hospice philosophy and practice.

*DR* I don’t actually remember the patient’s face because, you know, he was never alert enough, you know, to have any sort of verbal communication. *(Z3:3-5)*

I also propose that ‘getting something back’ was an ‘unspoken’ criteria for admission to a hospice unit and is closely linked to the need to have a meaningful relationship with the dying person, a finding present in other studies *(Froggatt 1995, 1998; Copp 1996, 1999; Li 2002)*.

*CNS* Because most of the patients that come are able to speak for themselves and ask, a lot of them gasp with relief at being here.

*Kate’s Fiancée:* ‘Just a gradual degeneration from really, somebody so bright, intelligent and happy to ... something more like a frightened animal *(IVD:175-177)*
But he didn't and that's what made it hard, because he couldn't speak at all.

We got nothing back. (Z1:586-590)

One CNS used the analogy that is not uncommon in speaking of people with dementia, wondering ‘if there's anything there’. This is an observation made by others in research with family members of people with dementia (Gubrium 1986; Orona 1990; Herskovits 1995). The observation made by this CNS was, however, made based on the observation of the possibility of the person being ‘locked-in’. It was reported in relation to discussing the person with variant CJD whilst in her presence. She had concerns that her husband spoke about her as though she couldn’t hear what was being discussed. The CNS felt uncomfortable and maintained a stance of conducting conversations as though the person with CJD could hear these. The possibility of the person with variant CJD being ‘locked-in’ was not suggested by any other participant.

Although they didn’t associate the behaviour with ‘locked-in’ syndrome, the eyes of the person with variant CJD were seen as indications of awareness and the possibility of a presence ‘inside’ the person. Uncertainty was expressed about whether the person with variant CJD was actually looking out of the window when facing it. They did, however, place the person in such way as to enable them to look out at the gardens. The team was in agreement that this person did have some awareness of the surroundings, commenting that the person’s ‘eyes weren’t empty’. This comment was not made in relation to the eyes of a dying person but in relation to the eyes of a person with variant CJD, i.e. dementia.
Here I propose that the personhood status is not as clear-cut as some of the participant discussion may suggest it is. Participants appeared 'torn' between the allocation of non-personhood status and uncertainty of the neurological symptoms of the disease and aggressive manifestations that can occur in dementia or when a person cannot communicate verbally.

_HCA_ She tried to bite you and she also clawed out as well. I think it was just her way of communicating or whatever. I don't think it was meant as nasty. She didn't come across as a nasty person at all. It was just part of the condition.

_INTERVIEWER_ What would be the reason for her to do that?

_HCA_ If you were feeding her, and she didn't want any more. (W1:87-92)

An aspect that contributed to the horror of the disease and the reaction of people to the patient was just how frightened the person with variant CJD was. In all cases, family members and staff, participants described the person with variant CJD as being frightened, a factor confirmed in other cases (Beyless 2001). In doing so they granted them a degree of personhood that contrasted with the analogies offered above, and again eyes were important in relating to the experiences. Terms such as 'petrified', 'anxious looking', 'distraught', 'fear showed in his eyes', 'tormented', and 'had wild eyes', were used*. They all indicated a response that demonstrated neurological damage that was not directly equated with dementia.

*Kate's Mother: Well she went back to being a child really. She was very, very frightened of everything. I suppose they were frightened get frightened, of what's happening within them. And she used to get so frightened. The most distressing thing for me was to see how her teeth, literally, I mean you read about teeth chattering with fright literally, and her teeth used to actually chatter. (TVD:186-191)

1Claire's Mother: As for that spooked look she got in the eye of her tantrums: I thought it was rage; now I could see it was terror. (Pearson 2000).
CNS He used to see things in his peripheral vision. Um, if we were walking round the garden and there'd be a movement over here, he'd be petrified of it, and then latterly he would turn and spit in that direction, um. I don't know what he could see because when we asked him he wasn't able to tell us, he was terrified of any movement in the peripheral vision, um, so even doing that was difficult. It was always difficult to distract him from his fear and his torment because whatever you did was ... (XI:382-389)

The possibility that these symptoms were linked to neurological changes and the implications of these in relation to psychological state was only addressed by one doctor, although it was hinted at by the CNS in the above extract.

DR I think that was one of the things that seemed hard and at the end, and in assessing what she was frightened of, also due to partly pain, whether she was responding to hallucinations or was not understanding what was happening. Looking at her face she appeared frightened, her, her body language although I've already said she had quite an abnormal posture, and the abnormal movements, but she also looked startled and frightened and certainly, I mentioned being quiet as you came in, more easily, she had strong sort of startle reflex. Yes, and I guess again, that cognitively limited you wondering how much it's frightened as we know it, or whether it's primitive reflexes and a lot of it looks like primitive reflexes and yet the human part of you has to hunt out anything else that you think they might be frightened of in case you can alleviate it and help. Um, so yes she appeared frightened. (W4:107-122)

The issue of communication (difficulties) returns again and again, supporting the core category of 'not knowing'. It is seen as a reason why people with variant CJD were not appropriate as admissions to hospice. Inability to communicate with the patient occurred because the symptoms of variant CJD and was a new experience for
participants. The point made that ‘nobody could tell him what was going to happen’, served to introduce the view participants held of the people with variant CJD, in relation to their cognitive status.

Understanding the psychology of grief has been a major focus of how bereavement counselling is managed (Walter 1993:283). This ‘understanding’ has been based on the awareness context framework (Glaser and Strauss 1965) through communicating with dying people. In the field of hospice work this has not extended to exploring the grief of dying people who are cognitively impaired and research is sparse in this area (Regnard et al 2003). This is despite the growing numbers of cases of dementia plus rhetoric about developing and promoting palliative care services for older people and people with non-malignant terminal illnesses, including dementia.

Staff appeared not to be able to differentiate or make the connections (of the differences) between psychological and emotional needs and physical needs, based on the behaviour of the person. I suggest that they were unable to make these connections because they could not have a normal communication relationship with the person who was unable to express themselves due to the dementia component of the disease. They did not have a repertoire for caring for people with cancer that they could apply to the variant CJD group. Interestingly, the patient group was not likened to people with brain tumours, a group which has the most potential commonality to people with variant CJD.

Attempts were made to make the connection between the emotional responses of the patient and their psychological anguish, but these were more often interpreted as signs
of physical distress/pain. Throughout this entire focus group interview CNS-2 was very focused on physical symptoms and returned to this as a cause of any distress demonstrated by the person with variant CJD.

CNS-1 On the Friday of the day after the student left and (STUDENT) left. She was really distressed on Friday afternoon and we just could not get her settled. And I don't know whether or not there was some understanding. She was in there for a while. She popped into the room to say good-bye to (PATIENT). I'm away now. Was that not the day she started. She was really distressed that Friday afternoon and we could not get her settled and I don't know whether or not there was some understanding because she was in there for a while with her. And the student herself was upset at having to go and leave her and she said right, bye, bye (PATIENT) I'm leaving now, I won't see you again because I have to go back into a surgical ward or whatever it was. And 10 to 15 minutes later and we heard all this crying coming from the side room and we went in and there was no body there with her and she was just sitting there crying.

HCA That was when we thought she had a really bad back pain.

CNS-2 That's right ... (W1:738-749)

The nurses could not make the connection that this person with dementia was 'intact' enough to be able to have emotional responses or to have been psychologically distressed at the loss of a friend and a reminder of her own imminent death*.

Kate’s Mother: She was crying one morning and I went back in there and, come on, what you crying for. She said, Mum I think I've got something really bad wrong with me. I said what do you think you've got wrong with you Kate? She said I can't remember, my brain mum, I think its three letters. And I thought Oh um, try and think what it is. And she said, BSE. Why do you think you've got this Kate? And she said I don't know, I just do. I said why are you crying and why, and she said I'm worried. And I said why are you so worried about, and she said I'm worried that, like, you and Dad, and everyone who comes in contact with me are going to get infected with it and they're going to be like me. (TVD:246-252)
They failed to recognise that the family member and the person with variant CJD were able to have a mutual appreciation of each other and share in a symbolic way that facilitated joint understanding of their situation (Nolan et al. 2002). My interpretation of this inability to make the connection was that it was due to her inability to communicate her psychological needs in a 'normal' manner. That is, in a manner that the hospice staff were familiar with.

When the system is unbalanced individuals become anxious and this further disturbs the equilibrium. Anxiety within the system can lead to the need to take controlling action. The concept of controlling lies at the core of most discussions on healthcare organisations (Clulow 1994; Hinshelwood and Skogstad 2000). My use of the term is closely allied to work that has been carried out on managing the emotional life of organisations, where emotions are seen as resources to be controlled and is directly related to maintaining system equilibrium.

5.4 Controlling – use of strategies to maintain the equilibrium of the system

The conflict between care and control is endemic to organisational life (Clulow 1994; Hinshelwood and Skogstad 2000). ‘Control’ is a term that is closely associated with hospice practices in that it is synonymous with the practice of managing pain and symptoms (pain control/symptom control). Controlling has been identified as one of the complex strategies of interplay of interactions between nurses and dying patients (Froggatt 1995; Copp 1996, 1999). In many ways it is an inappropriate term to use in conjunction with terms that align palliative care with concepts such as autonomy and choice. I argue that it is possible that the controlling aspect of providing palliative care has taken a prominent position in many of the care practices. I propose
controlling as a first level category and as being central to management of in-house hospice care (Figure 6). Within the community, the locus of control was with the carer/family member in the home. The ‘agenda’ of hospice in-house teams was not the same as those of family members and both parties were often unaware of these differences, but not always.

Equilibrium seeking is central to maintaining the steady state of the system (Katz and Kahn 1966) and the feelings of insecurity and uncertainty which the novelty of variant CJD engendered in the system led to an increase in the need to reduce anxiety and manage the system (Menzies Lyth 1988, 1990). Controlling was essential to maintain the inner balance and equilibrium of the ‘container’. Not knowing unbalanced the system equilibrium and I argue that not having answers for many of the questions, the novelty, and horrifying disease trajectory of variant CJD engendered a need to be in control. In discussing this category I will highlight the differences and similarities between the in-house and community experiences and between family and hospice staff. Two themes supported this category. These were ‘managing care’ and ‘maintaining the environment’.

5.4.1 Managing care

A significant part of the data addressed how the teams managed the care of the people with variant CJD, identifying issues and concerns that arose in doing this. As discussed above they were initially ‘in the dark’, having little knowledge of what the care needs were for this patient group. They needed to use background skills they had from managing, generally, the cancer patient group, and apply this to people with
A new disease (variant CJD) entering the system

NOT KNOWING

System boundary

Finding a place for the new, curiosity, and disturbance of system equilibrium

Fitting in
'Opening the floodgate'
Did fit
Didn't fit

Gossiping
Ghoulish voyeurism
Ignorant outsiders
'Drawn' to stories
Bullying

Horrifying
'Worst possible nightmare'
Personhood status

CONTROLLING
Use of strategies to maintain the equilibrium of the system

In-house

Community

Managing care
Restoring dignity
Normalising
Granting autonomy

Maintaining the environment

Figure 6. Controlling – use of strategies to maintain the equilibrium of the system
variant CJD. For in-house nursing staff I propose that it was believed that in taking control of the physical body of the person with variant CJD 'dignity' was restored and 'quality of life' maintained.

5.4.1.1 Restoring dignity

Hospice philosophy has a focus on the process of the person ‘being allowed to die’ and is frequently equated with ‘maintaining dignity’ and providing ‘quality of life’, both concepts laden with subjective values and judgements. Participants in this study used both of these terms repeatedly. However, as pointed out, in relation to tabulation of other terms (e.g. ignorance), ‘dignity’ and ‘quality of life’ were terms that were used more frequently by some participants, highlighting the subjectivity of these terms. They were used only by staff, at no time did family members actually use the terms dignity and quality of life, however, dignity and quality of life issues for the person with variant CJD were implicit in their language.

The dementia type symptoms that were experienced by people with variant CJD were the main cause of the use of these terms. All of the illness-specific factors for a ‘bad death’ identified by Kristjanson et al (2001) were present. The person was believed to be suffering, was undignified and had intractable symptoms. The judgement on the dignity status of the person with variant CJD was determined by the ‘spectators’, i.e. dignity as a spectacle (Radley 2004). Dignity (as understood by some of the participants) was restored primarily through the practice of symptom control, but included other means of ‘making the person comfortable’. Quality of life was also equated with being ‘allowed to die’ as opposed to supporting care practices that maintain life, where the death is ‘postponed’.
Not postponing death is one of the fundamental principles of hospice care and appeared to have a high priority in the practices of the in-house teams. Keeping going, maintaining hydration and food supply would appear to be the antithesis to the hospice care where ‘not dying’ creates an imbalance. The safety of the patient was also a significant reason for taking control. This highlights dilemmas and conflicts that teams faced in attempting to allow control (family autonomy) whilst believing they needed to keep the person ‘safe’ and also ‘let’ the person die. These practices are understood philosophical principles of hospice care where the person is ‘allowed’ to deteriorate, is allowed to die. It also captures the concepts of ‘good’ and ‘bad’ deaths which may be equally attributed to family member responses, when the patient can no longer respond (Hart et al 1998). In this case the implication was that the family member was contributing to the ‘bad’ death by not wanting to allow the patient to deteriorate. The following extract exemplifies how the nurses struggled with their beliefs in the practice of ‘letting die’, in preventing the ‘bad’ death, and also how this needing to let die was closely allied to the communication ability of the person who was dying.

CNS He was eating and drinking, very small amounts, and we were worried because we didn’t think he was safe with his swallowing and the impression we had before meeting the family was that they would want to be going with all the, you know, keeping going and stuff, um and the message we got was that his mum felt that although he didn’t seem to be responding he was responding to her. And we were all thinking no, you know, this, it’s one of the situations when this poor patient is deteriorating and not being allowed to deteriorate, so to speak. Um, (PAUSE). And then it was very soon after admission within a couple of days when he stopped taking anything by mouth because then we had the issue of
approaching the family and explaining that we don't normally sort of um, give intravenous fluid and they were absolutely fine with that and I remember them saying, I think it was to me and (HCA), um, you know, all we want to do is make him comfortable and then we could actually see how he did respond to her voice, because we didn't think he was taking anything in. (Z1:76-91)

There was an element of surprise expressed by participants to find that the person they thought was unable to communicate, who met all of the criteria of someone without personhood, was responding to the voice of family members. Due to this (assumed) inability to communicate, people with cognitive impairment had no (assumed) real quality of life and were not able to recognise other people. This is in direct contradiction of the views of family members, all of whom repeatedly reiterated that the person with variant CJD recognised people that they were already familiar with.

**FM** You knew when she knew somebody. She'd recognise the voice or something she would ... (PAUSE) ... She was more relaxed. Holding the nurse's hand that was quite nice. I think she did. She knew who I was a lot of the time, I don't blame her because I was there all the time (LAUGHS). (W4:126-130)

The relational-based model of being fully human has implications in the belief of the family that the person with variant CJD was aware of them and fits with the Confucian definition of personhood (Fu-Chang Tsai 2001). This can occur within the family relationship where boundaries between the self and others may not be clear. Within families there may be continuous interaction between members in such a way that allows dignity to be seen as an 'event' happening between persons (Frank 2004a).
The view that the person should be ‘allowed to die’ was in direct opposition to the desires and perceptions of the families. The process of stopping interventions was not always the desire of family members. They never the less agreed to reducing or removing interventions because they believed that the health professional ‘knew better’, that they were in control. I propose that the staff, working in the in-house hospice system, may (at times) forget, or lose sight of, the hope that remains with families, even to the very end.

FM-1 But I, I, you know I just think of all the places (PATIENT) went to, even 24 hours before he died I still had hope you know (TURNING AWAY—CRYING)... And here it made me feel that way, I still had the hope ... (CRYING).

FM-2 Yes, somebody ...

FM-1 Something’s going to happen. A doctor’s going to turn up from somewhere and say I’ve got, I know what it is, you know. (Z1-1323-1330)

In all cases family members retained a ‘hope of a cure’ even when all possibility for this had passed*. This was due to the nature of the newness of the disease and that much was still unknown about it. This hope-to-the-end was particularly pertinent to variant CJD. It was a disease that so little was known about and potential for cure was of paramount interest to families (and the scientific community) and is confirmed in the Douglas et al (1999) findings on the experiences of the families of people with variant CJD and in the media stories of families accessing potential ‘cure’ regimes. Family members, ‘wanted to keep him going’, ‘did not believe she was going to die’ and struggled with the potential loss as a result of this previously ‘unknown’ disease.

