THE STORIES WOMEN TELL: LIVING WITH CANCER AND CARE

by

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This research was aimed at listening to the care stories of people living with cancer in remission. The participants spoke about relationships with their families, medical professionals and their spirituality, thereby giving a voice to personal experiences of cancer as part of family life.

Postmodern social construction discourse guided the explaining of how cancer invades and affects people's lives and relationships. This participatory action research was situated in a contextual practical theology.

Narrative conversations with the participants spoke about experiences of both care and communication by medical professionals, their struggles in communicating with their partners and families, their spiritual search and longing for pastoral care to sustain and guide them.

Key terms:
Cancer, women living with cancer, relationships, communication, medical profession, spirituality, care, ethics of care, narrative pastoral, contextual practical theology, qualitative research, participatory action research.
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CHAPTER 1

INTRODUCTION

1.1 BACKGROUND TO THE RESEARCH

In this chapter, I provide an overview of the path the research followed in the literature study and conversations with the participants telling their stories of their experiences living with Cancer\(^1\). I also guide the reader through the research paradigms and process. The paradigms used were social construction discourse, qualitative research and participatory action research. The participants and I co-constructed the research process. The background information set out in this chapter also covers my personal interest regarding Cancer and people living with it.

As I live in South Africa, with its many cultural differences, it should be noted that the voices of the literature included in this study express Euro-American cultural perspectives. It should also be noted that the participants come from a Western cultural background and that their stories reflect this.

1.1.1 My own experience and illness

My curiosity about ‘care’ with regard to a person who is ill and nearing death, and my interest in that person’s family grew out of my personal experiences with my grandmother, who suffered from Alzheimer’s disease and my aunt, who suffered from Cystic Fibrosis. These two women in my life both died of the disease they had suffered from, and in both situations, I felt a void, an emptiness that I could not explain.

I started wondering what it was that I had missed. What was the emptiness that I was feeling? What would have filled this void for me? The answer for me was simple. The void was caused by a lack of care for both patient and family. During my grandmother and my aunt’s illnesses, there was no one who helped me to deal with their impending deaths, someone who could perhaps have shown me how to talk to my grandmother and aunt about their illness and dying, someone who could have assisted them and me in the process of letting go and in saying goodbye to them.

\(^1\) Cancer will be externalised for the purposes of this study and is capitalised whenever it is externalised. See p 18.
My grandmother passed away on 16 January 1999. Not even her immediate family was present. I experienced the same emptiness when my aunt passed away on 6 June 2000. Not a single person, no one from the medical staff, not the physician or the minister, assisted or supported the extended family to realise that the end was near and that it was time to say goodbye.

This is when I realised that what is needed is somebody to facilitate and assist patients and families through the difficult times of saying goodbye to loved ones before they die.

1.1.2 Why cancer?

The reader might ask why I have focused on Cancer patients and their families for my study. I have always wondered about what it was like when Cancer invades a person’s life and how this affects his/her loved ones. So when I decided to do research, this was the experience I wanted to document, as well as the assistance given to the patients and their families at such times.

The dominant discourse for me regarding ‘Cancer’ was that ‘Cancer’ was a ‘death sentence’. Aldredge-Clanton (1998:11) notes in her ministering to Cancer patients that, despite advances in medical technology, the development of alternative Cancer treatments and the increasing number of Cancer survivors, the diagnosis of ‘Cancer’ still evokes images of suffering, dehumanisation and death.

1.1.3 A definition of health and illness

Wolinsky (1980:72-75) examined the collective works of Parsons in his search for a definition of health and illness. Parsons gives a definition of health that is worth considering:

Health may be defined as the state of optimum capacity of an individual for the performance of the roles and tasks for which he has been socialized.

Parsons is also of the opinion that health is relative to a person’s status in his/her society. Illness, for Parsons, means that a person cannot perform his/her socially expected tasks. The person should then do everything possible to return to his/her original state of health as soon as possible, so that he/she can return to the particular task or roles in the social system that have been ascribed to the person. This definition made me wonder whether people are being reduced to their roles and functions in society and whether this definition emphasises a capitalist construction of people. Should people only be viewed according to their contribution to society and not as human beings in trouble? I will reflect on these questions in Chapter 5.
1.1.4 Cancer and care

I started to inform myself by reading about Cancer and its effects on people's lives. I soon noticed that the physiology of Cancer is such a broad field that I had to keep information on Cancer general. In Appendix A, I set out common Cancer terms and explanations for these terms.

1.1.4.1 Characteristics of Cancer

Despite the fact that there are several hundred different types of Cancer, it is still possible to list certain general characteristics. Cancer is a cellular disorder, and so these general characteristics pertain to cancer cells (Oppenheimer 1982:6).

First, cancer cells experience uncontrolled and disorganized growth. Whereas normal cells only divide about fifty times before they die, cancer cells enter the cycle of dividing and reproducing over and over again and never differentiate. Normal healthy cells stop reproducing when they encounter each other. In the body, a cancer cell divides to form a growth, or tumour, that invades and destroys neighbouring healthy tissue. The cells are disorganised because they do not differentiate into the tissue of the organ and therefore they never fulfil the function of the organ. To support their growth, cancer cells release a growth factor that causes neighbouring blood vessels to branch into the cancer tissue. This phenomenon has been termed vascularisation (Oppenheimer 1982:9-12).

Second, cancer cells detach from the tumour and spread around the body. To accomplish this, the cells must often make their way across a basement membrane and into a blood vessel or lymphatic vessel. After travelling through the blood or lymph system, the cancer cells can start new tumours elsewhere in the body. This process is called metastasis. If the original tumour is found before metastasis has occurred, the chances of a cure are greatly increased. This is the rationale for early detection of cancer (Oppenheimer 1982:12).

After I had found out, in broad terms, what the physiological aspects of Cancer are, I decided that I should talk to people about their experiences with Cancer in their lives. Having never before dealt with strangers that had an illness like Cancer, I decided to orient myself by attending seminars offered by the Pretoria Academic Hospital's pastoral division for laypersons who care for the sick. Here, I met Dr de la Porte, who is the director of pastoral service at the hospital. After a couple of seminars, I joined the support groups and, by doing so, I met some Cancer patients. I started off by
speaking to a couple of Cancer patients regarding their experiences, but these were limited conversations due to the hospital environment. These patients were undergoing treatment, so that it was sometimes difficult to find a time that would suit both the patients and me. Conversations were generally about hospital experiences, but some patients did talk about difficulties regarding their families’ involvement or the lack thereof that confirmed the literature in this regard (Aldredge-Clanton 1998; Cullinan 1990; Frank 1991). In addition, I had discussions with De la Porte about his counselling of dying patients and their families. He spoke about the mechanical side to a ‘call out’; mechanical, in the sense that he knows how to facilitate the dying process and that he has developed a certain way of doing things. The farewell is the primary issue. The process starts with contacting with the family, and inquiring about the situation, then moves on to facilitating the parting between the family and the patient, assisting the patient to get everything in order, as well as arranging for the family to see the patient after he/she had died so that the family and friends can start the transition from the terminal sick stage to grieving.

1.1.4.2 Areas of care

What also emerged from the literature (Aldredge-Clanton 1998; Cullinan 1990; Frank 1991) as well as from the conversations with patients at Pretoria Academic Hospital were discourses different to the one that claims Cancer to be a ‘death sentence’ as I had believed it to be. These discourses spoke of areas of care in the lives of people living with Cancer that I had originally not considered. They also brought with them a range of social constructions of illness, which I divided into the three areas of care, which I explain below.

The first area of care was the level of communication between patients and their families. Sometimes one finds a lack of communication between patients and their families due to the keeping of secrets and the hiding of information, all in the name of ‘protecting’ one another. When such secrets are kept, communication between Cancer patients and their families is strained, largely because of cultural stories regarding illness and death. Patients tend to be isolated even if it is only on an emotional level and have to deal with their fears and suffering on their own if there is a breakdown in communication. This isolation can be by choice, for example, where the patient fears that the family does not have the strength or skills to deal with the situation and therefore the patient keeps the details to him/herself (Carter & McGoldrick 1989:3-13). Secrets are discussed further in Chapter 2.

