

**Honouring Sacred Spaces:
Voicing Stories of Terminal Illness**

by

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Submitted in partial fulfilment of the requirements for the degree of

MASTER OF THEOLOGY

in the subject

PRACTICAL THEOLOGY

WITH SPECIALISATION IN PASTORAL THERAPY

at the

UNIVERSITY OF SOUTH AFRICA

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NOVEMBER 2002



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I declare that 'Honouring Sacred Spaces: Voicing Stories of Terminal Illness', is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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ABSTRACT

The marginalisation of palliative and pastoral care practices by conventional approaches to care for terminally ill patients, motivated the research curiosity. The significance of terminal patient's spirituality, their language practices and communities of concern are endorsed as being the major contributing factor to meaningful 'living' with terminal illness.

Listening to stories has been the qualitative research practice, revealing meaning-making, quest stories. Feminist theology and post-modern ideas and discourses have assisted me, and the participants, in the deconstruction of power, patriarchy and dualism as the primary contributing factors to marginalisation of people due to illness, race, gender, poverty, culture and education. Pastoral care practices and feminist theology have guided us to emphasise the necessity to recognise the God of Grace as an important part to ensuring holistic patient care.

Recognising the 'God-Self', respectful narrative and pastoral care practices paved the way to honour sacred spaces and voice stories of terminal illness.

KEY WORDS:

Palliative care, feminist theology, dualism, marginalisation, pastoral care, narrative pastoral therapy, patriarchy, grace, holism, choice, meaning-making, doing hope, ethical care. relationship, interconnectedness, languaging,, sacred spaces, storytelling, community, deconstruction.

PREFACE

I would like to celebrate those seemingly insignificant things that encouraged, sustained and motivated me to believe in myself and the importance of what I have been writing - the endless cups of tea, the reading and re-reading, the hugs, cooked dinner and patients exercised. Thank you to my partners John, Jean, Ian and Hazel, my parents, hospice colleagues, Elmarie and Dirk. I would also like to acknowledge and honour the sacred relationship between the patients and myself. I trust that the reproduction of our encounters has been just and ethical. Thank you Kirsty Berry for your encouragement and careful editing.

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'It is my opinion that the profession's role in a free society should be limited to contributing the technical information men [sic] need to have to make their own decisions on the basis of their own values. When he [sic] preempts the authority to direct, even constrain men's [sic] decisions on the basis of his own values, the professional is no longer an expert but rather a member of a new privileged class disguised as expert.'

Eliot Friedson

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1. ENCOUNTERING THE SACRED

1.1 Introduction

I have been interested in and worked in the field of cancer and terminal illness and care for twenty years. As well as having an honours degree in psychology, I am also a psychiatrically trained Registered Nurse; I have done the oncology (cancer) nursing course at the Royal Marsden Hospital in London and have worked in the oncotherapy unit in Bloemfontein. I have both been employed by and worked as a volunteer for the National Cancer Association of South Africa, have completed the Palliative Nursing Course and am currently employed as a Hospice Nursing Sister doing home care.

The hospice movement started in England in the 1960's, by Dame Cecily Saunders, as a reaction to 'the increasing emphasis on technology rather than on patient-carer contact, often to the point of making the patient feel entirely negated' (Bouwers 1996:95). This emphasis on technology has resulted in domination by curative medicine practices highlighting the need for palliative medicine practices to emerge. The hospice philosophy emphasises palliative care principles and states the following, as reproduced from the Standards of Care document 1996 – Hospice Association of Southern Africa:

Hospice affirms life. Hospice exists to provide support and care for persons in the last phases of incurable disease, so that they may live as full and comfortably as possible. Hospice recognises dying as a normal process and neither hastens nor postpones death. Hospice exists in the hope and belief that, through appropriate care and the promotion of a caring community sensitive to their needs, patients and families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them. Hospice recognises grief as a normal response to loss, and therefore, support to the families continues into the bereavement period.

The hospice movement endeavours to allow patients to die with dignity, honouring and accepting the patient's preferred way of living and dying with a terminal illness, these principles often appear to be in conflict with curative medicine ideals that see illness as a failure of technology. The debate around curative versus palliative principles is on-going and at present, it appears as though both curative and palliative medical practices experience the other as threatening to their philosophy of care.

1.1.1 Palliative care

A terminal illness is diagnosed when no further active curative treatment procedures will either cure or arrest a disease process. Palliative care is active symptom control or prevention of the disease side-effects. The side-effects of a terminal illness may include symptoms such as nausea, pain, swelling, infections, constipation, diarrhoea, pressure sores and wounds. Doctors are usually involved in active treatment of disease aiming for a cure, anything less may be seen as failure on behalf of the medical treatment.

Geertje Bouwers (1996:95) acknowledges that '[s]ince the beginnings of contemporary Western medical tradition in the late nineteenth century, doctors (usually male) have taken the role formerly ascribed to God: they have been seen as the givers or withholders of healing.'

There is thus a major paradigm shift that needs to take place in the minds of the medical professionals when palliative care principles are acknowledged as having equal significance as that of curative care. Palliative care needs to be seen as an extension and part of curative care principles and not as a failure of western medical practices if comprehensive, holistic care of a terminal illness is to be achieved.

In the palliative care environment, the patient¹ first, and then his/her family, are seen as the head of the treatment team. All procedures are negotiated with the patient and his/her family and it is the responsibility of the medical professionals² to empower the patient with sufficient medical knowledge so that they can make an informed intervention or treatment choice. There is thus a constant interchange of roles between being a medical expert and acknowledging the patient's expertise and autonomy in decision-making and accepting whatever the patient and his family may decide. For example, if a patient decides not to have surgery against medical opinion, that decision needs to be honoured by the medical professional, if the professional is convinced that the patient has made an informed choice.

The medical professionals, and I am one of them, often find this conflict between curative and palliative care principles very difficult to deal with as palliative undermines the fundamental principles and goals of curative medicine, which is the foundation of modernist medical training.

¹ I will use 'patient' in this document, but I see the term as being interchangeable with 'client'. Neither patient nor client do I consider to be suitable words, but due to a suitable word and the medical environment in which I work, I will use patient.

The questions arising in the minds of the medical professionals may include: Are we failing in our role to cure when we accept that the patient cannot be cured, and that there are no more active procedures that we can perform? Are the patient and his/her family questioning our expertise and competence as professionals? Who is responsible for taking the lead in patient health care; are we failing in our duty by acknowledging patient autonomy or independence?

Another question which medical professionals need to ask themselves is: 'Whose life is it anyway?' this question is often forgotten. The fundamental conflict that we as professionals have is the need to mediate the conflict between curative and palliative medicine practices.

1.1.2 Whose life is it, anyway?

An involvement and interest in palliative care, hospice philosophy, narrative practices, feminist theology, pastoral care, post-modernist ideas and listening to stories of patients with a terminal illness, has uniquely positioned me to journey with people facing death and talking about life and death. Working for hospice has exposed me to patients' sacred spaces to which few are privileged.

'The sacred refers to that which evokes reverence and awe due to its association to spiritual or religious experience' (Griffith & Griffith 2002:25). Sacred spaces are areas that are private and need to be honoured as being uniquely individual and profound. The patients' sacred spaces are their hopes and dreams, experiences, pain, joy, anger, fears, comforts, loss and sadness. They are personal, private areas, which may only be entered on invitation and with circumspect. They are spaces that need to be seen as holy and honoured as such - they command reverence and respect. Sacred spaces are 'where individual dignity and integrity are honoured in mutual relating, where life-giving power replaces life-denying power and people are enabled to accept their humanity joyfully' (Isherwood & McEwan 1993:134), and they need to be celebrated as such.

The questions: 'Whose life is it anyway', and 'to whose benefit', are treatment practices, which have been useful and a constant reminder to me to remain respectful and honouring of sacred spaces as patients face the end of their lives. Remembering that patients are unique individuals responsible for their personhood (Isherwood & McEwan 1993:25) and we cannot, and may not, presume to understand this sacred personhood. Often, as professionals, we make decisions based on expert professional knowledge gained through years of experience and training and

² Medical professionals I see as being doctors, nurses, social workers, physiotherapists, occupational therapists etc., anybody who is medically trained and belongs to a registering medical body.

enforce these opinions on patients for what we presume to be their benefit, but have we asked to whose benefit the decision has been made? Have we asked the patient if the treatment is their choice? Have we exposed them the choices available? Is it not often easier and less time-consuming to presume that we know the answers without asking?

The encounter that I had with Adriaan, his family, and the doctor, made me aware of how easily we, as professionals, become blinded by an expert paradigm of knowledge and become guilty of abusing our position in disregarding sacred spaces and the voices of patients.

1.1.3 Encountering Sacred Spaces

Adriaan lives in a small, well-kept, white-washed house, situated in the middle of a vineyard of trellised export grapes at the foot of Paarl Mountain. When I stand on the 'stoep' of his house, facing Paarl Valley, I am very aware of the presence of the imposing hill, which climbs up behind me forming Paarl Mountain. The panoramic view from his 'stoep' extends from Franschoek to the right, through Paarl and includes Wellington. It is a picture of different shades of green interspersed with towns and buildings and the mighty Drakenstein range frames and lifts your vision to the clear blue sky. It is a peaceful, almost quiet inspirational vista, one that always fills me with awe at the beauty and joy at being able to be a participating member of this valley and its community of people. My ancestors were born on a farm in this valley as were many of the patients and their families such as Adriaan and his family.

Adriaan has been diagnosed with advanced lung cancer. He is 36 years old. His wife Katriena, works as a domestic worker in the big house on the farm. They have three children, the youngest being Pieter, age 8. Adriaan is a farm labourer. He was a gangster in his youth. He tells stories of a care-free life, where crime and alcohol abuse was not unusual. This tale is supported by the many scars and tattoos on his body. His life-style changed drastically when he started working on the farm. He merited a responsible job, soon alcohol lost its controlling influence and he had the support and love of family, community of friends and relations, who are neighbours.

Adriaan became the farmer's right-hand man. He is a truck and tractor driver, can do welding and is a good mechanic and supervisor. The farm owner and Adriaan started farming together as farmer and labourer 15 years ago. They are of a similar age, have a respectful relationship and spend every day in each other's company. They mutually rely on each other for support, caring, honest interaction and at times, friendship. The authoritarian power/knowledge, boss - worker

interaction that existed in the beginning of the relationship between the farmer and Adriaan evolved into a caring supportive relationship.

Adriaan told me, with a twinkle in his eye, about his son Pieter. They have a very special father-son relationship, one of working together and enjoying each other's company. They are best friends. Pieter has not been attending school much lately since his father is sick and because it has been raining heavily, which makes going to school very unpleasant. In the afternoons after school Pieter would usually find his father in the fields, join him where he is working and becomes his 'right-hand man.' On Saturdays they work together in the garden. Pieter is just as adept as Adriaan with a spade. Adriaan tells me that Pieter is known as 'Adriaan's shadow'.

Katriena is a well-groomed, round, proud woman. She has asked her sister Magriet to help her look after Adriaan, as she would not like to give up her job at this time, they need the income. Katriena told me how sad it was that she could not look after Adriaan herself, as she would like to do. I have often been welcomed into the house by a smell of fresh bread and there are always neighbours or family visiting - it is not usually a quiet place. Katriena told me that she knows that the doctors cannot do anything to arrest the illness that is threatening to take Adriaan's life away. 'I trust God is protecting us and looking after us and I put our lives in His hands,' she said to me. 'But, he is so young and I will miss him so much. I also do not know what to expect. What is going to happen?'

Katriena phoned me early this morning and humbly asked if I would visit Adriaan, as he is very sick, he has difficulty breathing and he did not get much sleep during the night. I consulted a volunteer Hospice doctor and he asked to join me on the visit. We pick Katriena up from where she works. Tearful, but very controlled, she relayed the events of the night before.

We find Adriaan lying in a single bed, Pieter standing next to the bed and Katriena's sister Magriet (who is looking after Adriaan), sitting on the double bed. A window overlooking Paarl Valley is open, as Adriaan is finding breathing difficult. The room is very quiet when the doctor, Katriena and I enter. Nothing is said, the silence heavy and expectant.

On request, Adriaan says that he is feeling fine but is very weak. He cannot get up anymore; he has pain and has difficulty sleeping. Pieter is quietly watching, there are tears in Katriena's eyes and Magriet is holding her hands.

The doctor does a brief physical examination, listens to Adriaan's breathing with a stethoscope, palpates and takes a pulse. He is quiet, looks at the family and says gently:

'You know Adriaan is very sick?'

A nod.

'He has got cancer. Do you know what cancer is?'

No answer.

'Cancer is a disease... Adriaan has got cancer of his lungs. Do you understand?'

A nod.

'Adriaan, you do not have long to live. You are a very sick man and we can't make you better. We can help with your symptoms, but we can't make you better. Adriaan, if you have anything that is worrying you, or that you need to sort out, you must do it now, you do not have much time left.'

The doctor turns to Pieter. 'Pieter, do you understand that your father is dying. He has only a few days left. He has cancer. Do you understand what cancer is?'

The doctor tells Pieter.

Pieter says nothing, he just watches.

The doctor turns to Katriena, puts his hand on her arm and said to her, 'Katriena, are there any questions you would like to ask?'

She shakes her head and tears well up in her eyes.

We leave, taking Katriena with us to drop her off at her place of work. Left behind at the small, white-washed house, surrounded by vineyards, are Adriaan, very tired and breathing with difficulty, Magriet (Katriena's sister) and Pieter.

I painfully reflected on this incident while driving back home. My agony was eventually to translate into the following questions: How can we access people's preferred voices and stories regarding illness and dying which is culturally appropriate and safe? How can patients resist 'our professional talk' and hold onto their own preferred language and way of conducting their lives? How can we ensure that we are available to hear these preferred choices and voices? How can we assist vulnerable patients (and their families) facing death to be held and nurtured during this potential crisis and their lives? How can we be respectful and honouring of people when invited to enter sacred spaces? I will elaborate later on the concept of sacred spaces.

1.1.4 Reflecting on stories of certainty

I was reminded of Melissa Griffith (1995:127) who says that she has been interested in the 'process of discovering "stories of certainty" that lure us into "already knowingness", away from curiosity and creativity.' Griffith and Griffith (1993:77) also acknowledge that the 'possession of expert knowledge is toxic for dialogue when its presence in a relationship silences the voice of one of the participants.' Why was the encounter between the doctor and Adriaan and his family, based on 'already knowingness' which informed the doctor to believe it to be appropriate to inform Pieter about his father's illness and inform the family about the expected length of Adriaan's life? What discourses informed the doctor so that he knew what information the family needed to cope with Adriaan's illness and approaching death? Did the family want to talk about the illness and what words would they have used if they did?

Do we understand the role the family, community or neighbours play in caring and holding Adriaan and his family? How are the relatives and neighbours acknowledged to be a part of and included in the care of Adriaan, for Katriena is not available, her family and community do the caring. I took a medical student to visit the hospice patients one morning. After going in and out of materially very poor homes, he remained quiet for a while and then said: 'For the first time in my life I am questioning wealth. These people have so little and yet they have so much. What they have is different from what we have what have we lost or have we never had it?' The student was overwhelmed by the sense of community, caring and interest that was shown to the patients. Do we, as medical professionals, acknowledge the patient's support structures that exist in community and family relationships? Are we perhaps guilty of alienating potential community care?

I was also wondering about imposing views of spirituality or beliefs and our meaning of life and death, on patients. Asking Adriaan about 'the things that were worrying him' or that he 'needed to sort out', was that maybe presuming that he would not have a 'good' death if 'it' was not dealt with, or that leaving things undone, is not advisable? Where does this notion come from and whose opinion is it? Katriena said that Adriaan's life was in God's hands, she experienced God as a caring, nurturing God, not one that would punish Adriaan if he did not 'sort things out' with a 'bad' death.

Spiritual or religious experiences and awareness is a 'sacred space' and has an over-riding influence on the understanding and meaning making of illness and dying. Arthur Frank (1991:1) recognises this and says: 'Illness takes away parts of your life, but in doing so it gives you the

opportunity to choose the life you will lead, as opposed to living out the one you have simply accumulated over the years.' Illness appears to create the opportunity for a person to think about life and its meaning, to think about hope and dreams and the future, may it also be life after death? Frank (1991:1) also says that 'you are both forced and allowed to think in new ways about the value of your life.' Illness is a 'dangerous opportunity' (Frank 1991:1) of meaning making, a time of questioning life and living, of finding new understandings for the reasons of life and death. It is dangerous because it may end in death or involve suffering or loss. However, illness often creates the opportunity for reflecting on the meaning of life, on spirituality, on sacred spaces, bringing with it new meaning and life transforming knowledges. How can the doctor and I have made space to acknowledge a meaning of Adriaan's illness?

The questions initiated the research journey and were part of the impetus that evoked the following questions:

1. What are patients' preferred ways of storying illness and dying?
2. What significance does community support have during terminal illness?
3. How does Spirituality contribute to meaning making of terminal illness?

1.2 Area of research curiosity

I have taken the research curiosity along with me when visiting the hospice patients I attend to. The research curiosity has acted as a guide to respectful nursing practice and patient intervention which has given a voice to terminal illness stories that are the reclaiming of life (Frank 1998:204). I listen to and tell illness 'stories not in order to fix them by doing something "therapeutic", but rather to honour them' (Frank 1998:207).

1.2.1 Introduction

The area in which I work extends to include Paarl Valley, Wellington and surrounding farming areas. Our patients vary across the broad spectrum of the South African population, but the majority of the patients are people who are disempowered and disenfranchised through race, poverty, unemployment, overcrowding, illness and lack of formal education. We see terminal patients, those who have been given a prognosis of 6 months to a year.

I have worked at the hospice for more than 2 years and these are the stories I tell. I have tried to include a broad cross section of the patients I visit. I am very sensitive about classifying people

according to race, religion or sex, but to illustrate the diversity of the patients I had conversations and interactions with. I will for this reason make the classification, but will not give names. For the purpose of this study I have included encounters that I have had with 5 men, 3 were classified as Coloured people and 2 are Black persons, and 7 women, 2 are White and 5 Coloured. Their ages range from 24 to 79 years old. Two, a man and one woman are Muslim, the rest belong to the Christian faith of various denominations.

Being a Hospice Home Care Sister I have access to all our patients. At any given time we care for 40 to 50 patients. During a period of 1 year, we have an average of 100 deaths, about 8 deaths a month. I had conversations with some of the patients at their homes and have included stories that I have recorded. I taped all the conversations gave a transcribed copy to those patients who requested one.

1.3 Theoretical Framework of the Study

1.3.1 Introduction

I have used the post structuralist and social construction discourses as guidelines to the research process as they specifically take a 'critical, progressive and political stance to the truth claims made by discourses which help maintain oppressive power relations' (Burr 1995:172) and because they focus on language, social organisation and the role of subjectivity. These views also aim to 'increase the "voice" of marginalised discourses' (Burr 1995:172) which I wanted to become aware of and identify. The post modernist approach reminds us that there is no ultimate truth, no right or wrong while leaving space for questioning and personal preferences to emerge.

The work of Jacques Derrida (Sampson 1989) and his deconstruction of discourses and language and Michel Foucault (Foote & Frank 1999) and his understanding of the significance of power/knowledge, I have also found useful. I have found it particularly empowering that Foucault concedes that: 'Power is positive and creative, not just negative or repressive' (Townley 1994:8) which has given impetus to voices of patients marginalised because of power/knowledge misuse. Flaskas and Humphreys (1993:38) question 'the effect of the therapist's stand of neutrality when working with abuse.' This connects with the feminist maxim that (Graham 1996:173) 'the personal is political' which is nowhere more true than when applied to pastoral care and hospice practices. As professional carers, it is our responsibility to cast light on the social causes of misuse and

abuse of power/knowledge, which may result in marginalising those very people we profess to care for.

Theology has also been especially important for I am focussing on sacred spaces, 'that which evokes reverence and awe due to its association to spiritual or religious experience' (Griffith & Griffith 2002:25) and having a terminal illness is one of those sacred experiences. Feminism and feminist theology has, however, been the backbone of this research as the feminist approach is particularly applicable to people who are marginalised. In the study, the patients may experience marginalisation due to illness, social status, lack of education, poverty and race, I tell patients' illness stories not to analyse the stories, but to enter into a relationship with the storytellers to honour them (Frank1998). Feminist theology supports the spiritual experience that I have when encountering the experiences of terminally ill and dying patients.

1.3.1.1 Post-modernist discourse

The post-modernist movement came about as a reaction to pre-modernism and modernism. Pre-modernist (Kotzé 2002:12) saw religion as the controlling knowledge that could distinguish between right and wrong. Religious leaders could both interpret the Word and speak for and on behalf of the Deity. Questioning religion was not encouraged and the Deity was 'omnipotent, unquestionably in control. Modernity (Kotzé 2002:10) encouraged people to explore, understand and control the world, seeing truth through scientific eyes. A patriarchal parallel developed between religion and science based on so-called 'truths' often resulting in 'oppression, suffering, exploitation and marginalisation of those people positioned at the unfortunate side of these "truths"', people have destroyed one another in the name of their deity's truths (Kotzé 2002:13-15). Post-modernist ideas support an 'ethical-political resistance – against the injustices resulting from the scientific and technological power regimes of modernity itself' (Kotzé 2002:11).

Postmodernity faces up to this realisation and attempts to interpret knowledge as a social construction process. Post-modernists tend to adopt an interpretivist idea of knowledge, replacing both pre-modern ideas of religious 'truths' and the positivist approaches that have shaped science, including Theology, for many centuries.

(Kotzé 2002:15)

The post-modernist discourse is supported by the post-structuralists with their 'analysis of language and knowledge' (Powell 1997:92) and by social constructionist interpretation of knowledge as a social construction.

1.3.1.2 Post structuralist and social construction discourses

One of the main arguments of the post structuralist discourse is 'against the authoritative posture on truth' (Freedman & Combs 1996:21). Social constructionist views have a critical stance on taken-for-granted knowledge because the world is understood in a historical and culturally-specific way, knowledge is constructed and sustained by a social process and each different construction leads to 'a different kind of action from human beings' (Burr 1995:3-5).

I have for many years been exposed to Elisabeth Kübler-Ross's Stages of Dying (Kübler-Ross 1969), Murray-Parkes, Bowlby's Phases of Mourning, Worden's Tasks of Mourning and Robert Buckman's three-stage model of the dying process (Doyle, Hanks & Macdonald 1993:47) as explanations and models for understanding death and dying. These theories have all been very useful in broadening my understanding of the emotions and reactions some people may experience in the face of illness and death. As a nurse, I have often been vindicated from dealing with 'emotional issues' as these were dealt with by psychologists or social workers. The physical issues are seen as the knowledge domain of the medical doctor while the spiritual aspects have certainly been the domain of knowledge of the pastor or minister. If I, as a medical professional, am restricted to specific aspects of patient care, because of perceived lack of expertise or knowledge, I often wonder what happens to the caring and local knowledges of partners, friends and family? Does this specialisation or fragmentation of care not often disqualify and disempower local knowledges, nurturing and caring that could be available to a terminal patient because it is seen as not good enough by the professionals?

The social constructionists would, therefore, question the grand narratives and theories of illness, death and dying. Social constructionists question the usefulness of generalised truths when 'truth' is often culturally and historically specific. Elisabeth Kübler-Ross's (1969) stages of dying, comes out of a modernist era and the observations were done in England, a first world country, are these stages applicable to the year 2002 in a culturally diverse South Africa? Arthur Frank (1991:45) said that '... theory has been used to categorize rather than open up people's experiences. Instead of guiding us into what is particular about individual's experiences of illness, these words create distance' and can draw other professionals into the illusion of understanding.

1.3.1.3 Professional knowledge privileging truth

Theories and 'expert' knowledge has assisted '[t]he professional disciplines [to believe that they] have been successful in the development of language practices and techniques that determine that

it is those disciplines that have access to the 'truth' of the world' (White 1991:36) and that they have 'privileged access to the truth' (White 1991:37). 'For the members of the professional disciplines who are operating under the apprehension that they have recourse to objective knowledge, critical reflection on their position is not an option. They are thus able to ignore facing the moral and ethical implications of their knowledge practices' (White 1991:37). It is easier and less stressful for professionals to take a scientific, modernist approach to health, one that has been verified in literature and scientific research, than to entertain the thought that there is no ultimate truth regarding terminal illness. Foucault maintained that (Fillingham 1993:75) '[o]pening up the corpses... gave Medicine the opportunity to subject all of the Body to the scientific Gaze', this scientific gaze assists the doctor to be the (Fillingham 1993:67) 'perfect doctor' which often disqualifies and marginalises the 'non-expert'.

'As mental health professionals (sic) our culture awards us tremendous privilege and power in our storytelling rights regarding persons and problems' (Madigan 1996:55). White (1991:27) agrees with Michel Foucault (1980), that a domain of knowledge is a domain of power, and that a domain of power is a domain of knowledge.

The working of this power is disguised or masked because it operates in relation to certain norms that are assigned a 'truth' status. This is a power that is exercised in relation to certain knowledges that construct particular truths, and is designed to bring about particular and 'correct' outcomes, like a life considered to be 'fulfilled', 'liberated', 'rational', 'differentiated', 'individuated', 'self-possessed', 'self-contained', and so on (White 1991:35). What 'correct' outcome did the doctor have in mind for Adriaan when he asked if he needed to 'sort things out'?

I believe that as we are trained in these 'expert' views, we can easily fall into the trap of believing that we possess the 'truths' that should be privileged above other knowledges. 'When this happens, we lose sight of the fact that these 'truth' claims are actually specifying of certain norms for how persons should live their lives' (White 1995a:72). Did the doctor presume that if things were 'sorted out' Adriaan would have a better life or death?

1.3.1.4 Just therapy is culture specific

Recognition of the influence of culture, living conditions, gender, race, socio-economic conditions, education and social status need to be privileged on the journey to make this a 'just' therapy and research journey (Waldegrave 1990). 'Racism exists when that prejudice is exercised by the

culture whose values and beliefs dominate the institutions and structures of a given society' (Waldegrave 1990:19). This means that working with people in a *different* culture and not being sensitive to *their* beliefs and customs and not having an 'imagination and curiosity' (Parry 1991:53) which could 'enlarge our individual perspectives', (Parry 1991:53) would make us guilty of racism. The 'just therapists' such as Waldegrave (1990:15) see culture as 'probably the most influential determinant of meaning in peoples' lives' - culture may, therefore, also be classified as a sacred space. If a patient or his caregiver's culture is not considered, the meaning of lives may be disqualified and they may be alienated and marginalised. I would estimate that ninety percent of the patients I attend to belong to a different culture and race from my own; they are mostly Coloured but some are Black people and a few are White. I believe that cultural, and therefore, language differences, have to be considered in therapeutic conversations.

1.3.1.5 Language is reality

Remembering that Michael White says that 'words are the world' (White 1995a:30) highlights the importance of language. This emphasises the constitutive power of language as a means to 'discover, to explain, to predict, and to effect change' (Anderson 1997: 33), to 'constitute meaning, experience and lives and reality' (Kotzé & Kotzé 1997:6). While embarking on this research I also acknowledge the need to engender a 'sense of agency', a positioning (Davies & Harré 1991) or developing an 'own voice' (Parry 1991:41) when 'doing hope' (Weingarten 2000:402) with patients.

'Post structuralism links language, subjectivity, social organisation and power. The centrepiece is language' (Richardson 1994:518). Language is seen as constituting our world and beliefs (Freedman & Combs 1996:28) and societies construct their views of reality through language. Burr (1995:6) sees language as a precondition for thought and Anderson (1991:30) argued that 'Language is reality. It gives order and meaning to our lives and our world.' White (1995:30) also emphasised this with saying 'We have to be very sensitive to the issue of language. Words are so important. In so many ways, words are the world.' In voicing stories of terminal illness, I endeavour to use peoples' own voice or words in the form of stories. Stories are individually-specific and thus qualifying of language used, helping to increase our understanding of a meaning. Griffith and Griffith (1994:80) in *The Body Speaks* say:

A conversational domain is present when all the conversational participants have engaged in a process of speaking, listening and reflecting, from which has arisen a mutually negotiated, specific language for talking about the problem of the Therapy and its needed solution.

Language is always changing in the postmodernist perspective and, therefore, meanings are also changing. Anderson (1997:33) describes language as 'the medium through which, and the tool with which, we exercise our entitled position to discover, to explain, to predict, and to effect change. Language can thus be seen as 'a form of action' (Burr 1995:7). Voicing stories of terminal illness gives me the unique position to discover, explain, predict and effect change in the way professionals (including myself) interact with patients who suffer from a terminal illness. This illustrates the power of language.

1.3.1.6 Power and language

Foucault identifies language as providing ways of understanding the world and ourselves and the nature of this knowledge is 'historically and culturally specific' (Burr 1995:8). Further, he also sees language as an instrument of power; this power is directly proportionate to the ability a person has to participate in various discourses that shape society (Freedman & Combs 1996:37-38). 'Talk is not the only way to elevate illness beyond pain and loss, but for most people it may be the most reliable way (Frank 1991:5)', through voicing stories of illness, dominant discourses around illness can be challenged. Derrida states '[m]eaning as not being carried in a word by itself, but by the word in relation to its context, and no two contexts will be exactly the same' (Freedman & Combs 1996:37-38). The argument, therefore, might be made that stories, which include context, more fully describe meaning. I shall tell the stories in such a way to reflect context, aiding meaning-making while being alert to dominant discourses.

1.3.1.7 Dominant Discourses

Michel Foucault speaks about internalising dominant narratives in our culture (Freedman & Combs 1996:39) which may not always be useful when looking at power (authority) structures and the meaning of illness and death. These narratives may include ideas about the 'right' way of dying primarily by disenfranchising persons with alternative ideas like denying or not talking about the illness. Recognising these dominant or grand narratives (Madigan 1996) and deconstructing them could be very useful in bringing hope to patients and caregivers. They may be accepting of and become more comfortable with the patient's own ideas and way he/she prefers to view the illness process. Dominant narratives about illness may also include ideas of personal responsibility for illness or health, illness makes you passive, dependent and disenfranchised the person, and it also excuses you from responsibilities, encouraging dependence. Knowledge, therefore, has an interrelationship with power.

1.3.1.8 Power and knowledge

Foucault identifies the interrelationship of power and knowledge (McHoul & Grace 1993:59), how power produces knowledge and knowledge produces power. Truth regarding illness and dying is also produced 'through power and we cannot exercise power except through the production of truth' (McHoul & Grace 1993:59). This means that people that don't have a medical knowledge are disempowered from illness and dying, and their choices are minimised because they are disenfranchised from access to power and truth. Empowering people by sharing power through knowledge and encouraging self-agency, goes a long way to assist the patient and his/her family to benefit from both knowledge and personal choice aiding meaning making of terminal illness.

Working within the framework as a nursing sister I recognise that I am not an 'expert' on people's lives, but attempt to be knowledgeable about the symptoms of illness. This confidence and knowledge engenders confidence in the both patients and colleagues, enabling us as professionals to offer patients choice regarding the medical component of the illness. I would never accept one opinion if I were diagnosed with a terminal illness and I do not expect the patients to accept my opinion either. I encourage patients to go for a second, third or as many opinions as they may decide to gather. I concur with Arthur Frank (1991:138), 'Choice can turn the worst circumstances into an experience of value.' I make choices available through attentive listening for knowledge that may assist understanding of the illness process and I listen for preferred choices for living with terminal illness and am respectful and considerate of choices.