*Claire’s Mother: One morning Claire woke and said, Mummy, if I’m in a coma and they come to you and say there’s a cure but it’s really painful, no matter what it is and if they ask your permission I want you to say yes. Because I want to live. (Pearson 2000).
The hope for 'miracles' remained, and any means, such as 'life support machines' to prolong the life of the person they are losing were considered desirable.

CNS I remember a conversation with the doctor and (HUSBAND) and (SOCIAL WORKER). And (HUSBAND) saying there must be something else you can do, this can't be it, there has to be more. (W1:289-292)

One of the most common practices in hospices towards achieving dignity and quality of life is the use of sedation where sedation is frequently seen as a means of restoring dignity for the agitated patient and achieving the 'good death' (Walter 1994; Lawton 2000). There is no agreement on what criteria should be used in identification of 'intractable distress' in the dying and personal judgements to administer sedation are often made by palliative care clinicians. This was an important factor for in-house teams but less so for community teams where sedation practices were carefully negotiated with family members.

In-house participants equated dignity with death or letting die and used this to convince and reassure family members that they should not continue with any interventions that would prolong life.

JN But he was still asking the weekend we put that syringe driver up. I remember speaking to (HUSBAND), and (PATIENT)'s father was there, they all came in together and even then (HUSBAND) was saying what about life support machines. He was still asking that while at the same time when you explained the rest of it and talked about her dignity he also agreed with that. So he just, was finding it very hard. (W1:314-319)
The dementia type symptoms that were experienced by people with variant CJD were the main cause of the use of the term dignity. The conceptualisation of dignity developed by Enes (2000, 2003) within a hospice framework is useful in attempting to explain the responses of participants to the symptoms of variant CJD, particularly personhood status. The dimensions ‘being human’, ‘having control’, ‘relationship and belonging’, and ‘maintaining the individual self’ appeared to be considered absent for people with variant CJD by many of the participants, including family members. Dying with dignity then, as seen by participants, required the person who was dying to be as fully human as they themselves were. Lawton (1998a, 2000) and Copp (1996, 1999) also suggest that bodily autonomy is central for personhood and that the modern person/self cannot be understood apart from the irreducible fact of embodiment (Lawton 2000:185).

Although some connection was made about the hope that remained for the family members, data suggests that the dying process, in hospice, may become a ‘conveyor belt’ process for some staff who see so many deaths, and regularly deal with the dying process. That is, that death itself was seen as the ultimate state of dignity. For staff each death is an ending and moving onto the next patient, whereas for families it is a lifetime of loss.

Dignity restoration and sedation appear to be one and the same, and discussion always returned to sedation. *The way she looked*, when she was sedated was seen a restoring dignity. The findings support literature where reasons for using ‘terminal sedation’, were the anguish, agitation, delirium, confusion, hallucinations, fear, panic, anxiety and terror of the patient (Chater *et al* 1998; Fainsinger *et al* 2000a, 2000b).
The practice of sedating patients in the hospice environment has become a controversial topic (Chater et al 1998; Morita et al 1999; Fainsinger et al 2000a, 2000b; Broeckaert and Núñez Olarte 2002), however, very little research on this subject has been conducted in the UK. The most common problem requiring sedation is delirium (Fainsinger et al 2000a; Lawlor et al 2000), or physical restlessness with or without delirium (Morita et al 1999) and 10-50% of palliative care patients receive sedation in the last days of life (Cowan and Walsh 2001; Sales 2001). Chater et al (1998) provide a scale of reasons for ‘terminal sedation’, following a postal survey of 61, selected palliative care experts. They identified pain as the most common reason for using ‘terminal sedation’, followed by anguish. Agitation, delirium, confusion, hallucinations fear, panic, anxiety and terror were identified as the third most common reasons. These are states that clearly do not allow straightforward assessment or consent processes to take place prior to administration of sedating medications.

A debate has arisen on the use of the term ‘terminal sedation’, based on the potential for it to be misleading in relation to using sedation for symptom management and the subject of euthanasia (Morita et al 1999, 2004; Broeckaert and Núñez Olarte 2002). Within this debate it is evident that there is no firm agreement as to what ‘terminal agitation’ or ‘intractable distress’ mean, yet they are terms used frequently within hospice settings. They are used often in conjunction with a judgement that delirium is present, and delirium has been identified as an indication for sedation (Chater et al 1998; Fainsinger et al 2000a, 2000b; Sales 2001; Lawlor et al 2000). Sedation is considered to be an appropriate treatment for delirium in palliative care settings, however it is a condition that is under-assessed and under researched within the field of palliative care (Caraceni and Grassi 2003; Caraceni et al 2004; Hjermstad et al...
and it has been shown to be misdiagnosed or overlooked by nurses (Inouye 1994; Inouye et al. 2001).

The results of a questionnaire survey of 2,607 Japanese nurses by Morita et al. (2004) found that a majority of the nurses experienced serious emotional distress when sedation was not initiated for patients with refractory and intolerable symptoms at the end of life. Centeno et al. (2004:187-188) refer to this as the emotional overload that leads clinicians to administer sedation prematurely, describing the process as a 'destructive triangle' of delirium-induced stress of proxies and overload in the therapeutic team.

The study by Morita et al. (2004) is one of the few that has explored nurses' experiences of using sedation at the end of life, and whilst the Japanese experience cannot be directly applicable to other cultures the study raises a number of questions that require further study. Of note, Morita et al. (2004) point out that other studies have shown that 50% of sedated patients are not able to participate in the decision-making process about the use of sedation due to cognitive impairment. In a Canadian study using focus group data from an interdisciplinary palliative care team Brajtman (2005) examined the challenges involved in providing care for patients who experienced terminal restlessness in Canada. 'Suffering' experienced by the patient led to using sedation as a treatment of choice and sedation allowed the team a critical measure of control over the patient's behaviour. However, there was conflict between staff and families in using these measures as families displayed strong feelings of ambivalence to the use of sedation and wanted to be able to communicate with the dying family member at this critical time.
Palliative care nurses are not experienced in dementia assessment and may misinterpret dementia behaviour as delirium, or simply be intolerant of, or distressed by, the way in which the person with dementia emotionally expresses their anguish. Equally non-palliative care nurses may not recognise delirium in a person with dementia (Marshelle 2002). Delirium generally develops as an acute event as a result of medication toxicity or multi-organ failure in the last days of life, whereas a dementia will have been present for some time prior to the terminal stage. Knowledge about the cognitive state of the person is crucial in enabling a judgement to be made about changes that may require medical intervention. In the absence of a history many tools exist for assessment of cognitive state however these tools are rarely used in hospice settings.

Lawton (1998a, 2000) found that hospice patients who became distressed, and particularly if they displayed aggressive behaviour and were shouting, were often sedated heavily. The reasons given for this were so that the person ‘looked peaceful’ (2000:120), and as part of the process of achieving the ‘good death’. In their study examining the ‘good death’ for people with Alzheimer’s disease, Bosek et al (2003) found that vigilance in assessment and interventions for symptom management during the dying process were desired by family members. A further, highly desired standard of care practice for family members was that the death of the person with dementia should occur in familiar surroundings. This potential was however, hampered by the uncertainty that the nursing home environment, in which many of the study cases died, would ever have been a familiar environment. This was due to most admissions
having taken place after the person had been diagnosed with dementia (Bosek et al 2003).

Most of these symptoms were displayed by people with variant CJD at some time during the dying period. The responses of staff also had components of depersonalized routines and rituals that are used in healthcare environments to screen out threatening emotional involvements (Menzies Lyth 1988, 1990). Both Lawton (1998a, 2000) and Copp (1996, 1999) found that patients were distressed by the drawn-out period of dependency and dying and often wished they had died suddenly of a heart attack. Copp (1996) also showed how nurses hoped that the dying person would die sooner rather than later so anguish was not prolonged.

This restoration of dignity through death, and control of dignity by sedation, appeared to be a means of dealing with staff anxiety and distress as found by Morita et al (2004). This suggests the emergence of another primary task of which participants were not conscious. The nurses needed to control the symptoms, not only to relieve the ‘suffering’ of the person with variant CJD, but also to relieve their own ‘suffering’ at having to be witness to the suffering that the disease caused. In the following extract the HCA acknowledges that she managed the care better when the patient was sedated, clearly indicating that it relieved of her distress.

JN It wasn't a problem with the relatives I think. They were quite pleased at the way she was looked after. They were very pleased once that syringe driver went up, they were.

HCA-1 They were. And I think for my part, I know damn well that I didn't enjoy nursing her one bit. It hurt me to nurse her, to hear her. And I nursed her far better when she was sedated than when she wasn't, it used
to just make, break you up basically, really, just to hurt her. You do everything in your power...

HCA-2 She would be screaming, and you would try to go very slow...
(WI:252-260)

For one CNS, sedation was the primary means of controlling the situation. From the outset of the focus group interviews she took this stand and repeatedly returned to it, constantly reiterating that sedation (control) was necessary because of ‘not knowing’. Not getting ‘any pleasure out of anything’, also appeared to be equated with dignity and I propose indicated an ‘assumed’ judgement of quality of life of people with cognitive impairment, highlighting the individual interpretations that abound on what exactly ‘dignity’ and ‘quality of life’ mean.

CNS The main issues seemed to be for me was that we didn’t actually know what she was experiencing. We didn’t know whether she was in pain, whether she was actually aware of her surroundings, or her or whether she actually got any pleasure out of anything that was going on whilst she was here. And the issue of sedation, personally for me is the biggest thing. I felt, I thought, we should have gone in with sedation earlier, than we did. (WI:1-7)

This CNS justifies herself, during a discussion about sedation by pointing out that sedation can ‘be withdrawn at any time’, that they are not doing anything ‘that is irreversible’. The question of reversing sedation at end-stage in the hospice setting is a moot point, as this is rarely done. In cases of sedation of people already displaying dementia behaviour, the possibility of recognising symptoms of delirium, should they occur, are reduced and further lessen any possibility of the sedation being withdrawn.
Restoring dignity, and ‘controlling’ the events through sedation, was seen as a ‘positive’ practice and also a means of supporting the family, particularly the children. This was seen as protecting them from seeing their mother ‘like that’. Demented, no longer a person, with no quality of life and unable to communicate. Protecting, as a strategy for coping with losses was also identified by Copp (1996, 1999). Metaphors identifying the patient as already gone (dead) such as; ‘they were grieving for her for ages’, ‘had already lost her’, ‘couldn’t say goodbye’ and ‘not able to speak to her’ are used to justify giving the sedation and are directly related to the inability to communicate. What they saw at the end (sedated) was seen as preferable to witnessing the person when they were displaying dementia type behaviours.

JN It was her inability to communicate, the inability for her to communicate with the family and for them to say their goodbyes to talk about their feelings. Then there was never any of that and I don’t know about the little girl but the little boy I would imagine there would be some memories of what his mum was like. That she was like that.

CNS-1 And that would be really tough.

CNS-2 Just about every conceivable . . .

JN Nightmare. What they saw at the end was a lot more preferable to that what they saw all along.

CNS-2 They lost the person, the person she was before she was ill.

JN Yes. Which is why you’d think there would be less issue about sedation really because they felt they were grieving for her ages before that. They had already lost her. They couldn’t say goodbye to her, were not able to speak to her so she didn’t have any quality of life.

CNS-2 There were only positive differences to be made from it (SEDATION). (W1:509-524)
Personal identification and the interconnection of the dreaded disease and horror of the disease contributed to the need to control the situation. Personal identification with the events led, in some instances to making the assumption that what the team member would want for themselves, if their family member had this disease, was the same for family members. Decisions about treatment and care were often related to how they personally would feel in similar circumstances. *I've got a daughter that age and I would want her sedated*, and *if that was my sister you wouldn't want to come in and see that would you*, putting themselves in the place of the family and how they would not like to be treated. The above correlates with conceptualisations of the hospice as a liminal space where the 'symbolic family' allows identification of the staff with family experiences (Froggatt 1995, 1997). Froggatt (1995) refers specifically to the nurse/patient relationship but it is equally applicable to the nurse/family-member relationship.

Part of the philosophy of hospice practice is to grant a high degree of control (autonomy) to patients and their families using a partnership model (Saunders 1990). However, the process of how this partnership model functions within hospice has not been explored in any depth (Martin 1998). A partnership model assumes a relationship that is structured on power sharing and negotiation with an assumed high degree of choice allocated to patients and family about treatment strategies (Gallant et al 2002). What the data showed was that there were significant differences in the approaches to granting autonomy between in-house and community teams.
5.4.1.2 Granting autonomy (in-house)

The debate within palliative care on the subject of autonomy is wide ranging and will not be addressed in detail within this thesis. Wood (2002) proposes that although there are now recognised differences in priority and scope accorded to the principle of autonomy, there is general agreement that it replaces the ethic of paternalism. For the purposes of my study I have used a simple definition of autonomy, in that it refers to the family members' possession of autonomous choice in relation to care interventions. This choice was either taken by them or granted to them by hospice staff. The subject of granting autonomy sparked a heated exchange within an in-house focus group on how much control (autonomy) should be 'allowed' by families in decision making about care of the person who was unable to communicate their own needs. This exchange demonstrated views that are directly contrary to the hospice philosophy of supporting maximum autonomy for patients and families. The two junior nurses were new to the hospice but were powerful and forceful in their opinions and views of how someone who was unable to communicate their own needs should be 'managed'. The CNS tried to suggest that these decisions were part of the decision making process that underpin hospice care and that sedation itself could contribute to taking away a person's personality. However, the belief that as professionals they were the ones in control caused her to lose the argument to the junior nurses and to even concede to the person with variant CJD not having a personality at all.

INTERVIEWER Did anyone ask the family what they wanted?

CNS We talked to (PATIENT'S SISTER) about sedation and she wasn't very keen for us to do that. (PATIENT'S HUSBAND) never stopped for
very long and I only had very short conversations with him. And he couldn't deal with it at all. That was more difficult ...

JN-1 It's all very well to feel around and get an opinion but at the end of the day he didn't want the decision he didn't want to make that decision and why should he.

JN-2 We're the professionals surely we should do what we think is right in that situation. Of course when we did, and it happened he much preferred what he saw then.

CNS At least we had an idea of what the relatives felt then. But for us to go in and say this is we feel, consider. It might be somebody's mother ...

JN-1 Yes I know ...

JN-2 For him to say we have to wait for him to say right do it now. That was the kind of feedback and I think he felt pressure I don't see why it has to be his decision.

JN-1 I think it is inappropriate that it is his decision because it's the patients' rights that we're looking after at the end of the day. It's like the business of telling the patients relatives what's going on with the patient.

JN-2 It's all the wrong way around. It shouldn't be his decision it should be our decision.

CNS Surely it's part of the decision process. I don't think the final decision should rest with him. I think their opinion should be considered as much as anybody else's.

JN-1 Yes.

JN-2 But as you say ...

CNS But some people look at it as long as they're shouting and screaming they're alive. You take that away and sedate them you've taken away their personality and everything else. They're just lying in a bed and you're turning them ...

JN-1 But she didn't have a personality.

CNS I know she didn't. But she was shouting and ... I'm just looking at it from the other side ... (V1:518-617)
In this case the assumptions of the less experienced staff were that they were promoting what is the philosophical foundation of hospice care. The moral ground on which they took their stand was that decision making was the responsibility of the team. This view was based primarily on the inability of the person with variant CJD to communicate, their lack of personhood and to the family members (assumed) inability to make decisions. It also appeared that when the family couldn’t deal with the situation decision making was made more difficult for the nurses. And he couldn’t deal with it at all. That was more difficult. The issue of emotional burden experienced by family members of people with dementia in their roles as decision makers was identified by (Forbes et al 2000). Decisions on behalf of their cognitively impaired relatives were an ‘overwhelming burden’ causing ‘undying guilt’ (Forbes et al 2000:253).

Conflict in relation to the experience of decision making in hospice practices both within and between disciplines is a subject that has received little empirical study.