2 A ‘call out’ is when Dr de la Porte is called out to a dying patient’s side.
A second area of concern regarding care was in the medical world where the patients found themselves lost and out of control. Patients experience some physicians as too clinical because they view the patient only as somebody who has to be saved from Cancer. Mishler (1981:243) notes that as medical and chemical interventions increase, the prolonging of the medical process sustaining of the body comes down to the technical expertise of the doctor. Medical knowledge and expertise separate the doctor from the patient and give the doctor special knowledge/power over the patient. Ainsworth-Vaughn (1998:42) comments about ‘structural power’ in medical encounters as the physician’s affiliation with a medical institution, the physician’s knowledge and thus power in these medical situations. Foucault (quoted by Flaska & Humphreys 1993:40) refers to ‘relational power’, which implies that power ‘shows itself’ in everyday interactions. Foucault also argues that the person who has knowledge is the person who has power. Therefore, one of the problems during a doctor’s appointment is that the ‘expert’ opinion of the physician can be imposed on Cancer patients and their families. However, when physicians follow a biopsychosocial approach, which communicates the idea that all problems are biological, psychological as well as social, the patient may find that more of his/her needs are met (Engel [1977] 1992:317). I still wondered where a patient’s spirituality fitted into this biopsychosocial approach: Is there a place for spirituality in this model? I had to conclude that this model opened up the way to increase collaboration between medical providers and psychosocial specialists but does not include pastoral/spiritual care. The biopsychosocial approach is discussed more fully in Chapter 4.

The third area of care was on a spiritual level. Some patients whom I spoke to at Pretoria Academic Hospital wanted to talk about their personal God and faith, as well as the faith crises and struggles they were experiencing, but found no one would listen. I wondered whether this was because, in some Western religions, authentic religious experience involves private intrapersonal dialogues with a personal God (Griffith & Griffith 1994:58-59). Hence, patients do not bring such conversations with their personal God into the therapy room; it is kept outside the awareness of the therapist unless the latter asks (Griffith & Griffith 1994:59).

1.1.4.3 Ethics of care

In thinking about care, the issue of ‘ethics of care’ became important. When care is seen as an activity, it can be viewed as involving the ability and willingness of somebody to see and to hear the needs of others and then for that person to take the responsibility for meeting those needs. Moral considerations arise with the assessment of needs and questioning whether these can be met at all. A caregiver has to find a balance between his/her own needs and those of the patient receiving
care. Moral considerations surface when the caregiver and the person being cared for have conflicting views on what is necessary or possible in a particular situation. Moral considerations become very complex when care is provided in a situation of dependency where the caregiver possesses the power resources. The term 'power resources' is used here to refer to knowledge and the 'know-how' of the caregiver who thinks he/she knows what is best for the person who is being cared for. Those who receive care and are dependent on others for meeting their needs are placed in a vulnerable position (Sevenhuijsen 1998:82-84).

One way to open up space for reflection and moral deliberation on whether the type of care offered is what is needed, is to listen to and interpret the moral deliberations about care expressed by providers and receivers of care. Sevenhuijsen (1998:85) suggests that research on the subject of care can be carried out by talking to patients about their experiences about the care they have received and are receiving on a professional as well as on an informal level. This is exactly what I intended with my research. In this study I had conversations with women with Cancer in remission (see Chapter 3) regarding the care that they had received and were still receiving. Together we tried to establish whether the care given to them was what they wanted and needed.

Walker (1998:7) refers to an 'expressive-collaborative' model of ethics when it comes to care. The crux of this model is that ethics can be regarded as interpersonal, and therefore needs to be negotiated by both the caregiver and the person receiving care. This made me wonder whether negotiation had ever entered the care relationships of the participants that I was to speak to.

Thus the focus shifted for me from Cancer as a 'death sentence' to stories of care. In their sharing of their stories, these patients assisted me in developing the research questions.

1.2 RESEARCH QUESTIONS

The first question that I wondered about was this: What did care look like for the persons living with cancer and their families during the time when they were ill? The second question was: If they had a choice as to their preferences for care, what would that care be?

The importance of these questions for the research was twofold. Firstly, they implied that the participants and I would ascertain together the type of care they have received and whether it was satisfactory. Secondly, it meant that we could determine, if the care received was not to their satisfaction, what they would have preferred the care to be. These questions have a special interest
for a pastoral therapist or spiritual caregiver, and the hope is that it will lead to renewed 'awareness/consciousness' regarding Cancer patients' preferred care.

The aim of the research is to give the participants a voice through their stories so that they can be heard and taken notice of, the creation of 'awareness'. Frank (quoted by Weingarten 2001:120) writes:

The ill person who turns illness into a story transforms fate into experience, the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability.

1.3 GENERAL RESEARCH PARADIGM

In deciding which research paradigm to subscribe to in this study, I looked at various care issues such as valuing the participants' stories as their own, being in the practice with the participant, being flexible in the research process, being able to build an intimate relationship with the participants as well as getting involved in the research topic. Eventually, I decided to use a qualitative research approach, leaning more towards participatory action research. The study is also situated in and motivated by a contextual approach to practical theology. Heitink (1993:175) prefers qualitative action research, in line with the political-critical current in practical theology that argues that a researcher should not remain detached from participants in the study. He therefore argues that the relationship between a researcher and the participants in the research should be a subject-subject relationship. This research is also positioned in a postmodern social construction discourse and such discourses are discussed thoroughly with regard to illness in Chapter 2.

1.3.1 Qualitative research

In Denzin and Lincoln's (1994:4) Handbook of Qualitative Research, they describe qualitative research as an:

... emphasis on processes and meanings that are not rigorously examined, or measured... in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry.... They seek answers to questions that stress how social experience is created and given meaning.

Janesick (1994:209-210) uses the metaphor of a dance to describe qualitative research. One of the reasons for choosing the metaphor of dance was that she views dance as a work of art. She
believes that art implies human experiences. The focus of dance, as well as of qualitative research, then falls on the lived experiences of the researcher and of the participants.

The elastic nature of qualitative research means that this type of research can adapt to the lives of the people participating in the study. So, as this study proceeded, it was the elasticity of the research approach that made it possible to adapt, change and redesign the research process to suit the social realities of doing research among and with the living (Janesick 1994:218).

The qualitative researcher is like the choreographer, who creates a dance to make a statement ...the story told is the dance in all its complexity, context, originality and passion.

I found that there was a continuous reassessment, reflection and refinement of the concepts of the project (Janesick 1994:214) for the duration of the research. This was evident in the adapting and changing of the research questions, the change of the original title and so forth.

1.3.2 Participatory action research

McTaggert’s (1997) work on ‘participatory action research’ was the starting point in my search for an appropriate research approach for the study. According to McTaggert (1997:28-29), participation in research refers to the sharing of the way research is conceptualised, practised and introduced into the world. Thus, it means responsible agency in the production of knowledge and improvement of the practice in which the study is being done.

Power-sharing practices were introduced from the first time that I started speaking to patients living with Cancer, giving them ‘agency’ of their stories and experiences. Agency for the participants in this study meant that the participants had a say in the use of their stories as well as in their sharing with me the way in which they wanted me to re-tell their stories. The participants had also a voice in the conceptualisation of the research questions through my conversations with them.

The task of an action researcher would be to question and challenge dominant discourses. In the light of this study’s position on power sharing, the participants and I set out to challenge the dominant discourses of care on the levels of communication between the participants and their families and between the participants and the medical world as well as communication on a spiritual level. It is in the challenging of these discourse that space can open up for further social action.

