Chapter 1: Introduction

Never perhaps have our relationships with death been as barren as they are in this modern spiritual desert, in which our rush to a mere existence carries us past all sense of mystery.

Francois Mitterand, 1997

The field of health psychology has long investigated psychological factors which form part of the experience of terminal illness. The diagnosis of a terminal illness – which can be seen as a death sentence – invokes numerous and varied reactions in individuals, including cognitive, behavioural, emotional, social or spiritual dimensions (Kelly, McClement & Chochinov, 2006). Spirituality has been a specific focus of recent research in this domain. It has become evident that, even though spiritual and existential issues are often not part of a scientific and rationalistic conception of the dying process, they have great significance to patients. Consideration and understanding of these matters contributes to holistic and effective palliative care (Woll, Hinshaw & Pawlik, 2008; LeMay & Wilson, 2008). This is especially true in South Africa, where a diversity of spiritual and cosmological views exists, and spiritual beliefs hold great salience for many (Mkhize, 2004; Rule, 2001). This study aims to explore spiritual and existential dimensions of the experience terminal illness.

Several psychological theories attempt to describe the experiences of those at the end of their lives. In terms of Erikson’s psychosocial theory of development, individuals facing death should ideally be in the ‘Integrity versus Despair’ stage of life (Hook, 2002). In this stage, the struggle against meaninglessness should end in an affirmation of integrity and meaning in life. When someone is diagnosed with a terminal illness before they have reached this stage, they may struggle to find meaning and collate their wisdom in the way the elderly are generally expected to (Butler, 1963 in Thorson & Powell, 1988). Even if they are older, this does not guarantee that they have reached this stage in their psychological development. Although the search for meaning implied by Erikson is relevant to this research, this binary opposition between integrity and meaninglessness excludes possibilities for complexity, variation and uncertainty. The most well-known and influential theory to date is Kübler-Ross’s (1969) conception of the five stages of dying. These stages propose a sequential transition from denial, through anger, bargaining,
depression, and conclude with acceptance. This conception has contributed significantly to the way dying and grief are perceived globally – by laypeople, medical professionals and psychologists alike (Friedman & James, 2008).

Popular attitudes towards death and dying have been influenced largely by culture, language, portrayal in the media, and to a limited extent by theory. Death is often positioned as a crisis point for society, and thus many elements of cultural and social structure are built around it – coping with it, or keeping it at bay (Bryant, 2003). As a consequence, the most popular discourse of death which exists in the scientific and medical fraternity is that death is something to be avoided at all costs. According to Zimmermann & Rodin (2004), Western culture is often accepted within the field of sociology to be death-denying, and this may have increased in the last half century due to the advent of new life-saving medical technology, such as chemotherapy and anti-aging medications (Connelly, 2003). The media may also contribute to this phenomenon. Although arts and literature have a great interest in portraying and examining death, these portrayals are most often of violent or traumatic deaths. It has thus been found that exposure to death in the media contributes to higher death anxiety (Hayslip, 2003).

Sociological perspectives propose that our fear of death is not innate, and that we can never separate individuals’ feelings about death from their social and cultural values. Some sociologists posit that death anxiety is a reaction we learn from our socio-cultural environment, and thus some societies are far more death-denying than others (Zimmermann & Rodin, 2004; Howarth, 2007). Lofland (1978, in Edgley, 2003) contended that Kübler-Ross’s (1969) book had provoked a culture of ‘Happy Death’, in which death was regarded as something nonthreatening, and its trauma could be resolved by simply talking about it. According to Edgely (2003), those trained in Kübler-Ross’s philosophies may even enforce openness and emotional engagement with death on those who do not desire it.

The attitudes society has towards death perhaps contribute to social and philosophical constructions of ‘the good life’, which involves continuous, even lifelong, health (Abma, 2005). Many individuals’ struggle to maintain a sense of normality, and not to give in to the illness, may reflect an investment in the value of continued health. In addition, often illness narratives reflect a sense of perceived control over one’s own health and illness (Abma, 2005). This supports Kant’s conceptions of a valuable life, which were supported
by control and prediction (Abma, 2005). Illness and death, therefore, are often seen as unrelentingly negative and destructive. However, it is possible that new meanings may be found within the dying process, and that death may have positive, creative functions on a personal level (Abma, 2005). Heidegger (cited by Taylor, 2003), for example, held that only by confronting our own mortality can we live truly authentic lives. This perspective had been echoed in much of existential psychology (Connelly, 2003).

This study sought to examine how palliative care nurses conceptualise death and dying in the context of their experiences with patients, as well as exploring how they view meaning-making within the dying process. Nurses were judged to be a more appropriate participant group than patients themselves for a number of reasons. Practically, many patients suffer a great deal with terminal illnesses, and placing further stresses on those already fatigued and in pain may be unethical. Patients with terminal illnesses have also been found to possess strong emotions about their dying process, and their feelings (or avoidance of feelings) have the potential to colour a narrative. Logistical, practical and ethical issues all make involving dying patients and families in research very difficult (MacDonald & Weijer, 2004).

Nurses are the professionals who bear the primary burden of ensuring the comfort of the patient (Brabant, 2003). Those who accompany the dying through their last months and days also have access to the intricacies of the dying process in a way, and on a scale, few others do. They may be the individuals whom patients speak to most about dying (Brayne et al., 2006). Palliative care nurses are, in fact, also privy to patients’ meaning-making processes, and can even aid in these (Abma, 2005). For example, nurses can help the patient to resolve unfinished business (Brabant, 2003). The perspective of palliative care nurses are composites of their experiences with many different kinds of death with many families. Thus, there was a potential for them to notice themes across patients, and have a more complex yet less emotionally influenced view of death. Even though their perspective is expected to be somewhat more objective than patients’, their unique paradigm must be considered, and the factors affecting them taken as integral to their narratives and the way they construct death and dying. Though research on caregivers is extensive, research on nurses who work specifically in palliative care is rare, which is a lacuna worth addressing. Nurses have been seen in previous research to be more open and revealing than patients (Lipsman et al., 2007); an outsider’s perspective was also expected.
to provide an additional level of understanding. Insight was thus gained into the experiences of both patients and nurses at a palliative care facility in Johannesburg.

**Rationale**

Death is faced by every human on earth. Over past centuries, death was often quick, or occurred early in life. As medical technologies have increased, however, people have been able to live much longer. This has led to a greater proportion of deaths in society being as a result of terminal illnesses, in a medical context (Enck, 2003). Research on death and experiences of dying also holds much relevance in this socio-historical context. South Africa is currently plagued by an epidemic of HIV/AIDS, which has grown into an assault on the human rights of its citizens. Roughly a quarter of the population is now infected by the virus (UNAIDS, 2007; Tick, 2007). The result of this is that an inordinate proportion of our population is faced with death before an advanced age. Death is a part of daily life for thousands. This does not imply that this project focuses specifically on the dying process in HIV/AIDS. Cancer sufferers will form a significant proportion of the patients in palliative care facilities (Enck, 2003). In addition, cancer is even more pervasive than HIV/AIDS, as one in three people develop cancer at some point in their lives (Guex & Goodare, 1994). The prevalence of cancerous diseases is also unequally distributed: individuals of lower socio-economic backgrounds have been found to be more likely to die of cancer. It is, however, prevalent in every sector of society; in fact, cancer is expected to become the leading cause of death in the 21st century (Enck, 2003). This being said, the disease being endured is not a variable in this study, so much as the individual experience of dying from a terminal illness, which is an all too common one.

Hospice care in South Africa aims to provide holistic and multifaceted care. However, it often cannot stretch to meet the needs of the multitudes who require assistance and support (Tick, 2007), especially given the rapid expansion required given the HIV/AIDS epidemic (Govender, 2006). Spiritual care, because of the complex and subjective nature of spirituality and individual differences in existential responses to the dying process, is a difficult undertaking, and it may be lacking in South African facilities (Govender, 2006). Research into these needs and experiences is important, both for the expansion of knowledge and for the practical gain of assisting doctors and nurses in understanding how better to meet patients’ spiritual needs – an important priority (Kluger, 2009).
The spiritual/existential dimension of the dying process is also the least focussed on in the study of psychology within palliative care contexts (Cobb, 2001), and warrants attention. In addition, most research on this element has been conducted in the United States, and generalising inductively from this raises problems regarding the contextual variation in levels and constructions of belief, as well as cultural factors (Merchant, 2006). This can contribute to theoretical knowledge, but in addition, practical utility can be drawn from the knowledge produced: managers and nurses in palliative care settings can gain information regarding how to provide holistic care which includes regard to spiritual or meaning-related issues. Research has shown that seeing patients as whole people, taking into account all spiritual, social and psychological elements, can significantly contribute to healing and psychological health (Mohr, 2006).

Kübler-Ross’s (1969) five stages are highly prevalent, not just in psychological theory but in lay discourse, to the point that this approach to grief and loss is almost impossible to ignore, and must be considered in a study such as this. It is important, however, according to critical theory (Parker, 1994), to question and deconstruct the knowledge we take for granted. Kübler-Ross (1969) admitted that these are only stages people might go through, and that they could recur, or occur in a different order. However, she did also state that all people experience at least two of the five reactions. This study questions whether this is true, and how useful and relevant the five-stage description is in our understanding of the psychological processes associated with dying. The dangers inherent in the uncritical application of the theory are also a factor (Friedman & James, 2008). The critical role of her theories in the development of the Hospice movement adds to the necessity of dissecting their influence in this particular context (Friedman & James, 2008). There is also recognition of the significance of societal factors in determining individual responses to dying, and in this vein, it will be seen what relevance a theory constructed in a Western, middle-class, individualistic milieu will have in an African, and South African, context.

Most studies in this area have used quantitative methods such as surveys and questionnaires (Lipsman, Skanda, Kimmelman & Bernstein, 2007), which may not capture the full richness of patients’ experiences. There is also little reflexivity in such research, as the epistemological and ontological assumptions of such research also dictate that data is objective (Parker, 1994). Qualitative research theory acknowledges that the knowledge produced can never be wholly separated from the researcher themselves (Davies, 2007). But qualitative research generally does not aim for universal generalisability – rather, it
sacrifices this for the value of in-depth, subjective experiences (Davies, 2007), and acknowledges how context-bound and unique all data is (Black, 2001). It is believed that the data gathered in this study, after being subjected to thorough analysis, will provide greater insight into the experiences of palliative care nurses and patients with terminal illnesses than has been gained in previous studies, and perhaps even generate new meanings around death and dying in South Africa today.

It is important to note here that the great majority of research on death denial, as with spirituality, has been conducted within Western (North American and European) contexts, and thus reflects the attitudes and values of these societies. It is important to ascertain whether the same views are present in South Africa: does our society reflect Western perspectives, or are variables present here which influence our context in unique ways? Little research thus far has addressed this question.

Spirituality has a significant place in the Hospice movement, and in palliative care literature. Despite this, spirituality has no standard definition amongst authors, and the concept itself has been under-researched (Berry, 2005; Cobb, 2001). There is thus good reason to explore it in more detail, and rather than create a prescriptive definition, this research will explore first of all what spirituality means in a South African context.
Chapter 2: Literature Review

What all of us have to learn is to accept death as part of life. When we have learned this, then maybe we can help our patients learn it, too.

Elisabeth Kübler-Ross, 1971

Death is possibly the only universal human experience (Bonsu & DeBerry Spence, 2008), and it evokes varied responses in individuals and families forced to face it. Psychological theory has endeavoured to describe and explain the intrapsychic aspects of facing death. Kübler-Ross’s (1969) theory of the stages of dying is explored in detail, and critiques of the theory are raised. Since patients’ responses to dying are inevitably influenced by their interactions with their loved ones and larger society, these dimensions will be explored briefly. Conceptions of a ‘good death’, so significant to palliative care philosophies, are also an important focus. The nature of palliative care, and the experiences of palliative care nurses, are important to discuss in order to contextualise the participant group. Finally, spiritual and existential meaning is defined and explored in depth. Its contested meanings, its role in the dying process and its connection to health are detailed. A possible integration of existential theory and palliative nursing is suggested.

Theoretical Perspectives

Although the pain of disease and physical breakdown is the most obvious consequence of having a terminal illness, there is evidence that psychological reactions are even more prominent in these cases than physical symptoms (Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasu, Sobel, Coyle, Kemeny & Norton, 1994). According to Kübler-Ross’s (1969) conception of the stages of grief, there are five reactions which are most frequently experienced by dying individuals: denial, anger, bargaining, depression and acceptance. Psychological disorders such as anxiety, depression and insomnia also occur (Mosley, 1985). Depression is the most commonly occurring of these (Wilson et al., 2007).

Denial was posited by Kübler-Ross to be a common response to initial diagnosis. However, it is theorised to occur at several points during the dying process (Kübler-Ross, 1969). This may be because the consideration of one’s own death may be so difficult, that a defense must be used in order to allow the individual to process it slowly and build up other defenses (Kübler-Ross, 1969). Denial is seen by many psychological theorists as a
response to death anxiety. Freud (1920, in Hayslip, 2003) theorised that fear of death draws libido from the ego, and the ego responds by using defense mechanisms to repress this anxiety from consciousness. The greater the fears are, the more energy must be used to defend against them, resulting in various life difficulties. Denial is, however, not necessarily an absolute concept. Some argue that denial may actually comprise of an acute recognition of reality, and consequent frantic efforts to keep that reality at bay (Zimmermann & Wennberg, 2006). Kastenbaum (2001, in Hayslip, 2003) suggests that there are many forms of partial denial: selective attention (aversion of death stimuli), selective responding (hiding one’s feelings about death), compartmentalising (allowing for incongruencies which allow two contradictory beliefs to coexist), purposeful deception (lying) and resistance (refusing to surrender to death). Although these are primarily intrapsychic phenomena, they may also exist in interpersonal interactions. In addition, repression of painful emotions could lead them to be expressed in somatic form (McWilliams, 1994). Kübler-Ross suggested that whilst an individual may be partly in denial, they could be partly aware of their reality. Denial may also be present in beliefs many people consciously or unconsciously hold, such as the belief that the world is controllable, ordered, and fair (Hayslip, 2003). Kübler-Ross (1969) believed that denial was usually replaced by partial acceptance, and rarely lasted until the end of life. However, in her opinion, the religious concept of life after death was itself a form of denial. Charles-Edwards (2005) agrees, warning that it can allow for the denial and suppression of grief, which is an important process.

Anger is the second stage in Kübler-Ross’s theory. She suggests that, once denial has been broken somewhat, and the response of “no, that can’t be me” progresses to a realisation of “oh, it is me that is dying”, the natural question to ask is, “why me?” Anger was thus at those who were not dying. According to Kübler-Ross (1969), anger is very difficult for both family and staff to deal with, as it may be projected onto anyone at any time. Everyone who is healthy serves to remind the patient of the unfairness and random nature of their becoming ill and others remaining healthy. If the family become avoidant or resentful of the patient in response, the patient may become even more angry. Kübler-Ross (1969) insists that this anger is in some ways a cry for recognition, a way of communicating that the individual is still alive and capable in some ways. It may thus be more common in individuals who have been in control of their lives, and have difficulty relinquishing this control.
Bargaining, the least well-known stage, is undertaken as a kind of postponement of death, and is a change in engagement with God. Kübler-Ross (1969) explains this reaction in psychological terms, comparing the patient to a child who had behaved badly (the anger stage) and has realised that a parent (God) will be more likely to respond favourably to good behaviour. This could be embodied in setting a deadline, such as an important life event, and wanting to live just until then, or bargaining with God, often out of guilt for not having been dedicated enough.