The approach of not including families in discussions about care did not occur in all circumstances. Families repeatedly reported on how they were included in any discussion on the interventions and care practices for the person with variant CJD and how their views were respected.

FM He did, (HAD ARTIFICIAL FEEDING IN PLACE) yes, because, and then the doctors wanted to stop it and I said, I well, because I wanted him to still have nutriments, and she said, well if that makes you happy that’s, that’s what was so lovely here. (Z2:671-673)
5.4.1.3 Granting autonomy (community)

Three of the people with variant CJD in this study were managed within the community and the family focus was that they should remain at home where they (the family) would be in control of the care. Two of these patients also attended day hospice and accessed respite (in-house) services. For both of these the experience of day hospice/respite was traumatic and in one case the person with variant CJD was not readmitted to the hospice after one attempt of a day hospice and one attempt of a in-house respite admission, as discussed earlier.

*FM* She's not, you're not, you know, she's not distressed *(WHEN SHE IS AT HOME)*. My main thing is that I don't want her distressed. *(Y2:578-579)*

The control of care at home by the family was all encompassing. One family member only contacted those whom he wanted to at the time. That is, those who would be of most use to him. Support from the CJD Society, and the funding support that was then in place, enabled this control. The effectiveness of a comprehensive home-care package for people with dementia was also demonstrated in the USA study by Volicer *et al* (2003). The researchers found that care recipients who received psychiatric care, were involved in hospice programmes, and had effective pain relief for chronic conditions that caused chronic pain, particularly arthritis, were more likely to die at home. Or stay at home significantly longer than those who did not receive this input. It was recognised that chronic pain worsened behavioural symptoms of the dementia and made it more difficult to keep the person at home *(Volicer et al 2003)*.
In the cancer care literature it has been reported that limited resources and over-stretched health professionals can be problematic in the management of dying at home (Grande et al 1997; Jarrett et al 1999). This, however, was not the case for the variant CJD group, as the home care package is elaborate (Turner 2004; CJD Support Network 2004). The family member was so well supported from this care package that the community team had relatively minimal input into the care, as they were only invited in when the carer wanted advice from them.

\textit{CNS} He knows who to contact, he, he taps into each one of us now, individually as he wants, he knows who to contact with each one. And sometimes if he doesn’t want to he won’t contact any of us, we have to do it would, I think he initially will contact one of us. I suspect if she stopped swallowing it would be (CJD Unit) that he contacts, not the speech therapist or the dietician, I think he, she (CJD UNIT LIATION) tends to be his main (CONTACT) because he’s involved with the CJD Society. \textit{(Y3:221-228)}

The 1997 case did not have this input, but the desire to maintain care at home was just as focused as is was for later cases, even without the support and care packages that have since been instigated. One family member did experience anxiety that he would lose control over the management of care. He had already removed his wife from other NHS care environments, including a psychiatric unit, because of several ‘bad’ experiences.

\textit{SW} He wanted to keep her at home, he was nursing her very caringly and one of his greatest fears when I visited was that we were going to whip her off and take her into hospital and he really needed to be reassured that it would be possible for him to care for her at home. \textit{(V1:45-49)}
The emphasis of control in the community was in maintaining the autonomy of the family members in any decision making about care and events was seen as a 'delicate' process. Any approach was seen as requiring care and sensitivity in not taking away control from the family. There was an understanding that what took place within the hospice was fundamentally different to what took place in the community and that at home the person was on their own ground, which gave the power and control to the families and by proxy to the person with variant CJD.

When discussing care options one CNS was careful '... not to sway him either way'. Suggesting that '... he doesn’t like to be cornered', implied that attempts were made to convince this family member of other ways of managing care, that were rejected. Maintaining the stability of the home environment, and the wellbeing of the person with variant CJD, were the pivot of all decisions that were made in the community. How care was managed indicated that within the community the focus was on negotiation of care options. The following comment (that was a feature in the three community cases) that they would not do the same as they 'would normally do', I interpret as meaning that they were fully aware that the practice in-house would be fundamentally different, and that decisions at home would be based entirely on what was acceptable to the family members.

SW And again it was a case of thinking on your feet and not doing necessarily the same as you would normally do. But you know what was going to be most acceptable to him. (V1:474-476)
Armes and Addington-Hall (2003) found that patients in the community did not always adhere to the prescribed drug regime. In this study it was the family member, responsible for the administration of medication, who did not adhere to the regime. This caused (internal) professional conflict for one CNS. Medications that were used for the patient, during the respite admission, were considered acceptable within the in-house system. The CNS had to deal with the conflict of believing that the medications were still necessary whilst supporting autonomy in the home. This suggested that internal conflict about treatment options and also supporting family autonomy may be more likely to occur in the community.

CNS But I think she had a lot of myoclonus then, that he wasn't addressing so they were giving her midazolam and diazepam and things like that and he didn't like it and when, as soon as she got home he cut her down again, so she does have more myoclonic jerking events and things but he doesn't think it needs to be addressed. Whereas in a specialist unit like this if they see it they will deal with it. (Y3:175-181)

The final statement in the above extract explicitly refers to the difference between in-house and community approaches to practice. Underpinning this is the question of what is the 'best practice', particularly in using sedation. The community teams believed, based on their professional knowledge, that medications were important in managing some of the symptoms.

However, in one case the home environment and the presence of family members, were in themselves, seen as a treatment that had the same effect as the medication. This was described as being, 'sedated without sedation', and suggested that reassurance was a form of sedation. In one case the sister of the person with variant
CJD did not want to have him sedated and wanted to, 'hang on to (PATIENT-as-PATIENT) as long as possible'. This confirms, again, how the family is frequently not ready to let go of the dying person and will strive to maintain them 'intact' and not sedated. The focus group, on this occasion, discussed the use of sedation as '... an easy option or an option to make it easier in the care', and correlates with the earlier extract referring to finding it easier to nurse the person when they were sedated. The fundamental difficulty that they had was not knowing what was the 'right' thing to do, the right practice to follow.

JN ... but maybe it would have been easier for (PATIENT) as well. I mean nobody knows what was going on in his brain, as I was saying if he was seeing things peripherally they were frightening him, upsetting him, it might have been easier for him.

HCA But (SISTER) used to sit with him a great deal, and cuddle him and talk to him, and she used to get his motorcycle magazines out. And he was quite content with that. So how much of it was going in I don't know, but um. The reassurance had kept him sedated if you like.

JN Sedated without sedation.

HCA Yes. And it worked. (X1:954-968)

Having a high level of autonomy gave family members confidence to maintain the control of the care within the home. Proot *et al* (2004) refers to this process as 'directing', rather than controlling, based on a grounded theory study of the terminally ill person's experience of care at home. Directing was seen as a process much like directing a play or orchestra, 'deliberation with the players as to what sort of actions you want or not, asking for properties, and anticipating future scenes' (Proot *et al* 2004:55). The term directing is useful, and in the situation of the person with cognitive impairment the family member could be seen to be directing by proxy. This
fits with the process of negotiation, Proot et al. (2004) propose that 'actual autonomy' is the situation of the terminally ill at home when directing their care. The context of home was important for realizing autonomy for the dying person (Proot et al. 2004).

The emphasis, for one of the family members, was so strong and aggressive that I would suggest there was no negotiation as far as he was concerned. In the following extract the reason for such a determined approach to maintaining this control was based on the family member feeling that they are somehow being criticised for their methods of providing care, suggesting that negotiation within the community is a delicate process.

SW 'Go to hell', basically he said to people who knocked at the door. The district nurses had very big problems and I did a kind of um with my colleague in the domiciliary team who should have been here today but couldn't, and we did a support group for them both before and after the death. Because they found him very difficult to cope with and I think somebody said something that he didn't agree with and (he) said I don't want them back again and he didn't allow them back again. (VI:299-305)

Family members having the power to allow, or not, the hospice teams access to the person at home forced community teams to carry out practices that are congruent with the philosophy of hospice care. That is, to provide maximum autonomy to patients and families.

There was a belief (in-house) that through sedation the person had their dignity restored and quality of life improved. What did not 'appear' to be recognised was that
Normalising is defined as a means of achieving a standard or 'normal' state, although this 'normal' state can only be individually defined. My interpretation was that 'normalising' was about practice that was not directly connected to the control through sedation. It represents the very 'ambiance' identified by family members where they refer to the friendliness and homeliness of the hospice. Clarke (1999) proposes a theory of normalisation for people with dementia. Within this model are several processes deemed to occur that support the process of normalisation. Amongst these was the kinship role and affection (love) within the relationship between the person with dementia and family carer. Through a process of interfacing (negotiation) and interacting (working together) normalisation was achieved, with however, some costs to the relationship, particularly the perceived dominance of the illness pathology suffered by the person with dementia.

In an attempt to identify professionals' perceptions of maintaining personhood in hospice care, Kabel and Roberts (2003) challenge Lawton's thesis, using a thematic analysis of interviews of 30 staff in two hospices. They propose that hospice staff do carry out normalising practices to assist patients in maintaining a sense of personhood, a process that Lawton suggests does not occur. Kabel and Roberts (2003) propose that when the patient was in a state of unconsciousness, the potential of the person remaining intact whilst the body disintegrated was allowed. They base this premise drawing on Copp's (1999) work on body-person split. Responses of staff towards the
personhood status that was attributed to the person with variant CJD has not been interpreted as a process of infantilisation and humiliation, as identified by Oliver (1999) in relation to dementia in old age. Although there was evidence of assumed loss of personhood there was no evidence of poor dementia care practices taking place. It was by far the reverse. Normalising practices were carried out much in the manner outline by Clarke (1999). Staff used care practices in their assessment and care and in normalising the lives of these people that I identified as ‘good’ care practices for people with dementia where family relationships and participation in care was supported. They used practices that could have enhanced lucidity as identified within dementia care literature, although they did not appear to be aware of this potential. This included playing music and dimming lights to create a calm and tranquil atmosphere. They were uncertain of the success of their practices because they did not receive confirmation from the patient due to the communication difficulties and inexperience in communicating with people with dementia. As a result they had difficulty making the connections between their practices and patient responses. That is, they had difficulty in believing or being confident of success in any practices they used and often related success to medication.

One JN comments that: ‘They were quite pleased at the way she was looked after. They were very pleased once that syringe driver went up, they were’, making no connections about the two very different care practices. That of sedating and that of normalising through care practices that were not related to medication. The above statement refers to the children being less distressed when their mother was sedated. However, data (confirmed by hospice records) shows that the children in this family became less distressed early in the admission. Specifically, when their mother was
moved from the floor to a bed (normalised) and before any sedating medications were given.

Some connections were made about psychological, rather than physical, responses that the person with variant CJD has to others and to the environment.

CNS-1 When (SISTER) left, she generally got more distressed shortly after (SISTER) went. We used to wonder why she was so quiet when she was there talking to her. As soon as (SISTER) went it was when she normally started to cry.

CNS-2 Within about a week (THE NOTES AND EARLIER FOCUS GROUP DISCUSSION SUGGEST THIS OCCURRED WITHIN A DAY, AND INCLUDED BEING PUT INTO A BED RATHER THAN NURSED ON THE FLOOR), I think, of being in a side room. She became much, much calmer. Whether that was the progression of the disease or the fact that she became more comfortable I don't know. She did change quite significantly. (W1:180-186)

Although there is some move towards making connections these were not often explicit.. The understanding of the families (of the two in-house patients) appeared to be that they were calm because of the 'care' the people with variant CJD were receiving. Such as the aromatherapy that had a profound impact on one of them for 24 hours. It had such an impact that the family saw it as a potential 'miracle'. Normalising practices, such as having their hair cut, a factor that was acknowledged by one HCA who refers to the patient having her hair cut as 'the biggest thing', for the family. Having their hair washed and brushed, being washed and having clean clothes were seen by family members as dignity restored and the person looking normal again.
These were also the type of activities that Kabel and Roberts (2003) categorised as normalising practices. The person with variant CJD being moved from the mattresses on the floor into a bed was a profoundly normalising event for family members. The two families constantly compared their experiences in NHS Units with the hospice experiences, where the person with variant CJD had been nursed on mattresses on the floor. Expressed by one family member as, 'that's no way to treat humans'. This confirms the findings of Douglas et al (1999) on cases of variant CJD up to 1999, where it was found that most of the families were unhappy about the care they received in the acute units and where examples of what families felt to be 'poor' care are cited.

*FM* No she, she seemed really restless up there. (FRIGHTENED) of things up there, you know. Yeah, so the difference was, there was a major difference in the care compared to ... Yes because they care here (HOSPICE). The first night she was on the floor here and I came again they changed her room, so she was outside reception bit, and she was back in bed. Yeah, it was sort of a caring, you know, she was washed, you know, brushed her hair. The other places didn't seem to care. (W3:77-83)

These findings are confirmed by Enes (2000) who showed how (as seen by family members) the hospice reaffirmed the worth and restored dignity that had been lost in other settings. The relatives feelings about dignity appeared to be 'shaped by negative experiences of seeing the loved ones treated without humanity or love and of their own love for them' (Enes 2000:72).
Interestingly, for some of the nurses the importance of not being nursed on the floor was the difficulty and risk implications for nurses managing the care of a patient on the floor, not the implications of normalisation that the families identified with. According to one CNS, ‘it was something quite terrible to have somebody on the floor’. This was expressed in relation to the nursing management and risk to nurses crawling around on the floor, but wasn’t such a bad thing ‘from his comfort point of view’. It was not comfort but the indignity of the position of the person that the family members were concerned about. This further supports the subjectivity of the use of the term dignity. The distress of the family at seeing the person nursed on the floor and as one family member considered, the inhumaness of it, which are all the implications of loss of personhood, does not appear to be an important issue for this CNS.

One CNS comments on the difference between the responses of the daughter of a patient, where, when her mother (with variant CJD) was crawling around on the floor the daughter responded to her as if she was something like a 'puppy dog'. Not referring to her as her mother but calling her by her name. When the illness became more advanced and she became bed-bound (in a normalised position) the daughter returned to calling her Mum.

Managing care through maintaining ‘dignity’ and providing ‘quality of life’ are considered the cornerstone of hospice care, even without clear conceptualisations of the terms dignity and quality of life. Promoting and maintaining this philosophy is considered to be the role of individuals within the organisation (system). One of the
means by which the system is maintained in a state of equilibrium is through controlling, of not only patients, but implicit within this is control of the environment.

### 5.4.2 Maintaining the environment – In-house

Hospices are considered to be environments of serenity and peace (Lawton 1998a, 2000; Walter 1994) and maintenance of the tranquillity of the hospice environment is of paramount importance for system equilibrium. This tranquillity includes the décor of the ward, and other typical features of hospice environments such as an abundance of flowers, integrated gardens often with water features, easily accessed chapel and Chaplain and an atmosphere of homeliness and calm. Dementia behaviour, or indeed any disturbing behaviour, disrupts the environment and disturbs the tranquillity of this and is considered to be distressing for other patients, visitors and staff (Walter 1994). People who displayed this type of behaviour are deemed inappropriate admissions to a hospice due to the impact their behaviour may have on others. In considering the impact of witnessing death on hospice patients Payne et al (1996a) found that other patients found a noisy or agitated dying patient distressing. Equally, within hospitals, nursing and residential homes, agitated individuals with dementia caused anxiety, fear and irritation for people who were lucid (Ragneskog et al 2001). Such behaviour upsets the equilibrium of the system and potential for system survival (Katz and Kahn 1966).

CNS We don't have, we don't take patients who have dementia. Um, because it's distressing for the other patients and to take somebody who is demented out of their normal surroundings, put them into new surroundings with other people they haven't seen before, it just makes the, makes them agitated, distressed, it makes everything more. It's the worst thing you can do. (X1:228-233)
Included in this is the acknowledgement that the experience could be equally distressful for the person with dementia, as discussed in relation to fitting into the system. The admission of people with variant CJD, and the behavioural symptoms that manifested as a result of the disease were seen as profoundly disturbing to others. Douglas et al (1999) also found one hospice wanted to discharge the person with variant CJD because the admission was lasting too long and the patient was hallucinating, shouting out and disturbing other patients.