I consider myself as being knowledgeable about pain management methods. However, some patients may prefer pain, to losing 'control' to pain medication. Deconstruction of the meaning of pain and pain management and control procedures may be important to find the patient's preferred way of dealing with pain. Being respectful of preferred choices of patients is nowhere more adequately propagated than within the feminist movement.

1.3.1.9 Feminist movement

Feminism is that which pertains to the advocacy of woman's equality and rights primarily in opposition to male dominance. Feminism has evolved to include the devastating and far-reaching effects which patriarchal separation and division (dualism) has had on our world (Waldron 1996:65). Feminism is now about the task of establishing unity and inter-relatedness of all creation. The feminist thinking has influenced practices of care and counselling to become more

collaborative in ways of working with people (Freedman & Combs 1996:12). The feminist movement is not so much seen as an anti-men movement, as much being a pro-people (Maimela & König 1998:122). The Feminist approach is about 'doing justice' to marginalised people and doing justice is applicable to those marginalised by illness.

Waldron (1996:68) says that feminist spirituality 'seeks to permeate the political as well as the personal realms, and to animate action as one of its responses to God whom it believes to be loving and just. It is a spirituality, which has the vision of transformation towards a relating society, where there is mutuality, acceptance and justice for all.' The theology of healing expresses the dire need for the healing of all of creation (Ackermann 1998:81-82). Feminism sees the personal as political and is, therefore, focused on action and transformation and makes a stand against the domination of Patriarchy, law and order, rules, regulations and truths. It is about *doing hope*, which nurtures love and resistance. Feminist theologians focus on participation and inclusion and embrace the God of Grace, the God of nurturing and caring. 'For healing praxis to be truly restorative, it has to be a collaboration and sustained action for justice, reparation and liberation, based on accountability and is empowered by love, hope and passion (Ackermann 1998:83). The personal has become political through voicing stories of terminal illness. It has become my desire to voice these stories to enable justice and reparation of our professional practices with resulting transformation and liberation of these practices making them more relevant to individual needs and requirements.

Doing theology in the hospice context is about identifying the patient's 'healing' and 'liberation' with the goal of wholeness and inclusivity in care. It is working together as an integrated, interdisciplinary team (the patient, his family, the community, the Nurse, the doctor, the social worker, hospice volunteers, the church) to bring about the patient's preferred way of being ill and dying. Doing theology is not only about holding a hand or listening to a story, it is about action, about making a difference, so doing theology actively encompasses the co-ordination and the involvement of everybody that can be of benefit to the patient.

1.3.1.10 Theology

I believe that the Hospice work I do is pastoral care, which is based on pastoral theology. Elaine Graham (1996:171) sees pastoral theology as being synonymous with writings on the activities and characteristics of the Pastoral agent. For the most of Christian history this means that pastoral theology has implicitly restricted itself to the study of the activities of male, ordained and professionally-accredited persons. However, the four traditional functions of pastoral care, as

discussed in *First steps to Practical Theology* (Theron, Hestenes, Dreyer 1999:135-140), are: healing, sustaining, guiding and reconciling. This, I believe, to be encompassed in the hospice philosophy and within my philosophy of care.

The healing function 'refers to the positive results which Pastoral actions can have on the health and well-being of people in the broadest sense.' 'Sustaining ('to stand by') involves forming and maintaining a relationship with distressed and suffering people, that will give them a sense of support and comfort.' 'Pastoral guiding means helping people to make their own choices and decisions based on their deepest convictions.' 'Reconciliation means the restoration of people who are alienated from themselves, each other, God and nature. Restoration means enabling them to accept themselves, experience forgiveness and learn to live in new relationships...[it] is the affirmation of harmony in the human world.' I quote the above from Theron, Hestenes and Dreyer (1999:135-140) and acknowledge them with a sense of sadness and anger as this is what hospice care workers do, this is what many nurses, doctors, teachers, social workers, psychologists, friends and colleagues do, without claiming it as pastoral care. How can we as professional carers ensure that Pastoral care practices are made part of and recognised as an aspect of *our* care and training? How did it come about that we were disenfranchised to do pastoral care?

Nicola Slee (1996:225) describes Theology as 'God-talk' from the Greek *theos* and *logos*. Albert Nolan a theologian recognises that: 'What confronts us is the ethical, epistemological and practical challenge of 'dialogue with the Other', a dialogue which takes our Self and the Other seriously, and which binds us together in the solidarity of mutual struggle for human freedom, dignity and understanding' (Nolan 1994:227). Unless we adapt in a 'practical, dynamic, based on real-life experiences way to the people of Africa, they will remain alien and alienating' (Pato 1994:157). Is this 'God-talk' not also the talk that takes place between one person and another, if we are made in God's image? (Genesis 2 verse 27: So God *created* human beings, making them to be like himself.) I also pose the following question quoted from Augustine, 'Who do you love when you love your God?' (This quote came from Johan Roux's lecture given in Somerset West in 2001) This is an unanswerable question, but a question that has generated much thought. Do you maybe love yourself or others? If people are made in God's image, who do you love when you know your God? Terminal illness experience, according to patients storytelling, touches the answer in Chapters 3 and 4.

1.3.1.11 Feminist Theology

Feminist Theology according to Isherwood (1996:226) rejects the Greek dualism between spirit and matter and so finds the notion of the transcendence of God problematic. She also mentions that even Augustine was aware that we look the wrong way for God, we look outside when we should look within to find the true God. Feminist Theology therefore considers personal experience to be the starting point of looking for God. The notion of transcendence connects with the notion of omnipotence. Isherwood (1996:165) suggests that 'God and the world are in process together'; 'God is becoming one with the world and so God suffers with the world.' 'The omnipotence of God renders humanity powerless, while the vulnerability and limited power of God actually empowers the created order.' Instead of the dualistic nature of God and people, feminist theology suggests that there is an interrelationship between God and people, which defies the relationship of domination propagated by patriarchy.

'[E]mancipatory Theologies arise out of the pastoral realities of oppression and repression, where people are hurt, stripped of their dignity, broken by deadly economic and political forces, left resigned or crushed and weak' (Cochrane 1994:26). Hopefully as pastoral narrative therapists we can learn from this and acknowledge and realise that people 'are not meant to be at the mercy of others, nor are they meant simply to accept the evils that others practise upon them' (Cochrane 1994:26). Black liberation hermeneutics claims that 'God is the Liberator of the poor and oppressed' (Maimela & König 1998:355) which is also liberating and freeing to me. 'For to be free is not merely to cast off one's chains, but to live in a way that respects and enhances the freedom of others' (Mandela 1994:617). This is directly applicable to professionals working in the area of terminal illness and care. Only through casting off the chains of conformity, modernity, patriarchy and allowing others to live according to their unbiased informed choice, patients will be free to experience making meaning of their illness. Viewed from this perspective, feminist theology, opens the door to journey towards honouring sacred spaces.

1.4 Journeying towards Honouring Sacred Spaces

1.4.1 Introduction

When doing the research on voicing stories of terminal illness, I journeyed with patients on how they prefer to speak about death and illness. I 'co-created new meanings and new stories about the [patients] life' and death (Andersen 1991:41) which influenced renegotiating many of my own

preconceived views and ideas based on 'expert knowledge' I have gained through conventional study, reading, experience and reflection which I now debate.

The conceptualisation of reality as a multiverse of meanings created in dynamic social exchange and conversation interaction moves [me] away from concern about issues of unique truths and into a multiverse that includes a diversity of conflicting versions of the world.

(Anderson & Goolishian 1988:378)

I have embarked on this study because I believe that '[m]atters of life and death are too hard, too onerous, too painful to 'do' alone' (Weingarten 2000:402), with this understanding we need to be respectful and inclusive of local meaning and local language because 'there is a range of experiences and a way of knowing these experiences that is sufficiently different from 'knower' to 'knower' (Anderson & Goolishian 1992:33) - beliefs, knowledges, values, needs and wants. These are sacred spaces, unique, personal ways of being in the world which are available only to those who are invited and willing to listen.

I believe that we need to find a way 'to be more accountable for the effects of our (mis)understandings and actions' (Freedman & Combs 1996:18) so that we are not guilty of abusing our powerful position as professionals. I aimed to be respectful of peoples' preferred way of being, 'linguaging' (Graham 1998), as well as resisting, modernism and patriarchy and I used narrative therapy to provide the platform to launch this respectful investigation. The narrative ideas lend themselves to respect and empowerment, not only of patients but also of therapists/nurses³ (O'Hanlon 1994) and opens the door to honouring sacred spaces through the hearing of and languaging stories.

1.4.1.1 Linguaging Stories

Partly, the aim of the study 'was to take a critical, progressive and political stance to the truth claims made by discourses which help maintain oppressive power relations, and to highlight the "voice" of marginalised people' (Burr 1995:172). Listening respectfully to patients' stories is a gift (Frank 1998:198-199) to the storyteller and listener as it implies a relationship between the listener and the storyteller that assists professionals to embrace the stories and to *know* the stories as they are *known* by the storyteller. Stories of terminal illness highlighted the many different and unique

³ Therapists/nurses, I use both these terms as I would like to acknowledge that nurses can also be therapists or counsellors, it is not an exclusive title belonging to psychologists or professionally trained counsellors. At times, I may however, use one or other of the terms. This does not mean that the other is excluded. I believe in an interdisciplinary approach, which means that therapists may do nursing and nurses may do therapy.

ways patients' experience and prefer to speak about illness and death and their relationship to their community and their God. Elaine Graham (1998:139) speaks about 'privileging and articulating' voices and Frank (1998) speaks about 'just listening', I particularly identify with these terms as I believe them to be acknowledging, respectful and honouring of the storytellers of illness narratives.

Throughout the research, I have attempted to privilege stories through listening carefully and checking on intended meanings through asking clarifying questions. Being patient, respectful and not interrupting stories opened wondrous doors to new journeys and discoveries. The patients' voices were articulated through my repetition of their words and active and 'empathic attention' (Frank 1998:198), 'just listening' to what was being said, not finishing sentences or adding new concepts or ideas. Arthur Frank (1995:25) says that '[l]istening is hard, but it is also a fundamental moral act...', therefore, I aimed to listen and transcribe as accurately as possible peoples' own voices. The act of listening and hearing people's voices is an element of pastoral care, it aids patients' healing, sustaining, guiding and reconciling, according to his/her choice.

Listening for community influence and support in meaning-making and clarifying illness stories has been one of the most heart-warming parts of my work amongst 'underprivileged' communities.

1.4.1.2 Community and Cultural influence on illness stories

When faced with extreme poverty and disadvantage in material possessions, the generosity and wealth of community support and care from family, neighbours or church brothers and sisters so often astounds me. Freedman and Combs (1996:17) see the social constructionist view as 'the experience of self exists in the ongoing interchange with others... the self continually created itself through narratives that include other people who are reciprocally woven into these narratives.'

The significance of communities to a patient's spirituality is a fundamental part of the research journey. The concept of community, as suggested by feminist theology, extends beyond that of people to include the environment and centres around ideas of 'mutuality and caring' (Gelder 1996:31). Feminist theology, therefore, supports the idea of the interrelationship, relationality (Ackermann 1994:203) between God, people and the environment. What I discovered is that the more mutuality and caring I observed, the greater the experience of God, light, peace, contentment, tranquility, wholeness and understanding I experienced with the patient. I will call this experiencing the *God-Self*, the connection and the relationality between God and Self. When

God and Self become one, when the 'God part' of Self is not only identified but also acknowledged as being part of Self.

These significant communities are thus also sacred spaces, spaces that need to be nurtured, honoured and cherished. Networking and creating a team in the community to make a stand against the controlling effects of the illness evokes many possibilities to strengthen the patient and his/her caregiver with the Grace of God. In this way patient and caregivers' lives become connected with others and their God-Self, enriching experiences and aiding 'solution knowledges' (Morgan 2000:115-119). Michael White (Freedman & Combs 1996:245) speaks of 'nurturing teams' and I think that with illness these teams can be very ably employed to support the alternative stories of hope, resolution, pain-free times or sound sleep. Could being alienated from community support in modern society mean that people are alienated from God? What impact does community support have on a patient exposed to supportive communities of concern? I wonder if this may be an answer to the resignation and acceptance of illness that is found in communities where support is paramount? Does getting closer to your God-Self help with meaning-making of illness?

1.4.1.3 Voicing stories about a Personal God

Through the research I have come to realise that 'language about God is crucial to our experiences of God, and to our spirituality, because language does not simply reflect, but also actively shapes human consciousness' (Ackermann & Bons-Storm 1998:146). I have, therefore, been very interested in talking about experiences people have 'with a personal God' (Griffith 1995:137). Patients have explained how God nurtures and protects them, others have experienced God as testing them and preparing them for life hereafter, patients have talked about God as a punishing God and God as a protecting God. Verbalising or languaging these stories has opened conversations and opened doors for alternative stories that have been a great source of comfort and support. Patients have spoken about the God of *love*, the God of *Grace*, of nurturing and caring which they have known, but which has historically been overshadowed by Patriarchy. They remember this God quite spontaneously and with warmth and affection. Where has this God been in their illness? I will illustrate this *God-talk* in Chapters 3 and 4.

God-talk is about a personal God and the qualitative research approach creates the opportunity to listen, hear and share these personal stories.

1.5 The Research Approach

1.5.1 Introduction

In deciding which research paradigm to follow for this study, I looked at the issues that I would like to highlight through the research process. The most important factor to me is being able to quantify a patient's story in a respectful and accountable way. The research paradigm, therefore, had to be flexible enough to allow the research process and curiosity to evolve or even change as the conversations with the patients progressed. I choose to do case studies and qualitative research as it is the most appropriate with terminally ill people for it is the least inconvenient and intrusive.

1.5.1.1 Qualitative research

Qualitative research fits my needs for as Denzin and Lincoln (1994:2) say:

Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials – case study, personal experience, introspective, life story interview, observational, historical, interactional, and visual texts – that describe routine and problematic moments and meanings to individuals' lives.

The epistemology of qualitative research requires an attitude of openness and receptivity, what Heshusius (1994:16) calls 'allocentric knowing'. Qualitative research 'requires a turning to the 'Other' which leads to 'loss of self' and 'a heightened feeling of aliveness and awareness' (Heshusius 1994:16). It required that I put my prejudices on hold, that I had to be open to thinking and behaviours that were foreign to me and witnessing these with curiosity and wonder (Griffith 1995) opened worlds that have been obscured through organisation and rigidity, good training. Imagination and curiosity according to Parry (1991:53) enable us to enlarge on our own perspectives and gives us the opportunity to extend our vision to include 'larger epic stories of our communities, cultures, our humanity, and of the great story of our survival itself.' I will tell such stories.

The aim of qualitative research methods is not to search for the 'truth', but to 'accept the existence of many alternative constructions of events' (Burr 1995:162). Qualitative research begins with a question and has real individuals in mind, which live in a social setting such as we have in the

Paarl/Wellington area. It is also accepted that qualitative research is ideologically-driven, there is no value free research and while I reflect on these in the final Chapter, I will highlight them throughout the research. Qualitative research requires passion for people, communication and understanding people (Janesick 1994) which I acknowledge.

My research stresses (Denzin & Lincoln 1994:4) 'the socially constructed nature of reality, the intimate relationship between the researcher [myself] and what is studied, and the situational constraints that shape enquiry.... [I] seek answers to questions that stress how social experience is created and given meaning.' Listening to stories implies a relationship as I, the researcher, reach out as one human to another. This kind of relationship is a gift to the storyteller (the person being researched) as he/she is known as he/she is known (Frank 1998:198-200).

The narrative and social construction approaches to conversations has offered guidelines to collecting stories that are respectful, non-intrusive and an accurate way of collecting data. I agree with Griffith and Griffith (2002:ix) that 'therapeutic conversations are sacred encounters' and have treated the process as such. Narrative therapy practices and social construction ideas have guided my conversations in these sacred encounters.

1.6 Approaches to Conversations

1.6.1 Introduction

The ideas of Narrative Therapy were first introduced by David Epston and Michael White (Morgan 2000:v) may refer to particular ways of understanding people's identities, problems that affect people's lives, ways of talking to people, ways of understanding relationships, ethics or politics of Therapy. Narrative therapy aims to be respectful, non-blaming approach to counselling and community work, it sees people as being the experts of their own lives and views problems as being separate from people (Morgan 2000:2). In the following section, I will discuss the aspects of Narrative therapy and social construction that I found useful, meaningful and applicable to the research curiosity and research practice.

1.6.1.1 Curiosity and Wonder

Griffith (1995) hopes to open these certainties of the professionals regarding what patients need to 'the refreshing breezes of curiosity and wonder, in which multiple realities can coexist and

relationships can evolve.' There is only one certainty that I have gained in the work I do with the terminally ill and that is that I need to constantly question certainties that professionals have developed in response to illness. Sally Ann Roth, in response to Griffith (1995:145) in *Opening Therapy to Conversations with a Personal God* said:

Any contact with another that invites me to think that which has been unthinkable, to speak that which has been unspeakable, to know that which has been unknowable, to question that which has been unquestionable, and to appreciate how much I do not - can not - know, is a gift to me.

Working for hospice and listening to illness stories has been a gift to me, I have found a great deal to listen to, honour and appreciate these stories for the *good* stories that they are (Frank 1998:210). I recognise that for something to be a gift there is an act of reciprocity, you cannot receive without giving and you cannot give without receiving, this reciprocity implies a relationship (Frank 1998:199).

1.6.1.2 Participatory Mode of Consciousness in conversations

'If we want to free ourselves from objectivity we need to fundamentally reorder our understanding of the relation between self and other (and therefore, reality) and turn toward a participatory mode of consciousness' (Heshusius 1994:15). 'The mode of consciousness in which egocentric concerns do not stand in the way has been referred to a participatory mode of consciousness' (Heshusius 1995:122). It is the ability to temporarily let go of all preoccupation with the self and to move into a state of complete attention to what the client is saying, it is 'being with' something or someone (Heshusius 1994:19). Participatory consciousness implies that the patient or storytellers view will be honoured and respected as being the 'expert' of their own lives.

1.6.1.3 The client in the 'expert' position, a 'not-knowing' approach

This approach implies that the therapist asks questions from a 'not-knowing' approach, not from preconceived ideas and wanting particular answers, but always moving towards the not yet known position (Anderson & Goolishian 1992). 'Not-knowing refers to the attitude and belief that the therapist does not have access to privileged information, can never fully understand another person, and always needs to learn more about what has been said or not said' (Andersen 1991:35). Freedman and Combs (1996:45) suggest that '[w]e are most successful in achieving a not-knowing position when we concentrate on listening and when our talking is guided by and secondary to that [of] listening.' Examples of questions during conversations that are conducted from a non-expert, not-knowing approach may include questions such as: 'How do you prefer to

talk about the illness, what words do you prefer to use?' and 'What do you understand about the illness?'

This 'not-knowing' position does not mean that we don't know anything, our knowledge is of the therapy process, 'not the content and meaning of people's lives' (Freedman & Combs 1996:44). The 'not-knowing' position frees people to tell their stories in an unhindered way, as there would be no preconceived ideas as to what they should say or what is acceptable to say. The client is thus seen as the 'expert' (White 1991:37) of their lives. This excludes the so-called 'expert advice' that I may have regarding medical matters like pain control, nausea or pressure care. However, even these expert opinions may have choices and preferences, which need to be identified are best managed when the symptoms or illness is externalised.

1.6.1.4 Externalisation conversations around the illness/death

O'Hanlon (1994:21) sees externalisation basically entailing 'a linguistic separation of the problem from the personal identity of the patient.' 'Through the externalising conversations, the problem is to an extent disempowered, as it no longer speaks to persons of the truth about who they are as people, or about the very nature of their relationships' (White 1995a:23). This is based on the idea that the problem is the problem, the person is not the problem (Morgan 2000:17). In this way the identity of the patient is expanded upon which assists the uncovering of unique outcomes and alternative stories to the dominant story of illness (Morgan 2000). Examples of such externalisation conversations are: 'What do you understand about *the* illness?' and 'Is there anybody else who could join you in being a shield against the controlling effects of the illness?' Often taking apart or unpacking a meaning ascribed to a symptom will help to alleviate the controlling effects of the illness or symptom. This is done through deconstruction of the meaning or event.

1.6.1.5 Deconstruction

Deconstruction refers to attempts to take apart texts, it is a way of looking at texts, or words, that reveal the 'hidden' contradictions which overshadow repressed or absent meanings (Burr 1995:164-165). Deconstructive questioning is thus a way of 'unpacking' (Freedman & Combs 1996:57) meanings, or finding different ways of looking at issues, investigating their limits and potentials. It is a way of looking at issues from a different perspective. Questions about preferred language when talking about illness, questions about the meaning of words used or not used and

questions about alternative meanings all helped to identify preferred ways of speaking about illness, this is deconstructive questioning. This type of questioning was conducted in a manner sensitive to sacred spaces and preferred choices. Part of deconstruction is also the putting together and storying of experiences.

1.6.1.6 Storying understanding of the illness/dying

'Conceptions people have about themselves are disjointed until they are located in a story' (Davies 1991:59). Frank (1998:201-203) calls these chaos stories. Giving patients an opportunity to story the illness, whether distant past or the present, created the opportunity for the patient to look at times when the illness did not have much influence on their lives or times when they managed well despite the illness. Talking about these times enables 'a crack of light to shine into areas that may be entirely dark' (Frank 1998:202). 'Stories provide the frames that make it possible for us to interpret our experience, and these acts of interpretation are achievements that we take an active part in' (White 1995a:15). Stories are personal truths, they occur in context and are told in a language that makes sense to the storyteller. Stories become the building blocks of hope, the crack of light. Stories were used to identify and acknowledge alternative ways of being and these were expanded upon. These are examples of the way questions were directed: 'What is the story of the illness? How do you understand the illness? What meaning does the illness have for you?' Storying also helps to situate the illness in a context of understanding, assisting illness to be 'lived as a quest: as a condition from which something can be learned' (Frank 1998:203).

1.6.1.7 Situating the illness/death in context

In the context that I work, 'problems only survive and thrive when they are supported and backed up by particular ideas, beliefs and principles' (Morgan 2000:45). There are many 'taken for granted' ideas, 'truths' and 'common-place understandings' (Morgan 2000) which may originate from cultural beliefs, ideas and practices which may support or justify problem stories. I asked questions to clarify origins of beliefs they helped to unpack the influence of problems. Such an example stemming from the research was when I asked a Moslem woman, 'Can you tell me where the belief that God is punishing you with your illness comes from? Do you know a different God from the one who punishes you with illness and suffering?'

'People's culture, their living conditions, and their gender, are crucial determinants of the meaning patterns they create... [and] culture is probably the most influential' (Waldegrave 1990:14). Being sensitive to these issues and acknowledging differences in a respectful manner gives agency and

is empowering to people (White 1991:38). Examples of these questions were: 'Are there any rituals or customs that we should be aware of?' 'According to your culture and customs, what is expected from us?' These questions opened doors to understanding and recognising the importance of a community of concern that knows a patient's culture and customs.

1.6.1.8 *Networking a community of concern*

The idea of networking or co-creating a team to make a stand against the controlling effects of the illness evoked many possibilities to strengthen the patient and his/her caregiver against the effects of the illness. In this way patients' and caregivers' lives, became connected with others, enriching experiences and aiding solution knowledges (Morgan 2000:115-119). Michael White (Freedman & Combs 1996:245) speaks of 'nurturing teams'. I experienced that with illness these teams can be very ably employed to support the alternative stories of hope, resolution, pain-free times, sound sleep and to help the patient and his/her family to accept the patients definition of illness, death and dying.

Opening questions to include 'God-talk' and to be able to acknowledge and include God is part of the networking of a community of concern, I found these questions a very important part of a conversation with a patient. Examples of these questions that bring the 'other' into the conversation are: 'Are there others who could be a support to you?' and 'Who stands with you to fend off the controlling effects of the illness.' Often questions about communities of concern, the body of God, has opened pathways to discovering unique outcomes.

1.6.1.9 *Discovering unique outcomes*

Unique outcomes (Morgan 2000:51-58) are those stories that stand outside or contradict the dominant illness story and stand against the problem's influence; it is anything that the problem dislikes. Examples of questions include: 'What are the things that trip up the influence of the illness?' or 'When are there times when you tell the illness to stay on the back bench?' These unique outcomes created the opportunity for the patient and his caregivers to create hope and alternative ways of dealing with the 'problems' of illness and dying. Margaret in Chapter 3 saw her illness as a holy time and the whole street looked after Fred.

Therapeutic conversations are 'sacred encounters' (Griffith & Griffith 2002:viii), when we listen to another with open hearts, the spiritual and sacred is within this connection. Acknowledging

sacredness also acknowledges ethical practices. Doing research in a participatory way, researching with people, the research becomes a 'participatory ethicising adventure' (Kotzé et al 2002:28), which is also a sacred endeavour. Griffith and Griffith (2002:ix) acknowledge that the stories people tell us are 'a gift people give to those listening to their stories [and] is a sacred trust.'

1.7 Ethical Practices

1.7.1 Introduction

I recognise that the research practices have to also comply with scientific social research practices, therefore, I have been asked to visit the patient and his family and have been given written permission to intervene in his/her treatment as deemed necessary (see Appendix A). I have also designed a consent form requesting permission to use people's stories. I have also referenced other peoples' work with careful attention to detail and have used peoples' own words to illustrate or tell a story where it has made sense to do so.

The social-constructionist view, the qualitative research methodology and the narrative approach to conversations, guides the telling and listening to stories in an ethical way which situates and guides my involvement in the research process.

1.7.1.1 Situating myself in the research process

Reinharz (1992:196) emphasises the self-reflexive nature of feminist research, this being a position of honesty and openness in the transparency of the therapist about what the therapist has learned from the research experience. It also involves reflecting the way power relationships operated in the production of knowledge (Kotzé 2002:26). This, I did by not dominating the conversation or giving my views, and by not talking overly much about myself, but rather sharing experiences (Freedman & Combs 1996:278). Working from the 'not-knowing', 'client is the expert' (1.6.1.3) model allowed for a respectful approach to the patient/caregiver which adheres to the requirements of being ethical by not giving unasked-for advice, treatment or opinions. 'When one forgets self and becomes embedded in what one wants to understand, there is an affirmative quality of kinship that no longer allows for privileged status. It renders the act of knowing and ethical act' (Heshusius 1994:19). 'A story needs a listener' and 'stories are not material to be analyzed; they are relationships to be entered into' (Frank 1998:198-199), relationships are sacred, therefore, listening to stories is an ethical act.

1.7.1.2 Listening and Asking Questions

I experienced that listening attentively, or as Rachel Remen (Frank 1998:198) puts it, 'empathic attention', and asking respectful questions can be a very powerful aid to ethical practice. There are various ways to ensure that listening and asking questions remains respectful and I implemented these. I listened deconstructively to get some idea of the patient's knowledge, history, culture and meaning of particular experiences. Spirituality, healing, God-talk, holy times and community are examples of patient's knowledges that were just so very unique and different from my knowledges.

I asked clarifying questions rather than interpreting, instructing or intervening in the conversations. The answers were often a surprise to me. I think of Margaret who experiences her illness as a holy time. I also asked 'preference questions' to 'be sure that the direction or meaning of the experience is preferred' (Freedman & Combs 1996:129), that it was flowing in an acceptable way to the patient.

A participatory mode of consciousness, which is respectful to the client's preferred way of being, ensues that conversations occur with the patient and not about him/her. Understandings are in this way co-created in what Dirk Kotzé (2002:25) calls 'co-searching' for new knowledges. The research thus involves both myself and the patients' as being 'co-authors of alternative and preferred knowledges and practices' (White 1991:37) and engaging these in an ethical manner.

1.8 Conclusion

Dirk Kotzé (2002:19) reminds me that 'there is no way to establish final, universal ethical truth, no matter how broad the basis of acceptance may be. Some group or person or situation will inevitably be marginalised.' I have learned and been reminded so often that there is no 'right way' of dealing with terminal illness and death. The main thing I believe, is for us, as nurses/therapists, to assist people to find ways of dealing with death that work best for them (Waldegrave 1999:181). Acknowledging the preferred voices and way of being of a patient with a terminal illness requires acknowledging the uniqueness of individuals, being respectful of these and allowing patients to be who they prefer to be, and to act in their preferred way. This may include stopping medical treatment, using complementary treatments or continuing with treatment against professional advice. The choice is a personal one, one that affects the patient's personhood and, therefore, there cannot be a 'right' or 'wrong' way of living or dying. This makes research a fundamental ethical act. 'To live is to ethicise, and to ethicise is to participate in living, or, to put it differently, to

live is to participate in an ethicising manner. Honouring sacred spaces is a way of ensuring that patient encounters are ethical' (Kotzé 2002:21).

In Chapter 1, I have highlighted the conflict I experience between curative and palliative medicine which instigated questioning 'expert discourses' that arose as a result of my reaction to 'expert' knowledge which has been disqualifying of patients, carers and nurses. Feminist theology and pastoral care, as well as power/knowledge relationships and the unpacking of language, has had a major influence on empowering the voices of the patients and making space for these patients' voices to be heard. The research arose out of a need to honour the stories of the patients and to find a way to celebrate the stories that are meaning-making of terminal illness. Narrative practices have guided the research process as that are respectful of others and recognise the value each person has in telling his/her own story.

In Chapter 2, I will discuss the issues, which I consider the most important in guiding therapeutic conversations and listening practices while doing research. I recognise that storytelling and listening to stories is an unconventional way of doing research and veers from the 'linear, progressive, and logically "tight" form of writing characteristic of academic prose' (Gergen 2001:47). This way of doing research intersects with 'performative psychology – that is psychology that uses modes of expression from the dramatic arts, visual arts, music and other media [which] promotes the mingling of the scientific with the secular' (Gergen 2001:45). I use poetry, folklore, conversations and letters as part of the therapy and the research process and in this way I 'endeavour to create the effect of a more entangled and supportive set of relationships between researcher and participants than is presented in more traditional forms of writing' (Gergen 2001:45). I have found the exercise very useful as it has helped me to view the research from a distance as I am very enmeshed in the process as it is both research and work and of a very emotive nature. The very nature of storytelling, poetry and prose helped to develop the research from being a routine task or clinical technique to developing the therapeutic process into a 'gift' to myself and the reader, a 'gift' of terminal illness stories (Frank 1998:199).

2. MEANINGFUL LIVING WITH TERMINAL ILLNESS

2.1 Introduction

In this Chapter I shall investigate the therapeutic practices that could foster making living with a terminal illness meaningful. The research journey relies heavily on entering relationships based on storytelling. I have already committed reasons for relying so heavily on storytelling techniques and metaphors. I base the rest of the Chapter on introducing characteristics of narrative practices that protect and nurture the sacredness of patients as being experts of their own lives as upheld by palliative care hospice practices.

Feminist theology makes a stand against all forms of marginalisation and injustice. Pastoral care, the nature of which is being respectful, nurturing and honouring forms the foundation of the therapeutic listening practices. The deconstruction of unethical, unjust professional practices clears the pathway to understanding the interrelationship of power/knowledge practices. Insight into and understanding of power, language and truth games, supports transformation and liberation, empowering the patient to make choices. These choices are nurtured and sustained through love, hope and compassion. Sacred spaces are honoured and hope is embraced creating space for God-talk, for being inclusive of a personal God, to light the pathway to meaningful living with a terminal illness.