Depression is conceptualised as a reaction to the many losses the patient experiences. These losses convince them that the illness, and their imminent death, are real (Kübler-Ross, 1969). Depression is a somewhat contentious stage. Many studies have investigated clinical depression in the terminally ill (Chochinov, Wilson, Enns & Lander, 1997; 1998), but as depression is also considered a ‘natural stage’ of dying, the question remains whether this depression should be considered pathological, and thus treatable, or healthy. Kübler-Ross (1969) also distinguishes between reactive depression, which is a response to the difficulties and losses of dying, and preparatory depression, which is a kind of grieving-for-self, or a preparation to leave the world of the living. Preparatory depression is constructed as natural and important, as the many losses the patient faces deserve grief. Reactive depression is described as a period in which patients are quite verbal, and need constant comfort and support from those around them. In contrast, preparatory depression is also associated with silence and withdrawal. It may bring hopelessness, in the most literal sense possible: there is truly no hope of recovery (Kübler-Ross, 1969). There is also evidence that some symptoms of depression may predict earlier death (Cooper, Harris & McGready, 2002), indicating the power of psychological withdrawal and hopelessness.

Acceptance, the final stage of dying, is positioned as a peaceful acknowledgement of the reality of death. It is not an exhaustion or a sense of resignation, or an unwillingness to fight anymore, as this implies that they were fighting death until the end; rather, it is a stage “almost void of feelings” (Kübler-Ross, 1969, p.100). The patient rests and is at peace, often having little need for stimulation from the outside world. Acceptance is a term which is often referred to vaguely in literature, and varying definitions exist (Friedman & James, 2008), which makes a precise conception of this phenomenon difficult. Yet, the dichotomy between denial and acceptance pervades philosophical, medical and lay understandings of response to death. Although individual reactions may be varied, in Kübler-Ross’s (1969) logic, denial is somehow the least developed or adaptive stage of
dying, and acceptance is the most, and the hospice movement aims to move the patient (and society) from denial to acceptance (Zimmermann & Wennberg, 2006; Sandstrom, 2003). Existential philosophers view acceptance as a human, or even moral obligation (Connelly, 2003). Acceptance is thus positioned as an ideal state: a goal for every dying patient and their family. Yet, one study has shown that many individuals never reach this stage, and may not even move beyond denial or anger (Weisman & Kastenbaum, 1968 in Sandstrom, 2003). In addition, there exists a perception that acceptance is necessary for a patient to receive palliative care, despite the fact that the psychosocial care Hospice provides may be a great aid to psychological adjustment (Zimmermann & Wennberg, 2006).

These psychologically framed descriptions may help us to identify and define reactions to imminent death, but they cannot be accepted at face value. Kübler-Ross’s theory has come under criticism for various reasons. Clinicians working with dying patients have called the stage theory “inadequate, superficial and misleading” (Corr, Nabe & Corr, 2003, p.139). Many other emotional responses to the dying process have been identified in research, such as apathy, guilt, fear, stoicism and surrender (Sandstrom, 2003). The concept of stages itself implies that the process is quantifiable and linear, as well as divisible into discernable experiences (Freidman & James, 2008). Research has suggested that the experiences of dying individuals are more likely to be cyclical and vacillating, and they may experience more than one stage simultaneously (Kastenbaum, 1998 in Sandstrom, 2003). Kübler-Ross’s methods were patently unscientific, in the sense that they did not follow any kind of design, standardisation or checks, and much of what was found was based on intuitive feelings or subjective experience (Friedman & James, 2008). Indeed, her own personal history and emotional life may have contributed significantly to the way she understood patients she interviewed, and the concepts she focused on (Friedman & James, 2008).

Another critique of the five-stage theory is that it, whether intentionally or not, sets up a discourse of the acceptable or healthy death (Govender, 2006). This implies that a death-denying society found a framework to apply to a previously inscrutable and threatening concept, and it seized upon it with prescriptive and single-minded fervour. Although it may be comfortable to rely on a structured and seemingly panhuman concept of the way death ‘should’ be faced, it can also create unrealistic expectations of the way the grief process will unfold (Friedman & James, 2008). Even though Kübler-Ross (1969) often
stated that the stages were not set in stone, she posited that anger was experienced by all humans, both dying and grieving. Ideally, everyone should reach the acceptance stage, but many never do. This can complicate the way both patients and nurses view dying and death, and lead to disillusionment when expectations are not met. If, conversely, we accept Kübler-Ross’s defence that reactions to death are different for every individual, it must be asked whether there is a purpose to trying to define universal stages at all (Friedman & James, 2008).

Several studies have explored the meanings which the dying, subjectively, make of their experiences. One such study conducted a meta-analysis of narratives of individuals facing terminal illnesses (Bingley, McDermott, Thomas, Payne, Seymour & Clark, 2006). Themes include the trauma of diagnosis, duty felt towards loved ones, the effects of illness and increasing dependency on body image, searching for alternative remedies, and intense fear of death. Interestingly, spiritual or religious figures were rarely mentioned; spiritual journeys tended to be individualised and specific to the person (Bingley et al., 2006).

Death anxiety, one of these factors, is a common experience, and involves elements of fear regarding possible pain of physical changes, anxiety at the idea of separating from loved ones, and uncertainty about what will follow death (Ardelt & Koenig, 2006). However, the primary task of the patient is to work through this anxiety. It has been suggested in anecdotal evidence that this letting go can be a conscious act (Brabant, 2003), which, if it were true, would emphasise the role of psychological responses to death within the dying process. Kastenbaum (1992; in Hayslip & Hansson, 2003) identified two different ways of approaching death. In the first, overcoming, death is seen “as the enemy, as external, or as a personal failure” (p.438). Conversely, the second type, called participators, view death as natural and even potentially positive.

Social Perspectives

The way palliative care nurses view death is often influenced by the way their profession, and society itself, view death (Govender, 2006). When doctors fail to keep the patient alive, or death is seen as the only option left, doctors have been reported to abandon patients, as they are seen as medical failures (Brayne et al., 2006). Kübler-Ross (1969), in her initial studies, found that hospital nurses working with dying patients often expressed anger, resentment and depression. They were found to be frustrated at having to help patients who had no chance of surviving, and often felt hurt or angered when patients died.
in front of them. They were found in another study (Edgley, 2003) to take significantly longer to respond to dying patients’ calls than to other patients’, even though this was unconscious. Death is also kept separate from the rest of society in various ways. In language, it is often euphemized in terms such as “passing on,” and in a spatial sense, people increasingly do not die at home, but are sent to hospitals or palliative care facilities (Hughes, Schumacher, Jacobs-Lawson & Arnold, 2008; DeSpeldor & Strickland, 2004). This avoidance and resistance to death may cause society to identify the dying person with death itself – at an extreme, the dead are seen as already dead (Corr, Nabe & Corr, 1994). This can isolate the patient, making the dying process even more difficult and painful. This separation and denial of death was challenged by Kübler-Ross (1969), whose landmark work On Death and Dying brought death to the awareness of society, stimulating both academic and popular interest (Doka, 2003). Her contribution was thus fundamental to the emergence of death studies, as well as the hospice movement.

**Family Responses**

Families of patients play an important role in the way death is perceived and managed by the patient and the palliative nurse. Relatives may be the patient’s only continuous company through every stage of the dying process (Andershed & Ternestedt, 1999), and thus their interactions with the patients may influence them to a large extent. One study found that family members exercised care of the patient in three ways: by knowing, by doing and by being (Andershed & Ternestedt, 1999). Knowing involved knowing medical facts about the patient’s condition (gained from medical staff) as well as subjective information about the patient’s experiences and suffering. Doing encompassed all the actions which families took in relation to the care of the patient, from helping behaviours such as feeding, to staying in contact with medical personnel and conducting administrative work. Being was described as being with the patient in terms of presence, and also as finding a way to be in the patient’s world with them (Andershed & Ternestedt, 1999). Whether the patient’s needs are congruent with their family’s caring behaviours will affect to what extent their needs are met. They may attempt to find alternative remedies from other doctors or different kinds of healers (Kübler-Ross, 1969), which the patient may or may not desire. They may also direct resentment at the medical practitioners who are causing them such difficulty, or even eventually at the patient themselves, for adding to their burdens and responsibilities (Kübler-Ross, 1969). There may be guilt at being unable to be perfect caregivers (Sherman & Simonton, 2001), or
about having not done more to protect the patient from harm; guilt may also derive from repressed anger at the patient (Kübler-Ross, 1969). Families may attempt to protect the patient by forcing optimism in their interactions, and avoiding engagement with difficult or painful issues. This may obstruct the important processes of grief which both the patient and the family must undergo (Kübler-Ross, 1969). The anger families direct toward patients, or their unwillingness to accept the patient’s reality, may make patients’ experiences of illness more painful or isolating. The patient’s role in the family may also change, and their identity may be eroded due to their exclusion from events in family life (Sherman & Simonton, 2001). It is possible that the patient’s emotional processes, or even their sense of meaning, may be influenced by the behaviours of those around them.

In response to the difficulties the patient’s family may experience during this period, the patient themselves may feel like a burden on the family (Sherman & Simonton, 2001). A review of current literature regarding self-perceived burden by McPherson, Wilson and Murray (2007) indicates that this phenomenon is common in terminally ill patients. This feeling may entail a sense of guilt, distress, a diminished sense of self, and feelings of responsibility for others (McPherson et al., 2007). Asking for help and relying on others was a main theme in a study of the experiences of patients with severe heart failure (Horne & Payne, 2004). This invokes a sense of hopelessness in many patients (McPherson et al., 2007). There are social aspects to this sense, in that the patient feels empathy for the difficulties of others, but also existential aspects, related to their own role in the world and the effects they have on others (McPherson et al., 2007). They may thus be hesitant to share their distress with other family members, and may even hide their diagnosis from them. However, rather than protecting the patient’s family from pain, this often has the effect of isolating the family from the patient when great support is needed on both sides (Sherman & Simonton, 2001). Unfortunately, a sense of self-perceived burden has been remarkably high in measured samples (McPherson et al., 2007). For patients, the absence of burden is strongly associated with their sense of a ‘good death’.

The Good Death

The ideas of a ‘good death’ or ‘death with dignity’ are also highly significant to discourses around death and dying. Initially used as a euphemism for euthanasia, it has in the last 30 years come to signify an ideal death for a certain individual (Hughes et al., 2008). Quality of life during the dying process seems to lie at the heart of a good death (Kim & Lee,
This concept encompasses notions of dying with a sense of practical and spiritual preparedness, meaningfulness, freedom from pain and interpersonal connectedness (Proulx & Jacelon, 2004). The idea of being at the mercy of harsh medications and life support machines until the end of their lives seems meaningless to many (Coulehan, 2005). Many view a good death as being located at home, with one’s family, away from the impersonal environment of a hospital (Zimmermann & Rodin, 2004). As mentioned above, many patients also feel that not being a burden to others is an important component of a good death, although this is not prioritised by their families. Burden is a component of general concerns about social relationships and dignity (McPherson et al., 2007).

From the standpoint of bioethics, dignity is synonymous with self-determination and autonomy (Coulehan, 2005). However, Coulehan (2005) also views dignity as a relational concept. Part of this relationality is communication, or empathic connection with others: this may not be present often enough in individualistic cultures, but empathy and openness with the dying person is essential to allowing them dignity. Another aspect is narrative, which allows dignity to be encompassed in a story, whether religious or secular. The third aspect is responsibility – of society toward the dying person, and of the dying person toward others. Palliative care seems set to serve this need. Within the palliative care field, an important component of a good death is the acceptance of both the patient and the family of the reality of death (Abma, 2005). However, it also emphasises self-determination and meaning-making, which implies that as far as possible, it does not impose specific values or ideas of a ‘good death’ upon patients; by definition, it allows patients to define this for themselves (Coulehan, 2005).

Related to dignity is the notion of control. Over the past few centuries, the medicalisation of death has led to more deaths occurring in hospitals and institutions, and thus fewer people have control over the procedures and processes which occur at the end of their lives (Redding, 2000). Belief in control is, however, an essential protector against life stress, and many studies have shown the importance of this feeling to dying individuals (Proot, Abu-Saad, ter Meulen, Goldsteen, Spreeuwenberg & Widdershoven, 2004). A feeling of having no possible influence on events in one’s life may be discouraging in itself, and thus lead to poorer coping (Redding, 2000). Thus, according to control theory, being able to partake in active problem-solving, and having a sense of control over one’s destiny, are crucial factors in well-being. Patients do not necessarily need control over every facet of their life, but rather need to be able to take part in decisions and seek support
which may improve their life (Proot et al., 2004). Even negative events which the individual has some control over are less distressing than uncontrollable negative events (Redding, 2000). This sense of control is important not only for psychological health, but physical health as well; the stress and coping a patient displays can directly affect the functioning of bodily systems such as the immune system. For those dying of terminal illnesses, loss of control may be extensive: they may feel they have lost control of their identity, their bodily functions, relationships, physical and sexual abilities, self-care capacity, and their future itself (Redding, 2000).

**Palliative Care**

According to the World Health Organisation, palliative care constitutes “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, n.d.). However, although it encompasses all the broad dimensions of palliative care, this definition provides little insight as to the ways in which these areas will be addressed. Only physical pain is mentioned specifically, and psychosocial and spiritual problems seem to be a less urgent priority.

An integrative view demands that end-of-life care should incorporate physical, psychological, social and spiritual aspects (Cobb, 2001). Thus, hospice care has two overarching objectives (Coulehan, 2005). The first of these is to alleviate the patient’s suffering in the physical, emotional and spiritual realms. The second is to allow the patient possibilities for active participation in the final stage of their life. This principle entails putting the patient’s rights and needs first at all times, even above those of their family (although family involvement is encouraged) (Brabant, 2003). Patients’ desires are thus respected as far as possible, even if this entails behaviours generally thought to be self-destructive, such as smoking (Leming, 2003). This in itself allows for existential growth, as patients make meaning out of both their life and their death. Existential issues, indeed, have been reported by numerous patients undergoing palliative treatment (Wilson et al., 2007).

As opposed to a medical approach, which may view death as failure, palliative care constructs it as a natural process (Adelbratt & Strang, 2000). Palliative care of the kind
Hospice offers is a broad and complex undertaking, as it no longer provides care in the traditional medical sense of curative treatment (which the patient initially received), but rather provides healing, as well as physical and emotional comfort in people’s last days or months (Cobb, 2001). This is often located in specific institutions, but has also often moved into patients’ homes, both as a cost-effective measure and a way to keep death as comfortable and non-medical as possible (Doka, 2003). The aim of hospice, more broadly, is to encourage patients to live out their own ‘good death,’ and thus quality of life is emphasised (DeSpelder & Strickland, 2004).