**JN** And what about the other patients. What the other patients were thinking about all the screaming. It must have been awful. (W1:261-262)

**CNS** It would have been nice for the family (IF SHE COULD HAVE BEEN ADMITTED EARLIER). But I just wonder, from a selfish point of view, if she had come here earlier if she was screaming and calling what it would have done for the rest of the unit if it was going to take that long for her to change. She would have been two weeks screaming like she was and that. (W1:426-430)

The need to ‘do something’, to stop this behaviour, becomes paramount, in maintaining and controlling the environment. The means by which hospices ‘control’ the environment is primarily with medication as discussed earlier. This focus led to conflict between participants within the system where different perspectives on this approach were present. The need to sedate and maintain the patient in a state that is conducive to the serenity of the hospice environment was couched in terms of ‘treating’ noisiness and distress.
The following exchange exemplifies the conflict within the system of different opinions or approaches to maintaining the tranquillity of the environment through control processes. My interpretation of the CNS saying, ‘We're not saying that hospices should be calm and serene and no noise, we're saying ...’, is that they really do believe that the real world of hospice care is that of a calm and serene environment. This belief in the need to maintain a calm environment was not held by all team members and this focus group singled out the medical members as those who did not support this. The one short (interrupted) comment by the HCA ‘They weren't there ...’ is not taken up by the group as a significant factor in confirming that the doctor not being present was why they lacked understanding and were unsupportive in sedation of patients due to noisiness and general disruption of the environment.

**CNS** And we've always had an issue, especially with the patients who are noisy and screaming, about sedation. We did have had one incident, a chappie screamed and screamed all weekend none of the doctors wanted to sedate him, at all.

**HCA** They weren't there...

**CNS** Plus you have to take into consideration, is he in pain, why is he doing that? The other patients who are dying, relatives, and staff and how they feel. We're not saying that hospices should be calm and serene and no noise, we're saying ...

**JN** ... but, A, its not dignified is it. No ones got dignity if they're like that. And B, I don't see why I should be in a position where I get myself at risk from someone who is aggressive or whatnot, or they are putting themselves at risk. I think you should be ...

**CNS** ... but the medical opinion seems to always be to stand on a soapbox and say we have to let the patients be themselves ...

**JN** ... we can't consider the other patients. But you do in the real world have to consider the other patients too. (W1:554-570)
Conflict over people being allowed to ‘be themselves’, was also identified by Walter (1994) where the peacefulness of the hospice has been couched in terms such as ‘the hospice smile’ (Walter 1994) and ‘chronic niceness’ (Speck 1994) which requires patients and staff to maintain this ambiance. The practice of ‘symbiotic niceness’ also contributed to conceptualising strategies of maintaining the peaceful hospice environment. However, Li (2002) does not provide a specific category for dealing with disruptive and cognitively impaired patients. I propose that one of the most important agendas held by the hospice nurses (in-house) is that of maintaining the tranquillity of the environment. They see this as upholding good hospice practice. The culture of the hospice is philosophically one that allows maximum autonomy for patients and families yet there remains a contradiction in this that clashed with the interests of ‘preserving’ the environment where any disruptive behaviour cannot be allowed to occur. It was not clear however, that this was the agenda for all members of the teams.

Hospice team participants in this study spoke and behaved differently depending on their profession. For example, the language used by HCAs can be equated (to some degree) with the ‘lay’ language of family members, it was spontaneous and generally unconstrained by medical jargon. The nursing staff used a more constrained language, maintaining a professional stance, except when the discussion became heated during the focus group interviews. Then the discussions were often as spontaneous as those of the HCAs’. Doctors and social workers, on the other hand, were generally very careful about the language they used, and in most cases needed to have the notes with them to refer to during the interview.
This raises questions about the oft idealised multidisciplinary team (MDT) work of hospice organisations. The concept of a MDT that has coherence and shared common purpose is also questioned by Stokes (1994a), as those members come from different trainings with different values, priorities and preoccupation. Stokes (1994a) proposes that these teams often have lack of clarity about the primary task which can lead to confusion, frustration and bad feeling that interferes with the working of the organisation. This aspect is highlighted by Walter (1994) where the following quote made by the social worker is clearly a criticism of other (unidentified) team members. This peacefulness is extended to producing environmental calm (Walter 1994).

It's very difficult to refuse or query treatment in our hospice, because the hospice is above criticism; the result is that patients are over-drugged in order to render them peaceful (Walter's 1994:132).

Carers within the hospice system experience many powerful and moving events that are related to death and dying experiences of others. With this there can often be a sense of powerlessness and awe. At one level I propose this as creating both a sense of loss of control which leads to a need to control. At a further level I propose that this powerlessness, helplessness or being out of control that was experienced by the participants in the care of people with variant CJD caused them to be humbled.

5.5 Humility – helplessness and realisation of system limitations

The culture of hospice still retains much of the historical Christian foundations and a religious presence, within which are implications of humility, at a level not found in other health care settings. This culture supports positing a model of liminality and sacredness for hospices (Froggatt 1995, 1997). It is possible that this so called 'sacredness' of hospice has become somewhat diluted and overshadowed by the
medicalisation of hospice care as discussed in the literature section of this thesis. However, as shown by Froggatt (1995) a ‘new’ sacredness has emerged that embraces the medical interventions where the nurses, as ritual specialists hold the special ‘knowledge’ of pain and symptom control.

Regardless of medical interventions hospice remains the one organisation that provides an environment in which, death, one of the greatest mysteries of life, is a regular and repeated occurrence. This must suggest that humility is present at some moments within this environment. I propose humility (Figure 7) as a first level category and base this on Kunz’s (1998) concept of the ‘power of weakness’. This ‘power of weakness’ proposes that the experience of meeting the weakness of the other, in this case the dying person with this new, horrific disease, moved participants in a way that is congruent with a concept of humility. Suffering is at the heart of the paradox of the power of weakness (Kunz 1998), and the hospice teams ‘suffered’ in the presence of the ‘powerful weakness’ of the person with variant CJD. This sense of the power of weakness is articulated by Ramsay (2000) in her response to carrying out an observation study in a hospice. ‘There was something much older and more powerful in the face of which modern medicine and my professional training was impotent’ (Ramsay 2000:147).

Kunz’s concept of the power of weakness is based on Levinas (1985) ethics of the responsibility of self-to-Other and is particularly fitting for people with variant CJD. These are considered ‘innocent victims’ of biotechnological tampering, the ‘undeserving’ sufferer (Kunz 1998). The weakness of the other calls to the responsibility of the carer, yet the carer does not have the power to reduce the
A new disease (variant CJD) entering the system

Hospice Service
'Container'
(Open system)

NOT KNOWING

System boundary

NOVELTY

Finding a place for the new, curiosity, and disturbance of system equilibrium

Fitting in
'Opening the floodgate'
Did fit
Didn't fit

Gossiping
Ghoulish voyeurism
Ignorant outsiders
'Drawn' to stories
Bullying

Horrifying
'Worst possible nightmare'
Personhood status

CONTROLLING

Use of strategies to maintain the equilibrium of the system

In-house
Managing care
Restoring dignity
Normalising
Granting autonomy

Community

Maintaining the environment

HUMILITY

Helplessness and realisation of system limitations

Figure 7. Humility – helplessness and realisation of system limitations
suffering and is humbled by this limitation. This is particularly pertinent in that the sufferers of variant CJD could not adequately communicate their suffering.

The Other is infinitely nearby commanding help, and infinitely distant, always exceeding our total understanding and our power to control (Kunz 1998:17).

The struggle to reduce the suffering of the dying does (to some extent) explain the use of sedation in hospice environments, as discussed earlier. This does not negate the need to administer sedation but does call into question some of the reasons that may be given for choosing to take that route. On some occasions the sedation may be administered not only to reduce the suffering of the Other but to reduce the carers own suffering or distress and anxiety, and those of others within the immediate environment.

Humility has been a neglected virtue in social and psychological studies (Tangney 2000). Within the literature, the term humility is used regularly without clarification and with an assumption that it is a virtue, particularly within theology, where it is more commonly associated with the concept of forgiveness. There has been little empirical work carried out that has directly addressed this construct (Tangney 2000). Means et al (1990) propose a concept of humility where they believe that humility is characterised in four ways. A willingness to admit one's real inadequacies, a recognition that one cannot control all interpersonal interactions, a general attitude of patience and gentleness with others, and a platform from which empathy is fostered. Humility has variously been equated with forgiveness (Sandage and Wiens 2001), attention (Sandage et al 2001), compassion, generosity, courage, loyalty, mercy, forgiveness, love, honesty, faith, tolerance, altruism and empathy (Brehony 1999) and
good psychological adjustment (Exline and Geyer 2004). Of note, in exploring the implications of the postmodern conceptualisation of the Other, Sundararajan (1995) proposes that what is needed is a new paradigm of healing, focusing on care instead of cure and measuring excellence in terms of humility and sensibility as opposed to power and mastery, concepts that very aptly fit the ‘ideal’ of hospice care.

I have chosen to use the Kunz et al (1987) construct of humility in my interpretation. Kunz et al (1987) carried out a dialogal phenomenological study of the experiences of 11 individuals, of being humbled. The researchers concluded that the phenomenon of humility cannot be identified or grasped in its entirety.

It eludes literal interpretation. It is the mysterious ground from which words and actions speak to another. By definition, it is hidden from the humble person. It evokes admiration from others, but cannot be managed by the humble person. Through the humbling event, humility emerges as a momentary self-acceptance from the ground of personal limitation. This is preceded by an experience of surprise, awe, and wonder. The humbled is disengaged from the trap of striving for an achievable perfection by beginning to accept his/her own imperfection. A person finds a new perspective for an understanding of his/her place in-the-world. Humility is manifest in compassion for others through the desire and felt-sense of responsibility to care for those in need. It is a nurturing respect for life in all its aberrant manifestation, as well as its beauty. Humility is an act of hospitality, which embraces the wounds of life’s alienation, and invites us into a larger, human community (Kunz et al 1987:18,19).

This definition has congruency with the origin of the word hospice in proposing humility as an act of hospitality, and much of the rhetoric on the origins of hospice use a language that proposes a humble approach to caring for the dying.

Humility occurs in the presence of the ‘powerful weakness’ of the dying Other, and was heightened in the presence of the person dying as a result of variant CJD. Some
experiences were emotional in nature, however, they were more often ‘indescribable’ and always related to ‘not knowing’, and at times participants became inarticulate. When I tried to press the nurses to say that they had managed the care of a person with variant CJD very well, as was repeatedly reiterated by family members, they became even more reticent or unable to articulate their experiences. They returned to the unknown factor with long pauses in the conversation, attributing any success to continuity of care and team work. Their performance (care practices) had evoked admiration from others, but dealing with this admiration was not easily managed by the humble person (the team). There was recognition that the team cohesion is part of the culture of hospice care and the desire and felt-sense of responsibility to care for those in need.

*CNS* I think the big thing was continuity of staff. You have a patient anywhere else you’ve got different people looking after them. You might miss something.

*HCA-1* Yes.

(LONG PAUSE)

*HCA-2* I think because you were working as a team, with the same people looking after her you can say, well yesterday I did this and it worked.

*HCA-1* Definitely helps. Yes.

(PAUSE)

*HCA-2* And you spread things between you. That's a big thing of continuity of the people looking after her. (W1:670-679)

Helplessness and powerlessness were expressed in many different ways by participants, and were generally couched in terms of ‘not knowing’. They found it difficult to agree that they had achieved a high level of care because they could not communicate adequately with people with variant CJD. They could only guess and
hope that they had managed this. The teams had disengaged from the trap of striving for an achievable perfection by beginning to accept their limitations (Kunz et al 1987). They were silenced by the inability of the person to demonstrate (through communication that they could recognise), that she has died peacefully, died a 'good death', by their definitions.

\textit{HCA-1 We hope . . .}
\textit{CNS-1 We like to think we did . . .}
\textit{HCA-2 We like to think she recognised our voices when we went in.}
\textit{HCA-1 This is something you'll never know . . .}
\textit{CNS-2 This is the hard thing . . .}
\textit{CNS-1 We'll never know . . .}
\textit{LONG PAUSE (W1:683-689)}

In a short critique of Levinas and his ethical stance, Wyschogrod (1992:66) offers a description of the 'space of ethics', as where the power of the vulnerability of the extremely sick 'solicit assistance in helpless silence'. This powerful silence of the dying appeared to have an even greater impact when the dying person was cognitively impaired. This also rendered the carer silent.

When I took my pilot findings (first data set) back to this focus group to confirm my interpretation, they could identify with and confirm all of the categories except that of humility. Their responses to this were, 'we were just doing our job', 'it was the team effort' and 'it was continuity of care', a point they had already made in the original focus group interview. My interpretation of this response was that what they were (again) expressing was humility, in that they were understating the high standard of care that was carried out.
Humility appears to be less a personality attribute that qualifies the individual person, and more a quality of an interpersonal relationship between people, or as the context of this relation (Kunz et al 1987:10). Disinterested effort in work for others requires collective humility, in which people labour for each other and the common good (Kunz 1998:187). I propose that the teams manifested a collective humility of this type and that it is a (paradoxical) feature of hospice care. I call this paradoxical as humility was present despite the earlier criticisms (I make) within the category of controlling. This sense of helplessness, of not knowing, of realisation of limitations permeated the hospice teams and family members at every level.

*CNS* They just didn't know what to do (DAY HOSPICE TEAM), they kept coming to me saying what can we do? How can we cope with this. And in the same, in a way we were all blind, never having come across it. (Y1:91-94)

Community teams were both moved and inspired by the level and standard of care provided by family members and felt privileged to be able to be with them. I equate 'privileged' in this way with humility as part of the compassion they felt in the face of the circumstances of family members' experiences, the sheer 'awfulness' of the situation that families found themselves in.

*SW* And a very positive man and his values and his traditions really did help him to cope with the uncopable with. Um and I think it's being alongside him really sort of inspired me to see how he did cope with this awfulness. The illness and its consequences. So, yes it was a privilege to try. (V1:678-682)
Witnessing the distress of the family members was profoundly humbling for participants and they were rendered helpless by the helplessness of the family. 'She knows' is uttered in a tone that expresses the sheer helplessness this JN felt about what impact the following (observed) experience must have been having on the couple.

JN One day he (HUSBAND) came to visit her and she was in a chair and he just sat there and put his head on her knee and absolutely sobbed and sobbed and we were saying, she knows. If she has got any perception of what's going on that must be very hard for her to bear. He can't even touch her (BECAUSE OF HYPERSENSITIVITY) he couldn't even help or reassure her in any way, hold her. It's not knowing what she's feeling, what she's thinking. (WI:221-326)

As discussed earlier, particularly regarding earlier cases, staff had no information that could assist them in providing the type of hospice care that they were familiar with and aspired to provide. Added to this were concerns that changes in the condition of the patient may have been due to some fault, 'whether it was something that we had or hadn't done', in their management of care, reminding them of their limitations.

HCA We couldn't help. Do anything...
JN You know, you couldn't make it better in any way.
HCA Trying to put his socks on because his feet were always cold. Always cold so he had two pairs of socks, wasn't there. And trying to get them on without him screaming because, because you were hurting him (LONG PAUSE) (X1:498-504)

Participants were completely open about their limitations and made no pretence at having a specialised knowledge about the disease to family members (for the earlier cases). As one CNS expressed, she was '... learning in the same way as he is', and
that 'potentially he knows far more' than she did and that this is 'because he's also there with her and because he's with the (CJD) Association'. She considered that her knowledge base was limited to the basis of hospice speciality, bereavement and symptom control for people who have cancer. This ability of the participants to admit to limitations, to not having answers, was seen as one of the reasons why the husband of one of the people with variant CJD had developed a close and trusting relationship with the hospice team.

SW But then I think that was really important for him because he had so many people telling him things that were wrong that he probably had a lot more trust in you because you were saying, 'I don't know'. Then he was with all the people that were saying it was this, this and this. (V1:649-652)

The horror of the image of the symptoms of CJD (dementia behaviour in a young person) was equated as being without dignity, as has been previously discussed. Helplessness in the face of 'perceived' indignity was expressed repeatedly and this was particularly poignant for participants due to the youth of the people with variant CJD.