Severe illness strikes a double blow. It stresses a person through physical pain and disability, while disabling some of the most effective mechanisms for coping with stress: communion with others, a capacity to hope, a sense of control over one's destiny, and a sense of purpose in living.

(Griffith & Griffith 2002:264)

2.2 Listening to stories

Arthur Frank (1995:xi) retold the story of the wounded storyteller of ancient times: 'Tiresias, the seer who reveals to Oedipus the true story of whose son he is, has been blinded by the Gods. His wound gives him his narrative power.'

By listening to the narratives of people with terminal illness, I became aware of how their illness wounds gave them 'narrative powers'. Illness does not give a voice but a voice is given to illness in order for patients to work through the situation they are in (Frank 1998:204-206).

Voicing stories of terminal illness gives me the opportunity to shift dominant cultural perceptions away from determining a patient with terminal illness as a victim of disease, to explaining stories patients tell about transforming terminal illness into a meaning-making experience. Frank (1998:206-210) said that, '...stories matter not just for themselves but for others, and ...stories can be told, and lived, differently, ...not grateful for illness, but grateful for a life that includes illness.' 'Stories show the healthy how they could be living' (Frank 1998:206).

2.2.1 Wounded Storytellers

The stories transform the wounded patients into storytellers that nurture and care for Self and Others, including me, their family, community and friends. The time spent with the illness provides reflection time and empathetic bonds are created between the wounded storytellers (Frank 1995) and their listeners. A relationship (Frank 1998) develops and expands as the stories are retold and the circle of experience is enlarged. The telling and re-telling of stories bring healing, hope and meaning with them. Frank (1998) calls these types of stories 'quest stories'. The stories bring new insights and ways of coping with illness. The stories also bring with them an impetus to tell stories and to share. The stories are about *doing hope* in situations that speak about despair, anxiety, depression, hopelessness and anger.

The patients revealed that they enjoyed telling the stories, they enjoyed being heard as they had something to tell. The reason for this could be that they had not previously been given to opportunity to be heard or that by telling the stories they were meaning-making, or quest stories, with others. Michael White (1995a:16) says: 'Stories provide the frames that make it possible for us to interpret our experience, and these acts of interpretation are achievements that we take an active part in.' In order to do this we need audiences to witness our stories, as the audiences provide the opportunity for 're-membering practices' (White1997:22) which acknowledge the significance of other people in the storyteller's life. The telling and possible re-telling (White 1997:12) and re-membering practices may occur because of interest and questions from the listener which gives the storyteller the opportunity to 'directly acknowledge the important and valued contributions' (White 1997:23) of experiences and other people on the storyteller's life.

I am very aware that the telling of stories is an ethical act. The authors deserve to have the stories retold in a respectful way and in the way that they would choose to tell the story or experience. Frank (1998:208) asks the question about whether 'every ill person has it right in every story they tell? The paradoxical response is that every teller does have his or her own story right just as that

story is: not fair, not necessarily accurate in a medical or sociological sense, but right as an expression of who and where they are.'

From a feminist theology (Hogan 1996:56-59) perspective, being ethical could be questionable in a male-dominated world. The male-dominated view understands moral knowledge from a disembodied view, which is a view that does not see the body or the person as being an integral part of moral understanding. Being ethical from a feminist point of view must begin with 'our bodies ourselves' (Hogan 1996:65). We must recognise that we cannot escape our bodies and must guard against the dualism that separates our bodies from ourselves (mind/spirit). This has far reaching consequences for those who propose feminists as being ethical if they come from a dualistic frame of reference.

Moral judgement is also seen to have two distinctive modes that are gender related. These are care and response. It has been suggested that women tend to function with an ethic of 'care and relationality' and do not concern themselves much with 'issues of strict equality and fairness' (Hogan 1996:57). This brings about another controversy where women generally claim their traditional value and purpose to be expressed through their ability to be carers, but that they also require justice in their rightful claim to equality and extension of rights.

Caring and nurturing comes from being able to feel and express our own bodies. It is the ability to feel the pain of others, to experience compassion, to experience the hardship of being hungry or to experience sadness. Sharon Welch (1990:173) says that 'the power of compassion is divine.' Compassion brings about the ability to care and nurture, it is a 'resilient connection' (Welch 1990:173) that we have with people and 'the resilient connections are the presence of Grace', the presence of the spirit or God.

Caring and nurturing is a characteristic that is acknowledged, but its value has been devalued by the dualism that has been established by the controversy between the ethic of justice and the ethic of care. However, I do not believe that these two aspects are mutually exclusive; care and justice can go hand in hand if the question 'to whose benefit' is asked. An embodied response is appropriate when it assists the care of a patient and also encourages autonomy; this is ethical care. We cried and we laughed together, sometimes we prayed together and sometimes no words were necessary, I just sat in silence, at other times we made plans or I made suggestions and asked for opinions.

Recognising that therapeutic conversations are about the mutuality of storytelling and reciprocity between the storyteller and the listener, has created a space for a relaxed atmosphere. I don't have the pressure of decoding (Frank 1998) and classifying stories or having to find answers or give advice, but I can embrace and listen to stories with empathic attention. The sharing of a story with a listener offers the teller some distance from his or her life, which turns the chaos of illness into something more manageable. It is not denying the truth of the chaos, but through listening with compassion a 'crack of light shines into a room that was entirely dark' (Frank 1998:202).

As 'health professionals our culture awards us tremendous privilege and power in our storytelling rights regarding persons and problems' (Madigan 1996:59). I have tried to be sensitive to this through being honest and transparent in the interactions that I have had with the patients and their families. I recognise it to be a privilege to have heard and to be able to retell the patients' stories and I honour the stories as such. In recognition of the need to comply with the ethic of justice, I used the patients' own words when possible or perceived to be appropriate. I also complied with the ethic of care by deconstructing words and experiences through clarifying questions and 'taking-it-back practices' (White 1997:146). 'Taking-it-back practices' are when the nurse/therapist acknowledges the extent to which the patient has affected the nurse's life, however, the patient's story remains the centre of focus.

2.2.2 The Significance of Stories

The development of stories occur when space in storytelling is opened to reveal unique outcomes (see Chapter 1) or preferred developments (Freedman & Combs 1996:131) through 'attentive listening.'

Attentive listening is when we try conceptualise the patient's story in their language (Freedman & Combs 1996:44). This occurred when I asked the patients questions that resulted in events being re-authored developing stories within a timeframe, within a particular context and with other people. In this way experience is re-experienced. Through questioning, the events are linked in sequence across time according to a plot, which is contextualised contributing to the interpretation of the meaning given to an event (Morgan 2000:5-16).

Questions that encourage meaning-making can significantly contribute to story construction (Freedman & Combs 1996:136-140), they invite people to think about the significance of different aspects of the story. Naming the meanings of experience assist in constructing the meanings of events or experiences. I also asked questions about motivation, hopes and goals, beliefs and

values and invited the patients to look beyond specific events. Looking beyond pain or beyond going for a medical procedure helped patients to hope for changed circumstances, for relief of pain and discomfort. I also invited patients to reflect on the moral, ethical and spiritual dimensions of their stories which opened up new dimensions of meaning-making that were a surprise to both the patients and me. Specific local knowledges concerning unique outcomes and preferred directions in life, highlighted cultural learnings and knowledges that the patients had developed to counter problems. Here, I think specifically of the uses of buchu for urinary tract infections and 'kankerbossie' (sutherlandia) that helps boost the immune system. They were not new ideas that I introduced, the patients have always known about the use of these herbs.

Often stories were told and illustrated with metaphors. Lakoff and Johnson (1988:3) propose that metaphors are:

Our concepts structure what we perceive, how we get around the world and how we relate to other people. Our conceptual system thus plays a central role in defining our everyday realities. If we are right in suggesting that our conceptual system is largely metaphorical, then the way we think, what we experience, and what we do everyday is very much a matter of metaphor.

Jesus used metaphorical speech to illustrate his teachings and messages. I think specifically of the story of Jesus dividing the loaves and the fishes amongst 5,000 people. Could it perhaps mean that Jesus was spreading the Word of God to the 5,000 and they became followers of his message? Consider the story of Jesus turning water into wine, could this suggest that Jesus managed to convert the unconverted heathens into followers of God at the wedding reception by turning the water (unconverted) into wine (converted)? I have found that the Coloured people use metaphors regularly in everyday speech to clarify and describe what they are saying. I have enjoyed listening to patients speaking about difficulties as being *heavy stones*, which are carried by a wheelbarrow made-up and welded together by community support and an illness that is a jackal trying to escape from a cage by digging under the fence.

Frank (1998) cites that folklorists have pointed out that there is a basic structure, which forms the foundation of stories and that children learn these narrative forms without conscious awareness. These narrative forms help us in our understanding of new stories and help us improvise stories of our own. Folk tales require a hero, or more accurately a protagonist who becomes a hero (the wounded storyteller). The hero seeks something and is challenged by the antagonist (the illness). The eventual defeat of the antagonist is often made possible by a helper (nurse/therapist/community) who at first appears minor and ineffectual, but eventually provides the hero with an essential resource ('the crack of light').

Frank (1998) also identifies three narrative types of illness stories, these are to be seen as pathways to enter into a relationship with a storyteller.

- Firstly, he speaks of a restitution story. In the restitution story, the nurses and doctors are the heroes. These are stories that are expected and encouraged by medical professionals. Disease is seen as the enemy and cure is conquering the enemy. If cure is not possible then the restitution narrative does not apply. Patients with a terminal illness have no story to tell and they become isolated in their suffering and further marginalised. Stories that are not worth telling have no place in society.
- The chaos stories are stories told by those who have a terminal illness. When the listener feels sucked into a story and only wants to get away, it is a chaos story. Chaos talk is void of any ordering, of a beginning, middle or anticipated end and can induce claustrophobia in the listener. Storying the talk about the illness, can bring about a transitory escape, a crack of light.
- The quest story is when illness is lived as a quest, as a condition from which something can be learned. The patient is not glad to have the illness, but they are grateful for how the illness has changed them and their lives. Quest stories express an unflinching view of the reality of the illness, but do not look for restitution, but rather at what they can claim of life. They are not grateful for the illness, but grateful for a life that includes illness.

To illustrate the significance of stories and metaphors and keeping with feminist ideas about research and writing (Gergen 2001:45-47) and with the idea that the 'researcher is like a choreographer, who creates a dance to make a statement, I tell a story. For the researcher, the story told is the dance in all its complexity, context, originality, and passion' (Janesick 1994:218). I will tell the story of 'The Lost Mother Moon' (Pinkola Estés 1995:Vol1, tape 2.), a quest story, that developed from a chaos story. Stories have particular significance to me. Stories assist to illustrate meaning, they externalise and make safe an interaction by the use of the unreal and so make the real more accessible. Stories keep one's attention by building to a conclusion or resolution (beginning, middle and end) and deconstruction (1.6.1.5) becomes so much easier because you are not dependent on truths or dominant discourses - there is a distance from real life (Frank 1998:202). Most stories are also universally applicable and acceptable, as they do not necessarily originate in a known culture, race or social status; stories can transcend all socially-constructed boundaries. Every culture, however, has similar stories to tell which become part of folklore and may be jealously guarded.

'The Lost Mother Moon' story is a beautiful story of hope, purpose, agency, communion, gratitude, and joy and represents meaning-making or quest for a community. It is about investigating opportunities and risk-taking in a goal-directed way that influences and cares for Self and others (Griffith & Griffith 2002:265) and brought about liberation and transformation of a community.

'The Lost Mother Moon' story is a metaphor for the way I choose to carry out my hospice work; it is grace and light that guides me daily and shows me the pathway to follow. It is the patients' stories that give me hope and purpose to face the day; they give me agency to find meaning-making in the work I do with the terminally ill; their families and the community, bring meaning to my life. People's stories of gratitude and joy in living, their stories of appreciation for what we do at Hospice, the communities, their families and for what life has to offer, propels and nurtures me to cope with difficult situations. The stories make the professional personal and the personal becomes professional.

I agree with Kaethe Weingarten (White & Hayles 1997:xi), I, too, I have had not really understood the dichotomy between the personal and the professional as the distinction between the two is a very fine line. Is it possible that the professional could not be personal or visa versa? Maybe the argument has something to do with what Linda Hogan (1996:56) speaks about with embodiment; that disengaged objectivity is not appropriate and from a Feminist ethic's view, knowledge is always body-mediated. My professional training, therefore, influences my personal reactions and my personal reactions influence my professionalism, the two are not dualistic, they are mutually inclusive aspects of bringing meaning to my work and life.

People's stories and stories like 'The Lost Mother Moon' are meaning-making for me, and so I am using this story to assist me in meaning-making of 'Honouring Sacred Spaces: Voicing Stories of Terminal Illness.'

2.2.3 The Lost Mother Moon Story

Clarisa Pinkola Estés (1995:Tape 2) tells the story of 'The lost Mother Moon'.

It is a story of a happy place, a pristine village where the community of people cares about each other, they look after the sick, they share their food with the poor, and they visit the lonely. There are lovers, parents and poets, children and old people, mentally and physically handicapped and sick people, a sort of idyllic place with enough for all. However, surrounding this place is a bog. A dark bog with black mud pools that contain sludge and slime, evil creatures, smelly objects, creatures with claws that don't care for people and prefer death and destruction. It is the sort of place where you get punished with death if you venture off the

straight and narrow. This bog has created an island of the village. To survive the people have to go through the treacherous bog, sometimes this must take place at night. The moon is their guide at these times, the moon protects, guides and nurtures them safely through the bog.

One night, a man from the village, ventured into the bog when it was dark and the moon could not show him the way. The evil creatures caught hold of him and pulled him into the mud. Down, down into the dark slimy mud. The moon saw this and heard the man's calls for help. She was so concerned and distressed that one of the people she cared for was in trouble that she decided to come down on a slow star to see what had happened. She disguised herself in a black cloak. All that stuck out from the cloak was a small light at her feet.

Near the centre of the bog she heard the chattering of the evil ones and then saw another man who could not find his way out of the bog. The evil ones were taunting him and were pulling him into the mud. The moon became distraught and risking her own safety, she decided to show herself to the man and started to drop her cloak to light the man's pathway. She then realised that he was drawn towards her light and there was a big black pool between them. He would surely drown! The vines caught hold of her arms and legs, but the moon shook and opened herself to even greater danger. By the moon's light, the man then saw the danger he was in and could take the right path out of the bog. As these stories go, the man thought no more of it, he was safe and went home.

In the meantime, the creatures of the dark tightened their grip on the Mother Moon; they tied her feet and hands and squashed, pushed and pulled her into the dark smelly mud. They then rolled a huge stone on top of her, firmly securing her and she was pushed deeper and deeper into despair. Nobody saw her and nobody could help her, she was on her own and had no support to fight off the evil ones. She could not call for help.

The villagers waited and waited for the moon to appear. Night after night they looked for their guide and carer. Misfortune befell the people of the village, no one could find their way home. Lovers and fathers and mothers were lost in the bog at night leaving orphans and sad women and men. The community was in disarray. After a while the people could not bear it anymore, they decided to stand together and risk the unknown. They formed a search party to look for the moon. They went out into the bog armed with torches and lamps. It was very dangerous, but they were brave and there was a community of people who could stand together to fight off the evil ones. They supported and held onto each other when taunted by the evil ones and because of their numbers and community support, they were not endangered. They faced the evil ones with confidence. When they neared the centre of the bog, they saw a huge stone with a strange light encircling the stone; it pulsed like a heart beat. It almost looked like music or a fragrance, it looked alive. They were very curious about this and decided to move the stone, but to no avail. Reinforcements were called for with more torches and lamps and lot more people-power. Together, they decided to push as hard as they could to see what was concealed under the stone. In unison and with a rhythmical great heave and shove, the stone moved. Encouraged by the movement they were even more inspired to work together in heaving and pushing and heaving and pushing again.

Finally, slowly the stone moved and slowly piece by piece that what was so carefully concealed came into sight and in front of them appeared the most

beautiful sight. A smiling, caring, luminous face filled with love of the carer and nurturer, the Mother Moon. The evil creatures ran away into the dark, the brilliance of the moon overshadowed the evil ones to such an extent that they could hardly be heard. The Mother Moon rose out of the mud and got bigger and bigger and higher and higher until she finally took her place like a golden orb, in the sky. She again guided the community through the bog, bringing peace and prosperity to the village. The moon's grace shone on the villagers; the poets now write poems, fathers play with children, mothers give hugs and lovers make love. The Mother Moon glows with grace on her people obscuring the evil ones and caring and protecting her people by bringing light.

2.3 Co-searching practice and research

The story of 'The Lost Mother Moon' illustrates and supports my vision of doing research and therapy, a vision that opens up a modality of resistance to dominant discourses (the evil ones), to finding healing despite the dominant views and power abuse of 'experts' or more powerful. By engaging community support and venturing into areas of the unknown and taking risks, Mother Moon became available and brought healing and light to all. So often the professionals' ignorant use of their power blinds helpful endeavours. Comments such as, 'The patient is too weak to deal with the truth' or 'What he does not know will not harm him', are unhelpful to the patient's wellbeing.

I found support for this view of resistance, liberation and transformation from the so-called 'victim role' of illness in the feminist movement and feminist theology. Feminist theology defies the ideas of dualism³ and encourages wholeness and I will base this Chapter largely on this approach. Isherwood and McEwan (1993:134) see '[t]he vision of feminist theology [as being] a world where individual dignity and integrity are honoured in mutual relating, where life-giving power replaces life-denying power and people are enabled to accept their humanity joyfully.'

2.3.1. Feminist Movement and Feminist Theology

The feminist movement and feminist theology are open to engage in criticism of traditional, dominant thinking; it aims to trigger investigation, deconstruction, rethinking, change and ultimately the transformation of patriarchal and modernistic views. Feminism strives to be inclusive of all people and the environment regardless of sex, race, financial status, culture, education or any of

³ In Feminist writing dualism usually signifies a relationship of domination, in which one party perceives him/herself as being significantly different from the Other (Boss 1996:41). I see dualism as coming about as a result of the distortion of androcentrism which has brought about the splitting of the wholeness of

those issues that discriminate and divide people or situations. Isherwood and McEwan (1993:92) support this by saying that Feminism is not about making the world woman-centred, but about bringing the world into balance, offering a way out of age-old dualisms and discrimination to achieve inclusion and mutuality.'

Feminists believe that we need to live deeply in our bodies and use our perceptions and feelings, this will ensure that we do not lose our connectedness and our ability to relate (Waldron 1996:6). Feminists have thus, always 'celebrated "embodiment"' and have lamented the distortion of body-mind dualism, which has been created by Patriarchy' (Waldron 1996:66). There are feminists that strive to make the world woman-centred, but they too are falling into the trap of dualism. Feminism in my view has to do with wholeness and mutuality. In the story of 'The Lost Mother Moon', all people received the light and nurturing, there was no discrimination, no earning of grace. The components of community support, and self-agency, represents knowing about and hoping for a better life and doing something about it, making a choice and acting upon the choice, *all* contributed to 'bringing peace and prosperity to the village' and the community.

I believe that self-agency during an illness and community support reveals an aspect of illness and creates an opportunity, however dangerous (Frank 1991:1), to choose the way you want to lead your life. Frank (1991:138) says that because we can choose how to experience illness, we can be more than victims. Choice can manage to turn the worst circumstances into an experience of value. There are times when a patient chooses not to see value in their illness, but even this is a choice. Being comfortable with a patient's choice allows a degree of self-agency and being 'more than victims.' Choice brings hope to the despair, purpose to meaninglessness, personal agency to helplessness, communion to isolation, gratitude when resentment occurs and joy replaces sorrow (Griffith & Griffith 2002:265) and thereby opening up possibilities for patients to be and experience whatever they choose.

The significance of power is also a major contributing factor which allows patients to make meaning of their illness and to have a choice about the way they prefer to live.

2.3.2 The Influence of Power

2.3.2.1 Justice for all

Feminism is a justice issue that involves the distribution of power (Hess 1998:58). Foote and Frank (1999:172) quote Foucault who says that 'We can never be ensnared by power: we can always modify its grip.' To unmask and use power beneficially we need to see it from another perspective, no longer as influencing the individual and being caught up in dominant discourses, but to see the possibility of resistance and the more effective social resistance. Foucault sees power as being relational (McHoul & Grace 1993:39); it exists between individuals and influences discourses and exists in communities and within relationships in communities, power is everywhere.

The people of the village found a way to change the grip of the evil ones by working together and making a plan. So too, with this research, I hope to voice the stories of the terminally ill so that power can be shared, so that we can experience a differing view, another way of experiencing illness. I hope to be part of a social resistance, acknowledging the voices of people who are marginalised because of dominant discourses that influence our reactions to people with illness. These dominant discourses may include treating the ill as being responsible for their illness, we may treat them as not being able to make decisions for themselves or as needing our protection. The ill person may also be seen as being a victim or needing to 'sort things out' or as having to make choices or behaving in a prescribed way.

2.3.2.2 Power is everywhere

In Foucault's argument, power is not *only* relational, it is also everywhere (McHoul & Grace 1993:39). Recognising that power is everywhere highlights the responsibility we have as professionals to be just in our dealings with patients. Being just involves 'analysis of injustice and sustained work to transform conditions of injustice' (Welch 1990:123). Injustice occurs when patients are not consulted for preferences of treatment or when they are not well informed regarding their illness. 'The Lost Mother Moon' involved the people making a stand against the evil ones. They saw it as an injustice that their community was being threatened, they worked together to find a way of changing the situation, of freeing the Mother Moon. This analysis and action was to the benefit of all, not only to the benefit of the group who went out with the torches. So, too, analysis and action for justice benefits the patients and the professionals.

2.3.2.3 Power instigates and requires resistance

The power of the professionals (when working with illness), is skewed to the side of the professionals. But, if one argues that power is everywhere, all is not what it appears to be. Professional power abuse may occur when prescribing medication or carrying out procedures without consultation with the patient. There are many ways of exerting power, but it is incorrect to assume that the power lies only on the side of the professionals. Professionals may wonder why patients don't keep appointments or why they share only what is deemed appropriate. Non-compliance with treatment or silence is a way patients exert power. If power cannot be expressed openly, it is expressed subversively and in the form of resistance.

To be just in the therapeutic relationship, there needs to be an awareness that 'power instigates and requires resistance' (Foote & Frank 1999:176). The villagers made a stand to defeat the evil ones, they decided to resist the evil forces together. Therefore, patients cannot be rendered 'docile' (Foote & Frank 1999) and be dominated with expert technologies. Consultation with patients ensures that treatment plans are understood and will be followed. Without consultation, resistance or non-compliance may follow. Sharon Welch (1990:126) talks about 'communicative ethics', which exists when our relationship with the patients are 'governed by the norms of formal equality and reciprocity' (Welch 1990:127), and respect, honesty and transparency between the professional and the patient will feed this communicative ethics to all the parties benefit.

'Whenever there are inequalities in power between groups, conversations that take place in the name of dialogue usually take place on the terms of the dominant group' (White 1995a:51). The inequality that exists in terms of the dominant group highlights the necessity for a professional attitude of openness and freedom which assists in creating a form of liberty, for both the patient and professional.

It was evident that the conversation with Adriaan was a one-sided affair, - the relations of power could not be used to anyone's benefit. Suppression, disempowerment and domination only shift the influence of power to an unseen area, which exists in the silence of Adriaan, Pieter and his family. 'Justice begins with the relationship of speaking and listening' (Eiesland 1998:108) and therefore an openness and receptivity to the patient may ensure a more equal, honest sharing of power, supporting justice. This usually involves a lot of diplomacy, patience, negotiations, sharing of knowledge and 'just listening' (Frank 1998).

The power/knowledge⁴ of the professional nurse or doctor needs to be deconstructed. Where does it come from, who and what gives us this power and to whose benefit is the power? These questions heighten our awareness of accountability. Are we accountable to our patients, their families and our professions? Are we accountable to the community and are we respectful and acknowledging in our dealings with the patients, the family and community? By being transparent in our interactions and asking questions such as, 'Are you comfortable with this line of questioning?' or, 'Is there another way you would like to deal with this issue?', - we may get closer to being respectful and using power to everybody's benefit, including those marginalised or terminally ill.

Pain management is one of the biggest challenges in palliative care, finding out about the meaning of pain and pain management for the patient encouraged me to make a patient pain management form (see Appendix B) and to ask questions in connection with pain. Pain management has become the patient's domain in being transparent, willing to share the knowledge about pain management methods and, most importantly, in listening to the patients unique pain story. Patients are thereby empowered to manage their pain.

'Power is positive and creative, not just negative or repressive' (Townley 1994:8) making space for liberation and transformation and individual choice.

2.3.3 Transformation and liberation

Transformation or change occurs as a result of resistance and 'resistance is no end state where one can be; rather, it is a perpetual state of arrival' (Foote & Frank 1999:179). Resistance is the mechanism for transformation and Nicholas (1998:158) says; '... good theology [therapy] is transformative and liberating' (Nicholas 1998:158). Transformation and liberation are usually accompanied by a certain amount of chaos. It is not a predictable or comfortable state but rather an 'unbearable lightness of being' (Parry 1991:39), which is an excitement about prospective change accompanied by the anxiety about unknown consequences. Kotzé (2002:17) speaks about being 'a chameleon on a rainbow' which I find to be a wonderful metaphor. It is being exposed so many different wondrous choices - and yet not knowing which one to choose and having to be constantly be on the alert to the possibility of change. It is being able to submerge into and be part of the rainbow, but also being separate and being able to step away.

⁴ Foucault shows that power/knowledge are different sides of the same social relations and the more is known about something, the more controllable it becomes. Power is relational, it is not a possession, therefore, Foucault does not speak about power, but relationships of power (Townley 1994:5-8).

Sharon Welch warns about the 'ethic of risk' (Welch 1990) that accompanies liberation and transformation. The result is not always predictable and need not go the way that is planned. Being receptive and listening to stories with love, hope and compassion and being non-prescriptive and comfortable with the idea of resistance and chaos enables change, transformation and liberation to occur. Patients can change from being victims to recognising that they have choices and stories change into quest stories. This is illustrated by the risk taken by Mother Moon to drop her cloak that brought light for the man to find the path and identify the bog. Although Mother Moon risked being captured, her love, hope and compassion and belief in changing circumstances were greater than the fear of the unknown; this choice changed the direction of the destination.

Engaging in 'God-talk' and allowing therapists to enter sacred spaces, is a very risky thing for patients to do. They do not know what the reception to their story will be, nor do they know to what personal benefit it would be. The professional and patient needs to acknowledge the element of risk and chaos that may result and this somehow goes a long way to clear the pathway and 'light the path', to bring order to the chaos, making transformation and liberation possible. This chaos I see as being exposed to all the different options or colours of the rainbow that become available when talking about sacred spaces. They may be issues that people have not wanted to look at, because they may be too scary or painful. These issues may include ideas around religion, the purpose and meaning of life, and experiences of death and illness.

Frank (1991:4) speaks about the benefits of ill people being given the opportunity to talk as they benefit from experiencing talking, or voicing stories, with another. He says that talking about sacred spaces embarrasses us. As professionals we do not have practice with this kind of talking. I wonder at this comment? Could it be that we believe we know the answers, or that we believe we should know the answers? This element of risk, therefore, belongs to both the patient and the therapist, we both feel vulnerable with loss of control and exposed to elements of chaos regarding issues such as power/knowledge, ideas on spirituality, illness and death.

'Conversation enables community to be built between and among individuals' (Griffith & Griffith 2002:109) and conversation with a personal God enables community to develop between the patient and his/her God. 'Selfhood', according to Bakhtin (Griffith & Griffith 2002:110) 'is composed not only through others' eyes, but through the witnessing of God's eyes.' Often questioning needs to be specifically directed to the interaction between the patient and his/her God, if God's voice is to enter the conversation (Griffith & Griffith 2002:118). Speaking out loud, a previously private

conversation between the patient and his/her God, expands the conversation and allows for new thinking. Such a conversation could enable transformation from dominant illness narratives to take place. God and religion were very important to the patients that I interviewed and I have found that through entering into conversation with the patients about their understanding of a personal God, space for entertaining the God of Grace was found.

Transformation and acceptance of patients' preferred way of living with a terminal illness could be a liberating experience for both the patient and the professional carer. This can only be of significance for patients if the choice about how he/she views his/her illness is accepted with love, hope and compassion. It is also a justice and ethical issue as everybody is accountable to himself/herself for their own salvation and we cannot, and may not, presume to know how somebody needs to conduct their lives or what their opinions and justifications are. Being open and receptive to ideas, which may be different from our own, has the promise of surprising us to knowledges that we are not aware of. This can enrich and add to our own lives.

2.3.4 The Significance of Love, Hope and Compassion

Denise Ackermann (1998:75) says: 'For healing praxis to be truly restorative, it has to be collaborative and sustained action for justice, reparation and liberation, based on accountability and empowered by love, hope and [com]passion.' Stories which people tell about their illness and loss raise questions about what the meaning of liberation and healing or transformation has for people living with illness and how it affects their communities.

Healing could be physical, emotional, spiritual or even intellectual and may have a different meaning to different people. Healing could be getting closer to God; healing could be being pain-free for a while; it could be reconciliation amongst family members or it could even be death. If the therapist is not receptive to being 'a chameleon on a rainbow', to hearing stories of transformation, liberation and healing, these stories could be disenfranchised essentially by socially accepted or prescribed ways of reacting to the dominant discourses. The dominant discourse as far as healing is concerned, has to do with physical healing and not the healing of family relationships or the relationship with God or being pain-free for a day. Healing could be seen as death and how strange is the concept to most people and just how consoling could this knowledge be to family and therapist/nurse. Death could be liberation from suffering and transformation could result as anger or devastation engages acceptance and reconciliation of the death and maybe the promise of life after death.

Love, hope and compassion are the ingredients that allow patients to experience healing in the way they choose. Love, hope and compassion cradle patients' emotions and assists in transforming suffering into meaning-making experiences, essentially into quest stories. The significance of these experiences may at times be difficult for professionals to understand, but it does not distract from the significance that it may have for the patient.

2.3.5 Truth games

According to Foote and Frank (1999:160-161), Foucault describes the human sciences (the medical sciences are part of this) as 'truth games' through which people aspire to know the truth. 'Truth [then] becomes a form of dominating power precisely because it is accepted as Self-evident'; these truths become dominant discourses.

Dominant discourses and theologies cannot claim to be universal truth, they are merely "particular" and contextual for they are the theologies [or discourses] of the dominant group and their position and interests' (Bons-Storm 1996:125). Foucault (McHoul & Grace 1993:30) sees discourse not as language or social interaction, but as relatively well-defined areas of social knowledge. The dominant group, as far as illness is concerned, is considered to be that group which has the highest qualification of academic knowledge regarding medical illness (the doctors and nurses) and is, therefore, considered to be the most knowledgeable on the subject of illness and dying, hereby accessing the dominant discourses.

Foucault also sees knowledge as power and power as knowledge (McHoul & Grace 1993:59), there is an interrelationship. Truth is constructed through power/knowledge, disenfranchising those without medical knowledge. This means that patients' voices are silenced, they are not considered to be experts about their illness and their stories are thus rendered unimportant.

