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) emphaisised 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.