3 The original title was ‘The Stories of Cancer Patients and their Families’.
(Zuber-Skerritt 1996:176). As quoted in Zuber-Skerritt (1996:5), Grundy and Kemmis give the following description of what they call 'symmetrical communication':

In action research, all actors involved in the research process are equal participants, and must be involved in every stage of the research. The kind of involvement required is collaborative involvement. It requires a special kind of communication...which has been described as 'symmetrical communication',...which allows all participants to be partners of communication on equal terms.

Along the same lines, one of the principles of action research can be seen as a collaborative resource (Zuber-Skerritt 1996:21-22). This is where everybody's opinion on the situation is valued, and is taken into account in the understanding of the situation. In this way, there should not be any one opinion that is taken as the final understanding of what all the other points of view really meant. The variety of differences between viewpoints makes it a rich resource: 'To treat all viewpoints as a collaborative resource is thus to suspend the conventional status hierarchy which gives some members' viewpoints greater credibility than others' (Zuber-Skerritt 1996:22). It was therefore important for me to regard every person who told me her story as the 'expert' of her own experiences and therefore as valuable to the project.

For an action researcher, the research focus shifts from questions about 'who' and 'why' to questions of 'how'. Thus, in this research, the question was: If the participants could have asked for their preferred 'care', how would it be different to the care that they received? Such a question can create spaces for new dialogues to develop. The researcher can then focus on the 'how' of power and the practices, techniques and procedures by which power operates. This involves the tracking of knowledge production and its power effects. Knowledge is an integral part to the functioning of power in relationships. When it comes to power and knowledge it is important to briefly look at Foucault's (quoted by Zuber-Skerritt 1996:174) understanding of the term. He sees the individual as being continuously constituted and constructed through social relationships, discourses and practices. Thus they are constructed and known – made 'objects' of knowledge and therefore are made targets for power. In such relationships, both historically and today, the financially poor person who is ill, becomes the object of a 'gaze', what was deciphered in him/her was seen as contributing to superior knowledge of and for the rich (Foucault 1973:83-85). The 'gaze' was not only that of 'any observer, but that of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention' (Foucault 1973:89).
In conversations with participants, I became increasingly aware of the power/knowledge relationship between participants and their physicians. According to Ainsworth-Vaughn (1998:42-43) both power and the identity of the person who is ill are constructed from moment to moment during medical interactions. This means that the person who is ill is conscious during the medical interaction that he/she does not have 'the knowledge' and should therefore relinquish his/her power to the physician, rendering the person who is ill 'powerless'.

An important feature of participatory action research that I enjoyed and found immensely valuable was what I learnt from the participants' experiences as they participated in this project (Zuber-Skerritt 1996:245). However, I also had the freedom to introduce my own situations and experiences, which, as it happened, I often shared with the participants, in the research situation (Zuber-Skerritt 1996:250).

Being part of ‘participatory action research’, I merged ‘being with’ the participants with the idea of a practical theology of ‘praxis’, a turning to the persons living with Cancer, listening to their stories as they told them and validating their experiences by giving their experiences a voice (Heitink 1993:174).

I chose to be guided by the writings of Heshusius (1994:16-17) about ‘participatory consciousness’ to develop my own attitude towards the participants and the conversations. For her it means that the person who initiates the study must change his/her understanding of how to relate to participants. She refers to ‘allocentric’ knowing, which she describes as a kind of knowing where both the ‘totality of the act of interest’ as well as the ‘participation of the total person’ is important. Thus, allocentric knowing requires of researchers a ‘total turning to’ the other, not losing themselves, but heightening their feelings of aliveness and awareness.

The other you are studying is no longer someone you can bombard with questions, but someone, ...who may just beckon you near. So it is important for the researcher to be able to temporarily let go of their preoccupation with their self in order to move to a state of complete attention for the other.

(Heshusius 1994:19)

In reading the above, I started pondering the fact that I should let myself turn totally to the participants and wait for them to tell their story. I realised that I would then have to wait for them to give me what they needed to give in their own time and not pressure them for the information that I thought I needed. This in turn guided me to use a conversational style of inquiring, and to come to
the conversations from a ‘not-knowing’ stance (Anderson & Goolishian 1992:26-38) (see Chapter 4).

I tried to give the participants a choice regarding how they wanted to tell their story and to tell just that which they were comfortable telling. Therefore, I decided to talk about a ‘conversation’ rather than an ‘interview’. Oakley (1986:48-49) gives three reasons why she did not follow the textbook code of ethics with regard to interviewing women. Firstly, she attempts not to be exploitative; secondly, she was looking for a strategy to allow participants to document their own accounts of their lives and, thirdly, she wanted to be able to give personal feedback during the conversations. Agreeing with Oakley’s reasons, I decided that I would like to move away from the idea of interviews to that of conversations. By having conversations with the participants, I hoped that I might be able to eliminate any exploitative attitude resulting from researching information of a sensitive nature. As I asked the participants to tell their own stories, my role changed from being a data-collecting instrument for research to being a data-collecting instrument for those whose lives are being researched. I was also interested in how research would be different if I could offer any personal feedback during the conversations and how this would influence ‘rapport’ between the participants and myself. Oakley (1986:53) states that the nature of the relationship between the researcher and the participants and how the participants perceive the ‘interviewer’ affects the kinds of information given. By not structuring the conversation into question-answer style but keeping to informal conversations, I believe that I set out to convey to the participants whose co-operation I was seeking the fact that I did not intend to exploit either them or the information that they gave me. This attitude could have had some influence in encouraging the women to regard me more as a friend rather than as purely a data-gatherer (Oakley 1986:44-47).

The focus for me as researcher was to learn from the participants and their families what it means to them to have Cancer as a family member and whether the care they received was what they wanted or what their preferred care would look like. I left it to them to be the agents of their own stories.

Because this study is positioned in practical theology and particularly contextual theology, participatory action research, which focuses on the participation of the participants in the research, was a perfect choice became both these approaches focus on ‘praxis’, which in this situation means research as care. The participants’ goal became the same as mine, which was to identify care through them telling their stories (Dixson 1999:233).
1.3.3 Practical theology

This research is embedded in practical theology, and pastoral therapy is one of its operational fields (Heyns & Pieterse 1990:3). Practical theology focuses on people's faith actions, with the emphasis on 'action' (Heyns & Pieterse 1990:6). According to Greimacher (quoted by Heitink 1993:174), practical theology is the 'critical theory of the praxis of the church in society'. Heitink (1993:151) therefore defines praxis as 'the actions of individuals and groups in society, within and outside the church, who are willing to be inspired in their private and public lives by the Christian tradition'. Heitink (1993:175) argues that the aim of research should not only be an increase of knowledge, but also to bring about change in the oppressive situation of those with whom researchers establish a close bond, although the goal of this research study is to bring about 'awareness'. He states that meaningful communication can lead to renewed support, and understanding (Heitink 1993:174-175). I would like to add to Heitink's list that meaningful communication should also lead to care that is more meaningful. The notion of a subject-subject relationship also resonates with Reinharz's (1992:194) statement that 'many feminist researchers report being profoundly changed by what they learn about themselves', during their research and the relationship between themselves and the participants. Denzin and Lincoln (1994:166) argue that there should be an 'intersubjectivity between the researcher and participant....participants are always "doing" research, for they, along with the researchers, construct....meanings'.

The 'subject-subject' relationship that was formed between the participants and myself as the researcher during the research process was an indication of my preference for a 'contextual approach'. I joined the participants in their world, not only wanting information from them, but also building a relationship with those who shared their stories of care or lack thereof with me. This approach emphasises 'praxis' in which the goal is transformation, in the way care is given. Although this study's primary aim is not to bring about this transformation in itself, I hope that it will contribute to change when the results are given a wider audience. The transformation implied can focus on the negotiation of care between the caregiver and the person receiving care.