The Hospice movement thus finds its philosophical origins in patients’ quality of life. This construct is multidimensional, and encompasses emotional, physical, spiritual and social aspects (Bussing, Matthiessen & Ostermann, 2005). Scales such as the Schedule for the Evaluation of Individual Quality of Life and the Patient-Generated Index (Carter, MacLeod, Brander & McPherson, 2004) attempt to measure quality of life as a whole. Objective measures of quality of life are more possible for physical symptoms, and thus these measures can monitor physical quality of life relatively precisely. However, many dimensions of quality of life are intrinsically subjective, such as pain, mood and well-being. Even physical symptoms are thus often measured through patients’ reports, with questionnaires such as the European Organisation for Research and Treatment of Cancer Questionnaire on Quality of Life (EORTC-QLQ-C30) (Grov, Dahl, Fosså, Wahl & Moum, 2006). Psychological variables are most often measured with subjective, self-report instruments such as the National Centre for Health Statistics (NCHS) General Well-Being Schedule or Crumbaugh and Maholick’s (1964) Purpose in Life Test (Ardelt & Koenig, 2006). Spiritual elements have been assessed with questionnaires taking both religious and spiritual well-being into account, such as the SpREUK-P (Bussing et al., 2005). These allow for quantitative measures of some of the intrapsychic components of quality of life. However, it must be noted that quality of life assessment tools have been critiqued for various reasons, such as a lack of clarity of the construct itself, difficulty quantifying it accurately, and the appropriateness of health practitioners measuring it rather than the patient (Carter et al., 2004).

Even though Hospice’s philosophies are becoming more integrated into traditional medical care, certain perceived oppositions between them may obstruct a full integration (Zimmermann & Wennberg, 2006). Callahan (2000) stated that, whilst the imperative of scientific and medical research is to eliminate disease, the palliative care movement
demands the opposite: that we accept disease and death. In line with this, Hospice is sometimes viewed as a space which is non-medical and allows for a completely ‘natural’ death. Although there is a divide between attempting to prolong life and simply alleviating suffering as nature takes its course, this does not imply that medical treatments do not have a place in palliative care (Zimmermann & Wennberg, 2006). On the contrary, often hospice care makes use of many scientific, medical treatments, and nurses possess medical training. Although the principles of medicine and Hospice seem at first to be opposing, it is possible for them to be integrated, and inform one another regularly. The drive to eliminate disease is likely to aid the aim of providing patients with more quality of life (Zimmermann & Wennberg, 2006).

Nurses not only witness all the stages of coping, and the meaning-making processes that a diagnosis of a terminal illness brings. They also come to construct death and dying in certain ways themselves, both in relation to others and (inevitably) their own lives. Palliative care workers report feeling special and privileged to work with the dying, but simultaneously acknowledge its difficulties (Brayne et al., 2006). Unlike other nurses, home care nurses are on call 24 hours a day, most if not all days per week, which creates considerable responsibility (Leming, 2003). It is very probable that the anxiety, depression, anger and other reactions the patients suffer are often projected and transferred onto those who deal with them every day. Palliative care nurses in a South African hospital have been shown to suffer from death anxiety (Govender, 2006).

Lipsman et al. (2007) uncovered several themes in the narratives of caregivers, including suffering giving rise to meaning and personal growth. Steinhauser, Christakis, Clipp, McNeily, Grambrow, Parker and Tulsky (2001) found that working with the dying evoked a feeling of mortality, and how well nurses had dealt with these affected the quality of care. Caregivers have been shown in several studies to suffer from negative impacts on health and emotional status due to caregiving (Doorenbos, Given, Given, Wyatt, Gift, Rahbar & Jeon, 2007). Milberg and Strang (2004) found that carers relied on open and symbolic or implied knowledge from the patient, as well as basic life assumptions, such as the idea that life is fair, to make sense of their reality. Palliative nursing can be thought of as emotional labour, in that as work it requires a strong emotional and sentimental component (Li, 2005). Power is an important issue, and the level at which it is perceived to be possessed by both the patient and the caregiver has great consequences for how they deal with the situation. In addition, a sense of togetherness – a general feeling of trust in
resources, and a sense of being a valuable resource in a system of caring – was drawn out as an overarching theme. The opposite of togetherness, conceptually, would be a sense of isolation and burden (Milberg & Strang, 2004).

One significant difficulty this profession faces may relate to attachment and detachment. Bowlby (1977, in Hawkins, Howard & Oyebode, 2007) defined attachment as “the propensity of human beings to make strong affectional bonds to particular others” (p. 201). Although attachment theory originally focused on the bonds infants form with their mothers, it has expanded to include adult relationships, which are thought to be fundamentally influenced by those early bonds (Bowlby, 1969). Securely attached adults have thus been found to have greater resilience and coping skills than those who are insecurely attached (Hawkins et al., 2007). In the case of palliative care, these bonds may be more quickly or strongly formed, since the cancer patient is emotionally vulnerable and needs support. Bowlby (1969) theorised that humans in vulnerable states such as sickness would reach out for attachment more strongly. The breaking of the bond with the patient’s death, however, can therefore be more difficult or painful (Hawkins et al., 2007). Nurses with insecure attachment styles – and even those with secure attachment, but who witness many traumatic deaths – may be at risk for emotional distress due to attachment difficulties. Thus, the attachment styles of nurses have potential to affect their narratives about their patients – either by making memories difficult to relate or by allowing nurses to distance themselves from the emotions of the situation.

Palliative nursing possesses many complex components, which may be difficult to balance. A review of studies of patient-caregiver communication (Clayton, Hancock, Parker, Butow, Walder, Carrick, Currow, Ghersi, Glare, Hagerty, Olver & Tattersall, 2008) shows that caregivers see instilling hope in the patient as very important, and indeed, hope is integral to a patient and family’s quality of life. Also integral to the work of palliative care nurses, in addition to caring for a dying individual, is an engagement with that patient’s family (Abma, 2005). The family and loved ones of a patient, especially those in a caregiving role, often have emotional needs which must be attended to, as well as stressors which need relieving (Abma, 2005).
Spiritual and Existential Meaning

_ Spirituality is not a simple reflex of hunger or fear, it is an expression of the will to live, the burning desire of the creature to count, to make a difference on the planet because he has lived, has emerged on it, has worked, suffered and died._

Becker, 1975

Nursing approaches to caring intersect with holistic theoretical frameworks regarding the patient, since both are open to the spiritual level of experience of the suffering or dying patient (Berry, 2005). Existential/spiritual issues, for the purposes of this study, will be defined as psychological reactions to death and dying, relating to finding meaning in life and the situation beyond the purely material, medical facts. These issues include, but are not limited to, hopelessness, existential distress, guilt, demoralisation, suffering, will to live, finding peace, relationships with loved ones, and transcendent beliefs (Breitbart, 2001; Otis-Green, Sherman, Perez & Baird, 2002). An important facet of spirituality is the ability of the individual to decide which elements in his environment and experience will have the most significance or value for them, and thus use these to construct meaning (Morgan, 2003).

Spirituality is a subjective matter, with very diverse conceptions of its meaning and significance existing (Kvåle, 2007). This is especially true when studying patients and nurses in a South African context, since a number of South Africans may subscribe to an African cosmology, which cannot be described as a religion per se. However, it certainly does serve as an explanatory dimension in dealing with questions of life, death and fate, and provides a means of transcendent knowledge and connecting with something beyond time and physical reality (i.e. God and the ancestors, the life force) (Mkhize, 2004). It can thus be seen as a type of spirituality, requiring the faith of followers in order to function properly. In addition, South Africa is home to several other religions or faiths, such as Christianity, Judaism, Hinduism, Islam and Buddhism; 80% of citizens report belonging to some religious faith (Rule, 2007). These faiths serve significant purpose within a believer’s life: although they may be private and personal or publicly held, doubted and criticised or adhered to faithfully, they provide the believer with a meaning within which
to approach life, a guide for decision-making, and a sense of what may follow death (Baumann & Englert, 2003).

Nonetheless, there may be a spiritual aspect to their coping strategy or view of dying which is not encompassed or defined by religion – something more on the ‘meaning’ side of spirituality, within their individual psychological processes. This also satisfies the needs of those working in a more biomedical or scientifically established framework: the unverifiability of religion are sidestepped for a more universal, psychologically defined process. A psychologically located explication of meaning-making focuses on the mechanisms of personal transformation, which are thought to occur through objects which inspire an individual. This process is viewed as a way to make sense of, and cope with, the human condition (Baumann & Englert, 2003). Part of this may involve finding ways to harness one’s own feelings of love and sense of joy, finding a sense of purpose, relating to others, and making peace with one’s existence. It must be noted that not all psychological theorists have been sceptical of the power of spirituality and meaning-making. Maslow (1962) emphasised that being fully immersed in an object was a way of becoming transcendent, and yet simultaneously truly coming to know and understand the self.

It has been said that what humanity fears most is not death itself, but death without meaning (Moore & Williamson, 2003). Religions can be seen as structures people use to make meaning out of life and death, and are thus a primary resource for understanding death (DeSpelder & Strickland, 2004). Often people’s attitudes towards death have been fundamentally determined by their religious beliefs. Buddhism promotes the concept of reincarnation, and thus death is not seen as separate from life – rather, it is another phase or transition (Wu et al., 2002). Hinduism, similarly, views death as part of a greater cycle, and even as a way to greater freedom and enlightenment when the soul reaches Nirvana (Wright, 2004). The mystical traditions of Islam, Judaism and Christianity also contain elements of everlasting life (Wright, 2004). These may act as comforts or ways of gaining control over one’s death (Wu et al., 2002) – after all, “underlying religion is power, and the foundation of all power is that of life over death” (Moore & Williamson, 2003, p.5). Religious belief may also allow people to suffer more deeply but also connect with others more fully (Wright, 2004). Believers may feel as if their lives and deaths have true meaning, and they retain the possibility of reuniting with other loved ones after death (called approach acceptance of death) (Ardelt & Koenig, 2006).
It has been stated that the common thread running through all religions is the preparation of the individual for death and what may come after death (Wright, 2004). Religion could be seen as an instinctual response to the equally instinctual fear of death, and thus the primary source of religious belief may even be death (Malinowski, 1948 and 1965, in Moore & Williamson, 2003 and Leming, 2003). Jung described religions as “complicated systems of preparation for death” (1969, in Ardelt & Koenig, 2006, p.185), and thus these beliefs often promote notions of finding meaning and hope within suffering and obliteration (Baumann & Englert, 2003). This study thus explores the ways in which patients’ religious beliefs contribute to the meaning they make out of death.

On a psychological and extra-religious level, humanistic and existential philosophers have emphasised the centrality of death to the search for meaning in life, and an awareness of death is thought to provoke a re-evaluation of the individual in question’s current circumstances and realities (Widera-Wysoczańska, 1999). It has been said that one of humanity’s defining features is that we are aware of our own mortality, and thus death is a dimension of living for us (Connelly, 2003). Frankl (1959), one of the leaders in existential psychology, survived, and found meaning within, the harrowing experience of internment in a concentration camp. Following Heidegger, we are thrown, without choice, into life situations which we are moved to respond to with some action (Willig, 2009). At many points, taking such action requires “an openness in the face of uncertainty, isolation, and contradictions” (Baumann & Englert, 2003, p.53). This often entails a re-evaluation of previously held beliefs and perspectives, and an ability to let go of beliefs and hopes which the situation no longer allows for (Baumann & Englert, 2003). A metasynthesis of qualitative research on the experience of breast cancer indicates that, when such a terminal illness presents a threat to an individual’s life, they are more likely to engage in questions around the meaning and value of that life (Arman & Rehnsfeldt, 2003). Growth and the exploration of meaning may include partaking in pleasurable and fulfilling activities, an appreciation and reverence for the world around one, interacting with others, remembering one’s life and finding beliefs which cohere with one’s outlook (Baumann & Englert, 2003; Frankl, 1959). For example, Unruh, Smith and Scammell (2000) found in a qualitative study that the activity of gardening allowed cancer patients to find meaning in reflection, aesthetic pleasure, and interaction with living things.

Several notions have been suggested to describe spiritual and existential difficulty, which is a phenomenon likely to arise when life or meaning are threatened. Spiritual pain, a
particularly relevant concept here, is defined as “the deep anxiety associated with the prospect of elimination of one’s personal existence”: it is the loss of meaning and purpose in life caused by the loss of self-integration (Mystakidou et al., 2007, p.1781). It may be precipitated by losses in areas which are of particular significance to the individual, such as relationships, physical strength, identity, or spiritual security (McGrath, 2003). Demoralisation, in turn, is a construct which is defined as a “disorder of meaning and hope”, derived from the work of Engel, Frank and Frankl (Lloyd-Williams et al., 2008, p1133). It may be seen as the psychological framing of a spiritual crisis. It is qualitatively different to depression, which brings out interesting questions about how it connects to Kübler-Ross’s stages. Symptoms include feelings of meaninglessness and helplessness, alienation and possible suicidal thoughts (Lloyd-Williams et al., 2008). Demoralisation also affects patient care, both in the sense that patients are less likely to consent to treatment, and in the fact that it can often be transferred to carers (Lloyd-Williams et al., 2008). It can thus be seen as a factor which may affect both the perceptions of nurses and the experiences of patients.

Death-bed phenomena have been recorded in various cultures across the last few centuries, and seem to be relatively common (Brayne et al., 2006). These phenomena have generally been described as visions or apparitions of deceased loved ones (death-related sensory experiences), or other spiritual experiences which occur shortly before death (Ethier, 2005). Recently, recognition of their psychological and existential importance has increased (Brayne et al., 2006). Sanders (2007) describes this as nearing death awareness: a state of increased sensitivity, changes in consciousness and spiritual awareness. However, it is still unknown how they originate or what they represent. It seems that they are different from drug-induced hallucinations, in that they are of a different nature, and have significant meaning for the patient (Brayne et al., 2006). They are seen as indicators both that death is imminent, and that death will be peaceful. Yet, deathbed phenomena can be defined more broadly than simply as the experience of visions; it can be argued that all psychological and existential processes which entail the dying patient taking stock and making meaning of their life, could form part of this concept (Brayne et al., 2006). Sanders (2007) reports that patients may speak in symbolic language, referring to taking a journey or transforming in some way. They may also become acutely aware of their own bodily processes, and may be able to sense or predict exactly when they will die (Sanders, 2007).
The discovery of meaning in life has been shown to be a fundamental element in coping and adaptation (Lloyd-Williams et al., 2008). Since Jung and Frankl first identified a spiritual aspect to psychological health and well-being, the field of psychology has probed the links between these variables (Berry, 2005). A sense of meaning has been found to correlate with happiness, psychological well-being and life satisfaction (Ardelt & Koenig, 2006). In response to anxieties regarding death, many individuals turn to religious activity to provide them with some comfort and meaning within their suffering (Ardelt & Koenig, 2006). Malinowski (1965, in Leming, 2003) calls religion the “great anxiety reliever” (p.120), pointing to its psychological function. According to this logic, religion would reduce anxiety regarding death. Quantitatively, this has been measured with tools such as the Religious Orientation Scale (Berry, 2005), the Spiritual Beliefs Inventory and the Duke Religious Index (Baumann & Englert, 2003). Death anxiety and death depression have thus often been studied in relation to religious or spiritual belief, with many trends pointing to the idea that these factors are negatively correlated with anxiety and depression related to imminent death (Alvarado, Templer, Bresler & Thomas-Dobson, 1995; Mackenzie, Rajagopal, Meibohm & Lavizzo-Mourey, 2000; Hebert, Dang & Schulz, 2007). Existential meaning and purpose in life, specifically, have been shown in some studies to be more significant in this regard than conventional religiosity (Ardelt & Koenig, 2006; Briggs & Shoffner, 2006; Bussing, Fischer, Ostermann & Matthiessen, 2008).