Foote and Frank (1999) see truth as a 'mutual obligation' of both therapist and the patient, both the therapist and patient need to engage in practices that would allow the patient's concept of truth/knowledge to be acknowledged. This requires an attitude of not-knowing and not being the expert and being genuinely interested in the patient's story and honouring that story. If this is achieved the patients' version of her/his truth/experience will not only be recognised but will also be acknowledged making space for a unique outcome, an unexpected meaning to experiences and clearing the pathway for a quest story. When I discussed 'cheekiness' with Emma in Chapter 3, she saw being cheeky as a means of survival, not being insubordinate or rude as was my

perception. The meaning of cheeky changed for me and I started to appreciate Emma's ability to be cheeky when the odds were not in her favour.

2.3.6 Making a commitment and taking a stand

2.3.6.1 *The personal is political*

Feminists challenge and question the traditional, accepted norms and values (McBride 1996:113). An example of questioning these norms and values of terminal illness are questioning statements that state that you have to get your life in order before you die or that you relinquish responsibility for your Self and become a victim when you are ill. Feminism questions the contribution dominant norms and values have in maintaining injustice that lead to the disqualification and disenfranchising of people marginalised because of illness, education, race, culture, sex or religion. 'Feminists know that the personal and the political cannot be separated' (Ackermann 1998:81), therefore, the feminist are prepared to take risks in making a stand against unjust and unethical professional practices.

This research makes a stand against the way the doctor enforced his opinion of dying on Adriaan and his family. By voicing the stories of terminal illness, I am making a stand against professionals who do not take the time to hear and listen to the voices of terminal illness.

2.3.6.2 *Hearing and Listening to voices*

'The common character of oppression experienced by a social group is the 'inhibition of their ability to develop and exercise their capabilities and express their needs, thoughts, and feelings. The 'faces' that oppression presents include: marginalisation, exploitation, powerlessness, cultural imperialism and violence' (Eiesland 1998:109). The aim of my research, which was supported by Feminist ideas, was thus to privilege the voices of people that are marginalised because of illness and find ways of listening and hearing them.

Bons-Storm (1996:11) quoted Nelle Morton who said, 'Speaking first to be heard is power over. Hearing to bring forth speech is empowering.' So often we, as professional medical people, give advice and information very freely. We actually think that it is our job to give our opinions as that is what we perceive patients require and we are taught this during our training and it is expected by some people that we come up with the answers. Is this actually so, or could it be *our* need to be heard; to be seen as knowledgeable and in control? How much more useful would it be to actually

ask the patient what information he/she requires; how they would like to monitor the progression of their illness, if they would like their family to be informed by us, or whether they would guide us to what will be useful? When I asked one of the patients how he would like to talk about the illness, he told me that he preferred not to talk about it, he knew he was sick but found it easier to cope with a day if he did not harp on the subject. He would do the talking if it needed to be done.

In the story of 'The Lost Mother Moon' (2.2.3), new stories were being told, stories of self-agency and empowerment to change circumstances. They were self-discovered stories which brought about self-agency and community support. Through questioning, Margaret (see Chapter 3) discovered the agency she had in making the God of Grace part of her life, she deserved grace through her actions in her community. How much more useful are such discoveries than those imposed by others? Credit for peace and harmony in the village wholeheartedly goes to the villagers. What may we deny patients by speaking first to be heard? I wonder what Adriaan and his family would have told us about his view of his illness and life and I also wonder in what way Katriena prepared Pieter for his father's death?

2.3.7 Sacred Spaces

Elaine Graham (1998:141) says:

Pastoral care embraces more than personal counselling or support and that the process of giving and receiving care is about building relationships of mutuality and empowerment, of presence at the cutting edge of social change, of solidarity with the marginalized and of the provision of symbolic, ritual and theological resources by which people can make sense of their lives.

Mother Moon was the ultimate pastoral carer, she guided, protected and nurtured the people to safety, regardless of education, culture, race, social status or religion, but she was not in control, she did not dominate, she brought light to illuminate the pathway. The people freed her, they allowed her to be in the sky again and be their guiding light. They had choice, self-agency and were empowered to do so. I see the nurse and pastoral carers role as being similar to Mother Moon, allowing patients choices and allowing them self-agency through the sharing of knowledge and acknowledging that they may have opinions and views that are different from our own and honouring these opinions.

The feminist theologians have expanded the concept of pastoral care beyond the conventional, traditional, patronising-giving, supporting, helping, holding, caring, nurturing, in a way, personal sacrificing mode, to one which has '...the intent [of] becom[ing] resisting, empowering, nurturing,

and liberating' (Miller-McLemore 1998:181). These words contain a promise of lightness, of hope, transformation, freedom and liberation from conservative, constricting so-called truths regarding that which is acceptable and normal responses to illness and health. Stories of terminal illness could contain unique ways of 'healing' and healing often has divergent meanings. Arthur Frank says (1991:21), 'We are free only when we no longer require health.' What does this mean? Does it mean that we are only free when we accept illness and death as part of life because then we will not be so devastated by illness or lack of health? Will ill health then not have the same controlling effect on our lives as it has previously? When Margaret says that being healed is getting closer to God, is this what she meant? (See Chapter 3).

Mother Moon promises light for the dark, she illuminates the patriarchal evil ones by dropping her cloak to bring light and show the man the pathway out of the dark bog. Through the act of grace Mother Moon challenged the rules and regulations, sin and punishment or judgements of right and wrong, law, order and truths. The light brings an energy and nurturing which empowers risk-taking to venture into the unknown, untraditional areas. This energy or light is the patient's guide on the path of transformation and eventual liberation from qualifying discourses obstructing 'healing'. Patients don't have to behave and be classified according to accepted medical models, they can (with the Grace of God) be seen as unique individuals with their unique stories of terminal illness. 'Witnessing the particulars of [the] experience, and recognizing all its differences, is care' (Frank 1991:49), and care enables patients to embrace hope.

2.3.8 Embracing Hope

When I read Elisabeth Kübler-Ross's book *On Death and Dying* (1969) the concept of hope made its first real impact on me. She speaks about hope as being part of and existing through all the stages of grief and dying. When the stages of dying have been taught to me, often hope was left out of the discussion.

2.3.8.1 *The virtue of hope*

I think hope is the most needed quality for life and terminal illness. But what is hope and where does it come from? What generates hope? Riet Bons-Storm (1998) sees stories that go against the grain of dread and despair as giving us a vision of hope. 'This hope nurtures the courage to love, that is, to be open to others and to see the best in them and to cherish them without being afraid' (Bons-Storm 1998:15). Ackermann (1998:88) sees imagination as being an essential component of hope. When one dreams utopian dreams for a better world and when these are

translated into actions for healing and wholeness, hope is nurtured. She says that 'living one's hope for a better world means realistically acknowledging brokenness and need while at the same time engaging with life in such a way that deeds express that which one hopes for' (Ackermann 1998:89).

For me, hope is the ability to look for and to find beauty or God within nature, experiences and people. It is the ability to not only see God when things are naturally beautiful or harmonious, but it is the ability to see God in even the poverty, hardships, illness and devastation with which we are daily contact. In addition to this, I support the words of Kaethe Weingarten (2000:399-402): 'Hope must be the responsibility of the community. Where this is so, and when this is so, there will be a sense of wonder, which has been called the abyss where radical amazement occurs.' She also says that 'Matters of life and death are too hard, too onerous, too painful to do alone' (Weingarten 2000:399), so together we need to do hope, to use our imaginations and to look for that which heals brokenness and brings about wholeness.

Hope is not about denying the brokenness and despair, but to look for that which heals it. Listening to illness narratives and by engaging in God-talk, patients have told me about their relationship with their personal God. Their God supports and cares for them, holding and nurturing them. These are stories of hope, where the patient does not suffer alone, but is in community with God and their spiritual communities.

'The Lost Mother Moon' story clearly illustrates how the villagers found support and strength from each other; they could not have done it alone, they had vision and hope for a better future. Facing a terminal illness is also 'too hard, too onerous, too painful, to do alone' (Weingarten 2000:399). Arthur Frank (1991:127) says: 'those that express their illness live their lives to the end of the illness', this was a story of doing hope, of alleviating some of the loneliness of being terminally ill. A sense of belonging, nurturing and caring that comes with storytelling, being listened to and community support, nurtures hope. Listening to stories and honouring stories are all part of doing hope, storytellers know that their stories matter (Frank 1998:210).

2.3.8.2 Doing hope

Doing hope is thus a community responsibility, the villagers heaved and pushed the stone together to find the light. We need the support and encouragement of others to sustain and build on hope. Hope then becomes self-fulfilling, it becomes a way of life and is self-generating. As negativity can

be infectious, resulting in pain, disillusionment and destruction, hope can result in resisting, empowering, nurturing and liberation. Hope has the added positive support of beauty, light or God, which engenders warmth and energy to expand and spread hope. It could become contagious. Denise Ackermann (1998:17) says that: 'Perhaps one person's vision of hope can touch the other's vision of hope' and then belief in the possibilities of the 'other' could nurture hope.

The patient, his/her family, church and friends all could be actively involved in doing hope (hoping), in imagining something better or an improvement. Hope could simply be drinking water without spilling; it could be not having pain tomorrow; it could be seeing a daughter next week or it could be coming closer to God. Hope is many different things. I see the building blocks of hope as honesty, reliability, dependability and transparency, if these do not exist then false hope and disillusionment may result in sadness and despair. Everybody can do hope, but how is hope done?

Hope was done when the patients identified the following: pain-free times, when medication prevented vomiting a meal, the prospect of a visit from a friend and appreciating a beautiful day or view. Hope in illness is embracing something good, something beautiful or peaceful. Silence or birdsong can be hope. Hope encourages living and energises the ill person to face a day or situation with courage and anticipation. There was a better time, 'I managed to sit up yesterday' or there could be an improvement, 'I know that I will sleep well tonight.' The villagers knew the Mother Moon so they knew that things could be different. Everybody has the experience of good times. Doing hope in the story is illustrated by the working together to achieving something better. It is the right and it is possible for all people with a terminal illness to live with hope, the patients experience this and it is this hope that helps patients cope with the most difficult circumstances.

2.3.8.3 Hope nurtures love and resistance

'Hope nurtures the courage to love, that is, to open to others and to see the best in them and to cherish them without being afraid' (Bons-Storm 1998:15). Hope, therefore, enables people to risk, to live life with a certain amount of chaos in their personal lives and in their medical treatment and to be a 'chameleon on a rainbow' adapting to changing circumstances. Hope enables the therapist to identify the 'unique outcome' (Morgan 2000) and to 'pan for gold' (Wylie 1994) and in the case of the story, finding Mother Moon.

Denise Ackermann (1994:208) also recognises that 'Hope is resistance. It actively avoids the void of hopelessness by wrestling with all that seeks to deprive us of hope and disempower us.' It

encouraged the people to stand together against the evil ones. Meaning-making of illness, imagining being pain-free, remembering a walk along a beach or a hug are things that nourish hope and Kaethe Weingarten says that nourishing hope resists despair (Weingarten 1999:24). Nourishing hope is, therefore, resistance to despair and hopelessness. Hope is nourished through talking about the possibility of improved circumstances. Hope is the prospect of having less pain or hoping for a good night's sleep or a visit from a friend. Hope is not an end state or expectation; it is a perpetual state of arrival; it is hoping for something better. Hope in terminal illness is not necessarily not being ill, but it could be hoping to control symptoms like nausea, headaches, breathing difficulty or pain. The community of carers did hope with the patients by nurturing and caring and by listening to stories.

2.3.9 The Significance of Language

The use of language is culturally-specific, but is also influenced by the community and spirituality of the person. I have become aware of terminology that is used for concepts such as *dying*, *God*, *illness*, *friendship* and even *pain* that are strange to me. I have come to realise that if my patient's terminology is strange to me, my terminology must be strange to them. Judicious language use is, therefore, essential to respectful patient encounters. Meaning-making of hope, thoughts and experiences occurs through hope.

2.3.9.1 The complexity of Language

Sampson (1989) writes about the work Jacques Derrida has done on language and acknowledges that all societal practices, including the meaning of subject and subjectivity, are not simply mediated by language, they are constituted in and through language. 'Words have the power to create human reality, to shape the world' (Isherwood & McEwan 1993:97). This, to me, means that when we speak about something, for example, pain, the pain becomes what we express it to be: the social construction.

The meaning and significance of the words we hear are questionable or to use the word of Derrida, under erasure. Derrida (Sampson 1989) explains it in this way: every word we hear needs to be under erasure, we need to write it and then cross it out and then to print both the word and the deletion. Everybody interprets words differently, it depends upon experience of the word, culture and context could influence that experience, as well as those things that are most fresh in their experiences. A word is, therefore, usually inaccurate, and it is crossed out since it is inaccurate,

but because it is also accurate and necessary, it remains legible. We have to use a word or term that we believe to be accurate and inaccurate, appropriate and inappropriate under erasure, reminding us that words, as signs, do not have a universal truth or meaning. Derrida also speaks about the traces or spaces, *the said* and the *not said*, these too are forms of language, of speaking, and need to be taken cognisance of.

The socially constructed nature of language, is for example, reflected in the word 'healing' and its multiplicity of meanings. I have found amongst my patients that healing could mean getting better, it could also mean getting closer to God, or even dying. Healing could be healing of relationships, not having pain or when vomiting has stopped. It could be going for a drive in the car or seeing a grandchild for the first time, it could be silence amongst noise or acceptance of death. Healing can also be observed by a perceptive on-looker without any words spoken.

2.3.9.2 Language is reality

Language being reality, has great significance for the research. 'It gives order and meaning to our lives and our world' (Andersen 1991:30), but I also know that the words I use have a different meaning to the reader and the choice of words I use have to be under erasure. I have to check with the patient on whether my choice of words reflects the patient's understanding of the word. 'We have to be very sensitive to the issue of language. Words are so important. In so many ways, words are the world' (White 1995:30). Hess (1998:55) also reminds me that: 'All theory and research reflects the class, race, culture, gender, history, and world view assumptions of the researcher.' This highlights the importance of verifying the stories that I researched with the patients. I asked the question: 'Is this what you meant? Could you clarify what you said? Could you explain what happened in a different way?' Together the patients and I negotiated meaning about the realities of living with a terminal illness.

2.3.9.3 Participatory Language

During the conversations with persons living with terminal illness, I aimed for what Heshusius calls (1995:122) 'participatory consciousness', that is where egocentric concerns do not stand in the way, but will be free to develop a 'kinship of Selfother' (Kotzé 2002:5). The *self* and *other* are not seen as separate entities, together they make up the whole, one is co-dependant on the other. To achieve this, an attitude of openness, compassion and receptivity is required. It changes from knowledge about another to knowing with the other. 'The fullness of knowing occurs in a

conversational context where there is a fullness of participation in those seeking to know' (Hess 1998:55).

In conversation with the other the perceived boundaries between the knower (doctor/nurse) and the known (the patient) are challenged, by embracing the patient's experience of illness with an attitude of profound openness and compassion. Through this *self/other* relationship the knowledge regarding living with terminal illness of both the doctor/nurse and patient are merged to create shared meaning. Often meaning is thus clarified and created in conversations with patients. For example, the meaning of pain is usually only discovered when pain areas are identified together, the type of pain is described and the intensity, quantified. Pain does not then take over the whole body; pain becomes pain in the back or tooth-pain (see Appendix B). Through sharing, listening and participating in the pain experience, the therapist and patient together discover the meaning of the patient's pain and can co-construct new meanings that are more useful. Back pain can, for example, be treated with medication or radiotherapy and a dentist could deal with the tooth pain. The pain story then changes from an all encompassing, uncontrolled pain, to a pain that can be dealt with and contained.

I am, however, reminded by Bons-Storm (1998:18) that nobody has privileged access to 'the way things really are', but an attitude of openness and receptivity goes a long way to helping us understand that which is being expressed. The meaning of the story of 'The Lost Mother Moon' is different to all those that hear it. It would depend upon each person's level of participation in the story. Does my interpretation of the Mother Moon being a feminist, caring God or God of Grace have significance to you? Has your community been an invaluable support during difficult times or do you maybe find it difficult seeing beauty because of hurt or hard times? Asking for clarification and listening to stories opens doors to wonderful worlds of different meanings and sacred spaces.

2.3.9.4 *Languaging experiences*

I attempted to do the research conversations with curiosity and wonder so as not to prescribe thoughts or make my own truths obvious, but I encouraged people to talk about their experiences and together we discovered new meanings. I find comfort in the words of Wylie (1994:48): 'We don't need to teach people anything new, just help them reach stuff that's already there.' I do believe that languaging about experiences are crucial to making meaning of that experience and necessary to help the person understand and optimise the experience. Arthur Frank (1991:15) says:

I have needed talk to express the changes that illness has brought to my life; through talk I continue to work out new ways of living with these changes. Critically ill persons need talk that recognises all that they are experiencing. They need talk not only for themselves, but also for those who are not yet ill.

Speaking to patients has opened many sacred areas of wonder and amazement that have been closed to me as a professional. These sacred areas include communities, religion, families, stories of abuse, neglect, poverty and crime and stories of courage and meaning-making, of reconciliation and forgiveness. Many of these areas have been closed because of dominant scientific ways in which I have been trained to think about people's reactions and experiences. It has been a wonderful world of discovery, such a freedom not having to know the answers.

Inviting patients to language experiences through the narrative practices of questions, deconstruction and externalisation, the patients expressed that they found meaning in their own experiences without me trying to give answers. Why was I so programmed to find truths and solutions? Why did I have to fear being wrong and what would the punishment be? What dampened my curiosity to know people's stories and how come I could have thought that I knew the answers before clarifying them? Asking these questions highlight the fears that I have had of not being in control and not being seen as the expert. However, the narrative practices have allowed me to risk not knowing and this has opened doors to wonderful discoveries and new knowledges. Asking about the nature of Margaret's personal God in Chapter 3 was a very difficult thing for me to do. When Margaret and I started the God-talk, I was plagued by uncertainty and inadequacy, but together we discovered Margaret's 'holy time'.

2.3.10 God talk

This section relates directly to one of the research curiosity that I investigated; how does spirituality contribute to meaning-making of terminal illness? The way patients have talked about God and their illness and the significance of their specific relationship to God has challenged the patient's, as well as my own ideas.

I have been particularly interested in the conflicting stories that I have heard about what I perceive to be a dualistic God. The God that punishes and who prepares the patient for life here after (by testing to see if patients can cope with suffering and pain) and the God of caring and nurturing, the God of Grace, that all the patients I have talked to know. (I will deal with this theodicy question in Chapter 3) The discovery and identification of the dualistic God, the patriarchal/grace dualism, has been an important part of the research curiosity.

2.3.10.1 The patriarchal God

We are emerging from a modernist society, one that relies on scientific proof, on finding the truth, that knows wrong from right and aims to achieve absolute answers to questions, a sort of dead end, an either/or. Questioning patients about the God that punishes people with pain and illness and who teaches very valuable life lessons revealed the patriarchal God of Christine and Gafsa in Chapter 4. It is the God that is feared if your life has been 'sinful'. The God I was taught about at school fitted this mould; He was a patriarchal God, a God of law and order, of right of wrong, of sin and redemption, He was all-powerful omnipotent God. He knew when I didn't do my homework or thought bad things about friends and forgetting books at home was sinful. It was the God I was taught about at school, but not the God I knew.

2.3.10.2 Understanding Grace

The God I know is the God of nurturing and caring, the God of love and forgiveness, the God of warmth and beauty, the God of Grace, the Moon God in the story of the Lost Mother Moon. This is the God who protects and comforts people, one who nurtures and holds you, who keeps you warm. It is the God that carries you in times of illness and gives the opportunity to make choices and use these opportunities. It is the God who is comfortable with shades of grey and with questioning.

The challenge that feminist theology gives us, is for us 'to let go an understanding of God that relies on a judgemental, demanding father figure, and which talks of suffering as the result of our fathers [or our mothers'] inability to get things right' (Nicholas 1998:168). This view is an injustice and is unfair to terminally ill patients, they do not deserve their illness and suffering and a just, fair, caring and nurturing God, cannot be held responsible for such injustice and unfairness. Riet Bons-Storm (1996:130) suggests that '[w]hat women [people] need is the Grace and courage to look at themselves as persons made in the Deity's image' and worthy of God's Grace. Once people can believe this, all those marginalised by modernistic patriarchy, will notice that they are embraced by the God of nurturing and caring. Riet Bons-Storm (1996:133) argues in support of this 'that women and men can only be liberated and made whole if they dare to risk taking 'Grace' seriously. For Grace is amazing; it distorts all patriarchal power relations, and has the power to make things change.'

2.3.10.3 Languaging Grace

'Several authors have written about the silences of women under Patriarchy' (Bons-Storm 1996:11) and in the same way marginalised people have been silenced. We need to find ways to rewrite this history of women and those marginalised and explore and explode the patriarchal myths (Isherwood & McEwan 1993:21). 'Women must speak out so that our reality can be heard and placed in the language of our society' (Isherwood & McEwan 1993:108), and so the terminally ill (being part of the marginalised) also need a forum to reclaim their voice. Feminists have taken the leading role in reclaiming the voices of those marginalised because of culture, education, race, illness and disability, we need to take cognisance and make a stand against this discrimination so that all people can take their rightful place and contribute to making society whole. It is for the benefit of all, as disqualification of women and the marginalised, has led to the undervaluing of more than half of humanity by defining some as being superior (Isherwood & McEwan 1993:21). The research provided a forum for the voices of patients, being marginalised by terminal illness, lack of education, poverty, culture and race, to be heard.

2.3.10.4 Grace is inclusive

By taking grace seriously, I believe we would be inclusive of all people and encourage behaviour that allows resisting, empowering, nurturing and liberation (Miller-McLemore 1998:181) and bringing about transformation, which would benefit all. This is also applicable with the terminally ill. They, too, have the right to resist the control of scientific knowledge and to be empowered to make choices about their care. The terminally ill also have the right to accept nurturing from their families and communities and to be liberated from oppressive dominant discourses based on so-called truths. Accepting the right patients have to resisting, empowerment, nurturing and liberation brings about a transformation of the relationship between the patient and the professional, making it a partnership instead of an authoritative relationship on behalf of the professional.

The post-modernist state is not an ultimate goal or aim, its goal posts are continually changing and adapting to changing environments and cultural conditions. We need the scientific side of Medicine, the diagnosis, the treatment and the discipline that goes with that. We need precision that does not accept anything but the best in care. We also need the warmth, nurturing and caring that is part of respectful, comprehensive care with the terminally ill. This kind of care offers growth, transformation and making meaning of illness. Science and grace become one, it becomes a

sacred science, a science that gives equal prominence to both science and the acknowledgement of the sacred spaces of an individual, aiding the discovery of the God-Self.

2.3.10.5 *The Light*

To celebrate the prospect of the union or coming together and tolerance of all, I wrote the following poem and include it as part of the research (Gergen 2001). It is my way of paying homage to a beautiful, diverse world, which, when treated with honour and respect, exposes beauty and light promoting mutuality in relationships.

The light

The moon

a large soft, squashable balloon

available to all

reconciling full of mystery, the unknown

inviting, captivating, ever adapting

containing:

an African woman carrying water,

a rabbit,

an old woman with children

or maybe cheese?

Predictable, but always different

- Sometimes there, sometimes not –

with a promise of returning...

never overpowering or overshadowing

reliable

always gentle, never harsh

a guiding light in the dark

influencing the tides

the cycles of growth

sustaining the rhythms of life

The God of Grace

The African sun

Round and defined

Strong, relentless

Predictable

Unheeding

Shimmering energy

Powerfully controlling and influencing

Life and death

Light or dark

Heat, cold

Punishment

Law and order

Redemption and sin

Present or absent

Omnipotent

The Patriarchal God

Together they contain the promise of:
empowerment to
resist,
nurture and
liberate.

2.4 Conclusion

We often cannot bear to listen or the stories of other people, because listening confronts us with the suffering of others and ourselves to which we will have to attend. Scientific methods have helped to protect us from this pain, it has helped us to objectify and classify the pain of others making it easier for us to cope with. 'To listen deeply requires that we can bear the anxiety in patients and in ourselves that wells up when issues of death, annihilation, separation, fragmentation, abandonment, shame, guilt, dependency, impotence arise. We "just" need to tolerate our own anxiety in the face of sickness to allow ourselves to stand or sit still for a moment and to feel' (Stein 1998:214).

In Chapter 3 and 4, I tell the stories of patients I had conversations with over a long period of time. I believe that 'To feel heard and understood is perhaps the most precious gift in life' (Stein 1998:215).

3. COMMUNITY NURTURING MEANINGFUL LIVING WITH TERMINAL ILLNESS

3.1 Introduction

The patients I work with range from the extremes of the materially rich to the materially poor. The rich live in spacious comfortable large houses in tree-lined streets and the poor live in shantytowns or municipal 'train-houses' or in wooden and tin 'homes' in the backyards of 'train-houses' houses. The 'materially poor' are exposed to the veracity of all the elements. Paarl experiences extremes of heat, rain, cold and wind.

The majority of the patients are 'poor'. I would estimate, that according to our patient profile, 90% would belong to this category, however, we do not spend 90% of our time with these patients. In the more affluent communities we usually engage the services of hospice volunteers to help bath the patients and to be a companion. Often 24 hour nursing care is also required and the Hospice Nurses visit very regularly, if not daily. Working within the 'poor' communities, I, like the medical student (1.1.4), also question wealth. When considering community support and caring, I started to realise that 'these [the materially poor] people have so little and yet so much. What they have is different from what we have, if we indeed ever had it.' What has brought about the split between people and community?

This split of people from their communities is a symptom of the dualistic split between the soul (person) and the body (the community as the body of God). Some feminist theologians have described the world as God's body (Stuart 1996:24) and 'reflect on the communal nature of creation' (Gelder 1996:31), 'the connectedness of all things in the cosmos (Raphael 1996:147) and community, in Christian feminism, is described as 'mutuality, interrelatedness and compassion' (Gelder 1996:32). Isherwood (1996:1650) suggests that 'God and the world are in process together.' Has material wealth replaced the body of God? Money attempts to buy 'mutuality, interrelatedness and compassion', but it does not succeed, wealthy patients are often lonely and very needy regarding nurturing and caring and are very demanding of hospice resources. (See feminism, theology and feminist theology in 1.3.1.10-12; 2.3.1 and 2.3.10.)

'Wholeness is a central theme in feminist theology; in terms of wholeness of the individual, integration of the human community, health of the planet, [and] inclusivity of language about God' (James 1996:233), is about wholeness. Lucy Tatman (1996a:218) said the following, which is

based on the work of Carter Heyward, 'because right relations are those which are mutually empowering, sin occurs whenever a person or group use or abuse an individual or natural resource for their own purposes, thereby disempowering, degrading and all too often destroying who or what was used.' I so often wonder about the mechanisms of achieving wealth, which disempower, degrade and destroy the resources that are engaged in the accumulation of wealth. 'We have to learn to recognise the interconnectedness of all matter and the pain and damage caused when the interconnectedness is denied or ordered in wrong relationships' (Stuart 1996:24) to achieve wholeness of body and spirit. Melissa Raphael (1996:210) describes Christian theology, which includes its feminist forms, as requiring 'divine-human reconciliation – mending the rift caused by sin as the precondition for redemption.' Acknowledging and nurturing the interconnectedness between God/Spirit and body in the God-Self brings about wholeness and a connectedness with the person and his/her environment and community. This wholeness, the feeling that connectedness with the community brings, is the main focus of this Chapter. (See 1.4.1.2 and 2.3.10)

I invite the reader to join me in honouring sacred spaces and sacred communities of the patients I have had encounters with, which gives them and me the opportunity to voice stories of terminal illness. The stories are sacred stories as they are about the experiences of life. I found it painful writing them. They are stories of sadness, beauty, dying and living. They are as fragile as a pansy shell and contain all the attention to detail and uniqueness of each shell, and like precious pansy shells they can easily be broken or damaged by carelessness. I invite the reader, therefore, to tread gently and with circumspect. Don't be too hasty - be patient and linger. Turn over the shell, look at the detail and I trust that you will journey with me into a world of sacred spaces where together we can honour and acknowledge the courage, conflict and opportunity of living with a terminal illness.

The research curiosity assisted me to constitute realities around spirituality, illness and community with terminally ill patients. These realities are woven into the stories as we co-created *communities* with others and as we lived and experienced our spirituality.

In this Chapter, I introduce the reader to Emma and Margaret, women who have opened their hearts and lives to others and in this way experience the caring and nurturing of God through the communities of which they are part. Their communities have become intertwined and self-sustaining.

Amongst the material poverty, I have not found it difficult to see the flowers. Flowers are symbolic in so many ways. They are a showcase of God's Grace and are, therefore, used for celebrations and funerals. They are used as a symbol in recognition of the God-Self in the giver and the receiver and for anybody who may appreciate their beauty. I have found flowers everywhere and will share them with the reader.

3.2 Lupines and Hyacinths

Emma is a beautiful young girl of just 24, with plaits in her hair and a big white smile; her slim body is always neatly dressed in a pair of jeans, 'takkies' and jersey. She lives in a crowded street where the houses are close together. Many are wooden, and tin shacks stretch onto the tarred road. There are a lot of men hanging around doing very little except for talking lazily to each other, smoking and maybe, playing dominoes. Dominoes is played very loudly. The pieces are all held in one hand and then, the appropriate one is crashed with force onto a wooden board. It is a serious game and not much talking is done when playing. There is not much other noise in the street because it is all muffled by the loud rap music coming from a portable radio. The streets are relatively clean; old women are always busy sweeping and old men sit on chairs in their fenced off properties.

When I first looked for Emma's house, I had the wrong number in Lupine Street. It was not a problem, there were many people to help, they all knew Emma. One young woman got in the car to show me the way. Emma's granny was sitting on a chair in the sun reading a library book. The grandchildren go to the library for her. 'It is too far to walk, my legs won't carry me anymore.' Emma came out to the car, 'the house is too full, I can't talk to you there, everybody listens.' I have known Emma for a while. She at first lived in Hyacinth Street in a comfortable three-bedroom cement and brick house in a neighbourhood that has no shacks and has not only tarred roads, but also tarred pavements. Her mother and stepfather sold the house to her cousin as they were both unemployed and were in financial trouble. Both her parents, as Emma chooses to call them, have a problem with abusing alcohol. 'My mother is two people. In the morning she is the mother who I like, but in the afternoon, I don't know her.' Her mother sometimes uses her illness to get sympathy for herself from others. Emma despises this behaviour, 'illness is not to be used or entertained as a friend.' I am reminded about the Inuit story of the stone child. An orphan child had nobody to love and nurture him so he picked up a stone and hugged the stone close to him. This became the source of his nurturing and it was hard to let go of it. He took comfort in his suffering.

3.2.1 To be free is to live

The main ingredients of trust are transparency, reliability, dependability and honesty. Only by being transparent about my involvement with Emma, by keeping appointments and by being honest regarding the things Emma wanted to talk about, did she begin to trust me. I was trusted with the sacred spaces of her family conflicts, the battle she had with drug dependence and violence and the caring and nurturing that she experienced from her God and her community. Emma has been in jail three times for violence and drug trafficking. We had a 2 hour long conversation around my kitchen table while drinking copious amounts of tea. I asked Emma how she would like to talk about the illness and assured her that I would follow her lead in this conversation. As Emma speaks Afrikaans, for the purposes of this research, I have taken the liberty to translate some of the taped conversation into English, but in such circumstances it's hard to be 'true' to the person.