1.3.4 Contextual practical theology

The emphasis on 'praxis' in my chosen paradigm contributed to my choice of a contextual approach to practical theology. According to Cochrane, De Gruchy & Petersen (1991:2), practical theology is:

that disciplined, reflective theological activity which seeks to relate the faith of the Christian community to its life, mission and social praxis.
Social action can only follow social analysis. The latter is thus important for a pastoral caregiver if he/she wishes to understand what is happening in his/her society as well as the lives of the people living in that society, who are also living with Cancer (Cochrane et al 1991:18).

Bosch (1991:423,425) writes that 'contextual theology is theology “from below”…its main source (apart from Scripture and tradition) is the social sciences, and its main interlocutor the….culturally marginalised' [his emphasis]. Bosch (1991:425) states that there is ‘no knowledge except in action itself, in the process of transforming the world through participation in history’. The contextual approach focuses on praxis, and therefore work in the community should not only be discussed, but should also be put into practice. The focus is then on society's economic, political, developmental, ecological and medical problems (Botha 1998:137-138).

I found that the above explanation of social action underlined my research paradigm. The reasons why I opted to listen first to the voices of women living with Cancer are firstly, that theology starts with these women in their context, secondly, that I participated in their lived experiences as they told their stories and finally, that together we suggested action, even though the ‘action’ in this study consists of bringing ‘awareness’ of the women's stories of living with Cancer and care and focusing the attention of others, like pastoral therapists, on these stories. It was important for me to build an 'intimate caring relationship with the participants' by listening to their voices, crediting them as the agents of their own stories (McTaggert 1997:28-29).

My research process developed from my choice of the participatory action research approach, working within contextual practical theology. Thus, the research process was built on the concepts of ‘praxis’, ‘participation’ and ‘awareness’ that may lead to ‘transformation’.

1.4 RESEARCH PROCESS

The research process was a journey that the participants and I undertook together. We did not make use of any prescribed method – instead the research process was more like a dance (Janesick 1994:209; Hughes 1996:30). There was continuous movement in the research, which was based on praxis, participation, elasticity and transformation. Therefore, it was not always structured or organised, it was sometimes out of order and confusing. It also changed a few times to accommodate the participants' stories.
1.4.1 Life story collage

Fellow students, friends and a minister heard about my study and referred women whose lives had been turned upside down by Cancer to me. My original intention was to have both women and men living with Cancer share their stories with me. However, only women living with Cancer responded to the various invitations to participate in the study, and therefore the focus of the study shifted to women living with Cancer. I contacted the women who had volunteered their time once their telephone numbers had been conveyed to me. During these initial telephone conversations, I discussed with each individual the aims of the study, as set out in the information sheet (Appendix B). This was general information, for instance, ‘what type of participants are being sought to participate, ‘what the participants will be asked to do’ as well as ‘what will happen to the information given’. Each woman and I also discussed how she saw her role in the study. After that we arranged to meet in person for the first time. The information sheet was faxed to two of the participants first, and after they had read it, they decided to participate and telephoned me to arrange to meet. The other three participants spoke to me without wanting to read the information sheet. They were so eager to tell me their stories and to give their experiences a voice that they were not very concerned with the ‘paper work’, although they read the information sheets after the first meetings.

The study included five women, with Cancer in remission. The husbands of two participants also wanted to share their experiences about Cancer with me, so I had conversations with them as well. Only one of these conversations with the husband was done in the presence of the participant. The husband and wife spoke to me as a couple. Their son joined the conversation for a short while, sharing his thoughts on Cancer with me as well. The other couple preferred to talk to me separately, which we did. Three of the women's husbands did not participate. One woman's children, aged 17 and 19, participated and I had to arrange a time with each child separately, since they had different time schedules. All the conversations were in Afrikaans and the transcriptions were translated to ensure a broader 'audience' for the stories of the participants.

I wondered why men who live with Cancer did not volunteer. Could it be that they handle emotional experiences differently to women? Alternatively, was it because of the way in which they were approached? Perhaps, since my fellow students and friends were all white Afrikaans-speaking women, they tended to refer only white Afrikaans-speaking women living with Cancer to me. The minister referred two white Afrikaans-speaking women living with Cancer, whose husbands both
wanted to participate in the project. Therefore, all the participants were white Afrikaans-speaking South Africans.

Because I was concerned with the confidentiality of the study, I drew up a consent form (see Appendix C) on which the participants gave me their consent to include their stories and comments in this study. I made provision for family members to be able to tell their stories also. A specific note on the consent form was made regarding the audiotaping of conversations and the matter was cleared with the participants again when I met them. The participants and those family members who shared their stories with me all signed these consent forms. All the information (audiotapes as well as notes) is kept in a safe at my office until May 2002. Then the tapes and notes will be destroyed (burnt).

The participants all had a choice whether they wanted to use their own names or not. Only two people felt uncomfortable using their real identities and therefore chose ‘pseudonyms’. In an effort to enhance confidentiality I did not indicate which these are.

I had between two and five conversations with each participant and her family regarding their experiences and the care they received. Due to time constraints, it was not possible to have an equal number of conversations with each participant. Some conversations lasted an hour, others two hours. It all depended on the participants and their families’ time. I also went back to the participants to clarify any information that I was uncertain of during the re-telling of their stories. In some situations, I went back to a specific participant two to four times. I found myself a participant in these conversations, probably because of the ‘casual’ nature of the interaction between us. As I listened to each individual’s story as it was told, these stories were recorded to be re-told later. During the conversations, I started by talking about Cancer as a family member. I asked the participants whether they would say that this would be a possible way of perceiving Cancer. They responded positively to the idea of externalising Cancer as a family member.

‘Externalising’ conversations (White & Epston 1990:38) encourage people either to objectify or personify the problem that they might find oppressive. In this situation it is Cancer. In this process, Cancer can become a separate entity and thus external to the person in whose life it has been wreaking havoc. Thus, by using externalising conversation, people can take up an opportunity to take control over their own lives back from Cancer. Externalising conversation can then empower a person to stand up against Cancer. It also can give the person space in which to explore his/her
preferred way of life as well as care. Freedman and Combs (1996:47) describe externalising conversations in the following way:

Externalising is a practice supported by the belief that the problem is something operating or impacting on or pervading a person's life, something separate and different from the person.

Externalising conversation was used as an element of my research conversations in order to explore the research questions. I found this a very valuable way both of doing research, and in re-writing the stories.

1.4.2 Life story re-telling

I made sure that the participants' preferences and suggestions regarding the re-telling of their stories were followed. The participants and I arranged that after I had completed the re-telling of their stories in writing, I would give the re-telling back to them to read. This was done in an effort on my part to be accountable, to ensure that the meanings that I attributed to their stories was what they intended. In doing this, I attempted to be as ethical as possible in my dealings with their stories. The participants commented on and made suggestions regarding their re-told stories.

As I listened, read and re-told their stories, I identified certain themes woven into them like golden threads. These themes are discussed in Chapters 2, 3 and 4. I focused specifically on what I learnt of the care that the participants received during this time.

1.4.3 Ethical considerations

Reflecting on my ethical practice I turned to the ideas of Epstein and Loos (quoted by Hirschhorn 1999:23), who argue that therapists need to respect all views as equally important and valid. Therefore, in the conversations with the participants and their families, this concept of 'everyone's experiences as equally valuable' was of the utmost importance to me. This equality was accomplished by giving the participants a choice regarding how they wanted to tell their stories to me, as well as how they wanted me to re-tell those stories. Thus I left it to them to be the 'experts' of their own stories, with me as the researcher joining the participants in a 'mutual exploration' of the participants' 'understanding and experiences' (Anderson & Goolishian 1992:25-39).