The idea that finding meaning in life can allow an individual to be more willing to let go of that life, deserves pause. Several theorists have proposed explanations for this paradox. Moody (1968, in Ardelt & Koenig, 2006) posited that meaning may be individual, collective or cosmic. He felt that the search for meaning as one approached death shifted from the purely individual level to the collective, relating to others, or even the cosmic and universal. Yalom (1980) also suggests that there is a divide between terrestrial and cosmic meaning. Terrestrial meaning encompasses secular and self-focused sources of meaning, such as achievements, leaving a legacy, material needs, interpersonal relationships and creative output (Ardelt & Koenig, 2006). However, Yalom theorises that when these sources of meaning fall away – when we are no longer able to be productive because of physical illness or deterioration – we need to connect to a meaning system which gives us purpose and helps us to define our place in the world despite our difficulties. This is most likely found through some spiritual or religious source (Yalom, 1980).
However, it has been demonstrated that not all elements of religiosity are beneficial to psychological health. Whereas many researchers report an inverse relationship between religiosity and death anxiety, others have found the relationship to be rather complex (Leming, 2003). Charles-Edwards (2005) points out that religions sometimes create a fantasy in which death does not exist, which can be problematic. Religious belief has been found to reduce certain fears, such as fear of the unknown, but increase others, such as fear of annihilation and fear for loved ones (Moore & Williamson, 2003). Some studies have found that death anxiety may only be reduced in highly religious individuals (Leming, 2003).

It is also important to distinguish between solitary and social religious activities, as well as the extent to which religiosity is intrinsic or extrinsic (Ardelt & Koenig, 2006). Allport and Ross (1967, in Ardelt & Koenig, 2006) were the first to define religious orientation on a continuum between the intrinsic and extrinsic poles. Extrinsic religiosity was described as the use of religion in one’s life in order to fulfil functions for the self, such as comfort, continuity or social contact. Those with intrinsic religiosity, conversely, internalise the meaning system of the religion, allowing them to locate possibilities for transcendence within the universe. Thus, it is more likely to be associated with a sense of meaning in life, as well as social religious activity (Ardelt & Koenig, 2006). Extrinsic religiosity has, in fact, been more positively associated with death anxiety than intrinsic religiosity or non-religiosity (Ardelt & Koenig, 2006). However, even those who seem to have dedicated themselves to a spiritual deity, and seem to possess intrinsic religiosity, may not always find peace or purpose. Dying patients immersed in religion may assume that God will heal them, which can cut them off from fuller and more complex religious experience (Kacela, 2004).

It is clear, as well, that meaning can be found beyond, or in addition to, religion. For theorists who believe that meaning resides in love, connection and intimacy with others, terminal illness can fundamentally threaten these relationships, and thus meaning itself (Baumann & Englert, 2003). The discovery of meaning in death is often thought to have a dialogical element to it, in that the dying patient must engage with another, on an open and genuine level, in order to undergo spiritual growth (Abma, 2005). This is an aspect upon which palliative care nurses can have a great effect, as they may be a transitional ‘other’ to which the individual can relate, as a route to eventually engaging their loved ones. In addition, if disease has regressed a patient and rendered them unable to care for
themselves, the nurse can provide a Winnicottian facilitating environment, which allows the patient to feel held by the physical ‘mothering’ rituals the nurse performs (Baumann & Englert, 2003). It is thus essential that palliative nurses are appreciative of the degree to which illness and dying can serve as existentially transformative processes (Baumann & Englert, 2003). Ethically, it is essential that they also maintain respect for the particular meaning system of the patient (Baumann & Englert, 2003).

In fact, spirituality has been shown to be a predictor of better health in several different contexts, to the point where a number academic journals deal with the connection between these two variables (Kluger, 2009; Berry, 2005). Spirituality has been found in qualitative research to be important in enhancing well-being, personal comfort, and as aiding in coping and finding peace (Walton & Sullivan, 2004). In addition, many health-promoting benefits arise from being a part of a faith, such as social activity, positive interactions, emotional support, community integration, a sense of meaning and stability, a healthy lifestyle, and opportunities to help and serve others (Ardelt & Koenig, 2006). Quantitative research had found positive associations between religion and happiness, as well as feelings of usefulness and life satisfaction (Ardelt & Koenig, 2006). It should be noted that the causal link in these associations is not clear. It is possible, for example, that individuals with poorer health are simply less able to take part in religious activity (Ardelt & Koenig, 2006), or that difficult life circumstances have led them to question their faith more. Nonetheless, the connection between spirituality and health deserves further investigation.

Wherever the benefits of religiosity may stem from, the fact remains that spiritual issues are important to a large proportion of the world. It has also been proven to be a primary consideration of those near the end of their lives: religiosity generally increases with age (Ardelt & Koenig, 2006), and being at peace with God was the most frequently named desire of the terminally ill subjects in one study (Steinhauser et al., 2000). Another study found spiritual needs to be second only to response to immediate concerns in importance to over a million patients (Press Ganey, 2003 in Walton & Sullivan, 2004). Despite the growing body of research showing that spiritual issues are important to patients and can be beneficial to treatment, most doctors and surgeons are still sceptics, or are unsure of how to broach the topic (Kluger, 2009; Woll et al., 2008) – leaving this more sensitive and ‘non-scientific’ issue to palliative nurses to deal with. Nurses themselves have also expressed a lack of confidence or time to explore spiritual matters with patients (Baumann
This leaves us with the question: how is spirituality managed in palliative care?

**Existential Perspectives on Nursing**

Parse (1998, in Hutchings, 2002 and Baumann & Englert, 2003) has suggested the human becoming theory as a possible way to integrate spirituality and meaning-making into palliative nursing. Human becoming theory understands humans as irreducible and unitary entities, experiencing their environment, and time itself, in a multidimensional way (Hutchings, 2002). Based in both existential and humanistic (specifically Rogerian) theory, it conceptualises nursing not as task-oriented and quantitative, but as “a way of being with persons as they explore meaning, shift their ways of being with what is, and uncover new directions for their lives” (Baumann & Englert, 2003, p.56). The theory values choice, and emphasises the power of patients to co-create their lives, believing that they are not forced to live or die purely as their situation dictates. This should be fully honoured by nurses – patients, after all, are the ones who know best how to make meaning of their situation. Parse (1998, in Hutchings, 2002) theorises that true presence (a kind of quieting, reflective love), transcendence and hope are fundamental to the nurse’s ability to offer herself to the patient, in a way which allows for present but also future visions. The theory of human becoming also encourages care of the whole person, and the acceptance and embrace of the paradox of human experience, both of which cohere very well with the values of palliative nursing (Hutchings, 2002).

Galvin and Todres (2009) describe a phenomenon called nursing openheartedness, which is also existentially informed. They depict it as consisting of three separate but coexisting and interrelated concepts. The first is the infinity of otherness. This dictates that, as much as identification and empathy occur between the nurse and the patient, the ‘other’ (the patient) can never be completely known by the nurse, as he or she cannot be reduced only to what the nurse knows and can conceptualise. This may tempt the nurse into separating herself completely from the patient, and refusing to identify with the agony and aloneness of the patient’s state (Barnett, 2005). Nursing openheartedness, however, requires that the nurse acknowledges and accepts what she cannot know, and yet allows for whatever human connection and presence is required by the patient at that moment.

The second component of nursing openheartedness is embodiment. This perspective recognises that our bodies are, in a way, our ultimate “shared heritage” (Galvin & Todres,
The suffering, breakdowns and limitations of the body are unavoidable to us all, and thus have great levelling power. This is thus a point at which the nurse may meet or connect with the patient – with a recognition of the human ability to both see the body as an organ separate from the self, and as a vehicle for the expression of the self. The third dimension is practical responsiveness. This entails an ability to act free from personal or ideological preconceptions of behavioural routines. Every situation has its own complex relational and momentary facets, which require a unique response in that moment, and the openhearted nurse will be best equipped to do this if she takes the moment for what it is, and responds to it in such a manner. Emphasised again, here, is the value of not knowing – the situation may present any calls to action from the mundane and medical to the deeply existential, but what is important is the nurse’s ability to respond spontaneously to these needs within the patient (Galvin & Todres, 2009).

Conclusion

Divergent opinions exist regarding whether death is a taboo in Western society, and especially in the medical profession. However, it is clear that the prospect of death can have significant psychological consequences, and thus several theorists have attempted to define it or make meaning of it, most famously Elisabeth Kübler-Ross (1969). Although many of her assertions have been critiqued, her theory still holds prominence, and thus it will be useful to explore the ways it manifests in reality. Less theoretically prominent, but highly salient to the dying experience nonetheless, is meaning-making on a more spiritual or existential level. This process is often put into motion by death, and, it may be argued, was constructed for the purpose of explaining death. Nonetheless, its implications and benefits extend beyond this single purpose (although, of course, it is not without its pitfalls). This study is interested in exploring both the psychological and the spiritual dimensions of the dying process as viewed through the eyes of palliative care nurses. Thus, the philosophies which underlie palliative care, as well as the particular factors which construct these nurses’ unique experience, are an important background to an understanding of the data.
Chapter 3: Methods

Research Questions

- How do palliative care nurses perceive the death and dying experiences of their terminally ill patients?

- How does spiritual and existential experience relate to or intersect with Kübler-Ross’s theory of the five stages of dying within these perceptions?

Research Design

The study used a qualitative approach, using in-depth, face-to-face, one-to-one semi-structured interviews. The design was non-experimental (Whitley, 2002; Rosnow & Rosenthal, 2005).

Procedure

The Witwatersrand Hospice in Johannesburg was approached, and permission was granted from the clinical manager to conduct the study with members of the organization. Once ethics clearance has been obtained from the university, individual nurses were contacted, told about the study and asked to participate. They were given an information sheet explaining the nature of the study. The participants were also informed verbally by the researcher of the basic interests and aims of the research. Potential participants were asked to sign a consent form to indicate their willingness to participate in the research. They had to consent to being interviewed and being recorded. If the consent form was signed, and written consent to be recorded was given, the interview proceeded at a time convenient to both parties, using the interview schedule (see Instrument). Interviews were held over a 2-month period, between July and August 2009. Interviews lasted between 20 and 80 minutes, and were conducted in quiet settings within the facility where the parties had a minimal chance of being disturbed. Initially, rapport was established: the researcher asked for information regarding the participant’s training and motivations, to get a sense of the participant’s context and beliefs. The interview was concluded when all prepared questions had been asked and answered, or when saturation has been reached. All interviews were recorded onto MP3 and stored in password-protected files on the researcher’s personal computer. After all interviews had been carried out, the researcher transcribed and
analysed them. Numerical coding was used. After the research project was concluded, the data will either be destroyed, or kept for use in further research.

Participants

The researcher interviewed 10 nurses and nursing sisters working in a Hospice facility in the greater Johannesburg area. Six of these participants were home care sisters, and 4 were inpatient nurses working at the facility itself. All were female. Their work experience at Hospice ranged from 6 months to 23 years. Six of the participants were White, and 4 were Black. Most (80%) of the participants claimed to have some adherence to a sect of the Christian faith, although this dimension ranged from skeptical and doubtful to highly devoted. One of the participants self-identified as an atheist, and one as Muslim. Over the course of two months, they were interviewed individually, and asked to comment on the spiritual and emotional experiences of individuals who have been diagnosed with terminal illnesses. This sample was a convenience sample (Whitley, 2002). The sampling method followed non-probability methods, due to the qualitative method being used, which does not emphasise generalisability, but rather depth and richness of data (Davies, 2001; Parker, 1994).

Instrument

Interviews are used in qualitative research to gain a description of the subject’s interpretation of an experience (Davies, 2007). It is emphasised that understanding the subject was the primary overarching goal in these interviews, even if some structure was sacrificed (Bogdan & Biklen, 2003). One semi-structured interview was conducted with each respondent. This allowed the researcher to adapt her questions and probes during the interview according to the way the participant responded (Burman, 1994), but still to retain a sense of structure and not lapse into a conversational style (Whitley, 2002).

An interview template was developed, based on the literature and structured around the research questions. It focused on two main themes: spirituality and meaning, and theories of death and dying, including Kübler-Ross’s five stages of dying. The interview contained certain questions and probes, but these were structured to be relatively open-ended. For example, initial questions regarding the construct of acceptance were: “How often do people reach a stage where they are at peace with dying?” and “How would you describe the way people behave when they have accepted death?” Depending on the participant’s
reply, several probes could be used to ascertain their ideas of acceptance, such as, “Do you think accepting death means not struggling with it anymore?” It was hoped that these questions would serve to open up new avenues of questioning, which were pursued as far as possible within the interview structure and research aims. Because of the flexible nature of qualitative interviews, the subject was given space to shape the interview to a certain extent (Bogdan & Biklen, 2003).

**Data Analysis**

This research aims to approach the notion from the bottom up: by taking the constructions of individuals as some form of subjective ‘truth’. A phenomenographic approach was thus used to analyse the data. The particular strategy utilised was interpretative phenomenological analysis (IPA), a method which not only seeks to represent the voices of those it investigates, but also aims to explore and understand these unique viewpoints (Larkin, Watts & Clifton, 2006). It uses an idiographic template, in that it works at an individual level, but this does not imply that it is limited to analysis at the individual, intrapsychic level; though subjective experience is its focus, it is nearly impossible for it not to take into account situation, context and construction. Nonetheless, it involves a richly detailed account of a small number of individuals’ experience, after which themes or “patterns of meaning” are extracted (Larkin et al., 2006, p104).

Interpretive phenomenology follows Husserl and Heidegger in assuming that the individual is a part of material reality, even as it studies human consciousness (Larkin et al., 2006). This is a rejection of the dualism often found in modernism that claims that subjective and objective reality can be separated (Giorgi & Giorgi, 2008). Situations cannot be disentangled from our “active intellectual construction” of them (Prigogene & Stengers, 1984 in Larkin et al., 2006, p106). Thus, even though the aim of the research was primarily to gain insight into the subjective experiences of the participants, the way they construct the world, and how it is constructed for them through language, was also considered. The first goal of IPA is thus to try to understand, and give an account of, what living in the participant’s world is like. This comes with the rider that the ‘true’, unvarnished experience of another can never be fully accounted for: it is constantly being constructed by the person themselves, then reconstructed by the researcher (Larkin et al., 2006). This is usually termed a “double hermeneutic” (Smith & Eatough, 2007), but in this case a third level of interpretation is added here, since nurses are also making meaning of
the experiences of others, i.e. the individuals with terminal illnesses whom they are in contact with. Thus, three levels of experience are being interrogated. The second aim of IPA is to position the description within a particular sociocultural and situational milieu, thus adding an interpretative dimension, and sometimes linking the data to existing theoretical frameworks (Larkin et al., 2006).