CNS It was just that image of her looking so young with two kids sort of kneeling on the mattress beside her and her screaming. And then it was just that there was no dignity, you just did not know how you were going to help the husband who was standing there and the sister who was very close to her and it was just like, Oh God, where do we start. (W1:32-36)

There was outright acknowledgement and acceptance of what may have (possibly) happened to people with variant CJD in another environment, with 'sedation' as the
straightjacket metaphor equivalent. The team were moved by the fact that (they believed) the family knew that they had gone to all possible lengths to provide the best care and is congruent with Seale's (1990) premise that much of the care that is carried out at home by family members of people with advanced disease, including dementia, is essentially altruistic.

**JN** You know, if he hadn't had family who cared that much, what would have happened to him?

**HCA-1** I suppose he would have been on a hospital ward, probably.

**JN** A psychiatric unit.

**HCA-2** Heavily sedated.

**HCA-1** Heavily sedated.

**JN** Mm, which would have been awful, really. But it would have been the only way I suppose that that kind of distress and agitation could be dealt with on a general ward. It's not. Well they (THE FAMILY) were able to give him some quality of life, weren't they. I mean, you know, that must be such a you know, well they must be feeling that now, now he's gone, they must be able to think, well we couldn't have done any more. You know, I mean it is on their conscience that they can't have done any more then ...

(X1:692-705)

Family members were also humbled through their experiences of the deterioration of the person with variant CJD, experiences that Kunz et al (1984:13) express as 'gut-wrenching'**1.

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**Claire’s Mother:** Dignity was the thing with Claire all the way through. The first time she crawled in here I thought my heart would break because I knew if she was crawling in front of anyone she had to be desperate. (2000)

**Jonathan’s Father:** And what we were told was. Nothing works. Take him home. Basically take him home, make him comfortable, there is no cure. He has a year to live at most. I'm sorry. Then, I mean, I recall going up to his bedroom, in the early hours. And he was laying sleeping. This is not something that I'm proud of, the fact is, but I'm truthful. He looked as if he was so at peace. I actually contemplated putting the pillow over his head and smothering him. (TVD:15-19)
**FM** And I think one of the, there were two sad times in my life, one when Rob himself asked if he was getting better, and the other when I said to the children, you have to say goodbye ... (TURNING AWAY CRYING) (Z2:751-753)

**FM** ... they had had a big argument and I sat there. She came and sat on my knees crying and said please help me, please help me ... (W2:148-149)

Participants were humbled by the impact of the disease on the person who had variant CJD where they had progressed from a state of having some understanding of the disease to one where they struggled to retain some cognition of what was happening to them. One person with variant CJD had been given his diagnosis at the early stages of his illness and at that stage was aware of the causes and implications of the disease. However, as the dementia progressed he could not remember what this illness was, but could still connect it with cows. The extent of the sense of helplessness and limitations in being able to deal with his anguish as the disease progressed was expressed in a number of ways. The tone used in the discussion reflected how moved the team were by this experience, by how he felt because he also ‘didn’t know’. It was beyond their experiences to work with a person who had this type of cognitive impairment and to manage his dying as well.

**CNS** And to watch such deterioration, I think, (PATIENT), his problem was he didn’t know how it was going to end, how he was going to die.

**JN** And that worried him, it worried him a lot.

**CNS** Right from when I first saw him. The first time we followed up, that was virtually the first question he asked, was, how long have I got, how long is this going to go on, and he couldn’t, he couldn’t tell what it was that wrong with him, um, he, what was it he thought he had. Um, foot and mouth ...  

**JN** Yes, he knew it was something to do with animals.
CNS Yes. That was, and, and he said is it foot and mouth that I’ve got, that was it. (XI:145-152)

What was occurring within the system was beyond any previous experience. Even though they were experienced in caring for dying younger people, which is recognised as stressful for hospice teams (Saunders 1993), these were not only young people but they were also unable to communicate due to the dementia. The death of a young person is recognised as a ‘bad death’, as is a death over which the nurses had no control (Froggatt 1995). They believed that it shouldn’t have been any different for them than dealing with the care of other terminally ill people. It was ‘the fear of the unknown’, and ‘dealing with not knowing’ that made the experience distressful for families and hospice teams. Family members were left with a sense of living in limbo, ‘you still feel your life’s on hold but you can’t change it because you don’t want her to ... (DIE)’, of having no control over events.

The care provided by family members was inspired by a type of love that I have equated with humility and altruism. I place their behaviour within Kunz’s concept of ‘radical altruism’. Radical altruism, according to Kunz (1998), is a radical alternative to egoistic theories of ethics. Egoistic theories centre on the assumption that the ego is instrumental in self-initiating its good intentions and actions.

The radical alternative to egoistic theories of ethics points out that the neediness and worthiness of others, calls us to responsibility prior to our reason, beyond our individual desire for happiness, before forming any contract with others, generates the ethical command (Kunz 1998:20).

Community hospice team members were essentially guests in the home of the family who were caring for a person with variant CJD. In all three community cases, the
team members expressed awe and great respect for the level of care, dedication and love (altruism) that was shown by the family member who was providing care. The use of the term dignity, in the following extract, again signifies the subjectivity of the term dignity and the different ways in which the term can be used. In this case dignity is depicted as ‘achievement’, where the family demonstrated how they suffered and yet remained dignified (Radley 2004).

**DR** I'm just amazed by how much he'd managed to do and how well he was coping, and I think it was sort of unforgettable going into a room with this poor lady who was totally unable to communicate with me at all. Really unable to communicate with him but aware that he was there, in absolutely squalid circumstances with an, an, I think it was a nappy he'd got on her you know, and little else other than that. In a room that was sort of totally bare, with just the bed in the corner. Um you know I can still see that now and it was, it was just incredible to see how somebody could be so dignified and you could tell that there was dignity in circumstances that were just so dire. You know that, you know I hadn't come across, well I had come across difficult circumstances but I don't think I've come across anything like that before or since actually. *(VI:691-703)*

There was also a sense of ‘satisfaction’ in having done a good job that is not incompatible with humility. If one can say one is humble then by definition this is not so (Kunz 1987). However, participants were not claiming humility, I am claiming that for them. Although they do not refer specifically to humility Norberg and Asplund (1990) showed how the helplessness of the dying person with dementia gave meaning to the carers caring. The carers felt an inner need to care for the patient. Norberg and Asplund (1990:83) further state that ‘the fact that the caregiver fulfils his or her own needs by caring for the patient does not necessarily mean selfishness’.
The hospice teams had ‘done the best they could’, reached their limits of expertise, and were prepared to admit to this. However, there was a ‘sense of self satisfaction’ in this that suggests pride in their work. One HCA excuses herself by suggesting ‘that sounds terribly pompous’, when talking with pride about the fact that the patient’s skin was still intact ‘and part of that was due to me’. I interpret this as humility in having felt she had overstepped the mark in even being proud of her work. This sense of satisfaction was also a component of the community experience that I interpreted from the behaviour of one of the family members when I visited his home to carry out the interview. When I arrived he was carrying out care activities. My (impression) was that he wanted to show me how well he was caring for his wife and that he felt a sense of pride in this and he had waited until I arrived so he could show me how well he was caring. The very high standard of care and the love that he put into this care is verified in interviews with others who were involved with this particular case*. The reward for caring is internal and comes in relation to a pride in a job well done that is not contrary to humility.

Pride in a job well done is not pretentious, it does not distance; rather it goes with an honest awareness of what I have done and the extent of my dependence on the co-operation of others and on various conditions. There is nothing incompatible between pride, in this sense, and humility (Mayeroff 1972:25).

Humility implies a space beyond emotion, a space that is silent because there is no way of expressing what is experienced, where there are no more questions that can be asked and therefore no answers to what is experienced. Being in the presence of the

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*Jonathan’s Father: We just put it down to love. It’s the only thing that I can think of. I’m just doing what he would want us to do. (TVD: 183-184)
overwhelming weakness of the Other, took participants into a space and experience of complete powerlessness, helplessness that is however, transient (Kunz 1989). Although humility, within the hospice environment, has not been researched I believe that this category reflected the historical and founding basis of the religiosity and spiritual focus of the hospice movement. It also, perhaps, reflects the 'type' of person who is drawn to work in the environment, where the ability to be present with the dying I believe contributes to experiencing humility. The 'ritual specialist' (Froggatt 1995) then becomes a very apt title for the nurse who is holding the dying person within this liminal space. Holding specialist knowledge, as in the 'ritual specialist' nurse, is a crucial ingredient for the management of the hospice system and the means by which care is controlled and the equilibrium is maintained in a balanced state. When the knowledge is 'missing', the system must adapt, i.e. gain this knowledge.

5.6 Becoming knowledgeable – adaptation within the system

To survive, the system must adapt, and here I propose that adaptation is the ability to maintain balanced, successful transactions, such as gaining knowledge, with the outer environment. Maintaining equilibrium through control requires the system to regulate the input and transformation processes (Katz and Kahn 1966). Gaining more knowledge contributes to maintaining equilibrium and can be a means of control. Staff needed to become knowledgeable about the new disease as a strategy to maintain the system equilibrium. I propose 'becoming knowledgeable' (Figure 8) as a first level category due to the novelty of the disease. At the stage of not knowing, the 'need to know' and curiosity and horror about the disease was heightened for hospice teams and the public. Becoming knowledgeable increased the confidence of the hospice staff but had a bewildering effect on family members. This category
A new disease (variant CJD) entering the system

NOT KNOWING

Finding a place for the new, curiosity, and disturbance of system equilibrium

NOVELTY

Fitting in
‘Opening the floodgate’
Did fit
Didn’t fit

Gossiping
Ghoulish voyeurism
ignorant outsiders
‘Drawn’ to stories

Horrifying
‘Worst possible nightmare’

Personhood status

CONTROLLING
Use of strategies to maintain the equilibrium of the system

In-house
Managing care
Restoring dignity
Granting autonomy
Normalising

Maintaining the environment

HUMILITY
Helplessness and realisation of system limitations

BECOMING KNOWLEDGEABLE
Adaptation within the system

Bewildered family

Hospice Service
‘Container’
(Open system)

System boundary

Figure 8. Becoming knowledgeable – adaptation within the system

‘Dealing with the Unknown’

An explanatory theory of managing the care of the person with variant CJD by the hospice service.
completes the theoretical explanation of dealing with the unknown in managing the care of people with variant CJD by the hospice service. When an admission was achieved, both into the community and inpatient services, a number of metaphors express the experiences of the participants in fitting a case of variant CJD into the hospice service for the first time. They were dealing with the death of younger people, extreme bereavement issues for very distraught relatives and attempting to answer questions they did not have answers for. Dealing with the death of young people is not unusual for hospice teams, but the mode of the death and the symptoms of the disease created disturbance (imbalance) within the system and they needed to work towards restoring the balance. Participants did not use malevolent watery or fiery metaphors, reflecting a sense of having some power over the situation that they didn’t have over potential numbers of people to become infected with variant CJD. They were not so powerless that they could be overwhelmed by it, nor even a suggestion that they would have been out of their depth. The metaphors reflected not knowing and a sense of not being able to ‘see’. They were ‘in the dark’, ‘we were all blind’, ‘going in blind’. This idea of ‘blindness’ or being ‘in the dark’ is demonstrated in Andershed and Ternestedt’s (2001) metaphorical model of hospice work, where the rapid illness trajectory was conceived as having ‘involvement in the dark’ and created a sense of non-meaningful involvement for staff and families.

Becoming knowledgeable was seen as a ‘constant challenge’ and was connected to the assessment process. Metaphors that reflected needing to get hold of the situation where, ‘get to grips with’, ‘sort out’, ‘trying to nail it down’, ‘get to the bottom of’, ‘work out’, get ‘things in place’, and becoming ‘switched on’, indicated potential for moving towards becoming more knowledgeable about variant CJD. At the very
beginning of learning how to manage the cases they were, *starting from scratch*. The metaphors suggested some sense of being able to become knowledgeable, that it wasn’t impossible but that it was *a tall order*. They saw gaining of knowledge as a requirement, *going on an information hunt*, and they attributed the successes they did make, particularly in relation to symptom management, as that of *trial and error*.

Although the teams were expert enough to apply knowledge of other terminal diseases to the management of variant CJD, such was the ‘newness’ of variant CJD that members of the system were hampered by the lack of access to the ‘scientific knowledge’ (earlier cases). Teams found they were missing information. It was coming out in, *little pieces*, *little leaks*, almost exclusively, at that time, through the media, and the information was *all very patchy*. The release of scientific information through the media has been a matter of debate for decades and remains a matter of debate (Pini 1995). As suggested by Lacey (1994) on the subject of BSE, there were serious implication for humans, identified by the BSE crisis, that were completely ignored by politicians and health care policy makers. This lack of important input from other sectors of the scientific/healthcare community also threatened the equilibrium of the system, in that knowledge on how to *control the symptoms* of any disease was an important component of maintaining balance.

One hospice team did have some experience of caring for other types of CJD but these experiences were different and not applicable to the case of variant CJD. The person with variant CJD presented with a completely different pattern of the disease to a
person with iatrogenic CJD. As discussed within the CJD literature cognitive impairment is not a major symptom of iatrogenic CJD.

*CNS* ... *we had one other CJD patient but his was through growth hormone and it was a completely different pattern he was able to communicate to a certain degree right up until he deteriorated.* (W1:40-48)

The important point, in relation to the ability to fit the person with variant CJD into the system, was that the person with iatrogenic CJD could communicate until at a very advanced stage of the disease.

The result of the 'new' admission and the decisions involved caused changes in the practices of some of the hospice staff. It manifested in attitude changes to the appropriateness of admission of 'unusual' cases to the hospice services. These were reviewed by teams. The following extract reflects how such an event can lead to reformulation of admission criteria into a service that was predominately focused on the cancer death.

*DR* I think once we'd all been in we felt that it was so right that there wasn't a problem but you obviously don't know what to expect. And I think um, I think it probably does reflect, I mean I think it, it changed. I think it sort of changed my attitude a little bit to, you know how precise we are about who we take on and we've got to do the best or whatever your criteria claim that you have to be a bit flexible. (V1:847-852)

Decisions about treatment changes needed to made quickly, 'thinking on your feet'. This idea of 'thinking on your feet' is not new for hospice environments, where
assessment is a constant process. Gaining more knowledge increases confidence. This then lessens the need to control. Knowledge was also seen as providing security for the families and giving them confidence in the care they were receiving in the hospice. It also served to give relief from anxiety to the team as well. The following comment made by the CNS is made with confidence in her ability to manage a case of variant CJD by dint of her previous experience. She uses this to inspire confidence in the family members of the ability of the hospice service to provide good care for the person with variant CJD.

CNS His parents hadn't realised until they got here that we'd ever looked after anybody with CJD before and we talked to them about we'd looked after three or four people and they were really relieved then weren't they. (Z1:591-594)

The disease was no longer a 'novelty', and even suggested by one doctor, in relation to a 2003 case, to be 'quite uneventful'. The number of times and various ways of expressing not knowing was reduced substantially in the focus group and single interviews with the team who had previous experience of caring for a range of types of CJD. This confidence in symptom management is also verified in the patient's hospice records. That is, there was no record of concerns about not knowing what interventions to use. Scientific developments and research into the disease was ongoing and it was no longer really new, at least not on the scale of the earlier cases.

DR I suppose looking back, his um terminal care overall was quite uneventful and you know quite sort of you know, he didn't have any very unusual difficult to handle kind of symptoms, which I perhaps go by the book you know. I certainly, you know, I can't remember his terminal care
Kunz (1998:63) maintains that knowledge is only powerful when it motivates. He equates understanding and intelligence with knowledge and proposes that understanding strengthens the possibility of, but does not guarantee, making good judgements and choices (Kunz 1998). By becoming knowledgeable, the practices within the system did not change substantially. That is, sedation practices were not reduced and changes in attitudes towards maintaining a serene environment had not occurred. Attitudes toward and understanding of, awareness contexts or emotional responses of people with cognitive impairment of the type occurring in variant CJD had not changed. The change that took place appeared to be merely functional. The team (who had gained some experience through repeated admissions of people with different types of CJD including variant CJD) used sedation measures earlier in the treatment rather than later. They used sedation for the same reasons as discussed in the section on restoring dignity. The focus of discussion was on symptom control and they felt confident enough to use the treatments they were familiar with. It remained based on 'not knowing' what the person was experiencing and making the assumption that any agitation equalled physical pain, or, even using pain controlling measure based on the 'possibility' of pain being present.