It was also important for me to look at what they thought would be an ethical way of re-telling their stories. The question was this: In what way would they like me to handle their life stories, and in
what way should I be relating (see 1.4.2) these stories back to the study? Although they did not have specific ideas about the format in which I should re-tell their stories, all the participants, except for one couple, wanted their own names to be used in the study. There were some instances while re-telling their stories due to an effort to protect the identity of the participants, I found myself in a predicament. The question that arose was: How do I write the participants’ story in such a way that I still protect their identity? The participants and I decided that, in order to make sure that their stories had been dealt with ethically, they would read these stories as I re-told them to verify their accuracy in their own eyes. By doing this, I feel that I was being accountable.

For Freedman and Combs (1996:278-282), the ‘problem that is built into relationships between therapists and clients is that therapists are in a privileged position in the context of therapy’. It is this ‘expert’ position that should be deconstructed. Accountability to me therefore means to negotiate ethics with the participants. Thus, it meant going to persons living with Cancer, letting them tell their stories in the way they wanted to, giving them insight into the re-writing of these stories and making sure that I knew how what I was doing would affect them. We discussed the issue of who will benefit from these conversations and they thought it should be the person reading the dissertation as well as themselves because they were telling their stories.

We also discussed the purpose of the stories being to identify the ‘care’, they had received and whether it was satisfactory or not. There was also a broader purpose for them. They took the idea of the study being made public to mean that there would be a wider audience for their stories and that it could be of value for many more people in the same situation.

1.5 CHAPTER OUTLINE

The chapter outline below reflects the literature study as well as a sense of the process as the participants and I wove the picture of ‘life with Cancer as family member’ and the ‘care’ participants wanted.

The reader is encouraged to participate by seeing the chapters that follow as a collection of the ‘stories’ of people living with Cancer on the ‘care’ they received. I have attempted to bring together various social constructions of illness with the constructions reflected in the stories I heard people tell. I also linked these constructions and stories with the role of the pastoral therapist in the process of counselling a Cancer patient. Firstly, there was the collage of life stories that explains how the participants came to know about the study, who participated, the growth of the relationship between
the participants and me, as well as the paper work and conversations. Secondly, there were the life stories re-told, where I explain how I went about re-telling the participants stories ethically, entering into ethical considerations, where my view is that everyone's viewpoint is of equal value and should be heard. Lastly, I reflected on the research process.

Chapter 2: Social and spiritual construction of illness

Chapter 2 focuses on social and socio-religious constructions of illness and death and the effects that these constructions have on the lives of people living with Cancer. I also attend to the types of stories people tell. Three themes are identified from the relevant literature as well as from conversations with patients. These themes are the relationship between the persons living with Cancer and their family, the persons living with Cancer and the medical system and the persons living with Cancer and spirituality.

Chapter 3: Dominant themes in care

Chapter 3 contains an introduction to the women and family members who participated in the study by telling their stories. These stories are the voices they gave to their experiences of living with Cancer. They spoke about the care that they had received as well as the care they wanted and their preferred care at different levels. The discussion of these levels was organised according to the themes identified in Chapter 2.

Chapter 4: Spirituality and pastoral care

From the conversations with the participants on spirituality, questions regarding pastoral care emerged. These are discussed in Chapter 4. The role of spirituality and pastoral care for people living with Cancer is given attention. A look is taken at a narrative way of care as a possible preferred way of caring.

Chapter 5: Reflections

Chapter 5 sets out reflections on the participants' preferred care, theology and the research process. I also position myself in the project as the author of the study, giving myself as the researcher a voice and exploring my own experiences during this study.

Reflections on the topic brought me to look closely at what I as a person have learnt from my conversations with women living with Cancer. It brought me to understand more than ever that care
should be 'done' by the people surrounding the person living with Cancer and his/her family. Reflections on theology brought me to look again at religion as a guideline with certain dominant discourses attached to it on the one hand, and to look at the all-embracing character of 'spirituality' on the other. Reflections on the research process clarified the happenings during the course of the study, obscured by the elasticity of the research, and the changes that came about during what was never a fixed process and developed over time.
CHAPTER 2
SOCIAL AND SOCIO-RELIGIOUS CONSTRUCTIONS OF ILLNESS

2.1 INTRODUCTION

I have chosen postmodern social construction discourse as the constitutive epistemology for this study. In this chapter I set out the descriptions of postmodern discourse and social construction discourse that have been applied in this study.

Both a social construction of illness and death and a socio-religious construction thereof are discussed at length to give the reader a background regarding dominant Western discourses surrounding Cancer and care. I found that the adoption of a postmodern, social constructionist perspective provided me with useful ideas about how power, knowledge, 'truth', and care can be negotiated inside family, medical and spiritual relationships (Freedman & Combs 1996:22).

2.1.1 Postmodern social construction discourse

Rossouw (1993:895,903) states that '[p]ostmodern culture does not abolish modern culture. It is the critical companion or interlocutor of modern culture, and both a reaction to and a result of the modern culture'. Postmodernists hold that there are limits to the ability of human beings to measure and describe the world in which they live in any precise, absolute and universally applicable way (Freedman & Combs 1996:21). According to Freedman and Combs (1996:22-35), a postmodern view of reality suggests that realities are socially constructed; that they are constituted through language; that they are organised and maintained through narratives and that there are no essential truths.

A postmodern view would therefore imply that illness and, in this case, Cancer are socially constructed. It is therefore helpful to find out what the dominant thoughts on Cancer are; how they were constituted; and what the effects are of these dominant thoughts on the lives of people living with Cancer.

Social construction is 'concerned with explicating the processes by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live' (Gergen 1985:266) – a discourse about the world is not regarded as a map or reflection of the world but as an 'artifact of communal interchange'. Knowledge is then seen as a communal
construction, a product of social exchange. This implies that people arrive at the meanings they attribute to the events and people in their lives by the language they use in social dialogue. Therefore, an individual can never, alone, give meaning to anything: '[A]nother is required to supplement action and thus furnish it with a form of meaning' (Gergen 1994:29).

Postmodernists focus on how the language that people use constitutes their world and beliefs. Thus the only world that humans know is the world that they share in language (Freedman & Combs 1996:28-29). Language can then be seen as a shared activity. People's realities are kept alive and passed along in the stories that they live, tell and share with others (Freedman & Combs 1996:30). Illness can therefore be seen as being constructed through language, specifically through the dominant discourses of medicine and science. Thus, the context within which persons meet their illness can shape the experience and their perceptions of what is happening to them (Woodward 1995:42-49). Cancer in this sense becomes a socially constituted reality that shapes people’s lives. It is in the sharing of their narratives that I became part of the lives of the women who told me the stories of living with Cancer and the care they received.

2.2 SOCIAL CONSTRUCTIONS OF ILLNESS

The social construction of illness can be found in the writings of people like Kleinman (1988). Kleinman (1988:18-22) argues that a statement such as ‘She has cancer’ carries various meanings for the patient as well as the people surrounding the patient. These dominant social meanings connected to ‘I have cancer’ can help construct the individual’s identity.

Based on the conversations that I had with patients in general and on what I learnt from the literature, I would like to emphasise two aspects in the discussion of the social and cultural construction of illness and the effects thereof on people and care. They are firstly, persons living with Cancer and their social relationships with friends and families, and secondly, persons living with Cancer and the Western medical system.

2.2.1 Persons living with Cancer and their social relationships with friends and family.

Many patients do not discuss worries they experience during their illness because they fear this would burden their loved ones (Cournos 1990:46). Thus the patients keep secrets from their family and vice versa because each tries to protect the other. Pastor Lubbe (2001) gave me an

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1 I use the term 'patient/s' in the study when the literature uses it to refer to individuals with Cancer. I prefer to use the terms 'person living with Cancer' or 'participants' elsewhere.
example of this. A patient told the pastor that the doctor had said that nothing more could be done for him, but he asked the pastor not to tell his family. Later, when the pastor spoke to the family, it became clear to him that the family also knew, but the family did not want the pastor to tell the patient what they knew. In such circumstances a pastor can talk to either the patient or the family or both, trying to get them to talk to one another about the reality of the situation. He can say something like this: 'If you were in his/her shoes, wouldn't you want to know?' Usually they would and that opens up the communication channels between the patient and his/her family. By sharing the secret of situations, people might come to know that it is not as terrible for others as they thought it would be. They might find that those around them are understanding and caring.

