

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 (avoidance 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; DeSpelder & 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,

2003). 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) (Grover, 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. Steihauser, Christakis, Clipp, McNeily, Grambow, 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 & Oyeboode, 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, Gherzi, 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 Ardel & 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 Ardel & 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 Ardel & 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 & Englert, 2003). 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,

2009, p.144). 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.