CNS We went in fairly quickly with the midazolam, between 10 and 20 milligrams, it wasn't a lot, but I remember we went in fairly quickly with them and some diamorphine because we didn't know if he was in pain ... (Z1:267-270)
The use of sedation measures are however, advocated as part of ‘good’ practice in managing the care of people with CJD (Barnett 2002; de Vries 2003a), so they were acting within the accepted medical practices of symptom control for this disease.

The experiences discussed in the sections related to personhood status and control still remained. The perceived need to ‘get something back’, analogies of non-personhood and surprise at the family claim that the person with variant CJD recognised familiar people, were still present. For this group it was no longer new and therefore no longer novel, so curiosity and horror specific to the disease was ‘blunted’. However, the second case of variant CJD that the team cared for presented a totally different profile from the first case. That is, their first experience was with a young woman who had young children. The second case was an unmarried man in his mid 30s, who also has a learning disability. Identification with the personal circumstances of the dying person had a strong emotional impact on the hospice teams, especially those who were at a similar stage of life and had similar circumstance as the dying person i.e. young children.

Variant CJD did remain a novelty for members of the public and this was recognised by the team. Surprise was expressed that family members were so open about telling other families at the hospice about the variant CJD diagnosis. The comment reminded the group about AIDS, a factor in all cases. There was a suggestion that there was more stigma attached to AIDS than to variant CJD and may explain why the family felt free about revealing their son’s diagnosis. This was the only time in the entire data that the term stigma was used and this was in reference to AIDS. ‘Stigma’ was however, implied at times (see category of ghoulish voyeurism). It can be argued that
despite Sontag (1988) suggesting that diseases, for example tuberculosis, cancer, and HIV, whose cause is uncertain and whose treatment is limited tend to evoke fear and revulsion, i.e. stigma, this has not extended to the variant CJD group. The mode of infection for variant CJD and the age of those infected fits with Sontag’s (1988) premise that some individuals do not necessarily experience stigma, such as ‘innocent victims of HIV’. That is, haemophiliacs and babies who have acquired HIV through blood products or maternal transmission.

The experience may have been less horrific for the hospice team but for the family it was new, horrific and profoundly traumatic to have a family member with variant CJD. This is also demonstrated in the continuing media reports of families as new cases are diagnosed. Any move towards becoming knowledgeable depended on individual responses to the experience. (see literature section on the drive for cure by families). Control, as a fundamental function of the hospice practice, as in all health care environments (Hinshelwood and Skogstad 2000), remained a feature for the team who had experience of previous cases of variant CJD. Becoming knowledgeable maintained a strong link with control and little link with the category of humility. Data that I interpreted and categorised as being humbled by helplessness and a realisation of limitations (from earlier cases) was absent in the team who had previous exposure to CJD cases. This absence suggested that humility was no longer present when the team felt more knowledgeable and in control. This has implications for even suggesting a category of humility. However, according to Kunz (1989), humility is a momentary experience. The lessening of expressions of shock and horror, lessening of in-articulation of the team who had previous experience in caring for
variant CJD, suggests a similar response of ‘blunting’ to the now-not-new that also lessens potential to be humbled.

The learning that took place for the hospice organisation falls into the ‘single-loop’ learning process proposed by Morgan (1997:87) who also raised the question of whether organisations can learn to learn. Single-loop learning requires the ability to detect and correct error in relation to a set of operating norms and is presented in a process of steps. Step one is the process ‘... developing an ability to scan the environment, set objectives, and monitor the general performance of the system in relation to these objectives’. This basic skill is often institutionalized in the form of information systems designed to keep the organization ‘on course’, or, in the language of Katz and Khan (1966), in equilibrium. In step two, this information is compared against operational norms, and step three is the process of initiating appropriate action (Morgan 1997). In ‘double-loop’ learning a further loop (at step two) is proposed where the process of questioning whether operating norms are appropriate takes place. The ability to achieve proficiency at double-loop learning often proves elusive for organisations (Morgan 1997). My findings confirm that very little ‘double-loop’ learning took place and that learning only occurred at step two of the process, i.e. that the hospice service was kept ‘on course’ and medicalisation was the focus.

Morgan (1997:89) discusses the universality of ‘defensive routines’ that may have become a central part of the culture of the organisation, as barriers to the double-loop learning. These defensive routines generate shared norms, and patterns of ‘groupthink’ that may prevent people from addressing key aspects of the reality with which they are dealing. New knowledge was focused on symptom control and
gaining practical skills in controlling variant CJD ‘symptoms’. There was little focus or development towards understanding and attitudes to the dementia behaviour, or consideration of the appropriateness of sedation for this type of illness. I suggest the person with variant CJD came to be seen as just another person with a range of neurological symptoms that needed to be dealt with pharmacologically. Normal ‘medicalised’ hospice practices of symptom control were integrated into the repertoire of skills used for other types of terminal illnesses.

For family members this heightened state was related to the ‘need to know’ and horror of the experience. For the family, curiosity was something they wanted to be protected from as they were the target of the curiosity. In becoming knowledgeable the horror and curiosity was blunted for the hospice team that had previous experience of the disease and they felt confident and ‘in control’. For family members there was no blunting of the experience, the effect of becoming knowledgeable manifested a state that I have categorised as the ‘bewildered family’.

5.6.1 Bewildered family

Finding out more about the disease was a bewildering experience for family members. They were bewildered by the media information and the scientific and medical information they were given, some of it conflicting. They were in some ways dealing with an equally bewildered scientific community. These experiences interlink with the concept of horrifying. It was difficult for them to come to terms with the concept of a new disease, with questions of how did it happen to them, what had they done
wrong, elements of guilt about food and anxiety about potential of other family members also being infected by the disease*.

*Kate’s Mother: I personally myself, being a mother, mother puts the food on the table, I still feel a certain amount of guilt really. Because I think she could still be alive if we, you know, hadn’t been. If we had fed her vegetarian food all her life, she would have still been with us and to think what an easy thing to have done and we didn’t do it. (TPD:222-227)

FM You realise that sort of thing’s happening. Because, um, well in a lot of ways she’s been killed, it’s like putting a bullet to her head, a gun perhaps and pressing the trigger really, because you know, they should be more careful with what they give their animals. We don’t even know how it starts which is hard but then you think that anyway. (W1:494-498)

In one case the family member made the diagnosis based on listening to a radio programme. Another family member (2003 case) couldn’t understand why his brother was not diagnosed earlier when he remembered an article he had read earlier that clearly identified the symptoms. Confidence in the medical and scientific community was undermined for all family members with expressions of bitterness and disappointment on how the diagnosis was made and how they were informed of this.

*FM It was only this Sunday he came to dinner with us and he said he couldn’t understand why doctors couldn’t diagnose it earlier because um after we found out what was wrong with (PATIENT), he remembered having read an article about CJD in a magazine, and thinking my God this is just like (PATIENT), so he said if I could pick that up, why can’t doctors pick it up earlier. (Z2:537-543)

One family member also found the language related to variant CJD and the neurology of prion disease extremely confusing, ‘to me its in gibberish, and you don’t understand the words that are written there’. The public has expectations of the
scientific community to provide accurate information on health risks, often based on research (Pini 1995). Variant CJD, as occurred in the early days of HIV and AIDS threw the public into confusion and turmoil. They did not know when or how their family members had contracted the disease*. Or why it happened to one family member and not another. Furthermore there was bewilderment for parents about the future potential for their children to become infected and for siblings what their risk might be.

5.7 Summary

'Dealing with the unknown' provided a theoretical explanation of the experience of caring for a person with variant CJD by the hospice service. 'Not knowing' or the 'unknown' was a core category that underpinned the four categories of novelty, controlling, humility and becoming knowledgeable. Other theories of hospice practice were used to inform the findings. The theoretical explanation also demonstrated change over time of the participant experiences which were presented within the category of becoming knowledgeable. I have presented the hospice as a metaphorical container in which dying was managed by staff who had specialist training and experience in the subject of death, dying and bereavement, that is focused on the cancer death. The experience of the admission of people with variant CJD into the 'container' caused an imbalance in the equilibrium of the system. The hospice is an open system with boundaries that are managed in a very flexible manner. This

*Claire's Mother: And I look at the pictures of her at parties back then (when she was six) and I think, did she eat a sausage roll? Is it then? Is it then? (Pearson 2000)

Kate's Mother: I look at her, all the photographs of Kate. I think she was the most photographed child that ever lived, because she was the baby. I look at her now and I think, you know, had she got it in her brain now. I look at her, six, seven, eight nine ten. We'll never know. (IVD:240-243)
flexibility of the criteria for admission allowed the entrance of the new disease of variant CJD. The appropriateness of the hospice as an environment in which such a disease should be managed was paradoxical. It was both appropriate and inappropriate based on individual family circumstances and attitudes towards hospice services. There remained an 'agenda' within the system where it was understood that all measures should be used to maintain a peaceful and calm environment. The in-house teams did not appear to be aware that they practiced in a controlling manner and that the practices did not correlate with how these were viewed by in-house admission family members, who saw the hospice as a site of excellence in care practices. This was contrary to the view held by one family member who likened the hospice admission to 'abuse'. Repeated exposure to the disease may have caused a 'blunting' of responses to the horrific nature of the symptoms and allowed the easing of anxiety where becoming knowledgeable about the disease inspired confidence for the teams giving them a sense of retaining control.

In Chapter 6 I conclude my thesis and provide a critique of the chosen methodology and methods of data collection and data analysis. I also offer recommendations for education, practice and further research.
Chapter 6 – Critique of the study and conclusion

6.1 Introduction
In the first section of this chapter I address the contribution the thesis makes to knowledge and provide a discussion on the theoretical implications of my findings. A critique of the methodology and methods used to conduct the study is offered. This is followed by a discussion on the education, practice and research implications of my findings and recommendations for further development are made. I then conclude the chapter with a discussion on the contribution the study makes to an understanding of hospice culture and practice and how this may be understood within an open systems framework.

The first and important point that must be made is that this study does not provide an explanation of activities within hospice services per se. It provides an explanation of what occurred in the event of the variant CJD admission. What the study primarily revealed was a number of paradoxes about how the practices within the hospice system were constructed, or understood, by staff, as opposed to family members, when they were caring for a person with variant CJD.

6.2 Contribution to knowledge
One of my research aims was to provide a theoretical explanation of participant experiences, in keeping with grounded theory methodology using a constructivist approach, i.e. a substantive theory would have been the outcome based on confining the findings to a specific group and through group consensus of the experience. This did not occur due to sampling issues, however, substantive theory is a strategic link to the formulation and generation of formal theory and emergent fit of existing
substantive theories of hospice care, plus open systems theory were used to develop the beginnings of formal theory. As pointed out by Glaser and Strauss (1967) the main benefit yielded by grand theories i.e. open systems, is their use of abstract models and that the integration of formal theory often requires more guidance from explicit models (grand theories) because of a greater level of abstraction. The theory presented thus has been derived from a small sample but lays the foundations for formal grounded theory about understanding how health care workers, family members and others may respond to 'not knowing' when faced with a new situation or a situation with which they were not familiar, within an organisation or system. To develop formal theory more completely the phenomenon would need be studied in multiple contexts and applied to a wider range of disciplinary concerns and problems (Strauss and Corbin 1998).

In presenting a theory of 'Dealing with the unknown' I have shown that the core category of 'not knowing' meets the criteria set out by Strauss and Corbin (1998) in that all other major categories could be related to it. It appeared frequently in the data and its relationship to other categories is logical and consistent. This included how 'Dealing with the unknown' was used to demonstrate change over time, moving from 'not knowing' to 'becoming knowledgeable'. Categories were congruent with the research objectives and related to the experience of the hospice team in providing care for the person with variant CJD, at the end of life, and within the hospice context. The meanings have been conveyed through rhetorical means such as metaphors, analogies, and paradoxes.
The results of this study cannot be viewed as a static piece of knowledge or interpretation of the events and experiences, but as experience and knowledge in a state of flux, as demonstrated by the change over time that occurred with participants moving from a state of not knowing to 'becoming knowledgeable'. According to Rock (1979:30), 'at best, a synthesis can lead to a temporary freezing of knowledge so that it becomes available for inspection, but it cannot do more'. No sociological understanding can attain a state of finality and closure and thought must generate more thought, just as action multiples itself. The successful communication of theory intelligibility provides the grounds for theory usefulness (Hassard 1993). That is, one criterion of credibility is satisfied 'if a reader becomes sufficiently caught up in the description so that he feels vicariously that he was also in the field' (Glaser and Strauss 1967:230).

Some confirmation of my findings conveying to others the immediacy of the experiences of participants was revealed to me on presenting data from my preliminary theoretical framework at a number of conferences (de Vries 2003b, 2004). This also occurred during teaching sessions on providing palliative care for people with dementia. Following the presentation, and at a number of teaching sessions, I have been approached by district nurses who have related to me how closely they identified with the experiences of my study participants. They reported how it brought back vividly their own experiences of having looked after people with variant CJD. However, I approach this confirmation with caution, in keeping with Rock's (1979:30) suggestion, that 'a theory cannot be more than one of an indefinite number of legitimate vantage points on social processes'. The real can never be wholly known, there is a most profound difference between a description and what is
described and all that may be accomplished is a cautious reconstruction by means of intellectual categories that enhance understanding (Rock 1979). I have presented the theory with these premises in mind.

I believe that the theoretical explanation presented in this thesis may provide an image of one aspect of hospice organisation. However, it is important to remember that the experiences of the admission of a person with variant CJD, into the hospice system, provides only a ‘micro’ view of one type of event amongst the many processes in providing care for the dying and bereaved within hospice services. As shown in Figure 4 the findings need to be understood within the wider context of other theories of hospice practice. It is however, a theoretical construct that could be explored, developed and applied to other settings (systems) where a new type of condition is introduced. For example, a case of SARS admitted to an NHS ward, or the introduction of children with learning disabilities into mainstream schools.

My findings contribute to, and build on, other studies that have presented hospice as an organisation, albeit not explicitly, particularly the work of Lawton (1998a, 1998b, 2000), where it has been suggested that hospice practices maintain a sequestered and controlled environment for dying people. They also provide some confirmation of Lawton’s (1998a, 1998b, 2000) premise that hospice is an environment in which death is ‘processed’. This processing is carried out by ‘expert’ palliative care staff or as Froggatt (1995) termed ‘ritual specialists’, who control the passage of dying in various ways. My findings confirm the view of hospice as a liminal space, as described by Lawton (1998a, 2000) and Froggatt (1995, 1997). Hospice was shown to be a place of protection and an environment of ‘family like’ ambiance, where close
and intimate relationships are formed between nurses and patients (Froggatt 1995, Copp 1996, 1999; Li 2002), in the case of my study, between nurses (more particularly than other hospice staff) and family members.

I believe my thesis makes an original contribution to the concept of humility. Humility is a mysterious and unexplainable event/experience that is difficult to define. It cannot be 'known' by the experiencer and can only be partially explained or interpreted by the researcher, through observation and interpretation of discourse, including 'silent discourse'. I use the term 'silent' as an expression of being beyond words to articulate the experiences of participants in being faced with their limitations in dealing with the perceived horror of, and helplessness in, providing care in the event of the variant CJD death.

6.3 Methodological and method critique and study limitations

6.3.1 Sampling

Sampling issues were discussed in detail in the Methods chapter. The study was constrained by the small sample size but this was an issue that could not be overcome due to the peaking of numbers of people diagnosed with variant CJD during 2000 (Andrews et al 2003; Andrews 2005) and thus puts limitations on the generalisability of my findings. The continuing decline in numbers, coupled with the support packages that were put in place, made access to the patient group even more difficult. The sample is from three hospices in the South of England, a larger sample could have enabled a broader perspective from a wider range of hospice sites. A further limitation was that I only had three full data sets, i.e. data sets that included interviews with family members. This was due to gate-keeping by hospice staff, and to
inaccessibility of family members. However, the data was comprehensive and rich and provided ample material for analysis of their experiences, particularly of the hospice teams. Although the data from the community family perspective was rich and detailed, only one family member of a person with variant CJD who was nursed at home was recruited. A larger data source for analysis may have affected interpretation of the experiences of this group. I was not able to interview all staff involved in the care of the people with variant CJD from each hospice site, as many had moved on to other positions by the time I gained access.