I completed my matric in jail, but it is not a good place to be in. I don't ever want to go back again. It is hard for me to be locked up; I hate not being able to move around where I want to. The illness has also caged me in. I am now dependent on people who I don't want to be with. I had a battle getting off drugs. In jail I took anything that I could lay my hands on and either smoked or drank it, and stuff was not difficult to get.

I have learned to live since I got out of jail. Nobody can tell me how to live, I have a choice and I have chosen to live every day as if it is my last. I can't waste time on being depressed; I don't know how long I have left. My mind and body are two different things and when my body started to influence my mind, I had to find ways to stop it. Then I read or listen to music. Sometimes I am scared to allow people to see how I am feeling when I have pain. There are times when I don't like sharing stuff. I don't like to be treated differently now that I am sick, I have not changed, and it is just my body that has changed. I can't pretend to be what I am not, people have to accept me for who I am.

After I was diagnosed and the seriousness of the illness became a reality, I said, 'God, come what may, Your will be done.' I can't entertain negative thoughts because they want to make me unhappy. My friends can't understand that I can laugh every day. I have the ability to stay happy and to take people with me. Nobody can stay unhappy for long in my presence.

If I didn't get ill I would have gone to the dogs, my life was in shatters. I don't like feeling dependent and the days when I can keep the Jackal in the cage, I feel good. If it was not for my faith in God, I think I would have given up the fight a long time ago. The days in hospital were important ones to me, I started writing notes in a book and thought about many things. God helps me to be at peace and to stay calm. I feel He is with me, I know He is with me even when there are days of uncertainty.

Being sick has influenced my life positively. I have a different view of life. I am at peace, I am peaceful Emma. I thank God because I didn't like the old Emma. I far

prefer this Emma. I have managed many things, so what is stopping me from managing this illness. The young children listen to me when I speak to them. I have learned that you don't need to shout at children, if you do, a child won't respect you. My parents and aunts did not talk kindly to us as children, but I have learned differently.

I used to blame my parents for everything in life, but if I examine myself then I know that they are not responsible for what went wrong - I am. I have had time to rewind my life and to look at where things went wrong and I decided to correct the wrongs I did. It is a painful process but the only way; I can't keep escaping responsibility. I walked over people and didn't care; I now realise that it was unnecessary. I now also realise that I was the loser in the end.

I now live only for God and one day at a time. I know that if it is God's will, then I will live for a long time, it does not help wasting time on thoughts that can't change anything. At present I am feeling fine and I am functioning. My younger sister needs me; she is my inspiration to carry on living. My mother has many things worrying her. I tell her that I go on my knees and ask God to take my problems from me and then I feel free. I can even die now; it will not worry me. A person must feel free to live.

3.2.2 Keeping the Jackal fenced in

Emma created the metaphor about the sly Jackal to deal with the illness and together, we make all sorts of plans to keep him safely locked behind a fence. We have had to find rocks to strengthen and anchor the fence and we have had to experiment with these.

Emma sees her cancer of the colon that has metastasised⁵ to her liver and lungs, as being a Jackal. A Jackal that is caged in and she has the lock to the door. Sometimes the Jackal is sneaky and tries to get under the fence. She is very vigilant at these times and works hard at keeping him locked up. Emma has externalised her illness as a Jackal. Externalisation is the separation of the problem and the identity of the person (O'Hanlon 1994:21) and in this way the problem is disempowered and no longer speaks about the only truth around the patient and made space for expanding alternative stories to the dominant illness story (see 1.6.1.4). Together we investigated ways in which Emma could keep the Jackal caged. She reads and listens to music, she sometimes does not 'share stuff', laughs often and her faith in her God brings her peace.

3.2.3 Fencing in pain

When I was asked to visit Emma in Hyacinth Street, I was told that she was a very aggressive angry young woman, who would not always open the door for visitors from the Cancer Association

⁵ Metastasis is when the cancer has spread to a distant area either through the blood or lymphatic system. In Emma's case it means that colon cancer cells are growing in her liver and lungs.

even although they knew she was home. Emma had a lot of pain and they needed hospice to help with pain control. Our first meeting was very cordial and quite formal.

I asked Emma about the pain and I told her that nobody except herself could judge the pain and, therefore, nobody had the right to prescribe pain medication, she had to prescribe her own medication and take control of it herself. She was the expert of the pain. Frank (1991:138) says that because we can choose how to experience illness, we can be more than victims. As I mention in 2.3.1, Frank (1991:138) says that because we can choose how to experience illness, we can be more than victims. Choice can manage to turn the worst circumstances into an experience of value.' Only Emma would know what the right dosage was and what medication suited her best. I showed her a pain form which I have designed (see Appendix B) and intended to help patients gain some degree of control and choice over pain control methods through the externalisation of the pain. It is the patient's form; they keep it and they can do with it what they like. The form is designed to identify the pain area. The pain is, therefore, identified as not being in the whole body, but located in the abdomen, back or shoulder. We then talk about the type of pain.

I have drawn pictures to identify the type, it could be burning, aching, stabbing, sharp, cramping or throbbing. I explained to her that each pain could have a different cause and would therefore need a different medication or treatment plan. For example, a cramp we could treat with an antispasmodic or diet control, a throbbing pain may need antibiotics, and a sharp pain may have nerve involvement and may need a different medication to that of an ache. Marking the pain and pain type helps to externalise and deconstruct the pain, making it easier to manage but also to establish the reason for the pain. We then looked at the times when the pain was worse and when it was better. If the pain is less in the morning she would need to take less medication than in the evening.

The aim with pain control is not to be totally pain free. We would aim to be pain free at rest, then with sitting and finally with walking. It is not an all or none, an either or, situation, it becomes a process that is a perpetual state of arrival. This pain control method therefore includes hope. It is hoping to have less pain. I have also included a daily record keeping of 4 hourly pain medication control that is titrated against the level of pain experienced. This acknowledges the bad pain with unhappy faces and less pain or painfree times with happier and happy faces. Apart from fulfilling the role of externalisation, this helps the patient to remember the times when the pain was not so bad. We also explore pain control methods that have previously worked. Pain takes over your whole body and all of your thinking, it is all encompassing, identifying less pain times is, about

hoping. Emma talked about how pain curtailed her freedom, how it kept her behind a fence and a lock. Deconstructing pain gave her the opportunity to get on the other side of the fence and to keep pain and the Jackal locked up.

As a nurse I am not invited into a patient's home for Therapy, but I see the interactions that we have with our patients as being 'therapeutic'. It is entering into sacred spaces and having conversations that are 'sacred encounters' (Griffith & Griffith 2002:viii) and are, therefore, therapeutic conversations. Dealing with pain, which we could externalise and give Emma self-agency over created a non-threatening, non-expert encounter that made it possible for me to be welcomed back into her home. The door was always answered when I came.

3.2.4 Finding rocks to strengthen the fence

Emma was very apprehensive to leave Hyacinth Street and go to live in Lupine Street. That is where she was previously involved with drugs and 'it is very hard not to be "stoned" when everybody around you is. It is hard listening to the 'rubbish' that they talk all day. My life is too short, too valuable, I can't sleep it away, there is still so much that I would like to do.'

We talked about the things that kept her away from drugs and kept the Jackal in the cage. She enjoyed talking to the young children and enjoyed reading bedtime stories to them. She also helped the high school children with their school projects; they fought about who Emma would help. She enjoyed listening to music, gentle music at times and had to make it quite loud to drown away the rap. Emma can also use her mind to escape her environment, she learned that trick in jail. Reading also helped her escape. I started to lend her the Harry Potter series of books and those she finds excellent for the purpose of escaping when she needs to. She uses morphine regularly 4 hourly now. The morphine is perceived as a big rock keeping the Jackal inside and she visits the people of Hyacinth Street. We then spoke about finding more rocks to strengthen the fence.

3.2.5 Day-care strengthening the fence

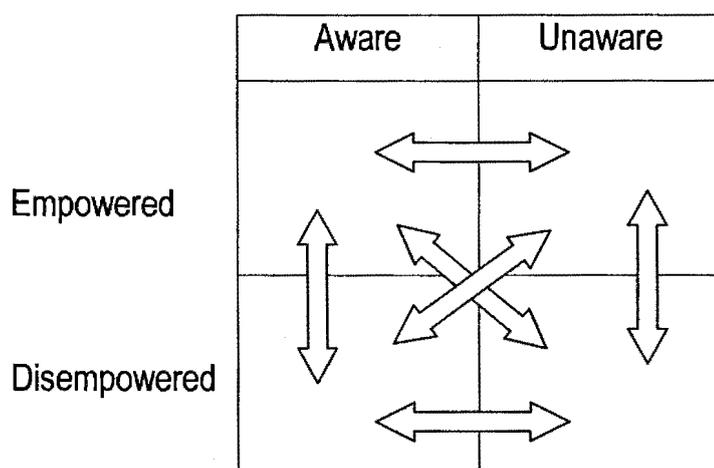
I introduced Emma to the Hospice Day-care. It is a weekly meeting of the ambulant terminal patients. They are fetched by volunteers and brought to the hospice building. Here they sit in a circle and are supported by cushions and nurtured by crocheted blankets over their knees, warm soup and cake. The staff visits them and the volunteers greet and chat to the patients. Often they

end up playing bingo and some of the patients may decide to play dominoes. It is a happy place, a community of sharing and caring with no expected reward. We all leave with our cups overflowing and lunch boxes filled with sweet and savoury things, with stories of courage and hope. We acknowledge the sadness of a friend dying, we say a prayer and say thank you for what he/she may have meant to us and send our love and light with them on their way. Day-care is not a sad place, it is a place of joy in community, a place that gives the opportunity of sharing and caring with others, it is a place of finding God within the community and within the self. It is where the God-Self is celebrated. Emma does not miss a day-care gathering; this is a hefty rock keeping the Jackal behind the fence.

3.2.6 Empowered and Aware

While taping and typing Emma's story, I realised that she had such an important story to tell. It is a story of hope in hopelessness, of meaning-making of illness and celebrating life. Also one of realising that doing hope is the responsibility of the community and that 'matters of life and death are too hard, too onerous, too painful to do alone' (Weingarten 2000:399), I asked Emma if she would like to tell her story on the local radio station. She was very excited about the prospect. I got her permission to give the transcript of her story to Uncle Karel from KC radio station to read. He phoned me and a date was set for two days hence.

Kaethe Weingarten (2000) designed a three-dimensional diagram two-by-two grid that she labelled 'Typology of Witnessing.'



Based on this typology of witnessing grid, I reflected on Emma's life. Before she knew about her illness she was disempowered and unaware. Having the knowledge of the illness she was aware and disempowered. Through empowering her with pain control information and telling the community her story, her life got new meaning, she was meaning-making of her illness story. She

changed the chaos story into a quest story. These positions can change over time and different illness stories are in different boxes. Through talking on the radio, Emma's boundaries of support expanded beyond the family to a community of people who could care and be 'containers into which she could "pour" the stories of her suffering' (Weingarten 2000:400). Antjie Krog (1998:143) quoted Archbishop Desmond Tutu, 'A person is human precisely in being enveloped in the community of other human beings, in being caught up in the bundle of life. To be ... is to participate.' Emma was participating in the community, she was sharing her stories and experiences and we were networking a community of concern (1.6.1.9). Arthur Frank (1995:17-18) says,

The idea of telling one's story as a responsibility to the commonsense world reflects what I understand as the core morality of the postmodern. Storytelling is *for* an other just as much as it is for oneself. In the reciprocity that is storytelling, the teller offers herself as guide to the other's self-formation. The other's receipt of that guidance not only recognizes but *values* the teller. The moral genius of storytelling is that each, teller and listener, enters the space of the story *for* the other. Telling stories in postmodern times, and perhaps in all times, attempts to change one's life by affecting the lives of others.

2.2.7 Broadcasting Emma's story

The whole of Lupine Street knew that Emma would be on the radio. Day-care was also informed and so the story spread. Emma walked tall into the radio station, she had been thinking about it and knew what she wanted to talk about.

Uncle Karel is a man in his 60's. He works as a volunteer for the radio station. His wife, Auntie Rita, joins him on the programme; she reads a story to the small children. Schalkie sits behind the controls and also does not earn a salary, but loves his work. Uncle Karel is very attentive and respectful of Emma and her story and assures her that he would not ask any questions that she does not know about and that she has not given permission for him to ask. This made her feel safe and was part of ethical practices and I think, was responsible for Emma's spontaneity and feeling 'free' to talk. The studio looks out onto one of Paarl's main shopping centres and people are walking about doing their business, life was continuing as normal.

I introduced Emma to the public as a beautiful, 24 year-old woman with plaits in her hair and a broad white smile, a confident person, who knows what she wants and who has the experience of somebody who has reached a great age. I thanked Emma for what she has taught me about the preciousness of life and living. On Uncle Karel's prompting Emma started to tell the story of her illness and the wake-up call that she experienced.

She told about the God of Grace that she knew helped her cope with the everyday; that helped with her pain and breathing and kept her safe and free to live. Neither Uncle Karel nor myself did much talking for the next 1½ hours. Emma told the young people about how special life was and how 'uncool' it was to risk your life by having sex without a condom. She told about how dagga numbs the brain and makes one disinterested in life and learning. How dagga just made it easier to go onto hard drugs and how these changed her personality and she became aggressive and violent and landed in jail. She lost her sense of caring for others. She then told about this caring being reawakened by the staff in the hospital, by Hospice staff and volunteers and by the other patients. She started caring for herself like others cared for her and then she started caring for and about other people and the children in her street. Throughout this process she said that she experienced God as being close to her, she felt God's warmth, caring and nurturing.

Was Emma experiencing God through the hospice community, her church community and amongst the children in her street? Was she experiencing God within herself? Was she getting to know her own God through the relationship with others? I also kept wondering how she managed to take 'Grace seriously' when she has always been exposed to the harshness and authority of Patriarchy in prisons and amongst the gangs? I experienced that Emma found the 'body' of God in the community and this was bringing nurturing and caring, wholeness. The gap that she felt between herself and her God during the 'wild' time was getting narrower (3.1).

3.2.8 Cheeky is survival

Some of the answer of how Emma's God-Self is made whole and how Patriarchy is contained is illustrated by the discussion Emma and I had. One of the Hospice volunteers made the comment that Emma was getting 'cheeky'. I was wondering about this and so I asked her while we were driving in the car one- day.

Elizabeth: Emma, do you think cheeky is a good or a bad thing, what is cheeky?

Emma: Elizabeth, cheeky is about survival; cheeky is survival. Cheeky is a good thing, without cheeky I would not have survived. Cheeky is also about honesty; it is about saying what you mean and not allowing somebody to shunt you around. I don't have a problem with cheeky. I prefer people who are cheeky, they at least have an opinion and stand up for this opinion. Cheeky is not about being insolent. Insolent is when you are rude and you stick your nose into somebody's business, it is about interfering where you don't belong. Cheeky is also only an issue for those who want to control you; cheeky is about power and control. They want to keep you in your place and control you, but I think to live is to be free, I don't want to be controlled. I want to be free.

When we returned to Lupine Street, we were greeted as celebrities. An old woman came to me and gave me a hug and thanked me for allowing Emma to tell her story. They all listened and many people told about getting tears in their eyes and I was very moved by the sense of community and sharing that occurred with Emma's story telling over the radio. This episode has been a very secure, large rock in keeping the Jackal locked away. It has given Emma recognition and status but more than that, it has enlarged the community of concern, as so many more people are now aware of her struggles with the Jackal, drugs, violence and pain and can be supportive, nurturing and caring of her.

3.2.9 Negotiating 'time-out' practices

This is not the end of the story. One Tuesday I got to Lupine Street at about half past nine. Emma met me at the car. Tears welled up in her eyes.

My tuberculosis (TB) results were positive; I have a very severe form of TB. My mother and father had had positive sputum tests and did not go for treatment. I told them that my resistance is low and that I can not afford to get TB. They did not bother to do anything about it. They have never really cared for me; they have never gone out of their way for me. I don't know what it is like to be loved by a mother. This is so hard. I am so angry with her, I feel as though I am losing control. How can this be happening and it is because my mother and father don't care about anything. I gave them R600 last Thursday. Today [Tuesday] there is no food in the house. The children went to school without food this morning; I drank my morphine and took all those TB pills on an empty stomach. They used the money for alcohol. They have been drunk since last week. I can't stay here; I can't face my mother.'

I had many patients to see, so I asked Emma if she would like to drive with me while I visited the other patients. She agreed to this and so followed a morning of at first, tearfully unpacking the stories of parental neglect and looking at stories that helped her previously cope. We deconstructed (1.6.1.5) parental neglect and then discovered unique outcomes (1.6.1.8). We discovered that walking away and having 'time-out' had helped and that not blaming, but also accepting responsibility, had assisted her in getting out of sometimes a violent and abusive situation. She then recalled how much happier she was in the community at Hyacinth Street. She had lots of friends there and they had asked her to come and stay. Her parents' drinking was not so difficult to cope with in Hyacinth Street as there was always a quiet house to go to or a friend to talk to.

After stopping off for brown bread and avocado pear, which we shared in the car, we drove the Hyacinth Street, but there was nobody at home. Driving down the street, we frequently had to stop

to talk to a familiar person. They all greeted Emma warmly and asked when she would visit. One man gave her a loose cigarette out of his top pocket and we shared some of our bread and avocado pear. Our next stop was another patient, Margaret. She does not live far from Hyacinth Street.

3.2.10 Expanding the community and nurturing

We then visited Margaret, who features in the next story. Margaret had listened to Emma on the radio and especially gone to meet her at the day-care. Margaret had not been attending day-care as she helps at a soup kitchen for street children. Margaret welcomed Emma into her home and gave her a big hug. Emma told her story and Margaret listened. Margaret praised God for bringing Emma to her and assured Emma that they would include her in their prayers and would include her in their community when she moved to Hyacinth Street. Margaret said that her church group would hold and care for her now, particularly when her physical need became greater. She also thought that it would be a good idea to live at Hyacinth Street because her friends were there and it was closer to get to the clinic every day for her TB medication. I was humbled by Margaret's reaction. She had only met Emma once and she herself had a terminal illness. I wondered if Margaret was not concerned about getting TB from Emma? Even if this was the case, she certainly did not let Emma know. Is this the Grace of God that is present in a community of concern?

Later that day, I picked Emma up from Lupine Street and we drove to Hyacinth Street. We entered the house where Emma and I first met. She pointed at the roses that she had planted and nurtured in the garden and which had started sprouting. The lounge did not have any furniture except for one chair, which her 'real' father's mother sat on, and there was a television on a wall unit blaring forth the afternoon soap opera. I was introduced to her granny, her aunt (whom she had met up with in jail) and her cousin (Janice), the owner of the house. They knew why we had come, and yes, Emma could stay. Emma is family and they have a responsibility to her and they love Emma. They don't have much, but what they have they will share, Emma won't be hungry. Janice, who was not older than 30 said, 'I looked after my father when he had cancer, I carried him to the toilet. I have no problem looking after Emma. She is very light and she is my family.' Through discussing the situation openly, both Emma and Janice were empowered and aware (Weingarten 2000) of the situation, they could make a choice and decide what to do.

The rest of the conversation went about how to not offend and anger Emma's mother. How would they plan it so that she did not feel rejected by Emma? It was decided that Hospice would lend

them a mattress for Emma to sleep on and the closeness of the clinic to get the TB medication would be the motivating factor. I was astounded, in the morning Emma was so angry, by six-thirty in the evening Emma had hope for a better day. What brought about this hope? Is it the Grace and the light of God, the power that exists in the community of caring and nurturing, the community of concern?

3.2.11 Giving and Receiving

Afrikaans has such a descriptive word for the type of community that I would like to speak about. It is 'gemeenskap'. It is more than community; it is a community of concern, a community of caring, of relationality or even closer, a community of being, it is a way of being in community with other people. I talk about community of concern (Freedman & Combs 1996:238; 1.6.1.9) as it closest to my idea of 'gemeenskap'.

What is important to me about communities of concern is the involvement of the community with one another. It is the ability of individuals to give of their time and energy⁶ to others without the offer of an immediate reward. It is also the ability of people to allow others to spend time and energy on them without being indebted or having to reciprocate. It makes me think of a story I read and remember from my school Afrikaans setwork book. I think it was entitled, 'Flowers for Bella'.

Bella and her friend always give each other gifts. Bella would give her friend a cake in a tin and then the friend would return the tin with sweets in it. To say thank you for the sweets, Bella would give her friend a plant and so it continued. When Bella died, the friend thought she had won; she was the last one to give, she put flowers on Bella's grave. But it was not to be, Bella won, she left her friend something in her will.

This is not the kind of community that I experienced with Emma, the Hospice volunteers, Uncle Karel at the radio station, the people of Hyacinth Street or with Margaret. This is a community who has very little materially but is wealthy in community spirit, in caring and nurturing, in experiencing and expressing the God of Grace. Emma's story is not an isolated incident, it reminds me of Jacobus and Fred.

⁶ Energy, I see as encompassing nurturing, caring, love, involvement and concern.

3.3 Orange-yellow asters

Jacobus a 79 year old bachelor, who lived with his two spinster sisters, Ellie (82) and Martha (91). He had cancer of his prostate that had metastasised to his back, which had left him paralysed and incontinent of urine and faeces. He needed assistance with eating, turning, bathing, dressing and keeping him dry and comfortable. If Jacobus's environment was not known, this scenario, from a medical point of view, would be considered a nightmare. Jacobus and his sisters lived in Waterbok Street. The 'bokkie' streets are well-known as a gangsterland and also have young men hanging around the streets. He lived in a small house with 2 bedrooms, a bathroom, kitchen and lounge. You have to walk sideways through the lounge to get to the bedroom as the furniture is so close together. The street is full of children playing marbles and the old men sit on chairs at the garden gates and are a comforting familiar sight when visiting patients. The children run to the car when I stop, and they peer in and flatten their noses on the windows. Some may ask for money or sweets. Getting out of the car I have to be careful where I tread as the street is full of papers, peels and tins. I greeted the children and locked the car. I open the garden gate and walk into a well-swept pathway with orange-yellow asters growing on either side. The curtain moved and the front door was opened. I was greeted with a 'Good morning, Sister. We are doing well.'

There were always people in this house, neighbours, a niece is visiting from Cape Town or the 'sisters' from the church were often there to visit. Jacobus was usually propped up on about 5 cushions. He wore stripy pyjamas and pink sheets were neatly turned over just below his chin. There were orange-yellow asters in a vase next to his bed and his medication was neatly lined up on the table together with a jug of water and a glass. A chair was brought for me to sit on. All the caregivers, Ellie, the neighbour, his niece and nephew joined us in the room. Jacobus was smiling; he had a sparkle in his eyes and assures me that he was well. 'I am fine, Sister. I have no complaints. I don't have pain, I am sleeping and eating well.' We discussed pain control, discussed pressure care and the possibilities of either a nappy or a catheter for incontinence. I am thanked profusely by all for coming and 'When will we see you again, Sister?' Just before he died, I was called to say good-bye. All the family was there and all the neighbours were in and out of the house.

3.4 A sprig of red and yellow flowers

Fred is 69. He has dementia and cancer of the head of his pancreas. When I asked his sister Sarah how she copes, she said, 'But Sister, I don't look after him by myself. The whole street

looks after him. I have buried 17 people in this street.' I wondered if she had attended 17 funerals but that was not the case. 'I slowly paid off the funerals as I could afford it,' she said. When I left Sarah, Fred was sitting outside in the sun on a chair in his pyjamas. A big white hat with a sprig of red and yellow flowers had been put on his head and he had a cup of coffee in his hands. Sarah did not even comment, it was just me witnessing wonder and hope with amazement.

3.4.1 Confidentiality isolating communities

I keep wondering about these sacred communities and I wonder if we as medical professionals do all we can to nurture and protect the communities. Do we know about the sacredness of communities? Does confidentiality, privacy and secrecy, benefit the patient? Confidentiality is a high priority in the Hospice. What does it mean? I am led to believe that it means that a patient may not be acknowledged or spoken about with other people. It is a high priority in our training, You do not discuss the patients with anybody. It is the patient's right to discuss or disclose his/her illness with whom he/she chooses and when he/she chooses to do so. To whose benefit is this? Have we asked the patients about these practices?

I have nursed about 10 AIDS patients. The illness has a stigma attached and people are very frightened about being infected. None of these patients could speak openly about their illness to others. They were 'locked away', and kept out of sight. At one home the patient was not allowed to use the toilet or come into the main house. In another, the patient was only taken into the front room at night when the neighbours could not see her. Another patient was neglected, she was not given her medication and left wet for long periods of time - there was nobody to look after her. One of the patients sent his wife away, as he believed that she cursed him into getting sick or maybe contracting AIDS like his brother. These people live in the same communities as I have written about. What message are we giving the communities through confidentiality and secrecy? Are we excluding the possible nurturing teams and is our attitude that AIDS is a death sentence and not a chronic disease, frightening patients and their families away from care that they could be receiving?

3.4.2 What does Honesty and Truth mean?

Honesty and truth is also one of those issues that are at times questionable. I would like to share a question that was put to me.

Imagine that you were in Germany during the Second World War and your family was harbouring a Jew. The Gestapo came to the door and asked whether there were any Jews in the house. You opened the door and knew that Jews would be sent to concentration camps where they may be put to death. What would you say to the Gestapo? The honest and truthful answer would be 'Yes, I do have a Jew in the house.' How do you then live with the knowledge that you probably sent somebody to his or her death? Should you answer 'No, I do not have a Jew in the house', what impact may that answer have? Is it honest and truthful? Answering the questions of benefit and honesty, truth and confidentiality, has been a constant source of conflict to me. I answer it for myself with the following question. Does the truth or secrecy give life? Does the truth or secrecy benefit the patient? If it does, then it is a truth, in that specific case. Truth is an individual truth and dependent on the context and circumstances. It reminds me of Emma's comment that being cheeky is about survival and honesty. That had certainly not occurred to me in the context that I live. There is, therefore, no universal truth. Secrecy or confidentiality can be dealt with similarly. Does confidentiality not sometimes isolate people and exclude the community of concern?

3.5 Sharing red roses

I first met Margaret when she was visiting Tant Bet (Aunt Betty) who was one of the patients that I visited. I remember her clearly, she is quite a comfortably round woman with a reserve but a calm attentive interest in what was happening. I would find her sitting next to Tant Bet praying, talking softly or just sitting. She was there but not intrusive and Tant Bet's daughter found her a great support. Margaret and two other church sisters visited Tant Bet regularly. Tant Bet's daughter called Margaret when her mother was dying. Margaret held and prayed with Tant Bet and said, 'It was so peaceful, Elizabeth. She went so beautifully, with God in her heart. Her death was a comfort to me, as at that stage, I knew that I also had an incurable illness.'

Margaret is 44, and had been diagnosed with cancer of her cervix stage 4, which is advanced as it had spread in her pelvic area. She is married to Freddy and they have 3 daughters of their own and a granddaughter for whom she cares. We perform a genogram of all the patients. It is a tool that I could not do without. It gives me the opportunity of focussing on other stories, not just the illness stories. While filling in the genogram I ask questions about interests; how come things are like they are; where the patient and family have worked and how long they live in an area; how many people live in the house and what the relationships are like in a home. Margaret's greatest concern is her husband and children and what will become of them. On the wall of her lounge is a photograph of herself and Freddy surrounded by long-stemmed red roses. In her lounge, when

first met, was a bowl of long stemmed red roses. She gave me one of these when I left thanking me for being prepared to support her with the illness.

Margaret is the second eldest of 10 children, her father grafted roses at a nursery and she went to work in a factory aged 14 to help put food on the table for the family. She is one of three women from the church who look after the needs of the people from their street and Tant Bet lived in the street. They visit the sick and have prayer meetings at each other's homes. They also have an outreach programme where they bring the word of God, food and clothes to street children and old people.

3.5.1 Margaret's God-talk

When I first met Margaret, her God talk was high-pitched, loud and a repetitive rhetoric. My instinct was to change the subject and look at more practical physical issues like pain control or an offensive discharge. I took courage by remembering Derrida's use of deconstruction (Sampson 1989:1-17), which is to undo and not destroy and putting words under erasure, finding what is said and not said and remembering that '[l]anguage is reality. It gives order and meaning to our lives and our world' (Andersen 1991:30) and is the medium through which we discover, explain, predict and effect change (Anderson 1997:40) and remembering that there are multiple realities (White 1995a:17), I felt more empowered to find the meaning of Margaret's God-talk. I felt confident that I could listen for the meaning of Margaret's God-talk and find an alternative story to the one I had of high pitched, loud and repetitive rhetoric (1.6.1.7). Margaret would say;

God is good, Lord Jesus, look after us, forgive our sins. It is only through your Grace, dear God, that we can live. Our lives are in your hands, Lord Jesus, be with us, protect us, not because we deserve it, but because you are kind and great. Dear God, you look after your children, I know I have been sinful, I know that I don't deserve your Grace, but you are wise and you know my needs and my suffering. Put your hand on me and all these people, dear God, not because we deserve it, but because you are a God of love and a God of forgiveness. It is only through your Grace God that our sins can be forgiven and we can be with you eternally. Bless this house, dear God. Bless these people, not for my sake but according to God's will. Take us sinners into your house, dear God. Protect us from evil, not because we deserve it, but because of your Grace.

The aspects of Margaret's prayer that constantly stayed with me is her understanding that she is sinful and only God can forgive sins. She is underserving of this forgiveness, but because of God's Grace, her sins will be forgiven. Margaret's God is the omnipotent God, the God who protects us, heals us, controls our lives and forgives our sins. We are weak like children and have no power. We are unworthy.

3.5.2 Expanding the God of Grace

Margaret experiences God as a warm blanket, something that protects her every day of her life. She feels and knows God's caring and protection. This, I saw as a unique outcome (Morgan 2000:51-58) or sparkling events (Freedman & Combs 1996:89). She did know the God of Grace; she experienced the caring and nurturing, but did not feel worthy of God's grace. We deconstructed being worthy and what would make her worthy of God's grace. Who were people she knew who were worthy of God's grace? What did they do to be worthy and why did she consider them to be worthy? Are there things that you do that make you worthy of God's grace? We discovered that the way in which she conducted her life (her caring for her family, the people in her street and her involvement with the street children) entitled her to God's grace. It was those 'self-sacrifice and self-negation' (Tatman 1996a:217) issues that traditionally are seen as virtues that Margaret considered as making her worthy of God's grace. We spoke about the virtues that men would need to earn grace and discovered that they were different from those she needed. Men needed to be liable, earn money, being sober and faithful. Margaret identified that she did not have to live through others, that looking after herself and her own needs could also earn her grace and she identified and named her God-Self: God within her and others. The earning of grace implied seeing God as superior and omnipotent (patriarchal God) and not seeing God as being part of the wholeness of creation as 'God and the world are in process together' (Isherwood 1996:1650; 3.1).

She could call on God to help her cope with her illness symptoms. God was not punishing her with the illness; he was giving her a chance to grow closer to God, to know him better and to spread his word. She sees her illness as a Holy Time, a time to experience God's Grace and spread His Word.

Margaret told the story of how one Sunday she had so much pain that she could not get herself to church. Her family left without her. She was bent double with pain and asked God aloud to help her cope, to ease her pain. At about the same time one of the church sisters got up in church and said that she had a feeling that Margaret was suffering great pain. She asked the congregation to pray for her. Margaret tells of how her pain eased and how a peaceful, calmness came over her as the pain subsided. 'Elizabeth, I feel when they pray for me. I feel so good and happy, I don't feel like a sick person. There is nothing in my body that has to do with cancer, and the pain just goes away.' The change in Margaret's thinking about her value and that she has been chosen to spread God's word, has empowered Margaret to live life fully and to make meaning out of the illness.