‘Protecting each other’ can be viewed as a positive function of keeping a secret in some situations. However, there are at least two other functions of secrets that are negative in the effect that they have on people. Firstly, secrets can give one person power over another. These power relationships should be examined and questions can be asked such as: Who benefits from keeping this secret? What effect does this secret have on the person keeping it and what is their motive for keeping the secret? Secondly, there are shameful secrets. ‘Shameful secrets result in isolation and pain, when we reveal secrets, we can externalise the shame’ (Imber-Black 1993:42). Secrets can function to keep people ‘safe’ from reality and pain. However, this can result in the isolation of a person living with Cancer and keeping it a secret.

When and if the person living with Cancer opts for social isolation and withdrawal from social support, this choice might be the result of severe stress. However, this could be a time when the patient might most need love and care from their loved ones (Cullinan 1990:135).

This brings me to the communication aspect where Cancer has invaded people’s relationships. Arthur Frank is a professor in sociology at the University of Calgary and he has experienced living with Cancer. For Frank (1991:3-7), thinking, talking and writing about his Cancer started a process of acceptance for him. He shared his knowledge of his cancer with his wife, who took care of him. In his experience, the most important thing about his wife’s caring for him was her willingness and ability to talk about what was happening to him and to her. For them the illness was happening to ‘them’ as a couple and not only to him.

Frank (1991:8) believes that too many patients are deprived of conversations if they think that they cannot talk about their illness with their families. During his own illness he desperately needed other people, but felt stigmatised. This made him cautious of others. Goffman (quoted by Kleinman
notes that when people have a specific stigma attached to them, their conception of 'self' changes and this in turn influences their presentation of themselves. According to Frank (1991:99-105), even the strongest relationships come under stress. The ultimate denial comes from friends and family who simply disappear from the patient's life. In staying away they are saying that everything is fine. When friends and family stay away, questions of 'why me' might increase because of the loneliness of being ill.

Kleinman (1988:18-22) sees Cancer as an unsettling reminder of uncertainty, unpredictability and injustice. For Kleinman, Cancer represents the human need to make moral sense of 'Why me?' It also forces us to confront our lack of control over our own or other's deaths, fear of an untimely death, the threat of disfigurement and the loss of body and self-image. The question of 'why me' could also be different, depending on the individual's specific positioning in his/her life cycle.

Carter and McGoldrick (1989:6) see each individual life cycle as taking place within a family life cycle. Therefore Cancer can be seen as an occurrence during the specific life cycle of a person's life as well as the life of his/her family. Cancer then might be regarded as an illness of the family. If the family is regarded as a system with roles and functions, what will be of value is the relationship between the family members and their ability to adjust to new roles and functions when Cancer becomes part of their lives. Thus when a parent develops Cancer during the centripetal child-rearing phase of development, the family's ability to stay on course can be severely taxed. Cancer can be like a child, competing for attention with the real children and for family resources. Another effect of living with Cancer can be that the family faces becoming a single-parent family forcibly because of the 'loss' of the parent who has been invaded by Cancer (Rolland 1989:449).

Not only does Cancer enter the family home, the life of the person living with Cancer and that of his/her family, but hospitals, physicians, medical staff, treatments and medicines now also become part of their lives. Therefore it may be helpful also to reflect on the social construction of Cancer, the person living with it and the medical field.

2.2.2 Persons living with Cancer and the Western medical system

Foucault (quoted by Friedson 1970:207-208) argues that contemporary Western notions of disease developed within the discursive practices of eighteenth-century medicine in Paris. The body became the primary focus of these medical activities and came to be regarded as the main
site of disease. Disease came to be seen as located in the workings of the bodily structures. This conceptualisation of disease within the anatomy was the product of what Foucault called the gaze. The gaze implies a ‘way of seeing’. It was through the medical gaze that things became visible to the doctor and, once seen, an object could be observed and analysed. Shumway (1989:47) describes Foucault as arguing that ‘seeing’ is being wholly conditioned by discourse. What the doctor see is influenced by his or her own culture and the dominant discourses central to it. According to Foucault, the act of the ‘gaze’ defines the patient-doctor relationship. In Foucault’s view this is a relationship where the doctor has the knowledge and the patients become the objects rather than persons, because they do not have the same knowledge (Shumway 1989:51-52).

Nettleton (1995:16) states that all knowledge is socially contingent, therefore medical knowledge is socially constructed. Duden (quoted by Nettleton 1995:17) argues that the history of medical knowledge does not involve a gradual unfolding of the ‘truth’ about the body and disease, but that these categories are contingent on their social, cultural and historical context, thus socially constructed. According to Herek (1990:113), illness is socially constructed as soon as the symptoms are noticed and then categorised. The disease gets a label and a theory sees the light. Thereafter responsibility for the disease is often assigned to the patient, who can either be a victim of the disease or a participator. To be a participator in one’s own illness, one would have brought it on oneself, for instance, through one’s lifestyle as a smoker. Kleinman (1988:18-22) also argues that Cancer can be seen to imply a person’s lifestyle, suggesting that the person could have done something that has led to his/her becoming ill, whereas the victim has no role to play in contracting an illness.

The experience of illness can bring exclusion from society through inactivity. Meaning is then created through the social behaviour of the sick or healthy person.

Kleinman (1988:44-55) describes chronic illness as follows:

The trajectory of chronic illness assimilates to a life course, contributing so intimately to the development of a particular life that illness becomes inseparable from life history.

When a person has a chronic illness, the person has to adjust his/her way of life as well as his/her participation in society (Herzlich & Graham 1973:40-55). Mishler (1981:164) talks about the ‘medicalization of life’. He explains this as medicine creating illness as a social state. For him the
physician transmits to individuals the social possibility of being sick, it is the physician who then decides what a symptom is and who is sick.

Faulkner and Maguire (1994:27) suggest that most patients take their cues from the medical staff and doctors. In a study done by Novak et al (quoted by Baider, Cooper & De-Nour 2000:481) they found that physicians agreed to the disclosure of a diagnosis to Cancer patients and that patients also believed that they should be aware of the truth, good or bad, about their illness. Degner (quoted by Baider et al 2000:482) reported that 22% of breast cancer patients wanted to select their own treatment, thus taking their own decisions. For 47% of the patients it felt better if the decision-making was done collaboratively with the physician, but for 34% of the patients it was important for the physicians to decide. Degner took this to mean that while information is critical for the making of medical decisions, the desire for information does not necessarily mean that the patient would want to share in the decision-making process. Although 90% of cancer patients preferred to have the information about their illness, a smaller percentage of patients wanted the physician to make decisions about the treatment. Various reasons can be given for this, according to Baider et al (2000:481-482). Firstly, this may be due to an 'underlying personality construct'. Secondly, patients might feel they do not have the skills to process the information given. Thirdly, patients may have learnt passive role-playing during previous interaction with doctors. Fourthly, there may be a generational cohort effect, with older persons deferring more to the physician for decision-making.

Szasz and Hollender (quoted by in Wolinsky 1980:173-175) specify three types of patient-practitioner relationships based on the severity of the physiological symptoms.

Firstly, in the Activity-Passivity Model, the patient plays a passive role to the physician's active one. This model represents the unilateral action, power, and decision-making of a physician working in a desperate situation. Whether or not the patient contributes to the process is irrelevant. This is usually the situation in trauma cases where the patient has suffered severe injuries on blood loss or is comatose. Secondly, in the Guidance-Co-operation Model, the patient contacts the physician for the alleviation of some acute condition. The patients can be ill but are still able to make their own decisions. The physician guides the relationship by way of the diagnosis, prognosis and treatment, while the patient co-operates by providing the information necessary for the physician's guidance, and then complies with that guidance. Thirdly, there is the Mutual Participation Mode. This model describes the management of chronic illness, where the
patient plays an active role. The physician helps the patient to help him/herself. The physician is consulted on a periodic basis. This model can also be applied in preventive health care.