IPA is, however, more a perspective on research than a method of analysis (Larkin et al., 2006). Thus, within the interpretive phenomenological framework, the technique of thematic content analysis was used. In this method, the researcher used coding procedures to isolate themes which recurred in the text, and thus attempted to decode “messages, meanings [and] symbols” (Neuman, 1994, p.262). Though qualitative content analysis is not seen as useful by most positivist researchers, it is a flexible tool which allows for rich, nuanced readings of data (Braun & Clarke, 2006). It is also well suited to interpretivist methodologies, given its usefulness in revealing non-obvious implications in data (Neuman, 1994). The basic analytic procedure followed Braun & Clarke’s (2006) steps. Data was transcribed and the researcher familiarised herself with it, by re-reading transcripts several times. A coding system was developed, and interesting or relevant features of the data were coded, which provided a framework to determine the frequency, direction, intensity and space occupied by the units of analysis (in this case, themes) (Neuman, 1994). Latent coding, or coding of underlying meanings, was implemented: the researcher attempted as far as possible to interpret the unsaid as well as what was said. Codes were then grouped into potential themes, after which the coded data was revisited in order to see if it collated with the themes. The researcher then, through thorough analysis, defined and named themes, and selected the most pertinent and interesting to report in the final written research (Braun & Clarke, 2006). Themes were determined using both a theoretical or top-down approach (Braun & Clarke, 2006), given the basis of the research in Kübler-Ross’s stages of dying, and allowing for new and unexpected themes to emerge through a bottom-up approach. Thus, the approach to identification of themes was theoretically guided, but still open to taking advantage of the generativity of semi-structured interviews.

The assumptions of this research were thus located in an interpretive framework, with a descriptive leaning, and this was appropriate given the aims of the study: to take the experiences of those caring for dying patients as a text, as their own truth, and work within that paradigm to explore issues and theoretical clashes. Commonalities and contrasts in
narratives were identified: the gaps or discordant elements are often as important as themes which unite narratives (Breakwell, 2000). This technique also works particularly well with the data collection technique of a few semi-structured interviews, which provides rich text data which can be explored in-depth. Although the research questions and instrument were drawn from theory and research, there was a hope that the research would be, to an extent, generative.

As always with qualitative research, it is acknowledged that neutrality and objectivity in the traditional Western positivist framework are impossible. Context and participant factors are thus not necessarily extraneous variables which contaminate the research, but rather important factors, unique to the particular setting and moment, which are inextricable parts of the research (Parker, 1994). Given the philosophical and epistemological assumptions of interpretive phenomenological research, what is found in research is necessarily a function of the interaction between the researcher and the subject (Larkin et al., 2006). Interviews set up an inescapable power dynamic between researcher and participant (Burman, 1994). In analysis, too, the researcher decides which themes are important, what themes are, and how they are defined (Braun & Clarke, 2006). It is acknowledged that the researcher is always a co-constructor of knowledge, and is inseparable from it (Snyman & Fasser, 2004). The role of the researcher must thus be acknowledged and explored, and this is especially pertinent in a one-on-one, face-to-face interview situation (Burman, 1994). The ways in which the researcher has determined and changed the research was thus carefully documented in a research journal, which detailed the researcher’s subjective experience of the research, including how she was affected by the research and how she may have been affecting it. It included both descriptive notes on the context and subjects themselves, and reflections on the researcher’s method, analysis, ethical dilemmas and frame of mind (Bogdan & Biklen, 2003). This served as a way to control for inevitable researcher biases (Bogdan & Biklen, 2003).

**Ethical Considerations**

This study was, by nature, ethically sensitive. It is acknowledged that the subject of dying is traumatic to many people, especially the patients themselves. This is exacerbated by society’s general resistance to dealing with death directly (Govender, 2006). However, nurses are constantly confronted with patients who are at a crisis point in their lives, and are thus thoroughly and intensively trained by their institution in end-of-life care issues.
and counselling. There was thus very little, if any, risk that the research itself could traumatising or re-traumatising participants, as they possessed both training and experience. The research was thus far more viable than it would be using most other respondents, as the response group was necessarily somewhat desensitised to the topic of death. This way of studying the important issues around spirituality and dying was perhaps the least risky method possible.

The researcher explained the purpose of the study and the method which would be used to the participants. She emphasised that participation was voluntary, and that they could withdraw at any time with no negative consequences. Additionally, no benefit was given to participants. The researcher also clarified that anonymity was assured, and that even though quotes would be used and themes discussed, no identifying information would be used in the written report. Interview raw data was seen by the researcher and her supervisor. The results of the study would be made available to the respondents in the form of an executive summary to the institution, and a list of counselling services, both in person and telephonic, was provided in case of any negative emotional reaction.

All ethical and procedural information was provided in a consent form which the participants were asked to sign in order to participate. They were also presented with a form giving consent to the researcher to record all proceedings and use quotations, which was always signed before the interview could begin. After the interview was concluded, the participant was again informed that if they had any concerns or felt they needed any help or counselling as a result of what had happened during the research process, the researcher would assist them in any way possible. This included recommending the counselling services at the Emthonjeni Centre at the University of the Witwatersrand, providing the telephone numbers of Lifeline and the South African Depression and Anxiety Group, and informing them how they could access the counselling facilities at Hospice itself.

Total anonymity could not be guaranteed, given the face-to-face nature of interviews: the researcher needed to access participants’ names and contact details for practical reasons. However, privacy was ensured, as the researcher did not request, record or use surnames, birthdates, or any other identifying information. Participants are referred to in the written report by numbers, e.g. Participant 7. Confidentiality was ensured, since only the researcher and supervisor of the project had access to the data.
Chapter 4: Results

The first research question related to how palliative care nurses perceived the death and dying experiences of their patients. Two themes emerged directly with regard to this: the first was the subjective emotional experiences of death and dying, and the second related to the meaning-making patients engaged in. The second research question aimed to explore the ways in which stages of grief and meaning-making intersected and interacted in the dying process.

4.1 Experiences of Death and Dying

The study aimed to gain a perspective on the experiences of patients with terminal illnesses. Thus, an important theme which arose related to the subjective emotional experiences of patients during the dying process. Markers of the five stages of Kübler-Ross’s (1969) theory emerged, but often in different or more complex forms than had been postulated in theory. At many points, they did materialise as coherent stages, and much of what Kübler-Ross suggested was reflected in the narratives of the nurses. However, it was agreed that these stages did not occur in any specific order. In addition, the stages appeared to vacillate, fading and recurring unpredictably.

PARTICIPANT 7: And then, ja, I mean, you get-you do get all those, um, those reactions that you read about, you know? Kübler-Ross and all that. But not necessarily in that order.

PARTICIPANT 9: They can move out of denial and go back again [...] So it doesn’t go the classic textbook sort of steps...They’re all over the place. And you think, “Now where are they today?” Yesterday they were in Acceptance, now they’re Denial, then they’re in Anger phase, though... [laughs] It’s very very hard to sometimes work out what’s going on.

Each ‘stage’ will be explored as a separate sub-theme, in order to highlight parallels and incongruencies with Kübler-Ross’s original conception. In addition, other emotional reactions which emerged from the data, such as abandonment and anxiety, will be discussed.

Denial was discussed by all participants in some form. It was described in some cases as a simple disbelief on the patient’s part that they were terminally ill. Denial, as perceived by the participants, was at these points identical to Kübler-Ross’s (1969) formulation: “No,
not me, it cannot be true” (p.34). There seemed to be a general difficulty for patients to ‘own’ the illness, and to conceptualise the disease, and the dying process, as happening to them. Incorporating this new information about themselves into their identity, and their self-concept, was a process they seemed to resist and defend against. It often returned in order to help the patient to gradually build up more defenses.

However, nurses also saw different manifestations of denial, which had not been envisioned by Kübler-Ross (1969). Some patients avoided speaking about their illness, either appearing not to know about it or openly expressing that they did not want to talk about it. An urge to fight the illness, at least initially, was viewed as universal. Kübler-Ross (1969) interpreted this as partial denial.

Many nurses disclosed that patients were not in their care at the time of the original terminal diagnosis, but nonetheless, they saw much evidence of denial at many stages of the dying process. Denial was thus not simply an initial response to a diagnosis, but returned at many points in subtle forms. Although it is often constructed as a healthy defense, many nurses seemed to feel that its extreme or extended presence was not healthy. One nurse, Participant 9, spoke of a patient who was already in a state of serious physical breakdown, but still refused to admit to or engage with the reality of his imminent death. This was both distressing to his family and harmful to his own psychological health. In fact, denial seemed to be such a powerful psychological mechanism that it could affect patients’ perceptions of physical reality. A nurse reported that a patient had been told that he had six weeks to live; he, however, reported having heard that his prognosis was good, and that he was not ill:

**PARTICIPANT 9:** They actually physically hear the doctor say, “You’re fine, you’re gonna be OK”. Meanwhile, the words are coming out, “You’re terminal, you’re not gonna get better” [...] The denial just changes that whole thing round. So that’s what they hear. They hear what they want to hear. And it’s only when you’ve had another witness, in the room, to say [whispers] “But that’s not what he said!”

Some nurses believed that ‘pure’ denial, in which the patient truly does not believe that they are ill or facing death, did not exist at the point at which they entered palliative care. Their view was that patients were undergoing such harsh medical treatments and physical deterioration, that it was impossible (or highly unlikely) for them not to know. Thus, their
denial was seen as a conscious avoidance of the emotional pain of engaging with their own feelings of grief.

The diagnosis of one member of a family with a terminal illness seemed to have an enormous impact on the way in which the family functioned. The nurses’ own narratives highlighted the ways in which the needs of families were often very different to the needs of the patient. In fact, families were often found to experience some of the five stages of grief as they came to terms with the imminent death of the patient. This appeared to be problematic for the patients themselves, as it had a negative impact on communications and relationships.

Denial by family members was also reported to be pervasive. Whilst the patient experienced the deterioration of their own body acutely, their family often found it difficult to empathise with this reality, and thus it was easier for them to remain in denial about the patient’s true physical state. Even when patients expressed a readiness for death, families had difficulty accepting this. Several nurses remarked that families in a way were losing more than patients, and they were often reported to suffer more anguish related to death. Only one nurse, participant 1, had had a different experience of families’ wishes; the general tendency was towards denial.

The denial by a patient’s family could have a significant impact on how much the patients themselves engage with the illness. Families were often witnessed attempting to protect the patient from the news that they were dying, by not informing them. Often, patients in turn desired to protect their families, and thus kept the same information from them. Both assumed that speaking about death would upset the other party too much, and thus it was avoided. The unsaid became greater and more significant as time went on and the patient’s condition became more serious. As has been mentioned, patients were mostly seen to be aware of their diagnoses and the implications of such.

**PARTICIPANT 9:** I had a little boy patient, he was about 8, and he had tumours on his knees, and in the bone, everywhere. And the parents – he had twin sisters who were 2 years younger than him, so they were about 6. And I was sitting talking to him one day, and his mom would say, “No, don’t mention to him anything about dying, he doesn’t know, he’s sick, he doesn’t know what’s wrong with him”. And I was talking to him one day – his mom was out – and he said, “I’m dying, you know”. And I said,” Oh, are you really?” And he said, “Aren’t you a nurse? Are you stupid?”, you see...and he said, “But don’t you
know?” And I said, “Well, I do know, but how do you know?” And he said, “Well, I’m not stupid”. He says, “I’m having chemo”, and he mentioned all the drugs and everything, and he said, “I don’t know if mom and dad know”. He says, “But I think they do”, but he says, “but I don’t think they’re coping” […] So I said, “Well, how do you manage it?” And he said, “I just don’t mention it around them; I don’t wanna upset them”.

In the opinions of the participants, what patients truly desired was empathy from others, as well as someone taking an interest in their feelings and speaking honestly and openly about their experiences. Emotional pain was even said to be more prominent in the patients’ lives than physical pain.

PARTICIPANT 3: “They never ask me. They tell me about the sport and the work and the...the car and the weather and the other mates, but they never say to me, ‘What...how are you dealing with this? This must be so hard for you. What’s going through your mind?’ You know? Or, ‘God, if I was in your position, I’d be terrified,’ or those kind of things.” And-and that’s the feedback they give us.

Instead, what family and friends often did was to focus their interactions on content unrelated to the patients’ experiences. It seemed that, as patients sensed the anxiety their loved ones felt about facing death, they often suppressed their own needs and appeased the family’s. This often involved the seeking out of alternative therapies in hope of finding a cure, and of ‘defeating’ the diagnosis, and even death itself. Patients generally accepted these to please their families, but this had the possible effect of demoralisation for the patient and the family when these remedies inevitably did not work. Food was also a focus for families: it was assumed that if the patient ate, he or she was or would become healthy. Patients were often not hungry, and again would force food down for the emotional benefit of the family. A patient ceasing eating was often perceived by families as an unnatural phenomenon, but nurses pointed out that it was part of any dying process – simply nature taking its course. Families also attempted to fill the patient’s time with their favourite activities; however, because of the patient’s weakened physical state, this was often exhausting and difficult for them, which in turn distressed families.

PARTICIPANT 1: I think that’s sometimes difficult for the family to accept. The person that used to watch, maybe, sport all the time; he’s not well, he’s not interested in watching the TV. And then they want to put on...or maybe if they travelled a lot. They, see, they haven’t got the energy...then they don’t wanna go anywhere [...] But the family wants to
take him somewhere, because then, I think, then they feel better. Because at least he went out and had a nice, um, day in the Kruger Park. But for him it’s a battle, it’s an effort. He just wants to be at home, wants to have air.

What seemed to emerge regarding death itself was a strong sense of the extent to which society denies death, which was directly spoken of as a source of frustration to several of the nurses. Death is often viewed by patients and their families as something terrifying, dangerous and even unthinkable. Working with death, as the nurses do, was assumed by many people in their lives to be difficult and depressing. Participant 2 described a case in which two young boys witnessed the death of their mother, although they had been very comfortable seeing her initially, and had sat with her and shown physical affection towards her both before and directly after her death. When the time came to tell the children what had happened, their reaction to her was completely different:

PARTICIPANT 2: And then the father said, after a few minutes, “Mommy’s dead.” And the—they got such a fright with that word, that they leapt off the bed, they ran down the corridor to their bedroom, they got under their bed, the two of them. Terrified. There I was on my hands and knees, trying to coax them out, saying, “Come out, come out,” whatever. And in their minds, they were thinking, blood, explosions, death, death...that’s what death meant when the word ‘dead’ was said. They didn’t look at her.

What also became clear were the ways in which Hospice and its staff attempt to counter this denial or avoidance. Hospice often marked a way for families and patients to begin dealing with and communicating about death. The act of entering Hospice was in itself some acknowledgement of the reality of dying. Although this led many families to avoid Hospice, it also signalled hope of acceptance for those who allowed it into their lives. Nurses often saw their role, in fact, as an active representative of truth and honesty. When they entered a family’s home, it was important to them to be honest and open about what was happening at all times, and they refused to lie or hide the truth from patients. Their presence was often powerful in its ability to stimulate emotional expression and communication in the family around dying. In the inpatient ward, as well, nurses aimed to reach the heart of a patient’s feelings, and their honesty often served as a model for patients. The participants generally felt that the knowledge was already there, but often families or patients simply lacked means to initiate communication.
PARTICIPANT 9: Often you find that if we go in and start making way for them to talk, it’s like a wall’s been broken down, because now somebody’s given them permission to talk about it...