I reflect with sadness on the dualism that has come about because of patriarchy. How did it come about that God's grace was not available to all, only to the deserving? Anne Murphy (1996:86) sees the roots of sin as being in the hierarchical way of seeing reality in terms of superior/dominant and inferior/subordinate. Margaret comes from a poor marginalised community where authority and domination was not questioned and labourers were inferior and subordinate. These thoughts have been continued in the realm of Medicine and religion. Margaret, as was Emma, was surprised that I gave the responsibility of pain control to them. It was unheard of that people can control the use of morphine as it is considered to be an addictive and strictly controlled medication. Margaret did not see herself as worthy of God's grace even although she deep down knew that she was. This is one of the injustices caused by patriarchy and injustice that feminist theology makes a stand against.

Margaret said that 'I used to struggle with the idea of healing. Why won't God heal me? ... I now know the answer. God has healed me. Healing is bringing me closer to God and that has happened, my soul has healed.' Is this getting closer to God getting in touch with the God-Self? Is this what dying 'peacefully' and 'beautifully' is about?

Margaret says that she asks God to make her positive and to give her wisdom, to keep negative thoughts from her because negativity prevents her from seeing what God or other people are doing for her. She saw a television programme where a man got up from his sick bed and delivered a positive message to his team-mates, a message of encouragement and looking to the future. 'Don't give up', was the core of the message. The cancer is not in your hearts, it can't take away your thoughts, and it can't change your soul. When she heard these words, she started to cry. Margaret said; 'I thanked God that my heart has not been hardened, that my thoughts were not negative. God must not heal my wound, but everyday he must heal my soul. That he must heal every day. When I open my eyes in the morning and I see a new day, I know it is a privilege.'

3.5.3 A wheelbarrow carries the stones

Margaret describes her illness, unemployment, poverty and family concerns as being heavy stones to carry. She saw our conversation as being useful because unpacking and observing (deconstructing) the stones improved knowledge and understanding of them and she could sometimes find meaning in adversity. She speaks of her community, friends and the church as being like a wheelbarrow that carries and holds the stones. The community is welded together to contain herself, her family and problems. I was wondering what keeps the pieces of the wheelbarrow together, why it does not fall apart. Does Margaret's community outreach act as the

weld? Could her smile, positive attitude and spreading of God's Word also be part of the weld?
Could her acceptance and support of Emma be part of the weld?

3.5.4 Sharing the load

I invited Margaret and her friend, Mercia, for tea. I thought it would be useful to share the illness with a friend, it may help to share the load. I asked questions of Margaret that would help Mercia understand her illness. I also asked Mercia questions about how she could be of benefit to Margaret. We also explored what their friendship meant to each other. We all cried and laughed and drank copious cups of tea and ate cookies. Little did I realise just how powerful Mercia and Margaret's friendship is. In support and acknowledgement I wrote the following poem. I have translated part of it.

Mercia

A friend, a soul mate,
of 7 years or 20?
that cares about the spiritual
and knows the stories and stones intimately.
She is prepared to lie underneath,
to be a cushion
and is a major part
of the wheelbarrow.

She recognises the heartache with a gesture.
A reaching out hand acknowledges and shares the pain.
She is large and anchored
and will be honoured
to embrace the children
like her own.
She will be a spiritual mother,
serving joyously with a broad smile.

She is part of a group
who shares love and agony,
joy and heartache, pain and suffering
gladness, friendship and faith.
With confidence they can ask;
'God, ease her pain!'

Margaret has all her life nurtured and cared for her family, now she looks after the people in her street and the street children and has extended her love and God's love care to Emma. She is happy to openly share her illness and concerns with her friends and family and so enjoys their concern and caring for her. A wheelbarrow holds, protects and cares for Margaret's life and illness.

3.5.5 Completing the loop

On the farm where I live, we have a cooking school to teach the women, and some men, cooking and the skills of being a waitron. A man who lives close to where Emma and Margaret live runs the school for no reward. I invited Emma, Margaret and Mercia for dinner at the school. We had a three-course candlelit dinner and were part of a party of 30 people. Emma and Mercia started to talk. Emma told Mercia about her father who does not acknowledge her, he does not treat her like a daughter and he always makes excuses not to visit or care. Emma is very saddened by this, she knows she does not have long to live and would so enjoy some support and acknowledgement from her father. Mercia asked his name, she said that she knew him, she knew him well. Mercia then asked Emma if she could organise a meeting between her and her father at her house. She would like to create the opportunity for father and daughter to talk at a place away from other family members. Emma agreed to this. Yes, she would very much like to talk to her father.

So the community of caring has increased. Mercia has taken the lead. I just sat and listened and gave Mercia a hug. I created the opportunity and the unexpected, the sparkling moment just happened. It was not necessary for me to be actively involved anymore, the community has self-agency and they are doing the caring and support. I threw the stone in a pool and the ripples continue.

3.6 Conclusion

Identifying the connectedness between community as being part of the 'body' of God was something that evolved as I interacted in 'poor' and 'wealthy' communities. At first I thought that it was due to a racial and cultural difference, but then I realised that the divide had more to do with material differences. This knowledge has provided the light to the pathway of identifying other areas in communities that are worthy of honouring and celebration. These areas include acceptance of children as being children and not small adults (as may often be found in affluent communities); the tolerance of people who don't conform to 'cultured behaviour' and the emphasis placed on people and not possessions, as well as the ability to unconditionally share with those that are needy.

Some feminists experience exploitation of natural resources, which includes people and the environment as a sin (3.1) as splitting off the spirit and body of God. The research curiosity has led me to honouring communities in which I have experienced sacredness. Whether this sacredness

comes from God or not, it is worth nurturing and, therefore, we as Hospice caregivers are obliged to include the community as part of our caring team.

Another area that I would like to honour is the influence of patients and families spiritual experience on meaning making and finding quest stories (2.2.2) in the experience of illness. All quest stories are meaning making for the patients but not all are conducive to 'healing' of patients. Listening to the spiritual influence of meaning making of illness has offered me the opportunity of understanding peoples' preferred way of being with a terminal illness.

4. SPIRITUALITY INFLUENCING MEANINGFUL LIVING WITH TERMINAL ILLNESS

4.1 Introduction

Holistic patient care has highlighted the significance of spirituality with people experiencing the symptoms and knowing that they are living with a terminal illness. Patients live with varying degrees of so-called 'acceptance' of the illness. This may include not wanting to talk about the illness to actively involving the community with the process, to saying 'what will be, will be, it is in God's hands.' Regardless of the patient's spiritual or religious framework to this process, 'acceptance' is not an end state or the ideal. Patients constantly oscillate between many different emotions and ways of reacting to what is happening to their physical bodies. These emotions directly influence their sense of 'well-being' and the professional view of 'acceptance of the illness.' The patient's relationship to the illness threatens the way patients not only know themselves but also how others know them (Weingarten 2001:112) and are prepared, themselves, to interrelate with the illness.

Spirituality is a large component of the viewpoint and attitude moulding the encounter criteria of both the patient to his family, friends and community and of the professional to the patients. If God is seen, as a God that prepares and cleanses people for after life, then pain may be reasoned to be a blessing to help this process of cleansing and pain control methods may not, therefore, be appropriate. I have experienced the punitive patriarchal God in the Muslim, and Protestant religions. Woven into the threads of Patriarchy I have experienced the flowers, the God of Grace (2.3.10), the hope (2.3.9) and 'light' (2.4.1) of nurturing and caring through community and the process of dying. The God of Grace is available to all and is experienced by all but so often, Patriarchal practices obscure this 'light'. Experience has taught me to see the 'light' in others and when bringing this 'light' with you, it helps to nurture and nourish the God of Grace. I, therefore, ask the reader to join me exploring ways of bringing 'light' to dominating patriarchal beliefs.

I would like to relate the stories of Taurick, Gafsa, Christine and Angie. Taurick belongs to the Muslim religion where I strongly experienced the God of Grace working in the community. Gafsa (also a Muslim), however, felt excluded by the community because of a supposed lack of graciousness in managing the pain. Christine knows the God of Grace intimately, but she seems to be overpowered by patriarchal ideas. Angie rejected the patriarchy of the Catholic Church and

found grace in a Pentecostal community, but even there, patriarchy slipped in to question her faith practices.

Spirituality influences the meaning making of terminal illness, but not always in a positive way. Acknowledging and challenging the sacred spaces of spirituality is like walking on eggs. You never know just how to do it or if you have the skills or knowledge about the practice. You don't know if there is a bird inside, or if the bird has died. You don't even know the strength of the shell. The safest practice is to test gently and with circumspection. If there is the slightest notion of a crack, you stop. Actually you have to be invited to walk on eggs as untold damage can be done through a hasty or misdirected step. I hope to take the readers, hand and together we will 'walk' in this sacred encounter.

4.2 Brightly coloured asters

Taurick was a man who belongs to the Muslim faith. 'Being a Muslim is a matter of deep personal conviction. Becoming Muslim is not something that any person can do at 'second-hand'. It is to be experienced in each individual heart, because it is a total commitment of submission of one's life to the belief that there is no God but One, and the Blessed Muhammad was His genuine Messenger' (Maqsood 1998:8).

Taurick and his family lived in a large comfortable home painted a sunny yellow. I knocked on the door and waited a while for it to be opened, an elderly woman dressed completely in white, her head scarf had gold and white lace trim, invited me into the house. I was aware that 'no person should enter another's home, or spy on it, without consent' (Maqsood 1998:50). The house was furnished in red and gold and there were 3D murals of Mecca and Arabic writing framed on the walls. I was asked to sit in the red velveteen lounge and to wait a while. I remember it was a large room; part of it was the dining room, the tabletop was framed by brass and beside it stood brass chairs with red velveteen seats. On the coffee table there was a very colourful round arrangement of brightly coloured asters. The curtains were heavy and red and the windows were covered with soft netting. The floor had big tiles and a thick pile of colourful carpet lay where the lounge area was. I noticed all of this as I had been sitting for quite a while waiting for somebody to come. I heard doors being opened and closed softly and foot steps in the passage, but there was no other noise. I sat back on the chair and observed the environment, waiting patiently.

4.2.1 The significance of patient

I remember wondering about the use of the word 'patient'. Was it a word to describe the aptitude of being able to wait unhurriedly or was it a wake-up call from patients to remind us proficient medical professionals that they need time to be heard and understood? I was very comfortable being patient (verb) as it gave me time to close off the previous encounter that I had with a patient (noun) and to be quiet and absorb the atmosphere and circumstances in which I found myself. Being patient allowed me to be sensitive and vigilant to the requirements of this patient and his family. I think patience is a very important ingredient of being ethical and respectful of others. It is also about being respectful to yourself as it allows the time to acclimatise and to engage with changed circumstances.

Within my practice, 'patient' is a better word than client, it gives agency to the ill person where the power is usually very skewed in the direction of the professionals. Is it maybe a subtle way of reminding us to be ethical and respectful? The word 'patient' originates from the Latin word *patiens*, *pati* means to suffer. I find this concept conflicting in the way I do Hospice work. I don't see patients as people who suffer. I know they are ill, but I don't see my role as alleviating the patient's suffering. I rather believe my role is to assist the likes of Taurick and his family with the tools, and knowledge and, inevitably, the choice to live with the illness. By sharing illness stories and through the exchange of information, patients and their families are empowered to have self-agency in managing symptoms of the illness. In this way, the importance and the significance of the symptoms can be contained, thus giving the alternative story of meaning-making prominence. The family's and patient's focus is redirected from a fixation on symptoms to nurturing and caring, to the meaning, and spirituality, that sacred space of being terminally ill. Preferred ways of living with illness come about through choice and agency within the illness process, this creates spaces for the sacred to be experienced and acknowledged.

I think the term 'patients' changed to 'clients' when professional or expert knowledge became a commodity to be bought. It is generated from a modernist era when caring and nurturing became a profession and got a price tag, disenfranchising those 'unprofessionals' that have always done pastoral care. I argue that pastoral care is care 'with' a person not care 'for' a client. Exercising patience in Taurick's lounge set the scene for an ethical, respectful and sacred encounter.

4.2.2 God does not give you more than you can bear

After a few minutes I was taken down the tiled passage, all the inter-leading doors were closed and my host knocked on the door. The door was opened and I was invited to 'please, come inside.' Taurick was lying on a king-sized bed. His yellow skin and dark hair and eyes were sharply contrasted by the bright white sheets. He was breathing with difficulty and there were beads of perspiration on his forehead. His wife, Shihaan, was dressed in white and lying next to him on the bed. His daughter, Miriam, 23, also dressed in white, was sitting on a chair on his other side. We greeted and I asked about his condition and asked if I may look at his wound. I am very aware that I do not understand the Muslim culture and would not consciously do anything that may offend. I know that there is a sanctity that exists between husband and wife and husband and other women. Maqsood (1998:153) also says, 'It is not proper for a Muslim woman or girl to be examined by a male doctor, or visa versa.' I did not know what my relationship as a medical professional was, so I asked.

Shihaan said that she managed to look after Taurick because God was with her. It was very difficult, but God does not give you more than you can bear, she said. God brought difficulties in their path to see how they would handle them. Difficulties were there to cleanse you and to prepare you for life after death. It was thus important that we did not interfere with the dying process and it was their choice whether or not to give Taurick medication that would end his life. I was able to assure her that it was not the Hospice's philosophy to either hasten or postpone death, but to allow people to die when it was their time to die. Shihaan thanked me, for that was her concern. I could also tell her that it was my experience that people died when it was the right time for them to die, when the family and the patient were ready.

4.2.3 Josef's journey

Shihaan said that her son, Josef, was having great trouble coming to terms with his father's illness and she asked me to speak with him. I agreed to this and we were shown into an adjoining bedroom. I asked if anybody else would like to join us. Shihaan said that she would. Josef and I sat on the bed and Shihaan sat on the dressing table stool. She did not say a word. Josef asked questions and I answered them as honestly as possible, always checking on what he wanted to know and how he wanted it told. This conversation was held in English and I recorded it when I had left them.

Josef: How sick is my father?

Elizabeth: What is your understanding of the illness, Josef?

Josef: He has inoperable cancer of his liver.

Elizabeth: Do you know anything about cancer of the liver?

Josef: I know that liver cancer has a bad prognosis.

Elizabeth: What can you tell me about your father's health at the moment?

Josef: He is very sick. He is not eating and drinking much, he is sleeping a lot of the time. He does not talk to us much, but he often talks to himself.

Elizabeth: Why do you think he is not eating much and sleeping so much?

Josef: I don't really know but I think the illness is taking over his body, he can't cope with food anymore, and he is getting tired.

Elizabeth: May I ask you your question Josef? How sick is your father?

Josef: I understand that he is very sick, I don't think he has long to live. Why don't you put up a drip, Sister, so that he could eat?

Elizabeth: You just told me that your father is too sick to cope with food, Josef. What do you think putting up a drip could do?

Josef: Would he not be able to cope with the drip, could it cause some damage?

Elizabeth: Adding fluid that your father cannot cope with may cause extra fluid to be in his body, which could accumulate in the lungs or in the tissues. Extra fluid in the lungs could inhibit the breathing capacity of the lungs.

Josef: Does that mean that he could have trouble breathing?

Elizabeth: It could interfere with his breathing.

Josef: Why is my father talking to himself so much?

Elizabeth: Have you listened to what he is saying, Josef?

Josef: He is talking about things that happened when we were young. He is even talking to his mother who died 10 years ago; it is as though she is still here.

Elizabeth: Josef, do you think it is a real conversation for him?

Josef: Yes, he is quite calm talking to her and it is just about everyday things?

Elizabeth: Do you then think that it is possible that he is experiencing her presence?

Josef: Yes, she is with him.

Elizabeth: What does that tell you about where your father is Josef?

Josef: Is he maybe sometimes in another world, is he in heaven?

Elizabeth: What do you think your father's talking is about Josef?

Josef: Is he maybe preparing himself for life hereafter?

The conversation continued for a while. Josef asked about whether his father knew about his presence? He asked what he could do for his father and what his father needed now? He asked how he could help his family. He told me that his family did not really understand his father's illness, there was a need amongst family members that he should see a specialist and that another opinion and different treatment should be found. 'The family is not just the mother and father plus a couple of children, as is common in the West. If a tragedy befell any relative, or even a member of a neighbour's family – it would be expected that the family would rally around and give support during a time of need (Maqsood 1998:173). Josef asked if I would speak with his family. A time was set for 8 o'clock that evening.

4.2.4 Encountering a sacred community

I arrived at 8 and was ushered into the red and gold lounge. Nobody else was in the room, I was asked to wait. Fifteen minutes passed. In this time an elderly man apologised that I had to wait, I am assured that it won't be for long. The Imam arrived dressed in white with a white and gold fez. He goes into the bedroom. Shortly the room fills with about 50 people. The men are dressed in casual clothes, but for a fez. The women are dressed in black and some of them have black veils over their faces.

I have been told that some women choose to wear veils. They can be who they wish to be behind the veil. This was an interesting comment to me. I found support for this and a description of the role of a Muslim woman's dress code in Maqsood (1998:99).

Muslim women expect to be appreciated for their characters and minds, and not just for their bodies. Modest dress does not degrade a woman, but the very opposite – it deprives the lustful male of a lot of free entertainment. Muslim woman can be smart or colourful, and their styles vary according to the traditions of different countries – but they should never be indecent or vulgar. In fact, Muslim women regard dress as the very opposite of 'female repression' – it is really 'liberation'.

I am curious, but cannot comment on the female Muslim dress code, as I am not a Muslim woman and have never worn a veil, a headscarf or other traditional woman Muslim clothing. The author of the book that I quoted from is Ruqaiyyah Waris Maqsood and I wonder if he/she is male or female? Does he/she wear the traditional woman Muslim clothing?

The room was silent, nobody said a word and movements were gentle and slow. Extra chairs were brought in, some people stood at the back. The men were in front and the women behind. No word was spoken, but I observed silent tears in the eyes of the women. The silence was calming,

not uncomfortable. The Imam returned to the room, said a prayer and thanked me for being there. The senior men got up and walked the Imam to the door; they greeted and exchanged blessings. They sat again. The silence continued. Shihaan entered and sat down, she was composed and dignified. An elderly man then gave me permission to continue.

4.2.5 Honouring the sacred

The responsibility and the sea of faces overwhelmed me. I thanked everybody for inviting me and I expressed my concern that my behaviour and language would perhaps not be appropriate as I was not familiar with Muslim customs. I asked for pardon if I might offend and asked to be corrected when this happened. I then asked about the concerns and where I could be of assistance.

Josef took the lead in the questioning. He asked me the same questions as he had asked in the morning and I helped him relay and discover the answers. What really astounded me was that nobody mentioned their own sadness or grief. The women had tears in their eyes, but I did not know what they were experiencing behind the veils. The women did not talk; they just listened from behind. Everybody was there to find a way of assisting the family in this difficult time of coping with a terminal illness. What could they do? I directed the question to Shihaan and her family and they took the opportunity to tell the other family members that they appreciated the continual support and interest and the endless meals supplied by the women and phone calls. They particularly appreciated the whole family getting together to show their solidarity and support.

What did concern Shihaan and Josef was that they experienced Taurick as having pain. He was very restless and moaning at times. I suggested putting up a syringe driver⁷ with pain medication and a sedative. After it had been discussed with the family I put the syringe driver up that evening and assured the family that if they changed their mind, I would take it down. With their assistance I would also either increase or decrease the dosage as required. I went home and wrote the following poem to acknowledge the Pastoral care and the community that I experienced with Shihaan and her family and took it to them the next day.

⁷ A syringe driver is a box the size of 2 floppy discs next to each other. It is battery operated and the medication is, which is in a syringe, is placed in the box and set to deliver a continuous dose of medication over 24 hours, subcutaneously, (just under the skin) by means of a thin needle.

Community of Concern

I am humbled by the privilege of being invited into your home
and the invitation to be part of this sacred time.

I have been deeply moved by the spirituality, respect, care
and community of concern that I have observed
and would like to thank you for what you have taught me.

I am overwhelmed by your unselfish focus on Taurick;
your ability to put your own needs aside
and to work together for the benefit of Taurick,
to find out what his needs are, what is right for him.

Your religion is such a comfort
and has brought calmness and acceptance in your home
that is visible and a strength to all.

I honour you for your strength, love and compassion.

4.2.6 Josef experiencing the sacred

Taurick had a good night and when I visited the next morning, the family was calm and satisfied. Shihaan was lying on the bed next to Taurick. Josef called me aside and said that he had many things that he wanted to tell his father and had not had the opportunity to do so. I asked him whether he knew if his father could hear him. He said that his father could, he had squeezed his hand that morning. I asked him if he could manage to be on his own with his father and could tell him the things that he wanted to tell him. This, he did, and when I came back in the afternoon he said that he felt very relieved at taking the opportunity to speak to his father, 'It will be okay now if my father died. I think I am ready to let him go.'

4.2.7 Challenging the usefulness of pain

The next morning Shihaan phoned and asked me to take the syringe driver down, she was scared that it was sedating him too much. She needed to have him aware and responsive. I took the syringe driver down at 9 am and at 3 pm she phoned again. Taurick was very restless and moaning, would I please put the syringe driver up again. I considered this process to be a very important one. It was necessary for the family to make sure that they were doing the right thing and I was pleased that they felt empowered to ask me to take it off and put it up again (3.2.6).

4.2.8 Invitation into the sacred

Taurick died the next day. Josef phoned to tell me that his father had passed away. I asked him what would be the appropriate cultural response for me. Shihaan said that it was their tradition to invite everybody for a meal, it was their way of acknowledging and thanking people for their support and concern. I was invited to come to their house at one o'clock.

The street was full of cars and the house was crowded with women dressed in black. Everybody had a plate a chicken briani and were eating with their hands. I was the only white woman; a path was cleared for me as I entered the door and the lounge. I was shown the direction of where I had to go by the space that was created. I walked down the passage to Taurick and Shihaan's bedroom. Shihaan and Miriam were dressed in white while everybody else wore black. Miriam lay curled up on her father's pillow sobbing. The white bedspread was pulled over her. The mirrors were covered with white sheets and the photographs were turned over. (I believe that it is a custom that is followed so not to frighten off the angels that come to take the person who has died. Everything must be clean and there must be no clutter.) The room, like everywhere else, was full of people eating briani. I was offered a chair in the bedroom and given a plate of food and a fork. Shihaan said, 'He died so peacefully, Elizabeth. He looked so beautiful and young. He looked like the man I married. I thank God for that. I thank God for giving me my husband and I thank God for taking him away so peacefully, he is at peace now, he is with God.'

When I had finished eating I left with a thank you from everybody that I passed. At the door a large container of briani was given for me to take home to my family. Shihaan said that she sends the food from her home to ours to say thank you to my family for allowing me to care for Taurick. It was a gesture that I will not forget and it was an honour to eat briani with my family and acknowledge the short while, that I, as a non-Muslim, was part of the sacredness of a Muslim family.

4.2.9 Protected by a veil

On reflection the autocratic, omnipotent God again confronted me. The God that tests people and prepares them for life after death. The God that chooses those that are worthy and the God that demands obedience. Suzanne Haneef in 'What everyone should know about Islam and Muslims' writes (1994:v-vi):

The meaning of the word Islam is 'submission' and 'peace.' In the course of making an individual Muslim – that is, one who is in a state of Islam or submission

to the One True God – Islam profoundly affects his thinking and behaviour. Islamic claims to provide such answers and solutions, ones which are compatible with reason, logic, the realities of the physical universe, and with human nature itself. For Islam is, above all, a view of the total Reality, encompassing the existence and attributes of the Creator, man's relationship with Him, his role and purpose in this world, and the relationship between this life and the life of the Hereafter, which puts all that exists into proper perspective and gives balance and direction to the life of human beings and their societies.

What confronted me was that I felt privileged and honoured to be part of the sacred experience of the Muslim community and dying. I enjoyed the protocol and structure created by the religion. I was moved by the total resignation or submission to the One True, All-powerful God and by the peace that existed in the house. I keep wondering what is behind the veil. Is there an opportunity to 'be who you want to be and to be?' What choices are there? Do we need choices? Can one be a 'cheeky' Muslim? Emma (Chapter 3) said, being cheeky is about survival and to live is to be free, is this possible in Islam and is freedom necessary? Will we ever know what is behind the veil?

I also wondered about the conflict the family had with the syringe driver. Maqsood (1998:80) said that; 'A most important point to consider is that Islam teaches that when people bear their pains without losing faith, it is not pointless or useless and meaningless suffering, but it will be counted for them towards the forgiveness of their sins.' Maqsood also said that Abdu Sa'id al Khudri and Abu Hurayrah recorded: 'No fatigue, not disease, not sorrow, nor sadness, nor hurt, not distress befall a Muslim, even if it were (as small as a) prick of a thorn, but Allah expiates some of his (or her) sins for it' (Bukhari 70.1.545). This has tremendous implications for pain control. Does not having pain through the use of medication limit the amount of sins that are expiated? What stress could we, as medical professionals, be inflicting upon patients and their families by not consulting with them on issues such as pain control and by not giving them a choice?

4.2.10 Suffering, sin and redemption

'Theories of the Atonement, interpretations of the crucifixion, doctrines of salvation and theological answers to the question of Theodicy traditionally have accepted, either implicitly or explicitly, the correlation between sin and human suffering' (Tatman 1996b:221). Suffering is, therefore, seen as divine suffering and a necessary response to sinfulness. This has tremendous implications for people who have a terminal illness. What sin did they commit to deserve such harsh punishment and suffering?

This question around sin and redemption highlights the theodicy crises that exist with patients who connect suffering to their belief in God. Louw (1983:54) suggests four examples of the theodic crises, which is translated by Grobbelaar (2001:76):

- God wants to prevent evil, but cannot (then God is a God of love, but not almighty).
- God has the power to prevent evil, but does not want to (then God is almighty, but not a God of love).
- God has neither the power, nor the will to prevent evil (then God is neither almighty nor a God of love).
- God has the power to prevent evil, but He/She wills suffering (then God is the author of sin).

Tatman (1996b:221) quotes Brown and Parker as saying that if redemption from sin is obtained through 'God-demanded suffering' then they have named such suffering to be 'Divine child abuse'. This knowledge and idea has generated many questions around God's love and the meaning of justice. What options do patients have that 'suffer' from terminal illness? What place is there for love and justice? Where there is not love and justice, despair reigns (Tatman 1996b:221) negating doing hope (2.3.9), choice (2.3.1) and empowerment (3.2.6) to changing chaos stories of illness into quest stories (2.2.1). Tatman (1996b:221) also says that 'the effects of suffering can be transformed, or muted, but they never disappear', which makes me wonder about the effects of a belief that illness is a punishment from God or to be revered as a test from God. I also wonder about the attitude of caregivers who are exposed to this type of doctrine. Do these caregivers see patients as deserving of their suffering and what implications would this have for respectful palliative care practices?

4.3 Mauve African violets

I then think of Christine. She and husband, Kleintjie, (Shorty) have retired and live in a large, very comfortable, upmarket home, in a quiet tree-lined suburb. They have one daughter, Ines, a nursing sister, who lives in a town about 2 hours drive away. Ines asked Hospice to help her mother. Her Mother is a very private person and will not talk about her illness. Ines has only now discovered that her mother has cancer of her breast, despite the fact that it has been growing for 5 years. It is a fungating tumour, which means that it grows outward, ulcerative tumours grow inwards. Her breast has increased excessively in size, her clothes do not fit anymore and the odour from the breast is very unpleasant. At times her breast also bleeds extensively, the blood squirts out and her mother does not know what to do, she does not know who to call for help.

It is summer when I first visit in a comfortable room where the window-sills are lined with mauve African violets, it is an air-conditioned oasis. Paarl can get very hot and in most of the houses where I work there is very little protection from the heat. The cool breezes don't mask the smell and Kleintjie is quite verbal about it. He can't stand the smell and can't be in the same room as Christine. He walks out. The story unfolds.

4.3.1 God is preparing me

Sister, I have always been a very independent person and believe that you have to look after yourself. Nobody else will look after you. I heard that if you cut on cancer, then it spreads like wildfire, nothing will stop it and those are the people who have pain. I have never had pain. I know of a few people who had surgery, and look what happened to them. It was just a short while later that they died. No, I told the doctor, they won't cut on me.

God knows to whom he can give what, and like I have told you, I can handle pain. I have managed all my life and I can take it. My daughter asks me why I don't take painkillers. I don't want to, but this morning it was very bad, so I took painkillers. They did help, but then I wondered, if I had closed my eyes and prayed to God, would the pain have gone away? I never ask why me God, I have never thought about asking. God knows what he is doing. I see healing as healing you of your sins and God is giving me time to think about my life and to prepare me for what is coming.

I don't want people to feel sorry for me. I never spoke about the cancer. I never had the need to talk about the cancer. Now people are saying that I need to talk about it and that I need other people. I don't want people to feel sorry for me and I don't want them to see me like this. Our whole family is like this, we are all very private. My granddaughter has been warned by her mother not to hurt my breast. Now she has distanced herself from me. She does not sit on my lap anymore, she chooses Kleintjie's lap instead. She told her mother that she does not want to get breast cancer one day. I am so grateful, eternally grateful, that you have solved the problem of my smell. I wish I knew about you sooner. I felt totally disfigured. I did not want people to get near to me.

Christine belongs to the Dutch Reformed Church. She, as Taurick's family, knows the patriarchal God. She sees her illness as a trial and tribulation that God brings you to make you stronger for life here-after. The theodicy question is again highlighted (4.2.10). She also knows the omnipotent God. If her faith was strong enough, then she would not have pain so, according to her logic, taking pain killers would mean that she does not have enough faith. She asked, 'If I had closed my eyes and prayed to God, would the pain have gone away?'

I also reflect on the role of the medical professionals. She only knows a part of the story about cancer. Did anybody inform her about her specific type of cancer and what could happen? She heard that if you cut on breast cancer then it spreads like wildfire, was she properly informed

(aware) was she given choices (empowered)? Did anybody tell her that her breast could get so large that her clothes would not fit?

Christine talks about her whole family being private and strong people. She has carried this tradition. I do wonder how useful this has been to Christine? It has certainly kept a lot of people away, including her daughter and granddaughter. Then I also wonder how somebody like Christine would manage if she did not have these traditions to rely on? Is it useful to question origins and the usefulness of beliefs?

4.3.2 Discovering the dualistic God

I asked Christine about the God she knew. She told me that she experienced God as nurturing and caring of her.

Christine: God is very important in my life. He gives me strength and he cares for me every day.

God is loving and caring for his people, he cares for us like little children.

Elizabeth: Is that the same kind of love that you have for Ines?

Christine: Yes, but it is even more, the Bible says God loves us even more.

Elizabeth: Do you experience this love of God?

Christine: Yes, daily, every day. I won't manage without his love. He holds me and carries me throughout the day.

Elizabeth: You are telling me about a God of love and nurturing. I was wondering about God's love being even greater than a Mother's love. How is it possible that a love, greater than a Mother's love, would punish you with such a terrible illness?

Christine: I have never thought about that Sister. I will have to think about it. I know God loves me and protects me? Do you think it is possible that the illness does not come from God?