Wolinsky (1980:180-184) also looks at the Stewart-Buck Study of Practitioner Knowledge and Response Model. Stewart and Buck were concerned about the patient-practitioner relationship in respect of the practitioner's knowledge of the patient's problems as well as the patient and the practitioner's responses to those problems. In short, Stewart and Buck found that practitioners are not very aware of their patients' social problems, and that even when they are aware of a patient's social or other problems, they do not respond very well to these problems.

When it comes to communication between the physician and the patient, Kleinman (1988:222-225) suggests that the work of the physician should include sensitive gathering of the patients' and families' stories. Frank (1991:69) is in remission from Cancer. During his illness his wife stood by him as his caregiver. He had this to say about the communication between him and his physician:

Talking to doctors always makes me conscious of what I am not supposed to say...The questions I want to ask about my life are not allowed, not speakable, not even thinkable. The gap between what I feel and what I am allowed to say widens and deepens and swallows my voice.

(Frank 1991:12-15)

He feels that critically ill persons need 'talk' that recognises all that they are experiencing. At one point, he had a doctor who was a brilliant technician but a terrible communicator. The physician blurted out directly what he discovered, without a hint of empathy: 'it was a triumph of science and a lapse of humanity' (Frank 1991:27). According to Imber-Black (1993:42), 'honesty without sensitivity can be brutality'. Physicians should pay attention to the manner in which they relate news to the person whose life the news will affect.

Every individual might experience his/her own illness differently. While the common diagnostic categories in which medicine places patients might be relevant for treatment, they may only get in the way of care by making the person feel like just another Cancer patient (Frank 1991:45). Therefore, after diagnosis as well as during the illness, caregivers should constantly find a way to allow the ill person to express his/her needs (Frank 1991:47).

The language that physicians and medical staff use may offend some patients. When a physician talks about 'investigating', it may feel to the patient as if the medical staff is just using
the patient's body as an object of medical investigation. The patient may feel as if he/she has become a 'this' (Frank 1991:51-52).

The nurse may refer to the patient as 'the seminoma in 53', allowing the diagnosis to erase the person's name completely. The hospital has created its own version of the patient's identity, so the patient becomes the disease. The patient can then become a passive object of investigation and nameless in his/her treatment (Frank 1991:53-54). Relationships between patients and medical staff can become based on medical categorising rather than on the recognition of the person (Frank 1991:55). It may be just as bad when nurses refrain from saying the dreaded 'C' word and only speak of 'c.a'. By not saying the word, they communicate to patients that this 'thing' they have is too terrible to even talk about or call by name. What the patient may ask is this: 'If it is so terrible to talk about, will I ever survive it?'

In the medical world the patient's life and body are an open book, but the same cannot be said for the medical staff, who can choose what they want to reveal and openness ends up being one-sided. Frank (1991:56) assumed that the physician at least would recognise what Frank was living through, but he found the opposite. He states: 'The more critical my diagnosis became, the more reluctant physicians were to talk to me. I had trouble getting them to make eye contact; most came only to see my disease.' So becoming a patient may mean that one can lose oneself, that one can be colonised to become medical territory. One can become a spectator to one's own drama. Frank (1991:102) writes: 'The only way I could get my surgeon,... to talk to me about the details of and alternatives to the operation he was planning...was to refuse to sign the consent form.'

Frank (1991:111-113) states that one dominant idea of what causes Cancer is the suppression of anger. Be that as it may, he believes that having Cancer and being treated for it requires further suppression of anger because medical staff does not acknowledge what patients are going through. He gives an example of a nurse asking the right questions, but asking them in the wrong place. The nurse thought that if she just pulled shut a curtain between him and the bed next to him, he would feel private enough to answer her questions. He did not, and therefore lied when he did not feel comfortable declaring an answer to the whole ward. Imber-Black (1993:30) writes that 'one person's "right to privacy" is often another person's victimisation and shame'.
3.2.9 Death is introduced

The brother of a Cancer patient said that nobody talked about the possibility of his sister's dying, not with each other and not with her (Lubbe 2001). The family talked about everything except the possibility of death. The family hinted that she should start looking at her affairs and getting things in order. In the brother's opinion, his sister 'would talk around the possibility of death, she would not want to talk or recognise the possibility of death. I think that she would interpret death talk as “losing hope” or “giving up”'. Another reason for the lack of talk about death is that the physicians could not give the family or the patient any indication of her prognoses. Medical staff argued that patients who deny that they can die should be allowed to do so. However, Frank (1991:67) states that the sad end is that, when patients are eventually dying, they can be too sick to express what they might then want to say to their family. He feels that patients and families should not be denied a final experience together. However, Henk, Naomi's son, said nonchalantly: 'I never think of the possibility of my mother dying.... I try not to think about the fact that the tumour can grow again and the “consequences” thereof....'

3.2.10 Taking over the household

When Cancer strikes a mother who is also the housekeeper, someone needs to take over the responsibilities of the household. This was a difficult transition for the husbands of the entire group of participants, because they were not used to it. Erika said: 'It was difficult for him in the sense that he had to take over not just the household but also a different role in the family. I believe that my husband was transformed because of this. He changed his opinion regarding the dominant role of women and motherhood that was evident in our relationship. This change has softened him as a man and as a father.'

Chris, Hester's husband, had to take over the household as well as the 'mothering' of Francois, especially during the last two sets of chemotherapy. The third chemotherapy 'was the worst'. Hester and Chris were both drained and stressed by the third treatment, and for Chris, having a house, a baby and a job was a bit much. As a couple and family they did survive, though.

3.2.11 Mastectomy and reconstruction

A topic of interest that emerged in the discussions with participants with breast Cancer was that of mastectomy and reconstruction. Erika had a double mastectomy. She said: 'My husband told me before both the surgeries and after that I should not worry, he loves me and not my “body”. He
Communication between the patient and the physician is of the utmost importance, seeing that information can help to reduce the uncertainty that 'Cancer' might hold for the patient. Bearison (1991:95-104) gives an account of what it is like for children to have Cancer invade their lives. One of the children said the following about things being kept from him:

They didn't want to tell me, and that's the one thing I hate....I don't care how bad it is, I wanna know what's going on....They were hiding stuff from me....I just want people to be straight with me on what's going on. So I talked to the doctor and I would ask him stuff when they weren't around....I didn't want any surprises.....I didn't let any of the doctors do anything to me unless I knew what they were doing and why they were doing it and what cause it was for.'

Clyne (quoted by Balint & Norell 1973:58-79) points out that naming the illness may lessen a patient's anxiety levels because doing so moves the illness from the unknown to the known. Clyne set out to change the 'traditional diagnosis', which has little or nothing to say about the 'person' who is ill, to a type of diagnosis which includes things like the external pressures on the patient, the patient's internal world, relationships between the patient and the people around them, and the way the doctor-patient relationship has developed. Clyne arrived at the medical aphorism: 'Listen to the patient, he is telling you the diagnosis!'

Rolland (1994:151) explains the point of view of medical training regarding the physician's being objective, promoting a they and we mind-set and not letting private feelings interfere with one's ability in caring for others. He relates a personal experience of loss and his feelings of professional failure, shame and sadness at not being able to distance himself from a medical situation of loss. When the above feelings are repressed, a process of 'psychic numbing' might occur. According to Rolland (1994:152), psychic numbing can influence a physician's ability to stay sensitive and available to the emotional needs of patients and their families.

Typically, clinicians who work with repeated loss...encounter a psychological wall that represents a combination of immersion-in-death experiences of families, unsustainable personal standards of professional competence, and reawakening of personal themes related to loss....clinicians may either change jobs, develop a rigid, self-protective, hardened clinical style, or actively re-examine basic issues related to life, death, and past losses.