Another common response which arose was that of anxiety. Patients feared leaving loved ones, suffering, rejection, or their own fate in the afterlife. This quote reflects the ability of religion to invoke existential fear:

PARTICIPANT 4: Cos a lot of them fear. They don’t al-always verbalise it – it’s a hidden ver-you know. So I say, “Well, where do-you know, are you going to heaven when you die? Do you think...?” [...] They say, “I don’t know,” and then it comes out. “I, uh, committed adultery, and aborted a baby.” From that, she says so. “I don’t feel, you know, that God can forgive me.”

Most nurses spoke of pre-terminal restlessness, a condition which occurs in a reasonable proportion of patients. It is described as a physical thrashing, fidgeting and inability to keep still. Nurses seem to perceive this as a difficult and painful experience for the patient. This seems to constitute a physical expression of psychological anxiety around dying. Nurses remarked that it often occurred when patients held fears about dying. Preterminal restlessness was also often spoken about in spiritual or existential terms, and to some it indicated the presence of unfinished business:

PARTICIPANT 4: I believe, in preterminal restlessness, people become restless because the spirit is aware that [...] they’re about to enter Hell. Now they don’t know it mentally, maybe, but I believe this is what happens.

Thus, those who had little spiritual affiliation or belief experienced a more restless death, according to some participants. Some disagreed, indicating that there was little clear or universal link between religiosity and death anxiety.

For both patients and families, control, structure and certainty were important, as ways to keep anxiety at bay. Having information was one way of gaining control over situations. A common question to nurses was how long the patient had left to live. Another way to gain control was to continue being productive in some way, in work or at home. One patient, mentioned by Participant 8, even wrote books and gave lectures well into his illness. Even when patients had lost control over many of their bodily functions, they were often determined to do whatever they could.
PARTICIPANT 6: They—they still want to do different things for themselves. And we allow them that dignity. Like, there’s a old lady in that one room there. Sh- like, she still try and battle to eat herself, and drink – try and drink her tea herself, no matter, hands shaking, battles, you know? [...] They want to have that little bit of control still over their lives, and we–we encourage it.

At some points, control was exercised purely psychologically, within the patient’s own mind. There was a sense gained from many patients that they refused to give in to the disease completely by admitting the truth – and as long as they did not give in, they believed would not die. Dealing with dying, or even talking about it, were seen as tempting fate. Patients felt that as long as they did not relent in their opposition to death, they were invulnerable to it somehow – they had control of it, rather than it having control over them.

Also important to families was the need to control their environment in some way. When exercised by families, it led to the patient themselves being controlled by the family. It seemed generally to be well-intentioned: families attempted to aid and comfort the patient (and themselves) by doing tangible things. The more families were accustomed to being able to control their environment, the more difficult it was for them to come to terms with a terminal illness in the family. Families also attempted to exert control over nurses themselves, dictating their hours or actions, but nurses were highly resistant to being controlled.

Anger was a reaction also spoken of by all the participants. Many patients seemed to have anger provoked by the fact that their life was ending. The question “Why me?” is a textbook example of Kübler-Ross’s (1969) conceptualisation of anger. This, theoretically, represents the period when denial is no longer possible, and when the realisation has occurred that death is truly imminent. Individuals had difficulty connecting that reality with their own narrative or self-concept – thus the question, “Why me, rather than anyone else?” This speaks to the perceived injustice of the reality of death, which often provoked anger. Again, as with denial, there was a perception of death as an enemy which must be defeated. A feeling of isolation from others, more commonly theoretically associated with depression, was also witnessed.

PARTICIPANT 3: But that’s the kind of anger, you know, it’s like, “Well who does care anymore?” Because they–they–they can’t believe that anybody really understands what they’re going through.
However, it is important to note that questioning was also possible without anger or aggression. The question “Why me?” could be asked, and reality fought against, without resentment being expressed. Nurses even spoke of clients who knew and acknowledged that they had a terminal disease, and had suffered through treatment, but still failed to understand why these things were happening to them. Rather than anger, this questioning seemed to indicate a need for meaning within their experiences.

**PARTICIPANT 7:** She knows she’s got cancer [...] And she’s still questioning: “I don’t understand why I’ve got it.” She almost wants an answer as to why she’s got it. And she’s been through the most horrendous side effects from chemo. Now got secondaries again. Still that same question: “Why?” But sh-h...it’s almost as if, the minute I give in, I’ll die. That’s almost the feeling you get.

In some ways, this coheres with the processes occurring during the anger stage, as the patient is questioning and attempting to understand why she, specifically, should have cancer. In other ways, it seems to represent a kind of denial – compartmentalising – which allows for incongruent realities to coexist. If patients were religious, this anger was often directed at God. There is a sense in which God seemed to have let the patient down, or betrayed them:

**PARTICIPANT 8:** They devote their whole lives, everything, to God, and then they get sick – young people, especially, are very angry at God. They think, because they’ve been living these good lives, they should never get sick. I mean, so if they do get sick, it means they’ve done something wrong.

The sense of betrayal and anger at God patients experience implies that there existed, before this stage, an expectation of benevolence or protection from illness by God. Implied in participant 8’s quote, as well, is an element of exchange, in which the individual will dedicate himself to God with the assumption that God will respond by granting him or her health. This is a point at which religious experience intersects with a stage of dying. Whereas anger, in general, involves asking the question “Why me?” of the world or life in general, religious belief can direct this anger at a specific object – the entity which decides the fate of the patient. Rather than being angry at the injustice of life, those who believe in God’s omnipotence can direct this anger at their perceived unjust treatment at the hands of God, and thus at God himself.
Anger could also be projected onto medical professionals. Often, however, anger was also directed at others in the patient’s life. Most nurses reported having experienced aggression from patients at some point. Their experience had taught them that this anger was not directed at them, and thus they were generally patient, trying to accept the patient’s feelings.

PARTICIPANT 3: “In some funny way,” he says, “because you were so neutral, that I knew, somehow, deep down inside, that you were gonna be there for me, you were just – everything came out at you.”

Kübler-Ross (1969) noted that anger was often expressed at any person, for any minor complaint, and thus she conceptualised patients as having a considerable amount of aggressive energy, which they would project into the closest target. This was confirmed by the responses. However, it was unclear whether, as Kübler-Ross suggested, anger originated in resentment of others for their health and capabilities. This did not seem to be the nurses’ perception of any of the patients’ anger. Rather, the fact that anger was conceptualised as projected implied that it was not seen as anger at these significant others, specifically; rather, they were the safest repository to hold the anger. God also represented a target of anger who was not resented for his health or relative well-being; rather, God seemed to be the recipient of anger when he was deemed by the patient to be responsible for causing their illness.

Some nurses, however, remarked on the contrast between the way patients treated them and the way they acted with their families. Families and spouses, especially, seemed often to endure the majority of patients’ angry reactions, whilst nurses were often presented with a mask of civility and pleasantness. Some nurses saw this as an expression of difficult feelings to the only people who would accept it – a projection which unfortunately was difficult for those loved ones to bear.

PARTICIPANT 9: He was like a little puppy, you know, so sweet. And the wife’s going [whispers] “But he shouts at me! He’s so horrible!” And he’s lovely, he’s so sweet. But obviously you project your anger onto someone, and it’s usually the closest. And this woman was getting the whole lot.

Anger was also often viewed as a response to loss. The loss of independence and control, first of practical elements of their lives and eventually even their own bodies, invoked
strong reactions in patients, and they often seemed quite resistant to allowing this loss to occur. The loss of a future, or of future prospects, also led to anger directed at the self for not reaching their own goals. Especially when the patient had been successful or dominant in the household, anger was seen in response to the role reversal of becoming totally dependent on their families. Certain objects, such as car keys, could symbolise the freedom they had lost, and thus families would find it difficult to separate the patient from these objects. Although this could occur in patriarchs and matriarchs, some nurses pointed out that men more often experienced these reactions.

**PARTICIPANT 9: And the male is the supporter. I mean, it’s a stereotype, but the male is generally the guy who’s in charge. And now he’s not in charge, and now his wife is taking over his role...it’s – it’s really difficult to give that up.**

Also common, related to this feeling of loss, was a sense of abandonment in patients. Although not a stage as such, it was a distinct emotional reaction which could give rise to feelings of anxiety or anger, and thus precipitate or contribute to the occurrence of a stage. It is connected to the feelings of anger which patients direct at doctors or God – they experience a sense of being let down by benevolent forces which were supposed to protect them. Thus, a doctor’s admission that they could not cure the patient’s illness was experienced as abandonment by the doctor. God, as well, seemed to have abandoned those patients who believed that a deity would protect them from harm. Abandonment was often expressed as anger.

**PARTICIPANT 3: They’ve placed every last bit of trust and hope and everything...and they use that word “dumped” a lot. “I’ve been dumped.”**

This perceived loss of support could also lead to deep insecurity and anxiety. Feeling as if they have been abandoned by so many they once relied on, patients may rely more strongly on the caregivers or support they do have. A reliance on any of these figures – God, doctors, loved ones – to ‘save’ or unconditionally support the patient is usually unrealistic, and this is inevitably disappointing. One nurse, participant 2, spoke of the way in which patients’ spouses leaving the house to do everyday activities could be magnified in the patients’ minds to feel like true abandonment.
PARTICIPANT 2: They feel...imprisoned, um, isolated, alone, afraid, and their security goes out the door – you hear the car going, and they’re terrified. Until that person comes back. And a half an hour feels like a whole day.

Patients may also feel as if their families’ love is conditional. Participant 7 spoke about a patient whose family was desperate for her to recover, and thus consulted alternative therapies and tried many remedies in order to find hope for a cure. However, when none of these were effective, it became clear that the patient feared her family would only love her if she was healthy. She thus felt abandoned both by all of the cures which had not been effective, and her family, who had shown their love through these means.

In turn, families could also express abandonment and anger. Some participants pointed out that the caregivers of the patients were often ignored by social support structures, with all support and sympathy directed at the dying individual themselves, when in truth, the caregiver needed more support. This had the potential to invoke resentment within the caregiver at being neglected, which was often directed at the patient. A caregiver’s response to a patient’s abandonment may be anger:

PARTICIPANT 2: And they say, “Sjoe, you’ve been away a long time,” or something, and then this resentful person who’s caught up looking after this sick person all the time screams back at them and says, “I was away 25 minutes! Or dadadadada...” So there’s a lot of friction.

In addition, many interpersonal conflicts which had existed or been suppressed for many years were played out in the dying process. The past misdeeds of one partner could be subtly punished by the other when they became ill and helpless. The illness and dying process thus became an arena for anger and revenge – not because of the spouse’s distress about the partner’s death, but rather because death was a catalyst for working through hidden feelings.

Just as bargaining is the least discussed by theorists and by Kübler-Ross (1969) herself, this stage was mentioned the least in this study. Often, nurses’ conceptualisations of the stage differed somewhat from the original theoretical assumptions. Bargaining was described by some participants as patients presenting themselves to nurses and doctors attempting to look healthier than they really were. Other participants saw bargaining in the pursuit of conventional medicine and alternative therapies, after a terminal diagnosis had
been given. Planning for an extended future – booking holidays, for example – was also viewed as a form of bargaining. Bargaining also occurred in a religious or spiritual sense, with patients attempting to bargain with God for more time – the stereotype of bargaining. Even those who had displayed little religiosity before, tended to turn to religion before dying; this in itself could be seen as a bargain. It was pointed out that religion had the potential to bring true peace. As Kübler-Ross (1969) suggested, however, a turn to religion could also be seen as denial.

**PARTICIPANT 6:** They try the different things, and there and there and there, and doing that, and doing this more, so that can-go that to that church, you know, trying to buy time [...] I think in the long run, it’s also desperation. You know. I don’t want to die – let me try this, or let me try that, you know. Maybe that’ll give me a bit more time.

The fact that nurses conceptualised bargaining as dressing well and wearing makeup also indicates that buying time could occur on many levels. Rather than only attempting to bargain with God, patients bargained with any person who was perceived to have some power over their life or death – in this case, doctors. Bargaining represents both the belief that the patient has control over when they live or die, and the resistance to accepting death, which is still seen as an adversary, or an unpleasant event which must be postponed.

Depression was observed often in patients, and seemed to be common near the end of life. In some ways, it also seemed to represent an awakening of patients to their true condition. It was described as exhaustion, hopelessness and meaninglessness. As Kübler-Ross (1969) hypothesised, it was generally a reaction to loss in various areas of the patient’s life. Interestingly, even though reactive depression seemed common, few nurses associated this with talking a lot and engaging in help-seeking behaviours, as Kübler-Ross (1969) did. Depression was described more in terms of clinical depressive symptoms, such as withdrawal, fatigue and rumination.

**PARTICIPANT 1:** While the disease is not that bad, while they’re still up and about, I think maybe they’d mos still be a little bit in denial, and think, OK, I’m going to be all right. But once they become bed-bound, and they can see their body – because it’s also a very destructive illness, cancer [...] so, you know, I think that – that breaks their hope. Then they say, “Oh, I’m tired of this battle”.

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However, suicide was very uncommon in the experiences of all the nurses who mentioned it, and was almost never attempted by patients. Thus, hopelessness did not translate to a desire to actively end one’s life—the only people who were interested in euthanasia seemed to be the patients’ families.

When describing depression, many participants referred to physical expressions of melancholy. Nurses often conflated physical and emotional withdrawal. The concept of withdrawal seemed associated with a weakening of the body, and a consequent physical retiring. Patients often lay in their beds facing the wall and refused to turn around. They could lie in a foetal position, and resist attempts to engage them in conversation. Withdrawal was not always described in passive terms—at times, it was actively rejecting:

PARTICIPANT 5: We did have, eh, one lady, so—it was a black lady. The boyfriend came to see her, and then she chase him away. It was over, uh, the weekend, that the-the boyfriend came to see her. And then she died Tuesday [...] “How can you come in and see me when you know I’m going to die?” And then that boyfriend said, “What do you mean? Because I’ve been with you for a long time. If you’re sick I must come and see you like we did before.” She said, “No no no. Don’t want anybody here.”

Again, the intersection with anger is noted: the above interaction contains both withdrawal from loved ones, and aggression. It was hypothesised by one nurse that withdrawal may be a way of preparing the family for the loss of the patient, and aggression may aid this to an extent. Withdrawal can also be a way of punishing family members, and showing aggression in a passive sense. However, it was also suggested that this silent aloneness may be a space in which the patient can process their reality and their emotions.

PARTICIPANT 9: I think so often they’re just internalising things. Apart from the weakness, and it’s just too much to talk, they’re doing their own thing. So they just withdraw, and they’re subconsciously sorting out things.