Elizabeth: How do you experience it, Christine?

Christine: I know God loves me and protects me, he looks after me every day, I feel his presence. I think it is possible that it does not come from God, not the God I know in my heart. I am starting to think that the God that punishes me and the God that loves me can't be the same God.

4.3.3 The injustice of Patriarchy

I reflect with sadness and anger at the unfairness of the patriarchal God and 'Divine child abuse' (Tatman 1996b:221). I think of the suicide bombers of Palestine. How did it come about that a group of people can believe that offering their life for a cause would purify their lives? How did it come about that the suicide bombers that flew into the twin towers could justify their actions even though they killed thousands of people? Then, on the other hand, I wonder, how the Americans cannot see and accept that they are constricting, stifling and controlling of other nations. Sharon Welch (1990:139) says 'We in the first world are not responsible for others; we are responsible for ourselves – for seeing the limits of our own vision and for rectifying the damages caused by the arrogant violation of those limits.'

Why do we not see our own limits and where does the knowledge of our power and control come from? I believe it all stems from the arrogance and control reflected in the patriarchal omnipotent God. Welch (1990:11) says, 'The idea of an omnipotent and sovereign God, however, assumes that absolute power can be good.' She also says that the Christian tradition does not attribute demonic or destructive traits to Deity. 'And yet absolute power is a destructive trait' (Welch 1990:11). This power is reflected in personal power of tradition, the power of God to punish or cleanse from sin, the power of God to test people and the power we have to withstand pain. Recognising the destructive traits of patriarchy and actively resisting these will go a long way to work towards a more just society where the power abuse of men and Patriarchy can be curtailed to make space to be inclusive of a God of Grace. Welch (1990:10) argues, 'Where there is justice it is very good to be alive. Joy in the abundance of life enables and motivates resistance to the exploitation and destruction that vanquishes the possibility of such joy.' Gafsa tells of the omnipotent, patriarchal God she knows.

4.4 Pink and blue flowered duvet

Gafsa is a Muslim lady, who cannot read or write. When I first met her she wore a pink nightgown and she was propped up in bed and covered by a duvet with large pink and blue flowers. Gafsa sees cancer as a lot of pain. She at first felt very unhappy and discontent about the disease and was very impatient, but now that she knows Hospice, she feels more content. She says:

4.4.1 God is punishing me

If I am discontent then God will punish me. God will punish me, He won't make me feel better, He will make it more difficult. I asked God what I did? Did I hurt anybody? I did not hurt anybody, but God must think so. An important educated woman, who has been to Mecca, said that I must not be dissatisfied, but there comes times when I feel depressed and I ask, why me? Why have I got cancer? The woman told me that God loves me. She told me it is because Allah loves me that he gave me 2 illnesses. I told her that I wondered if I wronged somebody or if I hurt him or her. She asked me to think about it. I can't remember whom I hurt or harmed in any way. God is the one that makes you healthy and gives you strength. My punishment is that I did something to someone that I am unaware of. There must be a reason for the illness. I lie awake at night and think about it, I don't know why I have to have cancer. I have had a very hard time in my life, why do I have to have such a difficult time now?

There is no easy way to introduce the God of Grace when somebody sees illness as a punishment and a preparation for life hereafter (4.2.10). Do we have the right to challenge such thoughts when all her life Gafsa has believed this and her belief has been the foundation on which she has build her life? Do we have the right to challenge her God? I did not, I listened and helped with pain and symptom control. I could not comment on Gafsa's God because I don't know that God and can't understand *that* God. What I can do is to bring my understanding of the God of Grace with me; my God-self and care and nurture for Gafsa with a participatory consciousness and an openness to *selfother* (1.7.1.1). I also, with Gafsa's permission, have introduced volunteer caregivers and a volunteer nursing sister. Hospice visits her every second day. She does not really want the Muslim community too involved, because they will notice that she is not bearing her illness graciously - she has so much pain. She does not take pain pills anymore, but drinks liquid morphine. 'It is better Sister, it looks just like water.'

4.4.2 God does not punish, God tests

I phoned a 26 year-old Muslim woman, Nuraan, who is a medical student. I told her about this story. She could not believe it. 'No, no', she said. 'She has it wrong. God is not punishing her, God gives us tests. Where does she get her information? I have been to Mecca for 6 years and I have studied my religion. We have to be grateful for the tests, they free us from sin and purify us and God won't give us more than we can bear', she said. 'God is a loving God.'

I have not been surprised that Gafsa's experiences her God as a God of punishment, law and order. It is very different from the God that tests you and does not give you more than you can

bear? I am not very surprised that Gafsa got 'it wrong'. Gafsa has been marginalised by her community because she does not want them to see that she can't handle pain graciously.

4.4.3 Questioning Patriarchy

Christine also knows that God that gives you tests. This God does not seem so very different from the God Gafsa knows, yet Christine is Dutch Reformed and Gafsa is a Muslim. I wonder who benefits from the fruits of this patriarchal God? How did this God come about? The answer lies in those who benefit from the churches that spread the doctrine and classically they have been men, considered powerful and educated. For transformation to take place so that we can 'dare to take Grace seriously' involves an element of risk and 'chaos'. The personal becomes political and those of us who are aware of the injustice of patriarchy need to find ways of strengthening and supporting whoever dares to make a stand. Angie made a stand against the patriarchal practices of Catholicism. She joined the Pentecostal Church hoping to find the God of Grace.

4.5 Yellow sunflowers with red roses and blue corn flowers

Angie was a beautiful, 32-year old Portuguese woman, with long, slightly curly black hair and dark wide-awake eyes; she had a slight figure and had spunk for life and living. She was unmarried when I first met her and her blond little boy, Romano, aged 2. Angie and Romano lived with Romano's father, Migiel in a meagre hired house on a farm. Migiel hired manual labour and chopped and sold firewood. Angie had been managing a container farm shop, which was her only income. She had to give up her work at the local printing press when she became ill. Her father, Tony, came to stay with Angie because of her illness, he came to look after his 'beautiful daughter' and he managed the shop for her. Her middle sister, Hilda, relocated and hired the next door house and found herself a job in the vicinity. Angie's eldest sister, Juanine, came to stay for an extended time. She had left her twin boys of 6 and son of 10 in the care of her husband 1,500 kilometres away. Angie's father's sister, Maria, also came to stay and help support her brother and the family; she stayed with Hilda in the house next door.

Angie had cancer of her cervix. They did not have much money and had no medical aid, but the family had clubbed together to pay for an operation. Angie developed a hole in her bowel and bowel contents were leaking out of her vagina. Family in Madeira and Johannesburg had also helped with the payment. This fund paid her telephone bill, so that she could phone regularly. I was assured that money was no problem. 'We will find the money, we just need Angie to get and feel better.'

When I first met Angie, she had just come out of hospital with a syringe driver to control her pain. Angie did not enjoy being hooked up to a tube and a machine, she felt that she had to cope with a colostomy bag for her faeces and that was enough in the form of attachments. I discussed pain control with her and we decided to take off the syringe driver and put her on oral morphine. I gave her a pain form and in this way she could feel that she would have more control over her own pain. She adjusted her pain medication on a daily basis according to her pain levels. I visited her regularly 2 or 3 times a week. We had wonderful conversations over a cup of coffee. We talked about Angie's childhood in Tzaneen; her father was a flower grower. There were always fields and fields of different colours. Her mother had a problem with alcohol abuse, so there was a lot of fighting and at times neglect from her. There would not be food in the house or they would be left at the bus stop. Her father was always there though. He did wonderful mothering. We talked about my family and me and she was keen to meet my children. We became friends. She enjoyed finding out about my day and what we would do over a weekend.

4.5.1 Questioning boundaries

Selma Sevenhuijsen (1998:2) poses the following moral question: '... whether care-givers can and should establish limits to their emotional involvement, intimacy and tenderness, those qualities, in fact, which are precisely what is needed in caring for ... people.' This, in the work I do, often seems to be in conflict with '... dependency, responsibility, vulnerability and trust; the importance, but also the fragility of intimacy and connectedness; the ever-recurring problem of establishing boundaries (Sevenhuijsen 1998:3).' In the same article (1998:20) she says that '... a 'good' motive, such as attentiveness and vulnerability, is no guarantee of good care: it can also lead to paternalism and undue protection', and 'personhood ... is directly linked to the possession of rights (1998:12).' Getting 'overly immersed' disempowers a patient by taking away his agency and responsibility for his own well-being, the nurse/therapist does the caring and thinking and taking of responsibility. It may even influence and change the attention to the nurse/therapist, as 'payback' may be needed because of the nurses/therapist's personal sacrifice and involvement. The patient starts to perform for the therapist/nurse instead of being honest to his/her own needs. Participatory consciousness should, therefore, create the space for the client to be 'not well', 'non-performing' or depressed if that is the case. Angie used these spaces, we cried and laughed together, we appreciated the view, the herbs in the garden and a cup of coffee together.

4.5.2 Patriarchy supported by guilt

Angie told me about her God. She was brought up in the Catholic Church. She experienced it as a church with many rituals, rules and regulations. She felt guilty when she did not go to church.

Anne Murphy (1996:89) has the following to say about guilt:

But there are two main problems with our feelings of guilt. In our immaturity, we often deny, hide or are unable to handle feelings of authentic or justified guilt. Secondly, in our brokenness and woundedness, we are often burdened with a sense of inauthentic, neurotic or so called 'imaginary' guilt. These distinctions are not clear to the one who experiences guilt, which is never 'imaginary' to the sufferer. Many people suffer greatly ... [from] that voice of authority within us, formed by internalizing the demands and expectations of authority figures outside and 'above' us.

Angie decided to leave the Catholic Church and to search for a church that was not punitive. A place where she could experience nurturing and caring, a place where she could find her God and where she could express her relationship with God. She needed to find such a place because her illness made her very scared. 'I looked after my friend last year when she died. She died in hospital on her own, her mouth was so dirty and she had bedsores. I don't want to die like that. Will you see to it that I don't die like that?'

4.5.3 Searching for Grace

Angie's search for a church led her to a Pentecostal Church. Herholdt (1998:420) explains that in the Pentecostal tradition 'believers experience his [God's] power and working in a way that is open to sensory perception. He is not above us, but in front of us and next to us; God is not far from us, but working within us. Religion is experience, not dogma.'

Herholdt (1998:420) also explains that 'The mode of the Spirit as the presence of God means that to the pentecostal believer that God is willing to make his power available.' This power finds expression in different ways, such as the gifts, the courage to witness, supernatural phenomena such as healing and, to a lesser degree, especially in charismatic circles, even dramatic joyful expressions such as 'laughing in the Spirit' or 'dancing in the Spirit'. Angie believed that her faith and belief that God would answer her prayers and heal her, was unquestionable. She heard of Father Joshua in Nigeria who could perform miracles, if your faith was strong enough. She was determined to visit him, her family would sponsor the trip, but she was too ill. She did question why she was not getting better. Was her faith not strong enough? This brought up the old feelings of guilt again, those feelings that she was not good enough for the Catholic church, but she continued to hope to be healed. We spoke about what healing was to her and she saw healing as getting

well, as being able to spend more time with Romano. She hoped that God would perform a miracle and heal her illness.

4.5.4 Patriarchy restrained by community

Herholdt (1998:421422) also explains that to the Pentecostals 'the Spirit is only there for the individual because the individual is part of the community' and emphasis that 'the Word is alive and that gives light and affects transformation.' Angie was saddened that Migiel did not want to go the church with her. Sometimes it was difficult for her to go to church as she had pain and discomfort. The church, at these times, came to visit her. She found consolation in this. I asked if there were other ways in which she could bring the Church closer. She talked about getting closer to God through praying and she also spoke about reading the Bible. She also knew that she was on cell-groups' prayer lists. This was a great comfort and she could feel their support and care. She knew that the church community held her. Angie's church brought joy in her life; she smiled when she talked about her church and the church community. She liked the people and Migiel was not part of that.

Angie's biggest concern about the prospect of dying was that she wondered what would happen to Romano when she died. Migiel and Angie decided to get married. She was very excited about the prospect; Romano would have a father when she was not there anymore. Family and friends organised the whole event, the venue, the minister, the catering and Angie's cream dress. It was made to hide her extended abdomen and colostomy bag. The photographs are beautiful: Angie is radiant; Migiel is holding Romano and the family is large! Lots of champagne was drunk and Angie said, 'I didn't need any morphine.'

The lounge furniture was covered with loose cloths, there was always soft music coming from the music centre in the corner and there always seemed to be a sound of the kettle boiling. After the wedding, the dining room table, which overlooks a view of the mighty Drakenstein mountains, had a bowl of bright yellow sunflowers interspersed with red roses and blue cornflowers. A joyous statement confirming life. This was used as Angie's wedding bouquet. I asked her if the flowers had any significance for her. The sunflowers were her favourite flowers as they signified sunshine and joy - living. The red roses were about love, caring and friendship and the blue comflowers reminded her of the blue sky and sea.

4.5.5 Expert knowledge interfering with ethical, respectful practices

Angie found talking about the illness as being very painful and it made her cry and made her body sore and it made her feel lonely. She did not like to be reminded about being ill all the time. She liked to hear other people's stories and to laugh and joke at times. It made her forget and helped her cope with the day. I remember a day when I introduced Angie to one of our volunteers. We were there when a 'counsellor' came to visit. While Angie was telling the volunteer about her illness and she started crying. The counsellor turned her back on the volunteer and myself and insisted that Angie 'get the sadness out.' She encouraged Angie to 'feel her pain and sadness' and to 'express' this. This carried on for about 10 minutes and I was getting more and more uncomfortable. I then interrupted the scene and asked Angie when Migiel was coming home. Angie replied that he would return at 8 o'clock that evening. I was wondering about our counselling practices. We would leave soon, leaving Angie to herself for the rest of the day. How ethical were these practices that encouraged patients to 'feel' what they were experiencing when there was no way that we could hold her? We would be leaving! What informed us that 'feeling' and 'expressing' were what Angie needed? Had we asked her how she would like to deal with the sadness? Did we ask what the sadness was about? What mechanisms did she have to help her cope with the sadness (1.6.1.7), did she want to talk about the sadness? Somehow our expert knowledge so often interferes with ethical, respectful practices and this knowledge makes us believe that we know what we are doing.

4.5.6 Gathering community support and knowledge

When Angie started to get out of bed less and her pain increased, her family gathered round, Juanine, Hilda, her mother and father, even though they were divorced, and her Aunt Maria. Angie was on a very high dose of Morphine, leaked urine out of her vagina and therefore wore a nappy. She used to fetch Romano at school and I often found her shopping at Pick & Pay. We spent many hours together making plans to make her day more comfortable. I was concerned that she would get a urinary tract infection and I remembered that my grandfather used to use a natural Western Cape fynbos herb locally called buchu (*agathosma capensis*) for urinary tract infections. I got her some buchu water to drink twice daily. An amazing discovery was made; buchu took away the smell of urine. She then felt free; she could go out without worrying about the urine smell. This is not new knowledge in our area, it is knowledge that has been suppressed as it has not passed strict medical research tests. There has not been research to prove this fact, buchu water is not prescribed by a doctor nor is it bought from a chemist. This was the start of a

wonderful journey of gaining buchu knowledge through trial and error and through talking to the locals. Buchu oil, we now use for wounds, it takes away the smell of tumours. Christine uses buchu oil mixed in aqueous cream on her fungating breast. All wounds are cleaned with buchu water as it is a natural antiseptic and has anti-inflammatory properties and it is therefore also excellent for sore mouths, helps breathing in chest complaints and sorts out urinary tract infections. This knowledge was gained through a not-knowing attitude (1.6.1.3) and through seeing patients as being the experts and asking them for local knowledges. It is a cheap and extremely effective way of treating many unpleasant symptoms.

Angie started to sleep more and more and to dream a lot. She told us about her dreams of when she was young. She dreamed about her cousin who had died, about being at school, about feeling well again and having no pain. 'They are such vivid dreams, it is as though they are really happening' she said. Her family thought that she was confused but when I invited them to listen, they found out that their confusion was not hers. She was reminiscing, talking about experiences from the past. Her family took turns sitting next to her, brushing her hair, holding her hands and putting Vaseline on her dry lips. There was calmness in the family; the great sadness and anxiety had gone. During the night her sister, Juanine, had long conversations with Angie, she was sure that she could hear and understand her and I think she did.

One afternoon I was in the room and her Aunt Maria was sitting next to her. Tony, Juanine and Hilda were there as well. Angie looked in front of her and smiled and spoke to Maria's daughter who had died two years previously. Angie greeted her, and asked how she was. Maria asked Angie what she was wearing. 'A long blue dress with a high waist, it looks as though she is floating above the bed, she looks so happy. She is asking me to come with her.' Maria said, 'Angie go, go with her.' Angie put out her hands, then pulled them back. 'No, not now', she said, 'not now.'

4.5.7 Family reconciliation and meaning making

Angie died peacefully a few days later. I inserted a syringe driver (a way of giving continuous medication) as she started to have epileptic type fits. This was very distressing to the family. I discussed it with all and together they decided that they could not cope with Angie fitting, it was too distressing to watch. We tritrated the dosage in such a way that we decreased the dosage during the day and increased it at night to ensure a good night's sleep for all. Everybody was getting very tired. I was there when she died, her family were all present and she had a hint of a smile on her face. She taught us so much about appreciating and celebrating life, about meaning making of illness of getting in touch with the kind and gentle part of herself, the God of Grace, her God-self.

The blue dress Maria's daughter wore at her matric dance. Maria found peace that her daughter is happy and that Angie and she are together - they were best friends. Juanine would like to start a Hospice in her town. I have a photograph of Angie and Romano playing in the snow on my pin board. Her love of life and sense of humour often boosts me when I am low. I know that she is still around sharing her bright yellow sunflowers, red roses and blue cornflowers with all those that risk looking for joy and beauty amongst chaos.

4.6 Conclusion

On reflection of this chapter of how spirituality influences meaningful living with terminal illness, I realise that it has been a cathartic experience for me as a 'wounded storyteller' (Frank 1995). Although I do not have first hand experience of a terminal illness, I have journeyed in an intimate relationship with the patients on their emotional roller coasters. Listening to the stories of terminal illness has contributed to my healing as a wounded storyteller and also as 'wounded healer' because of the nursing and pastoral care function, which I perform. Rachael Remen describes the wounded healer:

My wound evokes your healer.
Your wound evokes my healer.
My wound enables me to find you with your wound
where you have the illusion of having become lost.

Voicing the stories about patients' spirituality has at times evoked a strong reaction from me towards the injustice of the patriarchal God, the God that tests and punishes patients with illness. Feminist theology practices that question the idea of sin and punishment (4.2.10) but that also engages the idea of holism has greatly contributed to my understanding of the way patriarchy has eroded meaning-making of terminal illness. Listening to the patients' stories has, however, contributed to moderating the strong reaction that I had to the injustice of a punitive God that punishes patients with a terminal illness to either test or prepare them for dying. Listening to the stories has helped to deconstruct the meaning of God and living with illness which has often created the opportunity for acknowledging the God of caring and nurturing, the God of Love and Grace. The rejection of patriarchy and dualism and the inclusion of interrelatedness and mutuality has greatly contributed to holism, to the unity of God-Self.

5. REFLECTIONS

5.1 Introduction

The deconstruction or decentralising of the belief that expert knowledge of professionals contains truths about health, spirituality, care, wealth and language, was the motivation behind this research curiosity. Being a nurse, I was aware of how the centralising and sometimes the subjugating of some knowledges affected me in my profession. The initial idea for a research topic was to look at ways of legitimising or centralising the role of nurses in terminal or hospice care. Working within a professional, team I often felt disenfranchised because of the lack of more professional 'expert' knowledge/power. Within many multi-disciplinary teams, the doctor is seen as the expert on medical matters, the social worker the expert on social, the psychologists the expert on psychological and the pastor the expert on spiritual matters. The opinion, experiences and views of the nurse (and sometimes the patient whose health or death is involved) do not carry similar weight as that of the other 'expert' professionals.

Hospice philosophy aims to work as an inter-disciplinary team as compared to a multi-disciplinary team. Instead of the areas of work being delineated into physical, social, psychological and spiritual care, these boundaries are a lot more fluid and interchangeable. The nurse, may, for example, do the work of the social worker, the social worker may give advice on medical matters and the doctor may assist with nursing or spiritual advice and spiritual carer may assist with nursing. However, the nursing accountability stays with the nurse, the social worker has the accountability of social and counselling issues, the doctor the medical and the pastor or spiritual leader is accountable for spiritual matters. This does not mean that they have to do that aspect of care alone, but may engage the person best placed to take on that aspect of care. The disenfranchisement that I have experienced as a nurse has often been as a result of delineation of boundaries and areas of care based on power/knowledge capability practices. Professionals without the 'expert' knowledge are not seen as proficient or competent to do holistic care.

The disenfranchisement that I have experienced has also highlighted some of what the patients and their families may experience when facing professionals. The questions that came to mind were the following: Do we as medical professionals take enough cognisance of the patient's views and do we consult with the family regarding their preferred illness management? If we do not consult with them sufficiently, how do patients and their families experience the lack of consultation and consideration of professionals? I also wondered how it came about that professional 'expert'

opinion is seen as being of greater importance and significance than the preferences and the opinions of the patient and his/her family? Do professionals not perhaps need to be inclusive of patients, family and communities as an integral part of the inter-disciplinary team? The research journey, pastoral care and narrative practices introduced ways to legitimise the voice of those marginalised by 'expert' knowledge.

5.2 Development of the journey

I started to explore where the reliance and belief in these so-called truths about expert knowledge came about and what possible role these beliefs have in disenfranchising patients regarding their own bodies and spirituality. The personal became the professional (White & Hales 1997) as my personal concerns for marginalising of alternative knowledges and the less powerful role of the nurse, changed to become a concern for the injustice patients and their families experience (1.1.4).

The development of the research curiosity and questions originated as I was investigating ways to honour patients' stories and the questions and curiosity highlighted the significance and value that these stories have in clarifying patients' preferred ways of being. I recognise that patients do not have scientific or expert language to express views, but they do have important stories, which constitute their realities (2.1).

5.2.1 The Development of Honouring Stories

Storytelling as a practice and a research methodology is in line with 'performative psychology' that uses 'modes of expression from the dramatic arts, visual arts, music and other media [which] promotes the mingling of the scientific with the secular and the spiritual' (Gergen 2001:45). Storytelling opens opportunities to alternative interpretations of reality. Frank (1995:18) says, 'telling stories of illness is the attempt, instigated by the body's disease, to give a voice to an experience that medicine cannot describe', but more than that, it is the only tool that terminally ill patients have to try and alleviate the chaos (2.2.1) in their lives.

The challenge to a listener of terminal illness stories is to learn to think *with* stories, not to think *about* stories, as the latter seriously reduces the stories to content only and then analysis of the content (Frank 1995:23). Thinking *with* stories requires entering into a relationship with the storyteller that ensures honouring and nurturing the story and the person as a gift of relationship. This relationship is not a professional technique (Frank 1998). Achieving the relationship of

listening, being and thinking *with* stories, requires entering into the relationship from a 'not-knowing' position (Anderson & Goolishian 1992) with reverence for the storyteller. The relationship and connectedness that developed between us (participants and pastoral therapist/nurse) during this research, is what Heshusius (1994:15) calls a 'participatory mode of consciousness,' which meant that there was a reordering of the relationship between the patients and myself. I had to temporarily let go of all preoccupation with self and move into a state of complete attention *with* the patient resulting in awareness of the level of 'kinship' between the patient and myself (Heshusius 1994:15-19). The stories moved me to forget 'the self' and to become part of what I was trying to understand and to discover about the patient's experiences. There appeared to be an affirmative quality of kinship that no longer allowed for privileged status. This rendered the act of knowing and discovery an ethical act (Heshusius 1994:19).

'Listening is hard, but it is a fundamental moral act' according to Frank (1995:25) and it validates patients' stories. Fundamental to the act of listening is having the time and creating the opportunity to listen. I made appointments with patients that I interviewed (Margaret, Emma, Gafsa and Christine) and have seen them at least twice a week for more than 6 months. I have visited patients in their homes, which has often created the opportunity for being available to listening at times when the patients may be emotional or stressed. This has also made me available to share in joys and quest stories (2.2.1). Being receptive and available to listening *with* stories is a prerequisite to doing justice to stories. A 'participatory consciousness' (Heshusius 1994) opened up the opportunities to be moved and informed by the stories, and also opened up the opportunity for the research to be ethical.

5.2.2 Expanding alternative resources

As a hospice nurse I am afforded the responsibility of the total care of the patient, with the proviso, that I will consult with experts (psychologists, doctors, social workers) and call in expert advice when needed. These boundaries are, however, defined by the availability of experts and are often dependent upon finances. Hospice cannot afford to pay for consultants, therefore, expert knowledge is usually *pro bono*. The availability of *pro bono* experts, (1.3.1.9) sets the boundaries to the areas of the nurse's involvement and care of a patient and his/her family. The difficulty which terminal patients experience with travel and mobility and the urgency of terminal illness, has also eroded the boundaries making them a lot more flexible and not as clear cut and predictable. These factors have afforded me the opportunity to venture into sacred spaces (2.3.7) of spiritual

and emotional areas of patients' lives. Listening to patients' stories around fears and preferences has guided this sacred intervention.

Even though my nursing training proclaimed to include the total person - the physical, psychological, social and spiritual, I was challenged anew by the post-modern viewpoint of listening differently to patients' stories. In order to be guided by the patients, I approached the patients from a not-knowing position (1.6.1.3) and made myself available to be directed by the patients' needs for pain management, family involvement, medical involvement and spiritual and emotional needs. The patients became the teachers and the guides to the way I re-approached hospice work.

Limited resources have necessitated Hospice to use all available resources for the benefit of the patient and his/her family. Volunteers and the community, with limited 'expert knowledge' have been used to help with care and support of patients. This opened a new dimension to care: a dimension that is inclusive of anybody that can assist patients and their families in meaningful living with terminal illness. Working in a interdisciplinary team, being inclusive of medical professionals, volunteers, family and community goes a long way to being inclusive of the total needs of the patient and maximising available sharing, caring and support. The benefit of the nurses, neighbours, patients, families, churches and community resources is illustrated in the research by the stories of Jacobus, Fred, Emma, Margaret, and Taurick. The whole street looked after Jacobus and Fred, not only their elderly sisters and Emma's nurturing team expanded to include Margaret's team members, her friend Mercia and her church. Together the family and I could decide on the best pain and symptom management for Taurick and the community felt included through the family discussion that we had.

The usefulness of enfranchising personal knowledge is also illustrated by the compliance that is experienced when the patients are empowered to manage their own pain (3.2.3) with the pain form and the acknowledgement of buchu provides a sense of this liberation (4.5.6) to patients as their knowledge of buchu is acknowledged as being worthy.

Disenfranchising local knowledge resources around caring and nurturing of patients has led to the marginalisation of patients' personal resources and knowledges. These resources and knowledges are those very treasures that assist meaning-making for the patient. Through constant devaluing of personal knowledge and responsibility patients have been made to believe that knowledge belongs to 'others' who are experts and resources are perceived as external to the person. Through my collaboration we deconstructed and included personal knowledges.

Through the research journey the danger of dualism and the negative effects of some modernist practices have been highlighted. In the stories of some of the patients, ideas were experienced as constraints to meaning-making and discovering quest stories (2.2.1). Deconstruction or an unpacking or undoing of the discourse of dualism, modernism and God-talk, has aided my understanding and meaning-making of patients' stories and experiences of living with a terminal illness. In allowing Christine, Gafsa and Margaret to deconstruct or re-think their ideas and experience of God or their God-talk, helped them to re-identify the God of caring and nurturing, the God of Grace that they knew in their hearts. This God-talk was silenced or overshadowed by the God-talk of sin and redemption, the punishing, testing God, that was centralised in patriarchy, socially constructed religious discourses and 'church-talk'.

5.2.3 Dualism

The concept of 'dualism' started to germinate as a strong reaction to experiences of patriarchy in the environment in which I live. Dualism, I perceive to be a situation where one group is placed in opposition to another. In feminist writings, dualism is seen as a relationship where one group is in domination of another and sees itself as being significantly different and consequently treat the subordinate group without distinction (Boss 1996:41) – everybody in the group is seen to have similar traits and to behave and react in a similar way to each other. These patients are further marginalised by being denied a voice as the dominating group presupposes answers without asking clarifying questions.

According to Boss (1996:41) 'dualism', in feminist writings, signifies a relationship of domination, yet at the same time, the power discrepancy is denied or made invisible. Dualism has been described as heresy, as splitting God's creation into good and bad (Boss 1996:42). Bosch (1991:441) quotes Gutiérrez who says that salvation 'embraces every aspect of humanity: body and spirit, individual and society, person and cosmos, time and eternity.'

This splitting of the body and the spirit/mind (2.3.10), is for example, also evident in the boundaries created by modern medicine, and may present obstacles to a holistic practice. Psychiatric hospitals are usually located in a geographically separate area from general hospitals. During my nursing training, patient care was very fragmented: some nurses took patients' blood pressures, others did dressings and others gave medication. This differentiation of training had the effect that patients became a 'diagnosis' and they were 'not understood as people with illnesses'. Nobody was trained to look after the whole person.

This dualistic spirit/body split I see in opposition to the God-Self (1.4.1.2 & 2.3.10.4) unity that I re-discovered during the research process. The experience of the holism of the God-Self has been a long road for me to identify and accept, as I too, have been nurtured as an academic in the modernist era with its separation and differentiation that sometimes fragmented the care that I wanted to give. The body and the mind/spirit have been studied as two separate entities: knowledge of the body is something that we can learn about and therefore, control. This knowledge base is very useful during pain management methods and discovering the causes of pain. Scientific knowledge in this regard has assisted medical professionals as well as patients to manage pain (3.2.3), but effective pain management can only be achieved through acknowledgement of all the aspects of the person – the ‘whole’ person – as pain is not only physical pain, it is spiritual, psychological and social pain.

Foucault (McHoul & Grace 1993:59) talks about the interrelationship between knowledge and power. Having knowledge about somebody's body provides professionals and patients power over their bodies. Foucault (Fillingham 1993:74) noted that ‘opening up the corpses’ gave the medical professionals the opportunity to subject all of the body to the ‘scientific Gaze.’ This scientific gaze empowers medical professionals with the status to prescribe to patients how they should care for their bodies. This power/knowledge opened up opportunities for better health care for the pain and symptom management of the terminally ill person. However, as with all power/knowledge and scientific gaze, the danger of disenfranchising patients from their own knowledge, confidence and responsibility regarding their own bodies and care developed simultaneously.

Medical knowledge and control of the body sometimes marginalised the spirit or mind resulting in a spirit/body dualism. Empowering the body part of the dualism, which is part of the scientific gaze, has resulted in centralising the importance of the body and emphasising the physical and medical management and symptom control of illness. Being able to quantify and manage physical needs created the space and opportunity to venture into the unknown and uncertain spiritual area of care. The importance of finding a pathway to the spiritual is illustrated in Chapter 3 and 4, often the physical emphasis provided the opening to the path, as it was less threatening.