I had also planned to use a second moderator in facilitating the focus groups to enable better note-taking that would have assisted me in identifying and recording group member interactions more precisely. This was not achieved because it required the person who had agreed to act as a second moderator to take time off work and travel with me to the different sites.

A further issue of interpretation of the experiences of the sample used in this study is the diversity of each situation. Each of the family stories and circumstances were individual, as were particular practices of the hospices and from this I have created a conceptual model that incorporates the commonalities within the participant experiences.

### 6.3.2 Trustworthiness

Every effort was made to maintain rigour throughout the study. One of the strategies for establishing trustworthiness is the use of participant confirmation (Silverman 2000; Stake 1995), although there are arguments against this process as discussed in
the Methodology chapter. This process was used only for the pilot study. A full manual analysis of this was conducted and taken back to some (not all were available) of the participants. Much to my regret I did not audiotape this focus group interview and had only field notes to use in further analysis of the interactions and discussion that took place within the group. This second focus group was useful in providing confirmation of my interpretation of the pilot data. Responses were similar to those from delegates at conferences and study session presentations on the preliminary theoretical explanation developed from my pilot as mentioned previously. Due to time constraints, distances to travel, difficulties in arranging even a first focus group interview, let alone repeated interviews, and changes in staff at different sites, I was not able to use this process for further data sets as I had initially planned.

Charmaz (2003b) makes the point that one-shot interviewing undermines grounded theory research. The logic of grounded theory method calls for ongoing analysis to direct data collection, in a self-correcting analytical, expanding process (Charmaz 2003b). According to Charmaz (2003b) one-shot interviews miss opportunities to correct earlier errors and omissions and construct a denser more complex analysis. Multiple sequential interviews chart a person’s path and permit independent checks over time allowing the ‘story’ to gain depth, detail and resonance (Charmaz 2003b).

I would have also liked to have carried out repeat interviews with family members, particularly following audio-tape transcription and early analysis, for the reason outlined by Charmaz (2003b). However, to do this I believe would have been ethically inappropriate based on the number of times that family members had already been interviewed and on the perceived traumatic nature of the experiences they were
being interviewed about. The interviews were also deeply emotional experiences and had a powerful impact on me. On one occasion I needed to speak at length to the social worker I had identified as support for myself and the family member. I was anxious that I had stirred up memories and caused distress to this family member. I had no 'real' evidence of having distressed him. I based this judgement on his reluctance to talk in detail about his experiences, and although I attempted to prompt and probe for responses I was also reluctant to do this at any length. I did not terminate the interview early but I allowed it to become a long conversation about work and travel and sport, subjects that he appeared to prefer to discuss. I had this sense of invading the world of this person's suffering, trying to collect research data about events that I could not imagine for myself.

Based on his own experiences Frank (2004b) offers a personal critique of suffering, asking; Can we research suffering and still show that we care about the person who is suffering? This is a dilemma for any person who is conducting research about the suffering of others. In dealing with some of the difficulties in conducting this type of research Frank (2004b:424) proposes that based on his own work, one method is, 'to use academic privileges of publication and platform to amplify the voices of the ill themselves, offering them previously unrecognised connections and a sense of community.' This also raises the point made in my ethical discussion about empowering participants in research. My feelings now, for post-doctoral research, would be to develop an approach that offered potential for research participants to openly own their own story. To move away from what Patton (2002) posed as a possible protective or patronising stance towards research participants. Further development of this work, i.e. post-doctoral work on end-of-life dementia care, where
other methods of data collection, such as repeated interviews, participant or non-participant observation or prospective longitudinal study methods, will enable the expansion of the findings presented in the thesis.

6.3.3 Retrospective accounts

The data for this study involved retrospective accounts of experience and as pointed out by Addington-Hall and McPherson (2001) the impact of bereavement on the memory of bereaved family members is as yet unexplored. Credibility is therefore questionable, as the data relies on accuracy of memory of events that occurred approximately a year previous to the interviews. All except one interview was conducted within a year of the death of the person with variant CJD. The hospice records did, however, provide a source of cross-checking data from the interviews. In the three-year-old case, participants referred to the hospice notes throughout the interview. They had also developed teaching material following their experience which they referred to during the interview. Their memory of the events appeared very vivid and may have been reinforced by the teaching sessions they had provided on the subject of variant CJD over the three years.

Retrospective memories could account for the discrepancies between what different members of staff remembered about the patients. Nevertheless, claims to obtaining accurate participant memory recall on any experiences must be viewed with caution. Focus groups did however, serve as memory prompting interactions. They allowed the potential of reminding each other and building a picture of the experience between the members.
6.3.4 Data analysis (tabulation)

A critique of my methods of analysis has been given in Chapter 4. However, I return briefly to the subject of the use of tabulation in qualitative research. Tabulation is an approach that needs to be used with caution, as discussed earlier, particularly using interview data. Its use in ethnographic methodology, for example using discourse and conversation analysis, provides a naturally occurring data, as opposed to the 'artificial' situation of an interview. However, I would argue that interpretation of the 'naturally occurring' data remains subjective, as does all qualitative research data. In their critique of participant observation and interviewing Atkinson and Coffey (2003) state that if we accept that interview talk is action it is therefore as legitimate a representation of events as an ethnographer's field notes, often written down retrospectively. Free discussion was intentionally developed within the focus group and interviews. This did provide a degree of naturally occurring conversation and may have provided a close representation of the actors' 'real' actions, expressions and feelings, therefore justifying the use of tabulation as a form of increasing rigour. Every effort was made to ensure that the use of tabulation was rigorously contextualised to the conversation. The use of tabulation within qualitative research has been likened to 'building bridges' between methodologies to add credibility to qualitative research (Garnett 2000; Li 2002) and is in keeping with the view that we are now in the decade of grounded theory diversification (Benoliel 1996).

6.4 Implications for education and practice

Education and practice implications are integral to the need for research that examines interventions that may enhance the care of all people with end-stage dementia. The predictions of numbers of people who may become infected with variant CJD are as
yet unquantifiable. Whilst variant CJD has a somewhat different disease trajectory to other dementias, my findings have implications for the education of health care professionals who are exposed to the end-of-life needs of people with other types of dementia. I make the following recommendations in relation to education and practice.

- The success of the variant CJD home-care package, where most people with all types of CJD are now cared for at home, suggests that these could provide a template for developing care packages for the wider dementia group and should involve collaboration between hospice and dementia care specialists. The success of such packages of care being put in place for the old age group with dementia has been demonstrated in the USA (Volicer et al 2003).

- In the coming climate of increased numbers of people with dementia of old-age, and the possible increase in numbers of people with CJD, either variant or sporadic, education initiatives are of paramount importance. Neither palliative care or dementia care knowledge and skills are taught as a core component of undergraduate nursing education whilst, most people with dementia are cared for by general nurses and approximately 56% of all people die in hospitals (NCHSPCS 2004). This anomaly needs to be rectified within nurse education programmes at both pre and post registration levels.

- Dementia syndromes are, in the majority of cases, caused by terminal illnesses, as in the case of CJD. Therefore assessment processes need to include making preparation for support during the dying process for this group
of people. This could be achieved through early discussion and documentation of preferred place of care, at the end-of-life (Pemberton et al 2003; Storey et al 2003), so that support mechanisms can be put in place as the dementia progresses. It could helpfully involve collaboration with palliative care community services and other primary care workers, to ensure a streamlined service of care provision. Practice developed through the Preferred Place of Care research for people with cancer could be further developed for the dementia group.

- Whilst it is important for palliative care professionals to extend existing skills in end-of-life care to include the needs of people with dementia, initiatives may be better employed in developing palliative care skills for people who already have skills in caring for people who are cognitively impaired. This calls for a more collaborative approach to the education on end-of-life dementia care, where the skills are shared between the specialities.

6.5 Recommendations for further research

The above recommendations for education and practice development also offer potentially areas for research in the field of CJD and dementia care. I make the following recommendations specific to potential research that stems from this study.

- Further study is required on the experiences of families and carers of people with variant CJD that is located within the community, with participants drawn from the wider primary care team of district nurses, community psychiatric nurses, general practitioners and social service professionals. As
this is a relatively unexplored area within the UK qualitative research approaches would be the most appropriate for early exploration of these experiences.

- An area of potential research is to explore nurses’ use of sedation within hospice practices. As demonstrated in this thesis, and shown by Morita et al (2004), there are implications of how sedation is used in dealing with organisational anxiety in end-of-life care. Based on her personal responses to an observation study within a hospice Ramsay (2000:151) notes, ‘Until professionals acknowledge the impact on themselves of working closely with dying patients, they are unlikely to recognise its impact on their clinical practice’. There are a number of methodologies that could be used to examine the use of sedation by nurses, both quantitatively, possibly replicating Morita et al (2004) questionnaire study, and qualitatively, through observation and interviewing processes. The focus group and interview approach used by Brajtman (2005) examining challenges experienced by the interdisciplinary palliative care team in managing terminal restlessness using sedation as a treatment of choice provides a basis on which to develop a more extensive qualitative study.

- The hospice movement has always placed the multi-professional team as central to its philosophy (Saunders 1990; Clark 1993; Clark et al 2005), yet a range of mono-professional grouping representing the individual teams of hospice professionals has emerged (Clark 1993). This confirms the diversity of roles, norms, values, priorities, preoccupations and culture of these teams
(Stokes 1994a; Haslam 2004) and suggests that these may have a range of influences on service provision within the system. There were variations in the type of talk and attitudes to practice between the different members of the hospice teams in this study. I did not attempt to separate the differences between health care assistants, nurses, doctors or social workers, as I wanted to retain a focus on the organisation as a whole in the management of the variant CJD death. Further research is needed that delineates between the roles that members of the team have, and how these contribute to understanding the organisational primary tasks, and to the balance and equilibrium of the hospice system as a whole. Research approaches that use organisational observation methods developed by the Tavistock Institute would be an appropriate and useful means of investigating these processes.

6.6 Conclusion

This study set out to explore the issues that arose in caring for people with variant CJD within hospice services, to describe those experiences, to identify strategies used by hospice teams and family members in providing care for people with variant CJD and to provide a theoretical explanation of the events.

The impact of the experiences of providing care for people with variant CJD was complex and challenged hospice staff to consider elements of care in different ways. It was evident that hospice palliative care skills could be applied in caring for this patient group. Hospices appear to be suitable and appropriate environments in which to provide end-of-life care for people with variant CJD and community palliative care teams are appropriately placed to work with the wider primary care team in managing
these deaths at home. I believe the success of this can be attributed to two aspects of hospice care. These are the level of specialist expertise that exist to manage symptoms that change rapidly and require constant reassessment, and the high nurse patient ratio (of in-house units) that enabled and created the atmosphere of 'family ambiance' identified by family members.

I have shown how the hospice may be viewed as an open system in which the variant CJD death was processed, using skills and knowledge that were extrapolated from those used to manage the cancer death. I have argued that hospices appear to operate at three different levels of consciousness in carrying out their primary tasks in the delivery of specialist palliative care. What they say they are doing and what they really believe they are doing is providing the so called 'good death'. What may actually be going on, at an unconscious level, is related to how the 'good death' is achieved. The primary strategy that was used (in-house) was that of controlling the anxiety that the event of the variant CJD death created within the hospice environment. The findings confirm other work that has examined the management of organisational anxiety within health care environments.

I have presented the hospice as a metaphorical 'container', i.e. an open system, with input, throughput and output of people who are dying, and their families. Within this model boundary management was an important consideration. The 'container', was shown to have metaphorical 'floodgates', through which the inputs and outputs were controlled. These 'floodgates' could both hold-out the 'floods' of potential cases of variant CJD, and close-in and protect the person with variant CJD and their family.
after admission. The opening and shutting of these gates was the way in which the system boundaries were managed.

This thesis will always be a ‘work in progress’ and ‘Dealing with the unknown’ is a theoretical explanation that offers some insights into hospice practices and how practitioners dealt with the new disease of variant CJD. It is also a theory that could be offered to explain a new event in other settings and as a framework for others to refine, revoke or develop.
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Appendix 1

Approval from LREC for first data set (pilot)
To: Kay de Vries,

Dear Ms De Vries,

RE: MANAGEMENT OF END-STAGE NEUROVARIANT CREUTZFELDT-JAKOB DISEASE IN A HOSPICE ENVIRONMENT

REF: 14KDCJ(312) - to be quoted on all future correspondence please

Thank you for your letter dated 31st May 2001 in response to our letter of concerns dated 21st May 2001 with regard to the above research project. This has now been reviewed and I confirm that Chairman’s Approval has been granted to go ahead with this trial.

In future, the Committee would like to follow up all new trials. Therefore, we would be grateful if you could send us an update after a period of a year from the commencement of the study with the following details:-

1. Is the research still continuing?
2. If it is, which stage has it reached:-
   2.1. Data being collected
   2.2. Data being analysed
   2.3. Research being written up
   2.4. Research published.

N.B. If you are sending any Protocol Amendments to us, please ensure that you highlight the areas of change.

Thank you for your trouble.

Yours sincerely,

Selina Harris,
Manager - ESLREC

c.c. JC

c.c. ShH
Appendix 2

Information sheet
TITLE OF STUDY
An investigation into the experience of caring for people with acquired new variant Creutzfeldt-Jakob disease [nvCJD] by specialist palliative care teams.

RESEARCHER
Kay de Vries
Senior Lecturer/Research Fellow

As part of my doctoral study, which I am carrying out at the European Institute of Health and Medical Sciences, University of Surrey, I would like to invite you to participate in a study on the experience of providing care for people who have died as a result of nvCJD. CJD is a rare and fatal disease classified within the spongiform encephalopathies. It is also referred to as prion disease and is closely related to a group of neurodegenerative diseases known to occur in humans and animals. The transmittable agent is either genetic or an abnormal form of prion protein. The emergence of nvCJD is believed to be linked to the bovine spongiform encephalopathy [BSE] outbreak during the 1980s [Will et al 1996].

The broad aim of this research is to explore palliative care staff experience of providing care for people who are dying as a result of nvCJD. To increase knowledge and understanding of providing care for people who are dying as a result of nvCJD, and to identify developments required by specialist palliative care teams in order to provide quality palliative care to this group of people.

Participation in the study will involve taking part in a tape-recorded interview or focus group interview. You are under no obligation to participate in this study. If you do agree to participate you are free to refuse to answer any specific questions and you may withdraw from the study at anytime without giving a reason. If you do decide to participate you will be asked to sign a consent form. Any information you provide in relation to this research will be confidential and will be accessed only by myself and my supervisors. No names will be attached to any information that you give, and the hospice site will be made anonymous.

If you have any questions you would like to ask before you make a decision regarding participation in this study I would be happy to talk to you further.

My contact numbers are:
01483 684635
k.de-vries@surrey.ac.uk
Appendix 3

Consent form
Consent Form

Title of Project: An investigation into the experience of caring for people with acquired new variant Creutzfeldt-Jakob disease [nvCJD] by specialist palliative care teams.

Name of Researcher: Kay de Vries

Position of Researcher: PhD Student, European Institute of Health and Medical Sciences, University of Surrey, Guildford

1. I confirm that I have read and understood the information sheet, dated 10th August 2002, for the above study, and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I agree to take part in the above study.

Name of Participant: __________________________
Date: ___________ Signature: __________________________

Name of Researcher: __________________________
Date: ___________ Signature: __________________________
Appendix 4

Interview guide for hospice staff - for both single and focus group interviews
Interview guide for hospice staff - for both single and focus group interviews

Introductory question:
What were the issues that were encountered when providing care for the person with nvCJD patients and their family [for the patient, for the staff, for the family and for the organisation]?

Focus on issues:
How was the admission managed?
What information was given on admission from other services?
What types of symptoms did they have to deal with?
What medications were used?
Who gave information to the family members/relatives?
What sort of questions did family members/relatives ask?
Were there any issues related to body disposal?

Focus on management:
How were any issues managed?
How was the team allocated?
Who took the lead?
Was there any conflict in decisions made within the team?
Were there any organisational problems?
Where could care have been improved?