Acceptance was a difficult concept to define within the interviews. Some participants saw it as a sense of peace, with patients being content and having little restlessness. Participants thought that most patients eventually reached this stage. However, often nurses portrayed acceptance as a feeling of exhaustion with life and with fighting the disease. Interestingly, it seemed exhaustion and hopelessness could coexist with a sense of serenity.
PARTICIPANT 2: Um, and they go through this whole journey, and eventually...they don’t have any more fight to stay alive because they’re so ill. But they’ve also been on a journey and quite often they’re peaceful.

Patients generally developed a good sense of when they were nearing the end of their lives. This related not only to their physical deterioration and weakening, but also to the ways in which patients become able to sense the workings of their bodies. As Participant 3 mentioned, this related partly to the fact that the patient’s world became gradually smaller as they grew more ill. As they became less able to be in the world, they spent more time alone with themselves and their disease. As a consequence, it was hypothesised that they became more aware of their bodies, and could sense when they were close to death.

PARTICIPANT 9: Most patients have a feeling that it’s coming. They might not have a feeling right down to the exact day, but they seem to know. Not just the physical sense, they just seem to have an awareness that it’s gonna be coming soon. So I often say to patients when they say to me, “how long do you think?” I say, “How long do you think?” And then they might say, “I don’t know”, and then if you ask them a bit later, then they start to give indications that they-they know things are coming.

Physical deterioration also seemed to contribute to the process of feeling as if one was ready to die, or “letting go.” Many participants spoke of this concept, and it seemed to them in many cases to be equated with acceptance.

PARTICIPANT 7: Some patients have just had enough, and everything’s in place, and they feel they’re a burden to the family, and they’re quite happy to let go. And I think that – I think that’s very very important, is the letting go. I think it’s a real thing in dying.

It is conceptualised as a psychological decision of patients to stop fighting to live and allow themselves to die. Often this letting go was influenced by external or emotional events. Unfinished business often featured: an argument, or an unresolved emotional issue, had to be resolved before the individual could let go. Waiting for something was quite commonly spoken of: patients were often found to wait for significant events or rituals to occur. These commonly included the arrival of relatives, or the birth or wedding of a child or grandchild. At the moment when this was fulfilled, the patient would let go. More often than not, when a patient delayed their death for a certain goal, they were reported to reach the goal. General control over one’s life had to be surrendered, in a way, in order for the
individual to be able to let go of life. Thus, patients who struggled with relinquishing control often struggled to let go. It seems that allowing the defense of control to be broken down allowed for acceptance to begin.

Patients who were worried about their families – either about separation from them, or the fate of the families after they were gone – also had difficulty letting go. Young families seemed especially vulnerable to this, since children were often young and thus not yet self-sufficient. In these cases, families themselves could allow the process of letting go, by releasing the patient. Participant 7 also spoke about the importance of conducting bereavement visits to bereaved families or spouses. She had noticed that spouses needed these visits more often than families did. They served as an opportunity for the spouse to tell someone the narrative of their struggles. This also served as a catharsis of many painful emotions they had not previously felt comfortable to express. Feelings of guilt were prominent, and spouses needed to know that they could not have done more for the patient. This could aid in their own processes of acceptance.

Despite the identification of some common or even universal reactions, the individual nature of the patient and the family played a significant role in the way the dying process unfolded. It was difficult for some nurses to identify any universal themes at all in the ways patients dealt with dying. They emphasised the importance of respecting each patient and each family for what they were, and accepting patients’ wishes as unique and important. They acknowledged that it was sometimes frustrating when patients or families did not move towards acceptance in the ways they saw fit, but they never allowed this frustration to interfere with their regard for patients’ autonomy.

One of the sayings often quoted by the nurses was “You die as you live” – a mantra which highlighted the influence of an individual’s personality upon the way they navigated the dying process. Not only were all the stages – denial, anger, etc. – mediated in their expression by the patient’s particular traits, but their movement through the stages was as well. People’s coping resources and stereotyped ways of dealing with crisis and difficulty – whether it was to express anger and resistance, or to accept it calmly and stoically – seemed to play an important role in their particular responses. Participant 9 even remarked that stressors exaggerated traits which were already present. It seemed, in the experience of the nurses, that the dying process usually did not fundamentally change individuals; rather, it often brought out the essence of who they were.
4.2 Meaning-making

An important aim of this research was to discover palliative care nurses’ perceptions of the spiritual and existential experiences of dying patients. Nurses and patients made meaning through religion in multiple ways. More secular or existential beliefs also informed many of their ideas. The dying process in general is seen as a catalyst for existential processes to occur, and thus seems to be an important time for meaning-making. Values and goals often shifted, as illness and considerations of mortality made patients reconsider what was important to them. At times, this meant that patients became more in touch with their spiritual senses, and could even turn to religion after having been relatively secular. Committed atheists were generally reported to remain firm in their views, but patients who had little spiritual belief could become deeply religious by the end of life. The meaning which religion offered seemed to be a highly appealing factor.

**4.2.1 Making meaning through religion**

Religiosity amongst the nurses themselves varied. The religiosity of the nurses seemed to be an important factor in their own perceptions of patients’ spiritual meaning-making, as well as their dying processes. Deeply religious participants, for example, had definite opinions on the importance of religion in the dying process:

*PARTICIPANT 5: Everything is in God’s hands. There’s nothing that you can do without asking God to help you, to put you through to what you want to do.*

Even illness itself was viewed in a religious framework by several participants. Some nurses believed that illness was a punishment for serving the Devil, or not being grateful or loyal to God. Others felt that illness and even death were ways to move closer to God, and that God did not cause illness, but rather supported patients through their suffering.

Nurses who had strong religious beliefs found much comfort in their own religious beliefs. Religiosity seemed to function, at some points, to make death and suffering easier to understand and easier to manage. The complete safety which came from religious faith gave these participants certainty about the meaning of death, and thus death was perceived as a positive event, as it reunited the individual with their maker.

At times, nurses’ religious beliefs also had an impact on the ways in which they interacted with patients. If patients were religious, it was easier for religious nurses to comfort them,
as religion was a ‘language’, in a sense, which they both spoke. Nurses would pray with patients if they were asked to. Religion also provided a way for families to feel useful and effective, as they could “do” something in the area of religion, such as calling a religious leader or saying prayers. When there was a difference in belief between nurse and patient, some nurses found it easier to avoid spiritual matters.

Several participants spoke of finding or coming to peace with God as being a relief to patients, which allowed their anxiety and restlessness to abate. However, the psychological benefits of belief itself were not the only comforts which flowed from religion. Social support also seemed to play an important role in the benefits of both religion and meaning more generally. Often, the most peaceful deaths occurred for patients who enjoyed substantial family, community and religious support.

PARTICIPANT 3: Generally those kind of people are having quite a lot of visiting and quite a lot of support from, from their, their religious or spiritual community. So there’s a lot of space and time for reinforcement of stuff, or if they are feeling anxious, there’s a lot of praying or a lot of, um, ja, I suppose just support really.

It is possible that religious beliefs also allowed for the perception of the mystical, or the supernatural, in the dying process. These included, often, patients’ visions of loved ones who had already died. This seems to be a reasonably common phenomenon. There were also instances of patients dying at moments which were perceived as meaningful.

PARTICIPANT 9: And often they see – they see relatives who’ve passed away at the end of the bed, or they start calling for their mother or their father. And it’s not – it’s not a coincidence. I mean, I’ve seen that so many times, you know, there’s obviously something there [...]. I’ve just seen it so many times, you know, that it’s not just confusion, or they’re not making things up. They’re – they are seeing.

Religiosity was perceived by several participants to be an intrinsic urge within humanity. In this sense, it was often thought that it was religious belief itself which was helpful to patients, regardless of which system of meaning they subscribed to. However, some experiences had taught nurses that religion itself could not always provide patients with comfort. Religious leaders could sometimes do more harm than good by engaging in death denial. Even religious belief itself, and the patient’s personal relationship with God, could be disrupted by a terminal illness. Anger at God was common.
Some nurses referred to the dying experiences of individuals employed by religious authorities, such as priests, nuns and rabbis. Surprisingly to even the nurses themselves – who assumed that these individuals would be most at peace – these highly devoted individuals often suffered the most agony and meaninglessness. Nurses explained this as a sense of betrayal by God, a loss of a primary source of meaning (their work), and a lack of social support. The fact that individuals as deeply religious as priests are reported to suffer deep spiritual pain at their deaths is unexpected. One reason was again the principle of exchange: they had believed, given their dedication of their whole lives to a religion and a deity, that they would be spared from suffering, or even from death.

4.2.1 Making meaning outside religion

Often meaning was made in ways which did not rely on a spiritual or religious framework. Since nurses often utilised religion as a heuristic for spirituality, many saw extra-religious beliefs as only encompassing atheists, whom they characterised as quite vehement. Many patients seemed to conceptualise religion as an all-or-nothing affair. When viewed in these terms, atheism was spoken of in terms of deficit and lack. This perhaps flowed from the notion that spirituality or religiosity was a natural and essential impulse for humanity. On the way that people with no religious affiliation responded to the dying process, some nurses spoke of the difficulty that accompanied a lack of spiritual comfort. It seemed that to them, without religion there was nothing to look forward to after one died, and thus these patients sometimes had more difficult deaths. However, several other nurses who possessed religious beliefs remarked that choice or strength of belief made no difference to the ways in which people died, or the level of peace they attained. Thus, there was little consensus on the influence of religion on the dying process.

Several nurses noted a distinction between spirituality and religion. This related to the location of the belief: religion was seen as an adherence to an external belief system, whereas spirituality was, for them, a more universal and personal, internal experience.

PARTICIPANT 8: Many people may not be religious, but most of the people we see have some kind of spiritual side. It can relate to a whole lot of different things. It's basically a sort of – a connectedness with the world, with a, a greater being.

This broader, more individualised definition of spirituality allowed for multiple possibilities for meaning-making. Taking into account not only experiences with a
religious deity or community (although existential meaning could certainly be found here) but also encounters with family and friends, personal growth and enlightenment, contribution to the lives of others, and moments of joy and poignancy. Participants described instances of existential significance for patients. Hope was also an important facet of the dying experience. Although goals shifted, hope could be found in small achievements, or in upturns in patients’ conditions.

A patient’s dying process could serve as a learning experience for others in their life. Nurses remarked that patients were teachers to them, but it seemed they could teach just as much to their loved ones. A loved one’s death could be a catalyst for psychological growth and self-exploration, and their negotiation of the dying process could be an inspiration to others. Human connection and growth could also take place on a smaller, more everyday scale within families.

**PARTICIPANT 9:** If somebody’s dying, all of a sudden you tell them how you feel about them [...] And also, family members are doing things for their- their loved one that they never thought they could do. You get wives who are mopping up vomit or something, which they always had a phobia about, and now they can do it. And they always say, “I never thought I could do this”. And they-they find that it’s such a blessing, in a way, to be doing something personal. Something... helpful for that person.

One participant told a deeply poignant narrative about a patient who underwent a remarkable transformation. Having entered Hospice as a member of an ultraconservative Afrikaner political movement, he had initially shown aggression and resistance to the presence of individuals of other races. However, in the course of his suffering with his illness, his roommate – an African gentleman with the same diagnosis, also in much pain – showed him such kindness and humanity that his prejudiced beliefs had been shattered. He experienced something of an awakening in his time on the ward, and even though he conceptualised it in religious terms, this moment of profound human connection, and growth and enlightenment of self, is also at the heart of many existential theories of meaning.

**PARTICIPANT 2:** Went over to – to this patient and took his hands – also, he’s never done – he-he “looked after his ‘kaffirs’,” but he never touched his ‘kaffirs’ [...] And he took this guy’s hand and he prayed with him, and he thanked him, and... it was amazing to watch. So
only when we’re at our lowest ebb, and needing help, and we see what someone in the same position can offer, does it trigger a change in an attitude.

Patients also commonly used symbolic language to negotiate their death, and these symbols, and associated rituals were often necessary to allow patients to let go. Packing bags, going on a train, passing through doorways or leaving on a holiday were common metaphors.

PARTICIPANT 9: One old man wanted to put his shoes on. He was determined to put his shoes on. His wife was getting so irritated – he hadn’t walked for, like, weeks and weeks and weeks. He was in his pyjamas. And I said, “Please let him have his shoes”, and she says, “What for?” and I said, “Because sometimes that’s also a symbolic thing: they need to have their shoes on to walk, to go where they’re going”. She was like, “OK,” and when he put his shoes on, he died within an hour. Very peacefully. He just needed to have those shoes on.
Chapter 5: Discussion and Conclusions

The intersecting and vacillating nature of the stages, as perceived by these participants, indicates that in this case real experiences are far more complex than Kübler-Ross (1969) suggested. Behaviours which were stereotypically thought to occur in one stage were present in very different contexts, with different meanings. Withdrawal, rather than being passive and ruminating, may be angry and active; questioning may be part of a search for meaning, rather than an angry feeling of victimisation. The ways in which meaning is made for different patients also often framed their emotional processes. Thus, even though these themes were separate, intersections were common.

As found by Steinhauser et al. (2001), work with death provoked meditation on the nurses’ own mortality. Thus, emotions related to their own deaths (if not resolved) had the potential to constitute recurrent countertransferences with patients. At some points, it was not clear whether nurses simply reported patients’ emotions, or projected their own responses onto the patients. When nurses reported feeling upset by emotions patients were feeling, it was possible that they projected or over-identified their own hopelessness, despair or anxiety onto these patients. This must thus be taken into consideration when the results are discussed.

Even though denial does not often present in the textbook sense of total ignorance of reality, it pervades many other reactions not traditionally conceptualised as denial. In many instances, denial is described as a conscious avoidance, which coheres with Zimmermann and Wennberg’s (2006) claim that denial actually consists of a strong sense of the harsh reality the patient faces, and thus the patient’s psyche works hard to suppress that reality. This represents a version of Freud and Kübler-Ross’s conception of denial – the difference being that the original theory asserts that these processes occur completely unconsciously. If viewed in one light, anything before acceptance itself may be a form of denial. Anger is an active way of resisting the disease; bargaining implies a refusal to believe that death cannot be postponed. This in some ways may reflect the dichotomous conceptions theorists have of acceptance and denial. However, it may also highlight the various forms in which denial may manifest, and how pervasive a defense it truly is.

Nurses’ reports that pure denial was impossible – that patients always knew to some extent what was happening – were contradicted at other points by patients failing, in various
ways, to fully accept their reality. The patient who was suffering through painful
treatment, and for whom dying was very real in a physical sense, still struggled to connect
this with her psychological reality. Her mind was undergoing different processes to what
her body was, signifying an almost dualistic split. Perhaps, however, alienation from one's
own body is the only way to defend against a reality which cannot be faced yet.

Denial and control seem to be the most common defences against anxiety. In many ways,
they are relatively similar. In psychoanalytic terms, denial would repress death anxiety by
creating an alternate psychological ‘reality’ in which the illness does not exist. Control, in
turn, creates a reality in which the individual is powerful and can decide when (and how)
they live and die. Denial may constitute a way in which patients gain control over their
environments; when death threatens them with chaos, denial can push death away long
enough for the patient to find resources to cope with it. When they are able to deal with
death, thus, denial can falter.