5.2.4 Scientific/Modernist era

The emphasis and reliance placed on the knowledge from the scientific era, has resulted in a splitting of our understanding of the spirit and the body. Stuart (1996:24) recognises that we have to learn to recognise the interconnectedness of all matter and the pain and damage that is caused

when the interconnectedness is denied. I have argued that there is an interconnectedness and interrelationship between the mind and body and therefore the distinction between spirit and body splits the God-Self. This spirit/body dichotomy could be guilty of 'amputating' God from the world. Death, to these feminists (Stuart 1996:24) is 'seen as a natural process in which we return to the earth - God's body - which gave birth to us.' Dualism disallows the patient from being part of God's body while living. This is not, however, what I experienced with Margaret's 'holy time' when she experienced God as part of her body. To me it appeared as though Margaret's spirit/body had become one, this was the light (2.3.10.5) and the meaning-making that was part of Margaret's illness experience. Margaret said that the illness enabled her to get closer to God. The 'light', I experience as the wholeness that occurs with re-inviting the spirit into the body, the interconnectedness of the God-Self. The light can occur during life as with Margaret (her holy time), Emma (feels God's presence) and Angie (she knew the church and community held her) and can be witnessed in death, as described by Shihaan, Taurick's wife, when she said, 'he is at peace now, he is with God.' It could be that the God-Self enables the 'light' to shine on: 'Relationality, just relations, which overcome the social death of uncaring, unsharing egotism, will be the true manifestation of life to the full, where death has lost its sting forever' (McEwan 1996:40). Through the research I came under the impression that the important task for carers is, therefore, to nurture life in all its facets making it enjoyable and enriching for all.

The exclusive reliance on the scientific during the modernist era and the development of knowledge/power, has split us from our 'spirit-self', resulting in a need to be self-proficient, self-reliant and independent, encouraging the accumulation of wealth and the building of high walls to protect our privacy and hide perceived lack of knowledge/power. Lack of knowledge/power is seen as failure, consequently, secrecy and confidentiality about illness is preferred, making patients dependent on 'paid for care'. A question that came to mind in this regard was: Could being secretive about illness protect the patient from a perceived lack of control or power that he/she could experience as failure? Christine (4.3) sees her illness as God testing her and did not share it with anybody. What would sharing her illness with someone mean? Could it expose to others a weakness that needs to be tested by God? She said that her family has always been very private and pride themselves in managing alone. I question the usefulness of managing alone as Hospice now visits her every second day and she is very grateful and dependent on these visits. They sustain and nurture her. Could it be that Hospice brings the community or body of God into relationship with Christine? I believe that the discourse of belief that failure is punishable by God and, therefore, needs to be hidden, is a reflection of dualism, patriarchy and the medical model, which is based on modernism and 'truths'.

Discourses within curative western medicine model may actually regard the death of a patient as a 'failure' on behalf of the medical professional or the power/knowledge base of the discipline (1.1.1). In this argument, health becomes an ultimate aim of not having disease or illness, anything else as failure. According to Clinebell (1996:32) such death-denying practice 'tends to be used to support illusions of control over the uncertainties, contingencies and vulnerabilities of the many experiences that really are beyond human control.' Angie (4.5.2) saw illness and dying as the failure of her faith as Father Joshua would heal her if her faith were strong enough. Angie's physical deterioration was perceived as a failure of her faith, which she understood to be within human control. Death to Angie would, therefore, be a consequence of 'punishment' for 'weak faith.' The splitting of the body and the spirit has made us lonely and scared of the failure and the unknown. The dying are taken away to die in hospitals or hospitiiums, the aged are taken to homes and frail care centres, and strangers are paid to look after them.

Through home-care and the empowerment of family and the community, Hospice aims to restore wholeness through interacting and interconnecting all 'parts of the mind/body', the family, community and environment.

5.2.5 Reflections

Hospice recognises death as being part of living for 'it recognises dying as a normal process' and death loses its sting (McEwan 1996:40). The challenge to hospice workers is to recognise the significance of pastoral care practices (2.3.7) and to find ways of including these on an equal footing with physical care practices, which will nurture the connection of the mind/spirit and body. The Hospice philosophy (1.1) creates the space for respectful narrative practices by being non-prescriptive regarding illness and dying. Hospice creates space for nurturing hope and resisting expert knowledge and created the opportunity for me to do this investigation of terminal illness.

5.3 The Development of the Research Curiosity

There were two parts to the research process. One was personal - doing and writing the research and the other, acknowledges the personal/professional to include the patients and the community. In other words, the personal became part of the professional. They were not separate processes, one continually influenced the other, through constant reflection, re-writing and re-interviewing and the interaction of processes, the loose ends started to connect as I describe in 1.7.1. In this way the research process, I, enabled by the patients' stories, carried out 'co-searching for new

knowledges' (Kotzé 2002:25), and upon reflection, willed me to reposition my thoughts and experiences.

In the beginning of the research journey, when I was confronted by the interaction between Adriaan, his family and the doctor (1.1.3), I was very keen to expose the disenfranchisement and disqualification of all, except for the 'expert' doctor, not realising that even the doctor was affected by the power/knowledge interrelationship and modernist discourse. The abuse of the power/knowledge relationship that existed when the doctor disregarded the relationship that I had with Adriaan and his family and Adriaan's voice in regard to the illness and his preferred way of living, initiated the research journey.

Through the interviews and conversations with patients, my motive changed from exposing a personal experience of injustice and marginalisation to exposing and celebrating the wholeness or God-Self that I experience with patients that are terminally ill. Instead of fighting for recognition to be heard and acknowledgement I started actively *doing hope* (Weingarten 2000) in my hospice work. I started to share the *light* that I experienced during the conversations I had with patients and these in turn helped me to identify undiscovered areas of *light*. This light speaks not of a centralised light as *the* answer but more as an "earth-up" rather than a "sky-down" metaphor that Sally McFague (Clinebell 1996:117) uses when thinking about earth-caring resources in eco-feminist theology as she describes the world as a meeting place with God and sees humans as 'inspired bodies deeply interrelated with all other bodies.' This light speaks of the circle or the sphere as the model of church favoured by feminist theologians as opposed to the triangle within tradition churches (Isherwood & McEwan 1993:85). It is an inclusivity and interconnectedness of all that is part of the universe.

Margaret's 'holy time' and experiencing her 'inspired body' and light, enabled and propelled me to honour Taurick's community of concern and to broadcast Emma's experience of the value of life and wisdom around good parenting and drug abuse. Experiencing the light challenged accepted boundaries.

5.3.1 Challenging boundaries

Narrative practices, pastoral care and feminist theology enabled me to venture into the area of spirituality that I had previously been excluded from in my nursing practices. The practice of deconstruction of Margaret's God assisted the discovery that Margaret is worthy of God's Grace.

This development reflected directly on me as I, too, questioned my worthiness of God's Grace. This re-visiting of Grace became available to me through the work of Riet Bons-Storm (1996), a feminist theologian. Identifying the significance of the 'grace' part of God as opposed to the patriarchal God, gave credit to the unique contribution I, as a woman, have to wholeness and inclusivity of all. Once I realised that the skills of 'grace', such as listening to someone, taking time to care and nurture that could be a catalyst in reconciliation with God, family, neighbours and oneself, is all part of pastoral care, I felt empowered to engage in conversations about sacred spaces. The significance and importance of Emma's experience of God and Angie's quest for a more just God, encouraged me to recognise and encourage talk about a personal God. For the first time in my 30 years of nursing practice, I can start to say that my patient-care is becoming holistic in practice - it includes the social, psychological, physical and spiritual aspects.

The ideas of confessional and contextual approaches to theology helped to clarify what I experienced in the research process. Confessional theology sees the Bible as being focal and the ultimate source of knowledge and definition of the norm. Training of clerical 'experts' is the main focus of orientation and clerical work is orientated towards the church and its ministries (Wolfaardt, et al 1995:7). In medical practices the reliance is heavily on scientific knowledge and investigation and is geared to training medical professionals to guide the patients. The contextual approach is a 'reflection within a living community about human experience and interaction, involving a correlation of the Christian story and other perspectives, leading to an interpretation of meaning and value, and resulting in everyday guidelines and skills for the formation of persons and communities' (Wolfaardt, et al 1995:11). The contextual approach recognises the communities and experiences of patients as being a valuable contribution to the interpretation of meaning and value of quest stories. This approach is inclusive of everybody that is part of a community and acknowledges the valuable contribution anybody can make as pastoral carers. The significance of the correlation between the contextual approach to theology and the contextual approach to medical care, helped to identify the value of being inclusive of the contextual approach to terminal care.

The God-talk that I had with patients included the body of God, the community. Discovering that the community is part of God, was a slow process. At first I was moved by how Margaret involved herself in the care for her community, even when she had pain and discomfort. Then I met Mercia, and her generosity of spirit and willingness to take care of Margaret and her family, sensitised me to notice other places and incidences where community had significance. The involvement of Jacobus and Fred's neighbours was something foreign to me; the medical student questioning of

wealth, and Mercia and Margaret embracing Emma - finally lit the spark. The community is the body of God; it contributes to renouncing the dualistic God that separates body and spirit.

5.3.2 The personal journey

The process of recognising the sacredness of the community of concern and support was part of a journey of writing and rewriting the chapters of the research. Slowly the ideas took shape as I re-told the stories of the participants.

My parents accompanied me on a four-day sabbatical to our house at the coast. My parents acted as my carers and admirers and as an outsider witness group (White 1995b). I spent 4 days reflecting on re-telling of the participants' stories. It was a very exhausting journey through my life and the lives of the patients. I was moved by the apparent coincidences, the courage and beauty that I experienced in telling and re-telling the stories, in writing and sharing them with my parents. Telling the stories to my parents helped me to find the quest stories, through the re-telling the chaos of emotional experiences, the light and hopefulness of the stories, started to emerge. It was a personal journey through which I was nurtured, fed and held by my parents, both physically and emotionally. Their encouragement came from honouring the patients' and my stories as being special (White 1988: 8-14). I had not yet identified it as 'special' for I was part of the chaos story. Through their witnessing and stepping out of the everyday rush of hospice work, I had time to honour the participants' stories. My parents' admiration, celebration and witnessing of the stories encouraged me to continue the re-telling. My parents' support and position as an 'outsider witness' group assisted me to progress towards 'settled stories' (Waldegrave 1999) around working with patients who have a terminal illness. I would like to call them '*settled quest stories*', as these stories have become meaning-making of the Hospice work I do.

5.3.3 Divorcing the personal to expose the spiritual

In writing the research story I was astounded how in Chapter 3 the story of Margaret and Emma became entwined, how it became 'community'. Margaret's care included Emma in her community of concern and Margaret's friend, Mercia, embraced Emma. I do not know if it was because I instigated it or if it was just bound to happen because of the community experience, because that is how communities surely work. Could it be that if communities (the body of God) are nurtured, the spirit and the body start the interconnecting process to becoming whole? Could it be that the

energy of the 'God-Self' propels nurturing and caring to develop? I propose that that is exactly what did happen.

5.3.4 Weaving personal, professional and political

The personal has again become professional and political. The research curiosity has forced me to think and re-think and to connect, to weave stories and to experience meaning-making of terminal illness. I have translated my personal story of experiencing a personal God-Self to include the experience of the patients' personal God. Christine's testing and Gafsa's punishing God and Angie's experience of a God that rewards with faith, were strangers to me. I did not know their God personally, but became comfortable in the presence of their experience of their personal God. I acknowledge and honour the sacredness of this personal God, even though I question the justice of patriarchy and omnipotence present in their stories.

Entering into conversation with each patient's experience of their personal God, we were able to unpack their experiences with their personal God, attempting to move beyond spiritual stories of a testing, punishing God. Together we identified the Other, the God of Grace, who is available and present to all. Gafsa found a way to allow herself to take morphine by drinking morphine that looked like 'water', she could convince herself that she was not taking pain medication and was, therefore, managing her pain graciously which she saw as a pre-requisite to earning God's grace. Christine knew that God cared for her more than she cared for her daughter, which allowed her to also take pain medication and accept the help from Hospice. Margaret experienced herself as being worthy of God's Grace and did not have to earn Grace, she could find comfort in God's care and nurturing, - in knowing God's presence.

5.3.5 Swimming in feminist theology

I was exposed to the confessional discourses of religion as a child and have always thought that theology was religion. In deconstructing theology, I discovered spirituality and feminist theology which supported many of my ideas. It was like discovering an oasis, I immediately jumped in boots and all, drank all I could and floundered because of the heavy baggage of preconceived ideas and misconception around feminism and theology. I discovered that feminist theology was about 'establishing the unity and inter-relatedness of all creation' (Waldron 1996:65). I was also introduced to feminist spirituality that permeates the political and personal realms to animate action

as one of its responses to a God whom it believes to be loving and just, leading to mutuality, acceptance and justice for all (Waldron 1996:67).

The knowledge around feminist theology liberated and propelled me to find ways of making hospice practices inclusive of patients, family, community and Hospice professionals and carers. I did this through actively engaging in getting to know neighbours and family members of patients and talking about hospice care in churches and being involved in hospice community fundraising projects like the big walk. This I did with the aim of making our interconnectedness as human beings visible, to work towards the creation of small pockets of communities, to emphasise "interdependency and mutuality" (Hogan 1996:202).

Establishing unity and inter-relatedness in the caring team at Hospice has also exposed the patient's role in the caring team emphasising and acknowledging the equally important role of the patient and his/her knowledges within this caring team. Emma and Margaret benefited greatly from their involvement with each other, day care and their communities as well as their management of illness symptoms like pain, nausea, constipation and urinary tract infections.

I have found a spiritual home in feminist theology. It helps me to address the injustices that I perceive on a daily basis in my work and where I live. I very strongly identified with the God of Grace after reading the article of Riet Bons-Storm (1996) and it contributed largely to meaning-making in my life and has, through the inter-relationship that I have with the patients, contributed to meaning-making in their lives. Riet Bons-Storm (1996:133) said that 'women and men can only be liberated and made whole if they dare to risk taking "Grace" seriously. For Grace is amazing; it distorts all patriarchal power relations, and has the power to make things change.' This was clearly recognisable with Christine, once she recognised the God of Grace, she could take pain medication because she realised that God loved her, more than she loved her daughter, and she would not wish her daughter to suffer.

It has been a 'risk' for both me and the patients to enter into their sacred spaces and to allow me to engage with their sacred experiences of having a terminal illness. They did not know if I would tread gently and respectfully, as their experiences had been to the contrary, their views had not been previously valued. Through Margaret, Emma, Christine and Angie 'daring to risk' taking Grace seriously and including my graciousness, they have come to acknowledge the Grace of God.

5.3.6 Reverence of the sacred

Awareness of the contradiction to dualism, *holism*, along with the process of being made aware of relationality (Frank 1998) has helped me to experience that we are not only made in God's image but that we are part of God, we are the 'self' part of the God-Self. It becomes possible, therefore, to treat people with the same reverence as we treat God. This understanding has opened the door to see people, the community and the environment as being the body of God and as sacred. Patients, the body of God, deserve reverence, and to be empowered with knowledge/power to resist marginalisation by medical professionals.

This research has highlighted the need for pastoral care to be part of professional medical practices. Using ideas of inclusivity and a weaving of mutual and pastoral care and counselling enabled me to include these practices into nursing procedures.

I now will reflect on the research questions.

5.4 Reflecting on the research curiosity questions

I will, however, separate the research questions again for one last time in order to reflect on the questions that I posed in Chapter 1. The research questions were;

- What significance does community support have during terminal illness?
- What are people's preferred ways of storying terminal illness?
- How does spirituality contribute to meaning-making of terminal illness?

5.4.1 What significance does community support have during terminal illness?

The understanding of the concept of community and community support has been a continuous developing process. I have always recognised the importance of friends, but I am shielded from experiencing the impact of seclusion, because I have a family and an extended family that live close by. I am involved in working with the community and live on a community-run farm and have money for transport, entertainment, care and have the electronic means to communicate when I choose. In marginalised communities these commodities (entertainment, cars, telephones) are not available to shield people from loneliness and neglect. People are dependent upon each other for companionship, entertainment, support and care, for everyday living.

What I started to experience is that the communities can be likened to the body of God. The mutual caring and nurturing that I experienced from the community for Margaret, Jacobus, Fred, Emma and Angie had a direct influence on disempowering the patriarchal, dualistic God and inviting the God of Grace. Taurick and Angie experienced wholeness through the power and influence of the community, the community sustained them daily, they felt the caring and nurturing that they received.

The medical student 1.1.4 saw 'wealth' in the communities that he visited even though there was extreme material poverty, he witnessed the interconnectedness, interdependence and mutuality. This knowledge compels professionals to engage the community of care in a way that is to the patient's benefit. One of the ways of doing this is to ask the patients and their families how they would like the community to be involved and how we could assist in this involvement. Failing to do this, we will be guilty of neglect and fragmented care. Disqualifying and disenfranchising the 'body of God' prevents holistic care. We, as professionals, are therefore compelled to find ways of overcoming negative stigmatisation and 'confidentiality' practices (3.4.1) through engaging the communities in our patient care practices actively promoting inclusivity and relationality. Asking patients how the community can be involved in their care and what they prefer the care to look like, is the first step to inclusivity.

There are patients who do not have a community available to call upon. In these circumstances we are required to be creative and engage a community on the patients' behalf, always with their permission. Church communities, welfare organisations, ladies' clubs, golfing partners, business associates or neighbours could be part of a community of concern. Involving the community cannot be enforced and has to be dealt with, with circumspection and, delicately, as you would handle a pansy shell. If patients decide that they do not want to include a community in their care, it is a matter of choice and we have to respect the wish. However, if we have been invited into a home we should be prepared for 'emotional involvement, intimacy and tenderness' (Sevenhuijsen 1998:2). This will not replace a community, but will assist in bringing a part of the 'body of God', ourselves, contributing to holistic care practices. Often patients comment that they feel a lot better after a visit from a friend or the hospice caregiver. I believe that the God of Grace, the nurturing-caring part of God is responsible for this feeling of wellness and well-being. Community support is, therefore, an essential part of experiencing God-Self and meaning-making quest stories of terminal illness.

5.4.2 What are people's preferred ways of storying terminal illness?

I would like to repeat two quotations I used in previous chapters. Michael White (1995a:30) said, 'We have to be very sensitive to the issue of language. Words are so important. In so many ways, words are the world.' Andersen (1991:30) said that 'Language is reality. It gives order and meaning to our lives and the world.' The use of language and words has been the one area, which in my experience has contributed most to understanding and meaning-making of terminal illness stories. Margaret experienced 'healing' as getting closer to God which alleviated the pressure on being physically healed and made the illness-time meaningful. Writing this dissertation has been a great challenge to me as I am very aware that the words I use have a unique meaning to me. It has, however, helped me to be vigilant about how I speak about illness and dying.

Patients' preferred ways of storying or talking about illness may not be seen in isolation to their community and spirituality. The meaning of illness and talking about death or dying is directly related to the meaning they attach to spirituality and the community. If the patient believes in life after death, she/he may prefer to talk about 'going away', or 'moving on' like Tant Bet, or even 'passed away' like Josef spoke about Taurick, or to 'go in peace' like Angie. The professionals talk about dying or to die. I wonder what that means to the patients? Is 'dying' maybe too final a word to use because it does not include the possibility of being part of life - it is an end state, which not part of the process of living. I believe that patients and family may find comfort within metaphors like 'going in peace', 'going away' or 'moving on'.

Thinking of Derrida (Sampson 1989) and his words that deconstruction means to put the words under erasure, for lack of a better word, 'dying' or 'death' is what we use. I believe that for this reason it is more appropriate to ask what word or words a patient or his family would like to use when talking about the dying process? Words need to be clarified and deconstructed as 'words are the world' (Andersen 1991:30) and therefore create reality. Words that need to be deconstructed may include the word preferred for 'God' or words to describe pain or the meaning of health. Margaret saw 'being healed' as getting closer to God and Shihaan experienced 'peace' when Taurick died and 'faith' according to Angie is when God took the illness away. The significance of words used may assist the patient and our understanding of the illness. Through deconstruction of a word, words like 'healing', 'faith', and 'peace' could be clarified and contribute to meaning-making and significance to the patient, his family and the carers.

5.4.2.1 Enfranchising language

There are also ways in which talking about illness can either include or exclude the patient and the community. I think here of excluding a family member from doing wound care because as professionals, we know better. This I have encountered in my daily work. Family carers feel incompetent in the presence of professionals. They ask their opinion when they have managed perfectly well without help. Our choice of words such as 'this is how it is done' or 'the correct way is', often disqualifies the families and communities of care, disqualifying invaluable care. Often expert knowledge and judgement dictates language use, and in effect could impact upon community and family involvement and contribution to the patient's care. Asking patients or the community about how they would like to be involved in the patient care or how they do a procedure and acknowledging and noticing what they do 'right' encourages community involvement. Saying: 'I think you have done this dressing well, it looks clean and well cared for, would you tell me what you did?' or 'How could I assist you with the management of the dressing?'

5.4.2.2 Metaphors

The use of analogies or metaphors to describe medical care can also contribute to inviting participation in an area of physical, emotional or spiritual care, which previously may have been seen to be strange or beyond understanding. To illustrate the use of metaphors, I related the story of 'The Lost Mother Moon'. The story of 'The Lost Mother Moon' helped me clarify concepts such as community involvement and participation that I wanted to describe, by allowing me to disentangle from the chaos illness stories into a fantasy realm which was less emotive but opened up more opportunities to understanding.

Emma (Chapter 3) used a metaphor to describe her debilitating pain, she saw the pain as a jackal and methods of pain control are ways of ensuring that the jackal does not escape. Telling people that morphine and codeine belong to the same family, help to alleviate the fear of taking morphine. I also think of Gafsa, she finds drinking morphine, that looks like water, easier than taking pills because she can convince herself that she is handling her pain more graciously drinking 'water'. I now talk about the 'water' that Gafsa drinks for pain. Using metaphors were for some of these patients' preferred ways of storying illness. As Michael White (1995:30) said, '[i]n so many ways, words are the world', words contain the promise of an opportunity to create a more comfortable or pain-free 'world' for patients with the appropriate, relevant choice of words.

5.4.2.3 Narrative therapy practices

Narrative therapy practices and language use has been very useful in meaning-making of patient's 'lives' who live with terminal illness. Deconstruction of events and suffering in the patient's life highlights the usefulness of rather talking about pain-free times; moments when the patient got out of bed and sat on a chair, the visit from a friend or the caring and nurturing experienced from God. It does not deny or disqualify talking about the hardships of being ill, the loneliness of the long nights and the punishing God. The hardship, pain and anguish are identified and contained and then conversations around 'sparkling moments' make space for discovering 'unique outcomes' which can assist meaning-making quest stories, this could be a part of *doing hope*.

The narrative practice of externalising conversations and in this case illness, has been a major contributing factor to encouraging self-agency of 'living' with illness. The patient is seen apart from the illness or pain, which opens up wondrous sacred spaces of community, family, friendship, spirituality, wealth and caring, as conversations about the 'other' become more easily available. When speaking Afrikaans, externalising seems to be an integral part of the colloquial speech. 'Die siekte – hy lol met my' as opposed to an internalised languaging: 'My pain is unbearable.' Translating the nuances into another language reminded me of Ortega Gasset (Becker 1991:226) who says:

...each language represents a different equation between manifestation and silences. Each people leave some things unsaid in order to be able to say others. Because everything would be unsayable. Hence the immense difficulty of translation: translation is a matter of saying in a language precisely what that language tends to pass over in silence.

Speaking Afrikaans has been a good practising ground for me and I have found that being comfortable with the externalised way of speaking (talking about the illness being external to the person), has assisted the patient's to experience their symptoms differently. Talking about pain as being external has assisted understanding of the areas, types and treatments for the pain. Valuing local vernacular and using it has helped to bridge the gap between being an 'expert professional' and being an integral part of the community of concern.

5.4.3 How does spirituality contribute to meaning-making of terminal illness?

The poem I wrote on *The Light* was the beginning of this research journey. I had the words on the computer and added thoughts on nearly a daily basis. The poem is still not complete; for holism is a developing, continually inclusive process of understanding. It is something such as *doing hope*

as hope too is guided by light. There are times when the sun sets and the moon is dark, when the injustice of patriarchy saddens and angers me and makes me feel vulnerable and impotent. These times I reflect on poverty and crime, on rape and violence, on autocratic management styles, unjust laws, wars and abuse of the environment. At these times Mother Moon drops her cloak and the warmth and nurturing from the light becomes the hope. The hug, the flowers, the smile, the peace on somebody's face when they have died, the joy and laughter, these things are all part of the light, part of the body of God, they make up the God-Self. They reconnect me to the eco-feminist theologies that identify that 'all things are related and interdependent' (Clinebell 1996:116) and the hug, smile, peace and laughter remind me to recognise the light and hope of a God of Grace.

The patients also talked about experiencing the warmth and nurturing of the God of Grace through visits from friends, the church community, being pain-free and going to Day-care. They also find God in flowers, the visits from Hospice, sunshine or a back rub. All these aspects are part of and indicative of the spirit or spirituality that makes life worthwhile and engenders a sense of wellbeing. The patients' spirituality or spiritual experiences with the community and the environment encourages the patients to feel included and worthwhile as part of the body of God. Angie and Margaret experienced their lives as being worthwhile and contributing to the body of God - as contributing to the well-being of their communities when they could share about their illness experiences with their church members. They experienced contributing to the understanding of others about serious illness and identified various coping mechanisms helping to make others more sensitive to the plight of those who are ill. Both Angie and Margaret said that they were pleased that they could contribute in some way to making the illness experience easier for both carers and those who are ill.

Pastoral care practices help to ensure the significance of being inclusive of spirituality in all our practices with people and the environment through connecting with the whole person and all his/her needs. Recognising the spirit and body of God, nourishes our care practices and creates the opportunity to experience the significance of the patients' and our own spirituality and sacred spaces. Spirituality is that which appears to give meaning to the experience of a terminal illness according to Margaret, Emma, Shihaan, Christine and Gafsa, it is one of the main ingredients responsible for meaning-making quest stories. Margaret sees her illness as an opportunity of getting closer to God, Emma sees her illness as a second chance, Christine has identified the God of caring and nurturing that would not make his/her children suffer and Gafsa experienced graciousness with the help of morphine. Spirituality contributes to the interconnectedness of the God-Self and experiencing hope and *light* in this connectedness as a part of celebrating life.

The research process has highlighted areas of future challenge in Hospice work and ways of honouring patient's stories.

5.5 Future challenges

I recognise that the future challenges are fundamental attitude changes that are difficult to achieve in a scientific/modernistic medical model approach to palliative care, but stories of hope allows the gift of dreaming about transformation of medical/therapy practices that honour patients' stories and sacred spaces.

5.5.1 Legitimising nursing pastoral care practices

I have argued that nursing practices are pastoral care practices (1.3.1.10), but that nurses are disenfranchised from using these practices with confidence and creativity because they are not seen as the 'experts' in this field. Making a stand against these disqualifying practices is partly the reason for writing this dissertation, but the audience is not big enough to make any difference to the situation. While teaching various home care workers and nurses, I have emphasised the importance of patients' spirituality and the necessity to create a space for patients to 'story' their personal God and meaning-making experiences and have emphasised that spirituality belongs to us all, not only the ministers or pastors. I hope to influence the Hospice syllabus for nurses and will send a copy of the dissertation to the Hospice Association of South Africa.

5.5.2 Expanding community care

I have spoken at length about the importance of expanding community care, especially in Chapter 3 and have highlighted the sacredness of the community as part of the research questions. Expanding the community of concern of patients involves asking the patients *who are* and *who can be* involved with their care. It is also important to be inclusive of people who offer help and to find a way in which this help can be of benefit without compromising the patients' need for privacy or confidentiality. Interacting and co-ordinating community resources like churches, schools, clinics and non-governmental organisations can also be a very valuable community caring resource. The belief that the community is sacred and invaluable is, however, the main ingredient to motivating community involvement as every opportunity that presents itself will be utilised.

5.5.3 Legitimising storytelling practices

Storytelling is often seen as a time-consuming and ego-boosting practice. The recognition of the significance storytelling has to meaning-making of terminal illness and the ability that listening has to validate stories and honour storytellers, elevates storytelling to surely the most important therapeutic practice that can be employed with patients who have a terminal illness. I have told the stories to a few other patients, and have become aware of how the impact of these stories have not only directed my nursing approach and added meaning to the work I do, but has also directly influenced the practices of my colleagues and patients' families. Storytelling is becoming part of my professional practice.

5.6 Resolution Invitation

Reinharz (1992:195) said 'Perhaps we can only hope that our research will clarify our vision and improve our decisions.' This is certainly what happened; finding the significance of the God-Self, storytelling and listening, has been invaluable in directing respectful patient care. I recognise that there are no definite answers or right or wrong ways of doing nursing/medicine or therapy, there are so many variations and shades of grey. I also know that it is not very comfortable having this knowledge as it leaves the caregiver with little structure or finite direction. A recipe is always very helpful and the end product usually 'looks' a lot better than if all the ingredients are just placed in front of you without instructions. Maybe it is time that we played in the flour and found new things to make. We could make cakes with icing on top, but what about paper maché animals or dough beads; we could make gingerbread men or a poultice for an infection. The limit is endless, but there is a lot of room for uncertainty and experimentation and the results may be wondrous and amazing.

The qualitative research approach invited experimentation with ways of listening to stories and establishing a relationship with the patients. Taping the conversations reinforced the 'listening' practice, as patients new I would replay and transcribe their stories. This process impressed them and it had great significance to them, as their stories had not been heard with the same interest before, their stories were notably important. The poems gave me the opportunity to, without many complicated words, reflect and acknowledge significant aspects of stories, bits of 'gold' (Wylie 1994). These poems have been laminated and displayed on lounge walls for all to see, again reinforcing their value. Listening to stories and the continued care and interest has contributed to establishing a relationship between the patients and myself, which is a 'gift' to all involved.

I have been humbled by what I have experienced and writing the stories has been a very moving experience for me. It has been a wondrous amazing journey into not only the patients, but also my own sacred spaces. I have questioned my beliefs about God and spirituality and have adjusted those through weaving my own and other people's stories into a 'garment' that is adaptable to many situations. I want to say that I own a chameleon coat, as this is a work in process, and not an end product. My mind has been racing and has been finding connections and making meanings from experiences, which have been recollected in the storytelling.

The interconnectedness, the relationship of 'self-other' (Heshusius 1994), has made it difficult to separate the patients' stories from my own. The colours merge as with the 'chameleon on the rainbow', often making separation of the stories, difficult. I believe that relating my story is a prerequisite to understanding the patients' stories as the relationship of interconnectedness requires a 'being with' the Other and is thus part of the Other.

The patients I interviewed gave feedback that they felt heard and held through telling their stories and thanked me for the honour of having their stories told. I can only humbly thank them for allowing me to journey with them. I recognise that I am only on the sidewalk, I am not aware that I am walking the final stretch. I am just a co-worker who has been allowed, at times, to hold a hand and I was carefully guided closer and have been part of the experience of co-journeying with them. What I have gained is not something that I can quantify. This personal gift that I have received, so many times over, moves and directs my action. The generosity of patients allowing me to experience their sacred spaces has propelled the personal to become political fuelling my resolve to honour sacred spaces and voice their stories of terminal illness.

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CONSENT FORM

Elizabeth Scrimgeour has explained that she would like to use my story as part of her research for the completion of her masters degree in practical theology. I am reassured that she will be respectful and ethical in the use of my story and will not reveal my full name at any stage. I have agreed to having our conversation taped and this will be transcribed by somebody else.

SIGNED:

Date:

SIGNED:

Elizabeth Scrimgeour

