

Chapter 4: Results

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

4.1 Experiences of Death and Dying

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

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

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

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

Denial was discussed by all participants in some form. It was described in some cases as a simple disbelief on the patient's part that they were terminally ill. Denial, as perceived by the participants, was at these points identical to Kübler-Ross's (1969) formulation: "No,

not me, it cannot be true” (p.34). There seemed to be a general difficulty for patients to ‘own’ the illness, and to conceptualise the disease, and the dying process, as happening to *them*. Incorporating this new information about themselves into their identity, and their self-concept, was a process they seemed to resist and defend against. It often returned in order to help the patient to gradually build up more defenses.

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

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

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

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

denial was seen as a conscious avoidance of the emotional pain of engaging with their own feelings of grief.

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

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

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

PARTICIPANT 9: I had a little boy patient, he was about 8, and he had tumours on his knees, and in the bone, everywhere. And the parents – he had twin sisters who were 2 years younger than him, so they were about 6. And I was sitting talking to him one day, and his mom would say, “No, don’t mention to him anything about dying, he doesn’t know, he’s sick, he doesn’t know what’s wrong with him”. And I was talking to him one day – his mom was out – and he said, “I’m dying, you know”. And I said, “Oh, are you really?” And he said, “Aren’t you a nurse? Are you stupid?”, you see...and he said, “But don’t you

know?” And I said, “Well, I do know, but how do you know?” And he said, “Well, I’m not stupid”. He says, “I’m having chemo”, and he mentioned all the drugs and everything, and he said, “I don’t know if mom and dad know”. He says, “But I think they do”, but he says, “but I don’t think they’re coping” [...] So I said, “Well, how do you manage it?” And he said, “I just don’t mention it around them; I don’t wanna upset them”.

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

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

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

PARTICIPANT 1: I think that’s sometimes difficult for the family to accept. The person that used to watch, maybe, sport all the time; he’s not well, he’s not interested in watching the TV. And then they want to put on...or maybe if they travelled a lot. They, see, they haven’t got the energy...then they don’t wanna go anywhere [...] But the family wants to

take him somewhere, because then, I think, then they feel better. Because at least he went out and had a nice, um, day in the Kruger Park. But for him it's a battle, it's a effort. He just wants to be at home, wants to have air.

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

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

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

PARTICIPANT 9: Often you find that if we go in and start making way for them to talk, it's like a wall's been broken down, because now somebody's given them permission to talk about it...

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

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

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

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

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

For both patients and families, control, structure and certainty were important, as ways to keep anxiety at bay. Having information was one way of gaining control over situations. A common question to nurses was how long the patient had left to live. Another way to gain control was to continue being productive in some way, in work or at home. One patient, mentioned by Participant 8, even wrote books and gave lectures well into his illness. Even when patients had lost control over many of their bodily functions, they were often determined to do whatever they could.

PARTICIPANT 6: They-they still want to do different things for themselves. And we allow them that dignity. Like, there's a old lady in that one room there. Sh- like, she still try and battle to eat herself, and drink – try and drink her tea herself, no matter, hands shaking, battles, you know? [...] They want to have that little bit of control still over their lives, and we-we encourage it.

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

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

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

PARTICIPANT 3: But that's the kind of anger, you know, it's like, “Well who does care anymore?” Because they-they-they can't believe that anybody really understands what they're going through.

However, it is important to note that questioning was also possible without anger or aggression. The question “Why me?” could be asked, and reality fought against, without resentment being expressed. Nurses even spoke of clients who knew and acknowledged that they had a terminal disease, and had suffered through treatment, but still failed to understand why these things were happening to them. Rather than anger, this questioning seemed to indicate a need for meaning within their experiences.

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

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

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

The sense of betrayal and anger at God patients experience implies that there existed, before this stage, an expectation of benevolence or protection from illness by God. Implied in participant 8’s quote, as well, is an element of exchange, in which the individual will dedicate himself to God with the assumption that God will respond by granting him or her health. This is a point at which religious experience intersects with a stage of dying. Whereas anger, in general, involves asking the question “Why me?” of the world or life in general, religious belief can direct this anger at a specific object – the entity which decides the fate of the patient. Rather than being angry at the injustice of life, those who believe in God’s omnipotence can direct this anger at their perceived unjust treatment at the hands of God, and thus at God himself.

Anger could also be projected onto medical professionals. Often, however, anger was also directed at others in the patient's life. Most nurses reported having experienced aggression from patients at some point. Their experience had taught them that this anger was not directed at them, and thus they were generally patient, trying to accept the patient's feelings.