Control may also be found in the principles of exchange adhered to by many patients. In
bargaining, anger and depression, patients can be seen to be reacting to a violation of an
implicit assumption of reciprocity. This assumption can be seen in many behaviours, but is
often connected to a powerful entity such as God, who seems to have betrayed the patient.
The notion of ‘giving in’ to death, which is constructed as an enemy or predator, positions
denial as heroic: as long as the patient does not admit they are dying, they have the
capacity to defeat death. The question is: why do so many individuals have assumptions
that life is fair, and that they have control over their own deaths? These beliefs seem
irrational, but it is likely that they are unconscious, and thus not consciously available for
interrogation by the patient themselves. In addition, if control theory is correct, an illusory
sense of control may be somewhat adaptive for patients.

Anger is seen as much as depression in response to loss and abandonment. It is possible
that they are alternate reactions to similar stimuli. Here the role of personality may be
pronounced, and may determine whether an individual responds to losses actively (anger)
or passively (depression). The role of gender could be relevant here. If anger embodies a
masculine ‘form’ of depression, it may be that males are more likely to become angry
when women tend to become depressed. Because men are more often dominant in
households, they also seem to experience loss of control and agency more frequently.
Thus, our analysis of the stages must take this into account. Anger has already been seen to
be far broader in scope than the stage theory originally allowed for; the significance of
gender and role changes, as well as personality, indicates that anger may be impossible to
limit to a single stage. Whether an individual becomes depressed or angry may depend less
on the stage they are at, than these extraneous factors.

Hope can be interpreted in two ways. One is that any hope is a form of denial: hope seems
by its very definition to anticipate improvement and recovery in the future, and this is not
possible when an illness is terminal. The other is what Kübler-Ross (1969) advocated: that
hope is possible, even necessary, in a healthy death. In this view, hope can be gained in
small recoveries, or the patient’s ability to hold onto their capacities. However, she
contradicted herself somewhat by emphasising the importance of hopelessness during the
depression stage. Here, she felt, it was necessary that patients did not retain any sense that
recovery was still possible. From this perspective, even the smallest instances of hope, as
patients displayed when they had a good day, would indeed be forms of denial. Again,
denial seems to be more present than was previously suspected.

Depression was, in many cases, the first instance of patients fully grasping the reality of
their imminent death. This ‘stage’ could thus be seen as the beginning on acceptance in
some way. Although cognitive realisation may have been present during anger and
bargaining, depression seems to mark a new level of awareness. The withdrawal of
depression and the withdrawal of acceptance are also not immediately distinguishable. The
fact that they seem synonymous in many nurses’ minds raises the question of how separate
these stages truly are. If, indeed, denial is somewhat present during anger and bargaining,
and acceptance begins to be present during depression, a new perspective on the five
stages can be gained. It may be that there are two more general phases: a phase in which
death is resisted, and a phase in which it is incorporated into the individual’s psyche.

Acceptance is traditionally seen as the final stage of the dying process, as it is by Kübler-
Ross (1969). It is possible that this normative assumption may have guided nurses’
perceptions of behaviours at this stage. Thus, behaviours signifying exhaustion and
hopelessness may have been perceived by the participants as acceptance, and they may
thus have inferred that these patients also had a sense of peace. This may explain the
assertion of most nurses that acceptance was reached by most patients, despite the fact that
real acceptance was described far less frequently. This highlights the danger of normative
concepts of stages being taught and internalised. It may alter the way patients’ behaviours
are ‘read’, and lead behaviour in the final stage of life to be seen as acceptance, although this may be false.

The stage model may also set up ideals for how death should proceed, and thus constitute the notion of a ‘good death’ for many nurses. If, as Connelly (2003) proposes, acceptance is an existential obligation, this attaches stigma or unacceptability to those who do not reach the stage of acceptance. Denial and acceptance seem to be positioned in a binary opposition, with acceptance being idealised, and denial consequently devalued. For those in a profession in which death is normal and everyday, it may be frustrating to witness many people not accepting it easily. As Weisman and Kastenbaum (1968, in Sandstrom, 2003) have shown, however, many individuals may never reach acceptance. Should acceptance thus be positioned as the “normal” stage which most dying individuals reach? The alternative would be for denial to be de-stigmatised, which in turn would mean that fewer patients (or nurses) would attempt to reach acceptance.

Alternatively, it could be concluded that our notion of acceptance itself should be revisited. If participants’ responses are taken as ‘truth’, acceptance is not simply a stage of peace and withdrawal. Patients’ emotional states often seem to be, to some extent, consequences of their physical conditions. Therefore, if a patient’s health has deteriorated to a point where incapacitation or suffering is considerable, it seems reasonable to assume that their attitudes toward death may be influenced by these bodily experiences. To view the stages of dying as an emotional process occurring in parallel with physical dying ignores the many interactions between the somatic and the psychological.

The notion of letting go seems to have been equated with acceptance, but it appears, upon reflection, that they may be distinct. Whereas acceptance is a stage of gradual withdrawal, letting go is a momentary decision. Acceptance is waiting to die, whereas letting go is making a choice to die. Whereas acceptance is desirable, therefore, at the end of life, letting go is necessary, whether reached in a state of acceptance of hopelessness. Letting go seems, in line with Brabant’s (2003) observations, to be a conscious act. This implies that, although many attempts to control death by the patient and the family may be futile, in this case death may be (to a small extent) under voluntary control. In addition, it seems possible for psychological mechanisms such as denial to fundamentally alter perceptions of the world, or to cut a patient off from their somatic reality. Mental and psychological factors may thus have a higher level of influence than has been recognised thus far.
The wide variation in views on the role of religiosity within the dying process indicates the highly subjective nature of both religion, and its power to alter perception and circumstances. As with emotional experiences, it seems that projections are common in the way nurses perceive the meaning-making processes of others. Thus, more religious participants were likely to view religion as important and influential. With constructions differing greatly, the objective ‘truth’ of the impact of religion thus remains elusive. From a postmodern perspective, it could be proposed that there is no such singular ‘truth’; rather, these many constructions coexist, and are again mediated by subjective perception.

Religion may provide a way for both patients and nurses to avoid facing the pain and anxiety of death. This confirms Malinowski’s (1965, in Leming, 2003) conception of religion as a powerful structure for anxiety relief. The function Charles-Edwards (2005) spoke of – creating a fantasy that death does not exist – is evident in some narratives of the nurses. Death is seen as a positive event, as it brings one closer to God; as comforting as this may be, it is also potentially problematic. Despair, grief and anger at loss do not seem to have a place here. Thus, important emotional processes which allow the patient to mourn for their life and their future, may be obstructed. In the broadest sense of the word, religion may even serve as a defense for some. As denial and control were seen to be the most common defences against death anxiety, it is possible that religious belief may serve to both deny and control. It denies death by positing that death is not an ending, and thus has no power. This coheres with Kübler-Ross’s (1969) sense that religion was a tool of denial. In addition, it may give individuals a sense that there is a greater plan for them, and that God will protect them. By allying with God, they are thus given control over their own death.

The religious patients who became angry at God, or felt despair and hopelessness, may have viewed benevolence from God in quite simple, all-or-nothing terms. This would entail that, if one contracted a terminal illness, one would either be healed by God or abandoned by God. Kacela’s (2004) point that this simplistic view may close off possibilities for deeper spiritual growth seems very true in light of the results. Most often, those angry at God were highly religious, but this belief may have been motivated by very self-focussed goals, such as the preservation of the self. God was constructed as a powerful but strict parent, who could abandon their ‘child’ at any moment. God’s abandonment would result in anger and rebellion. Those who constructed God in a different way – with less power over earthly affairs, and more constancy and benevolence – were more able to
retain faith and meaning, as illness could be seen as part of God’s plan. The determinant of these different views of a creator, again, seems to be individual perception.

Locations of meaning seem to change for many patients and families during the dying process. Religion was a common source of meaning, and thus both suffering and peace could be found within this framework. However, often patients seemed to move closer to or further away from the ‘answers’ that religion provided. Anger at God signified an inability to make sense of their situation within their religion; patients who moved closer to God, or found religion, seemed to struggle to make sense of death without religion. Religion (and religious deities) could thus be viewed as either comforting or malevolent, as abandoning or holding the patient. It is difficult to find unity in these vastly differing perspectives on religion, except to again appeal to subjectivity. Individuals’ personalities, and their own perceptions of the role and power of religion, differ so widely that they may not allow for the role of religion to be generalisable. Thus, the religion itself may be less important than the patient’s perception of God, their views on death, and their own psychological needs and resilience.

Ardelt and Koenig’s (2006) assertion that extrinsic religiosity was more associated with death anxiety, and intrinsic religiosity more associated with a sense of meaning in life, is thus perhaps too simplistic a view. Intrinsic religiosity may not be a unitary concept, since it does not define the subjective perceptions individuals have of God and religion. In this study, highly intrinsically religious individuals have been witnessed becoming angry and feeling betrayed by God, and thus even losing meaning in the face of death. In addition, the benefits of religion itself were sometimes ascribed to social factors such as support. Perhaps the prospect of death alters the way in which religion is associated with meaning-making, and forces a re-evaluation of beliefs.

In an extra-religious, spiritual sense, meaning also shifted. Initially it was found in a wide range of locations, such as work or achievement of goals. During the dying process, however, the most common source of meaning and peace seemed to be found in interpersonal interaction and connection. As Abma (2005) proposed, meaning may indeed be dialogical in nature, found in engaging with another. In fact, meaning seemed often to be found through processes, rather than objects or events. As Baumann and Englert (2003) surmise, finding existential meaning here required an openness to uncertainty and contradictions, and an ability to transcend these. Thus, hope could be found even in the...
face of death, fulfilment could be found in carrying out meaningful tasks, and lifelong prejudices could be re-evaluated. Without a pre-constructed explanatory framework which would make sense of death, some patients had to undertake this task with their own resources. Although this could often be more difficult, it is also possible that a fuller and more honest appraisal of the reality of death may have been allowed. Finding meaning and acceptance within this reality may thus have brought these patients closer to true acceptance of death, as death was accepted without the comfort of an afterlife.

Spiritual significance was attached to many moments and occurrences which seemed in some way special or coincidental. Most participants held an assumption that some unseen external forces were present in the lives of dying patients – hence, individuals died after they had performed certain rituals, suffered pre-terminal restlessness if they were non-believers, or spoke of death symbolically without realising it. Much socially constructed mysticism seems to surround the moment of death. However, rather than supernatural forces, this may also be ascribed to the heightened intuition of dying patients. By becoming far more aware of the workings of their bodies, and less in touch with the outside world, patients may have a good sense of how close they are to death, and when they are ready to ‘let go’.

**Conclusion**

The stages of death seem to occur in such different incarnations to the original theory, that the value of a normative stage model must be questioned. Although Kubler-Ross (1969) emphasised the possibility that the stages could occur in different order, the variation here is even more pronounced. Denial seems to be at the heart of many reactions to death, even at times the behaviours within the other stages. As a defense, it coexists (and at points overlaps) with control in order to moderate the impact of imminent death. Whether these defenses are fully unconscious, or are consciously constructed, is uncertain. The link between anger and depression, briefly explored here, warrants further investigation. The gendered variations between them, and their common antecedents, emphasise their similarities. However, depression (in its classic form) is distinguished by a full grasp of the reality of death, and thus it must be asked whether it does not cohere most strongly with the processes of acceptance. Whether acceptance is valuable in its current construction is debatable; what seems certain, however, it may be valuable to draw links and contrasts with letting go.
The role of religion, spirituality and God in the dying processes of patients differed so widely that it is difficult to draw general conclusions. What has been established is the importance of individual personality. This factor was mentioned by participants as an important mediator of emotional reactions, and it holds for existential experiences. The patient’s conception of their deity, how religion is used in their lives, and how they make meaning out of life to begin with are possibly the most significant factors in determining their meaning-making processes during their own death. However, the presence of shifts in meaning and spiritual feeling during dying seems more universal, and it is clear that the prospect of death provokes a re-evaluation of an individual’s pre-existing sense of meaning.

Limitations

This study contains various possibilities for improvement. The small sample size of ten participants limits the generalisability of this study. Qualitative research by nature emphasises individual experience, and the interpretive framework assumes that reality is fundamentally shaped by the perceptions of the subject (Bogdan & Biklen, 2003). These findings must thus be considered in this light. Given that the demographic composition of the participant group may not echo that of palliative nurses in general, it is likely that their responses are not representative of South African palliative care nurses as a whole. The location of this Hospice in a relatively affluent sector of Johannesburg also raises possibilities that the patients described are not representative of the majority of South African citizens.

It must also be taken into account how integral the nurse’s own individual lens – coloured by their experiences and beliefs – is to the construction of their narratives (James et al., 2007). Inevitably, no account of an experience can be neutral and depersonalized, and the narrator herself takes part in the construction of her story. Both the nurses’ emotions and their values, or ethical standpoints, are important in reading their responses (Abma, 2005).

This analysis of the data would not be complete without considering the researcher’s acknowledgement of her own part in influencing and constructing the data. The ways in which the researcher constructed and phrased questions directly influenced what data was elicited. Her relative inexperience in interviewing may have meant that her ability to elicit information was not equivalent to that of more experienced researchers. In the course of
some interviews she struggled to guide the participants toward her preferred line of questioning when they spoke of tangential issues. During one interview, after the allocated time had been reached, she was forced to conclude the interview even though she had hardly asked any questions on her schedule. Thus, although the same themes were explored in the interviews as far as possible, they were not all touched upon in each interview. What stood out for the researcher in the interviews also determined which lines of questioning she pursued, and undoubtedly, many salient points may not have been explored.

The researcher’s age, gender and presentation may have affected the ways in which the participants responded to her. In addition, these variables – as well as her own life experience, and perceptions of death and spirituality – may have affected her analysis of the data. Interpretative research, by its nature, involves a fair amount of the researcher’s own “reading-in” and subjective construal of what the research might mean. The discussion of the data, even though it relates to relevant literature in the field, is thus also influenced by the researcher’s own evaluation of themes, patterns and salient data.

**Implications for Future Research**

Although generalisability is not a primary aim of qualitative research, it is important for research to contribute to its field, and generate possibilities for new understandings of the topic in different contexts. The area of death and dying research is nascent in South Africa. Thus, this research may constitute a basis or developmental node which can encourage further exploration of themes around death and dying. Since this study’s data was focussed on experiences of dying mainly from cancer, the similarities and contrasts with HIV/Aids deaths may be a focus of future research. Palliative nurses in various other contexts, such as other hospices or hospitals, may provide similar or vastly different conceptions of spirituality and the dying process. It may also be of interest to contrast and compare nurses’ perceptions with families’ and patients’ experiences of the same events, in order to refine the value palliative nurses’ accounts bring to research.

This research illustrates some ways in which theories of death and dying – in this case, Kübler-Ross’s (1969) theory – differ from real experiences of dying in this particular context. However, research in other contexts may reveal differing results. The similarities and differences of the theory with real experiences has gained limited attention, especially in
recent literature, and extension in this context is advocated. It has also been found that spirituality is highly salient to a great proportion of South Africans, and its effects on the dying process deserve to be explored in more depth.
Reference List


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