

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 Edgely, 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.