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

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

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

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

Anger was also often viewed as a response to loss. The loss of independence and control, first of practical elements of their lives and eventually even their own bodies, invoked

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

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

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

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

This perceived loss of support could also lead to deep insecurity and anxiety. Feeling as if they have been abandoned by so many they once relied on, patients may rely more strongly on the caregivers or support they do have. A reliance on any of these figures – God, doctors, loved ones – to 'save' or unconditionally support the patient is usually unrealistic, and this is inevitably disappointing. One nurse, participant 2, spoke of the way in which patients' spouses leaving the house to do everyday activities could be magnified in the patients' minds to feel like true abandonment.

PARTICIPANT 2: They feel...imprisoned, um, isolated, alone, afraid, and their security goes out the door – you hear the car going, and they're terrified. Until that person comes back. And a half an hour feels like a whole day.

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

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

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

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

Just as bargaining is the least discussed by theorists and by Kübler-Ross (1969) herself, this stage was mentioned the least in this study. Often, nurses' conceptualisations of the stage differed somewhat from the original theoretical assumptions. Bargaining was described by some participants as patients presenting themselves to nurses and doctors attempting to look healthier than they really were. Other participants saw bargaining in the pursuit of conventional medicine and alternative therapies, after a terminal diagnosis had

been given. Planning for an extended future – booking holidays, for example – was also viewed as a form of bargaining. Bargaining also occurred in a religious or spiritual sense, with patients attempting to bargain with God for more time – the stereotype of bargaining. Even those who had displayed little religiosity before, tended to turn to religion before dying; this in itself could be seen as a bargain. It was pointed out that religion had the potential to bring true peace. As Kübler-Ross (1969) suggested, however, a turn to religion could also be seen as denial.

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

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

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

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

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

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

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

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

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

Acceptance was a difficult concept to define within the interviews. Some participants saw it as a sense of peace, with patients being content and having little restlessness. Participants thought that most patients eventually reached this stage. However, often nurses portrayed acceptance as a feeling of exhaustion with life and with fighting the disease. Interestingly, it seemed exhaustion and hopelessness could coexist with a sense of serenity.

PARTICIPANT 2: Um, and they go through this whole journey, and eventually...they don't have any more fight to stay alive because they're so ill. But they've also been on a journey and quite often they're peaceful.

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

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

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

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

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

individual to be able to let go of life. Thus, patients who struggled with relinquishing control often struggled to let go. It seems that allowing the defense of control to be broken down allowed for acceptance to begin.

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

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

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

4.2 Meaning-making

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

4.2.1 MAKING MEANING THROUGH RELIGION

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

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

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

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

At times, nurses' religious beliefs also had an impact on the ways in which they interacted with patients. If patients were religious, it was easier for religious nurses to comfort them,

as religion was a 'language', in a sense, which they both spoke. Nurses would pray with patients if they were asked to. Religion also provided a way for families to feel useful and effective, as they could "do" something in the area of religion, such as calling a religious leader or saying prayers. When there was a difference in belief between nurse and patient, some nurses found it easier to avoid spiritual matters.

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

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

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

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

Religiosity was perceived by several participants to be an intrinsic urge within humanity. In this sense, it was often thought that it was religious belief itself which was helpful to patients, regardless of which system of meaning they subscribed to. However, some experiences had taught nurses that religion itself could not always provide patients with comfort. Religious leaders could sometimes do more harm than good by engaging in death denial. Even religious belief itself, and the patient's personal relationship with God, could be disrupted by a terminal illness. Anger at God was common.

Some nurses referred to the dying experiences of individuals employed by religious authorities, such as priests, nuns and rabbis. Surprisingly to even the nurses themselves – who assumed that these individuals would be most at peace – these highly devoted individuals often suffered the most agony and meaninglessness. Nurses explained this as a sense of betrayal by God, a loss of a primary source of meaning (their work), and a lack of social support. The fact that individuals as deeply religious as priests are reported to suffer deep spiritual pain at their deaths is unexpected. One reason was again the principle of exchange: they had believed, given their dedication of their whole lives to a religion and a deity, that they would be spared from suffering, or even from death.

4.2.1 MAKING MEANING OUTSIDE RELIGION

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

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

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

This broader, more individualised definition of spirituality allowed for multiple possibilities for meaning-making. Taking into account not only experiences with a

religious deity or community (although existential meaning could certainly be found here) but also encounters with family and friends, personal growth and enlightenment, contribution to the lives of others, and moments of joy and poignancy, participants described instances of existential significance for patients. Hope was also an important facet of the dying experience. Although goals shifted, hope could be found in small achievements, or in upturns in patients' conditions.

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

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

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

PARTICIPANT 2: Went over to – to this patient and took his hands – also, he's never done – he-he "looked after his 'kaffirs'," but he never touched his 'kaffirs' [...] And he took this guy's hand and he prayed with him, and he thanked him, and...it was amazing to watch. So

only when we're at our lowest ebb, and needing help, and we see what someone in the same position can offer, does it trigger a change in an attitude.

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

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