Focus on feelings:
How did you feel about caring for patients with nvCJD and their families?
How were you supported in providing care for the patient/family?
What previous experience did you have of caring for people with a dementia syndrome?
What were the responses of other team members?
What were the family responses?
What were the responses from other people in the hospice?

Focus on learning:
What have you learned as a result of the experience?
What were the sources of information on CJD?
How accurate was the information?
How useful was the information?
What were the gaps in knowledge previous to the admission?
Where are the knowledge gaps now?
Appendix 5

Interview guide for family member interviews
Interview guide for family member interviews

Introductory question:
What was your experience of having your family member nursed in the hospice?

Focus on issues:
Where did you learn about the hospice?
Who arranged the admission?
How was the admission managed?
Was the hospice near to your home?
How long did you have to wait for a placement?
How was the team allocated?
Who gave you information at the hospice?
What sort of questions did you ask the staff?
Were they able to answer your questions?
Were there any issues related to autopsy?
Were there any issues related to funeral arrangements?

Focus on management:
How were issues managed?
Were you consulted regarding any treatments?
Did you have a specific contact person?
Was there any conflict in decisions made by the staff and how you wanted your family member to be treated?

Focus on feelings:
How did you feel about using the hospice?
How do you feel about the hospice now?
Appendix 6

Manual coding of interactions for pilot study
INTERACTIONS

Conflict
- Decision making re interventions - who should make the decisions?
- Was this an appropriate admission?
- Level of personhood [did she still have a personality?]
- How people with dementia should be treated [generally]?
- Should have come to hospice earlier/should not have come earlier?
- Professional / personal

Inarticulate
[Beyond helplessness]
- Silences
- Uncertainty

Agreement
- Cohesion
- Comradeship
- Bonded [emotionally]
- Compassion
- Reminiscing
- Team spirit
- Collaboration
- Indignation [re doctors]
- Horror [at disease]
- Helplessness
- Pride [re good care]

Hierarchy
- Language
- Power
- Professional / personal
Appendix 7

'Mind map' of categories for preliminary framework from pilot
Between nurses
Between Dr & nurses
Family [Internal]
Family [external]

Appropriate admission
Risk/no risk
Sedate/not sedate
Person/non person
Aware/not aware
Body disposal
Decision making
Professional/personal

Fascination with unknown
Wanting to know
Experts didn't know

Because of not knowing
Didn't know
Fear of unknown

Contagion Risk
Novelty

Conflict

Distress

Helplessness

Awareness

Humility

Language -
professional/personal
- power

Agreement
Good care
Pride
Hospice right place

Inarticulate
Not knowing
Silences[s]

Hierarchy

TABULATION
List

Not knowing
Appendix 8

Manual tabulation for 'not knowing' from pilot
TABULATION

'Not Knowing' - some of these were repeated several times in various ways

Terms used – ‘don't know’, ‘didn't know’, ‘couldn't tell’, ‘unknown’

- 1:2 whether she was in pain - communication/distress/helplessness
- 1:1 what she was actually experiencing - communication/helplessness
- 2:6 that it would be that bad - distress/helplessness
- 2:7 how you were going to help - helplessness
- 33:6 if she was aware of her surroundings - communication
- 38:7 if she understood you - communication
- 1:3 whether she got any pleasure out of anything that was going on - communication
- 33:17 if she was happy [with care provided] - communication
- 33:4 if she liked what was done to her - communication
- 33:21 who were they doing it for - conflict/distress
- 1:17 what sort of prognosis to look for - professional
- 3:19 so little known about it - professional/helplessness
- 2:1 that this was going to be the course of events - ??/distress/helplessness
- 2:18 how you were going to help the husband and sister - helplessness/professional/personal
- 3:18 whether the children had inherited it - professional/helplessness
- 3:12 anything about the disease - professional/helplessness
- 2:17 what to say to the family [about various aspects of the disease] - helplessness/professional
- 4:4 whether they were at risk from contamination - conflict/distress/professional
- 4:5 that in years to come they will find that they were at risk - personal/professional
- 4:12 prion centre didn't know - professional
- 5:10 whether she could see - communication
- 5:22 if she was comfortable - communication
- ++ whether they had done a good job - conflict/professional
- ++ what were the major symptoms to look for - professional
- 11:1 what they were dealing with - helplessness/professional
- 27:5 doctors didn't know whether - professional/conflict
- 6:5 what effect it was having on the children - helplessness/professional/distress
- 31:22 whether [changes in condition] were the progression of the disease or something they had done or not done - conflict/helplessness/professional
Appendix 9

Manul tabulation of sedation for pilot
<table>
<thead>
<tr>
<th>TABULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sedation</td>
</tr>
<tr>
<td>1:6 1:6 sedation was the most important issue for me - personal / professional / conflict</td>
</tr>
<tr>
<td>1:7 1:7 should have sedated earlier - conflict / professional</td>
</tr>
<tr>
<td>7:10 7:10 sedation best option if risk of falling - professional</td>
</tr>
<tr>
<td>7:14 7:14 sedate because she was screaming - awareness / professional / personal</td>
</tr>
<tr>
<td>7:18 7:18 hoo and cry about sedating - conflict / personal / professional</td>
</tr>
<tr>
<td>7:20 7:20 sedate because she was distressed - professional / distress</td>
</tr>
<tr>
<td>10:14 10:14 not sedated until final week - ?</td>
</tr>
<tr>
<td>11:12 11:12 if it was my daughter I would want sedation - personal</td>
</tr>
<tr>
<td>13:1 13:1 nursed her better when she was sedated - distress / avoidance / professional</td>
</tr>
<tr>
<td>13:9 13:9 did not sedate until had lost ability to swallow - professional</td>
</tr>
<tr>
<td>14:2 14:2 we were giving her her dignity back [with sedation] !! - professional / culture</td>
</tr>
<tr>
<td>18:20 18:20 we all wanted sedation - but doctors wouldn't agree - conflict / professional</td>
</tr>
<tr>
<td>25:23 25:23 might consider sedating a patient with dementia if they were noisy and distressed - professional</td>
</tr>
<tr>
<td>25:13 25:13 you'd think there would be less of an issue about sedation because the 'person' was already gone - awareness</td>
</tr>
<tr>
<td>26:4 26:4 would sedate a patient with the super-sensitivity thing - professional?</td>
</tr>
<tr>
<td>27:5 27:5 we sedate patients who are noisy and screaming - awareness / cultural [professional!]</td>
</tr>
<tr>
<td>27:7 27:7 the doctors do not like to sedate if it is for noisiness only - professional / conflict</td>
</tr>
<tr>
<td>28:10 28:10 sister was not keen to have her sedated - decision making / conflict</td>
</tr>
<tr>
<td>29:17 29:17 if you sedate you are taking away their personality - conflict / professional</td>
</tr>
<tr>
<td>30:1 30:1 sedation can be withdrawn if it has a detrimental effect - professional</td>
</tr>
</tbody>
</table>
Appendix 10

Invitation to hospice Medical Director to participate in study
Dear Dr

As part of my doctoral study, which I am carrying out at the European Institute of Health and Medical Sciences, University of Surrey, I am conducting an investigation into the experience of caring for people with acquired new variant Creutzfeldt-Jakob disease [nvCJD] by specialist palliative care teams. I am writing to a number of hospices to ask if they have had experience in caring for people who have died as a result of nvCJD. If you have had any patients either as inpatients, or cared for by the specialist palliative care community team, who have had nvCJD, within the last 12 months, I would like to invite you to participate in this study.

Participation in the study would involve giving me access to staff who were active in carrying out care for a person with nvCJD, to carry out focus group and/or single interviews. It would also involve having access to the notes of the person who has died as a result of nvCJD. I would also be interested in interviewing any family members of the patient, however, I would only approach them through your staff if you agree to the study. At previous sites I have found that the family members were very enthusiastic to participate in research that would benefit future nvCJD sufferers.

I am experienced in palliative care and in research processes and I would be grateful if you would consider taking part in this study. The broad aim of this research is to explore palliative care staff experience of providing care for people with nvCJD. To increase knowledge and understanding of providing care for people who are dying as a result of nvCJD, and to identify developments required by hospices and palliative care teams in order to provide quality palliative care to this patient group.

Attached is the information letter that would be provided to participants in the study.

Yours truly

Kay de Vries

Telephone: 01483 684635
Fax: 
Email: k.de-vries@surrey.ac.uk
Appendix 11

Agreements from hospice sites
TITLE OF STUDY
An investigation into the experience of caring for people with acquired new variant Creutzfeldt-Jakob disease [nvCJD] by specialist palliative care teams.

RESEARCHER
Kay de Vries
Senior Lecturer/Research Fellow

I ...................................................... *agree/do not agree to allow the hospice to be involved in a research study on the experience of caring for a person who has died as a result of new variant Creutzfeldt-Jakob disease. I agree to allow staff to be approached to participate in single/focus group interviews and I consent to the researcher having access to the medical records of the relevant patient [*Delete as appropriate]

Organisation [Hospice]: ............................................................

............................................................

Name: ............................................................

Designation: ............................................................

Telephone Number: ............................................................

Email Address: ............................................................

Date: ............................................................
Appendix 12

Acknowledgement of agreement to participate in study
[Letter to Medical Directors of hospices who have agreed to participate in study]

Contact address

Date................

Dear.........................

Title of study: An investigation into the experience of caring for people with acquired new variant Creutzfeldt-Jakob disease [nvCJD] by specialist palliative care teams.

Thank you for agreeing to participate in the above study. Following completion of gaining ethical approval from the Multi-centre Research Ethics Committee [MREC] I will contact you to arrange dates and venues for the interviews.

Yours truly

Kay de Vries

Telephone: 01483 684635
Fax:          
Email: k.de-vries@surrey.ac.uk
Appendix 13

Letter of confirmation to participants
I am writing to thank you for agreeing to participate in the above study and to confirm that your interview/focus group will take place:

On ....................................................................................................................................

Time ................................................................................................................................

Venue ................................................................................................................................

I look forward to meeting you. If there are any difficulties please do not hesitate to contact me.

Telephone: 01483 684635
Fax: k_de-vries@surrey.ac.uk

Yours sincerely

Kay de Vries
Appendix 14

Flow chart of stages of data collection and analysis
Flow chart of stages of data collection and analysis

**Pilot – first data set – (In-house admission)**
- Using interview guide
- Manual data analysis
  - Open coding of data
  - Categorising data
- Preliminary framework drafted and coding scheme developed
- Potential core category of 'not knowing' identified
- First data set re-coded in NUD*IST

**Main study**
- Second data set (Community admission)
  - Analysed in NUD*IST using coding scheme
  - Beginnings of conceptualising 'Change over time'
  - Changes made to categories
  - Core category strengthened
- Third data set (Community and day hospice admission)
  - Analysed in NUD*IST combined with a return to manual coding
  - Changes made to categories
  - Core category strengthened
  - Firm decision to use time context
  - Importance of metaphors becoming apparent
  - (Symbolic Interactionist literature refocus)
- Fourth data set (Community and day hospice admission)
  - Analysed in NUD*IST plus manual coding
  - Changes made to categories
  - Core category strengthened
- Fifth data set (In-House admission)
  - Analysed in NUD*IST plus manual coding
  - Changes made to categories
  - Core category weakened
  - Time context introduced to conceptual framework
  - Systems theory interpretation applied to data

**Synthesis and interpretations of findings**
- Theory construction
Appendix 15

Example of line-by-line coding of raw data
CNS 1: The main issues seemed to be for me was that we didn't actually know what she was experiencing. We didn't know whether she was in pain, whether she was actually aware of her surroundings, or her family, whether she actually got any pleasure out of anything that was going on whilst she was here. And the issue of sedation, personally for me, is the biggest thing I felt. I thought we should have gone in with sedation earlier than we did.

CNS 2: Also there was conflict in the communication we got from them. They said that she liked to be hugged and touched. From the hand-over. And then when she got here she did not, she could not bear it at all, even to wash or move her or anything. And it was the screaming as well.

HCA 1: She screamed and howled like an animal in a corner. Because she couldn't be in a bed at first. And that was not very nice for her family to see.

CNS 1: We also didn't know what sort of prognosis we were looking at all. There had not been that many similar cases that we knew of when she first came in. We found out more about it afterwards. But according to the literature that we had we could have been looking at a couple of years. As it was as she deteriorated really rapidly but we didn't know this was going to be the course of events or whether it was something that we had or hadn't done.

CNS 2: I think there was a lot of emotion as well, she was 25 years old with two kids and the youngest being 18 months. And with all the media coverage on CJD we didn't really expect it to be that bad, somebody...
Appendix 16

Approval from MREC for main study
Dear Ms de Vries

MREC 02/01/98 An investigation into the experience of caring for people with acquired new variant Creutzfeldt-Jakob disease (nvCJD) by specialist palliative care teams.

Revised application form dated 28.10.02
Protocol – version 1
Interview guide for both single interviews and focus group interviews – version 1
Interview guide for family member interviews – version 1
Letter to Medical Director at Hospice – version 1
Consent form for hospice – version 1
Information sheet – version 1
Letter to Medical Directors of Hospices who have agreed to take part – version 1
Consent form – version 2
Letter to participants who have agreed to participate – version 1
Participant consent form – version 1
Ms Kay de Vries Curriculum Vitae

The Chairman of the South East MREC has considered the amendments submitted in response to the Committee’s earlier review of your application on 9th October 2002 as set out in our letter dated 16th October 2002.

The Chairman, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our approval on the understanding that you will follow the conditions of approval set down below. A record of the review undertaken by the MREC is contained in the attached MREC Response Form. The project must be started within three years of the date on which MREC approval is given.

While undertaking the review of your application the MREC noted the research involves the use of an existing database collected for previous research or other purposes with subsequent patient contact. For this reason you are asked to read carefully the sections concerning Local Research Ethics Committee (LREC) involvement and local NHS management set out below as there are specific requirement involved when undertaking such research.

MREC Conditions of Approval

The Central Office for Research Ethics Committees is responsible for the operational management of Multi-centre Research Ethics Committees.
• No research procedures are undertaken until the appropriate local research ethics committees is informed of the research including the name of the local clinician involved.
• The local clinician must inform his/her NHS organisation of their co-operation in the research project.
• The protocol approved by the MREC is followed and any changes to the protocol are undertaken only after MREC approval.
• If projects are approved before funding is received, the MREC must see, and approve, any major changes made by the funding body. The MREC would expect to see a copy of the final questionnaire before it is used.
• You must promptly inform the MREC of:
  (i) any changes that increase the risk to subjects and/or affect significantly the conduct of the research;
  (ii) any new information that may affect adversely the safety or welfare of the subjects or the conduct of the trial.
• You must complete and return to the MREC the annual review form that will be sent to you once a year, and the final report form when your research is completed.

LREC involvement

When undertaking the review of your project the MREC observed that there is initial contact by a local clinician for purposes of recruitment. It is felt that these tasks appear well within his/her routine professional competence and adequate facilities for such procedure are available as part of his/her normal professional practice.

For this reason you are asked to only inform the appropriate LREC of the project by sending a copy of this letter and also giving the name and contact details of the local clinician involved and what procedures will be undertaken by this person. If (unusually) the LREC has any reason to doubt that the local clinician is competent to carry out the tasks required, it will inform the clinician and the MREC that gave ethical approval giving full reasons.

When such tasks are performed by centrally based researchers it should be assumed that the MREC has reviewed their competence to undertake the tasks and it is not necessary to inform the LREC of the contact details but only that the research will take place.

You are not required to wait for confirmation from the LREC before starting your research.

Local NHS Management

The local clinician must inform his/her NHS organisation of their co-operation in the research project and the nature of their involvement. Care should be taken to ensure with the NHS organisation that local indemnity arrangements are adequate.
Legal and Regulatory Requirements

It remains your responsibility to ensure in the subsequent collection, storage or use of data or research sample you are not contravening the legal or regulatory requirements of any part of the UK in which the research material is collected, stored or used. If data is transferred outside the UK you should be aware of the requirements of the Data Protection Act 1998.

ICH GCP Compliance

The MRECs are fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and a Statement of Compliance were included on the computer disk containing the guidelines and application form and are available on request or on the Internet at www.corec.org.uk.

Yours sincerely

DR JM LAMBERTY
CHAIRMAN, SOUTH EAST MREC

Enclosures MREC Response Form dated 12 11 02