(Rolland 1994:152)
Rolland (1994:151) suggests that there is a space for

.... incorporating into training the need for self-understanding about illness, loss, and acceptance of personal limits that are consistent with a positive professional self-image....Our own inability to share our limitations with others can covertly communicate to families the same unwavering, 'tough-it-out' mentality.

Rolland (1994:154) deconstructs the above medical viewpoint when he states that physicians should give themselves 'permission to step back from a case in order to reflect and consult with colleagues' and in so doing keep themselves from reaching the point of 'psychic numbing'.

Health professionals who are experienced in interacting with Cancer patients and their families state that an important reason for their reluctance to ask about their patients' social and psychological problems is that they feel they have had insufficient training in key assessments skills (Faulkner & Maguire 1994:14). McDaniel, Campbell and Seaburn (1990:11-12) state how important it is that physicians are aware of the fact that they are part of the larger treatment system, and when the latter is failing, need to ask questions on their own involvement with their patients and their families. I take this involvement to mean being interested in the patients and their families' lives outside of the 'illness'.

Faulkner and Maguire (1994:17-28) list some distancing approaches that physicians interacting with Cancer patients use, in an effort to protect themselves from the stress of caring. These techniques are the following:

Neutral material: Sometimes the doctor first tries to build a 'trusting relationship' by keeping the conversation neutral, while patients only want to talk about their real concerns. This then leads the patients to learn to follow the doctor's lead as to what is going to be talked about (Faulkner & Maguire 1994:17-18).

Ignoring cues: Often the topic that the patient needs to talk about is seen as unacceptable and the doctor opts to ignore the cues given by the patient (Faulkner & Maguire 1994:18-19).

Selective attention to cues: When a patient presents a few concerns, a skilled doctor should summarise the concerns and then follow the patient's lead on priorities, but all doctors do not do this (Faulkner & Maguire 1994:19-20).

Inappropriate encouragement: This technique is used when a patient's concerns are trivialised because the doctor encourages the patient to think positively. This tactic can lead to the patient's
not articulating his/her concerns in the fear that he/she might sound foolish for having these concerns. The technique can also damage the patient's self-image or lead to anger towards the situation (Faulkner & Maguire 1994:20-21).

Premature reassurance: The doctor may try to give reassurance before the patient's concerns have been heard. The patient may feel that the doctor is not interested. The doctor may attempt to soften the situation and in doing so avoid the patient's reality (Faulkner & Maguire 1994:21-22).

False reassurance: When a doctor uses this technique he/she tries to avoid emotional realities by not telling the patient the truth about the diagnosis and/or prognosis, all in the name of protecting the patient against painful information (Faulkner & Maguire 1994:22-23).

Switching the topic: This technique can be seen as a form of social control that allows an individual to raise a subject and to drop it if it is unacceptable (Faulkner & Maguire 1994:23).

Switching the focus to relatives: Doctors use neutral material to change the topic. They do this in an effort to 'take the patient's mind off morbid thoughts' (Faulkner & Maguire 1994:23).

Passing the buck: Where one of the previous tactics did not work a doctor can use the 'passing the buck' technique by claiming that he/she is not the right person to talk to and then referring the patient to a colleague (Faulkner & Maguire 1994:24-25).

Premature problem-solving: 'Sometimes, there is an attempt to solve the patient's (or relative's) problems before exploring the nature of the problem or its relationship to other facets of the individual's life' (Faulkner & Maguire 1994:25-26). The professional does seem to be fulfilling his/her role while maintaining interaction at a superficial level.

Avoiding the patient: The ultimate distancing tool is to try to avoid the patient. When this happens to the patient, the patient can become withdrawn, introspective, even frustrated and angry (Faulkner & Maguire 1994:26-27).

Within this relationship of the person living with Cancer and his/her physician attention should be given to the aspect of power and knowledge. Physicians should at all times be aware of the power relationship between themselves and their patients and should reflect on whether they are attending the patient or the illness. Foucault (1980:141, translated by Gordon) states that 'power is always already there and one is never outside it.' To Foucault, power is knowledge and knowledge is power. Thus Foucault sees language as the instrument in which power is being
applied. People therefore have power in a society in direct proportion to their ability in the various
discourses that shape that society. Freedman and Combs (1996:37-38) state:

He [Foucault] argues that there is an inseparable link between knowledge and
power: the discourses of a society determine what knowledge is held to be true,
right, or proper in that society, so those who control the discourse control
knowledge. At the same time, the dominant knowledge of a given milieu
determines who will be able to occupy its powerful positions.

According to Foucault (quoted by Friedson 1970:207-208), medicine must be viewed as a powerful
institution of social control. It has become so by claiming expertise about areas of life which were
previously not regarded as medical matters, areas such as ageing, childbirth, alcohol consumption
and childhood behaviour. Therefore, medicine constructs, or redefines, aspects of ‘normal’ life as
medical problems. By being too dependant upon medical expertise, ordinary people can be
stripped of their abilities to cope with their own problems.

Wolinsky (1980:163) argues that medical practitioners have a considerable advantage in the
distribution of authority within the relationship, resulting in an asymmetrical power relationship
because of the relationship between having the medical knowledge (being an ‘expert’ in the
medical field) and lacking such knowledge. One of the reasons that social constructionism is
characterised as postmodern is that it challenges the relationship between the so-called medical
‘experts’ and lay people. It deconstructs hierarchies of knowledge, with the results that the status
of the ‘expert’ is put on par with the ideas and accounts of the non-expert (Nettleton 1995:31-33).

In addition to the relationship with their family and medical staff, persons living with Cancer might
also have concerns surrounding their spirituality and their relationship with their ‘personal God’.

2.3   SOCIO-RELIGIOUS CONSTRUCTIONS OF ILLNESS AND DEATH

The construction of illness and death has always been a ‘socio-religious’ construction rather than a
spiritual one. Spirituality for the purposes of this study means ‘to be able to move outside of the
dominant discourses regarding religion’. In talking to participants about their experiences (see
Chapter 3 & 4) I found that spirituality played an important role in all their lives. So, just as illness
is socially constructed, I find that illness and death are also socio-religiously constructed. The
views that I looked at were those of the Judaeo-Christian tradition. According to Fontaine
(1996:289-294), the ‘Bible’s representation of the sick...reflects the social world out of which it
came’. In the biblical period’s so-called ‘medically naive’ society, people who could not participate
fully in their common tasks of survival because of illness were seen as living a more precarious
and less desirable life. Thus the ill person presented a potent reminder of mortality and death to the ones observing him/her.

2.3.1 Illness

Illness in the Old Testament is a very wide-ranging concept, which is associated with a process in which people are robbed of their strength. Thus they become weak and defenceless (Louw 1994:29). Illness and health are two concepts that indicate the absence or presence of life and peace as distinctive characteristics of a living relationship with God. By healing, the Lord is seen as wanting his 'shalom' to return so humans can live with joy. According to the Old Testament, there is an inseparable link between sin and illness. This link was often seen causatively. This implies that, personal sin should not be seen as the explanation for illness but rather that illness could be a consequence of personal sin (Louw 1994:30-31). The intention then is to bring the sick person back into the covenantal communion with the Lord: 'I said, “O Lord, have mercy on me, heal me, for I have sinned against you”' (Ps. 41:4). In the Old Testament, it is clear that illness was associated with the judgement and wrath of God. The affliction was meant to bring the patient to gratitude before God for remission of sins (Louw 1994:32).

The New Testament sees the concept of illness as being part of the general weakness of humans, and emphasises the influence of demonic powers. The New Testament also sees a link not only between illness and the general sinfulness of humans, but also between illness and personal sin. Therefore, according to Louw (1994:32), is it important that patients personally confess their sins before God. Confession can then be viewed as an important part of the healing process. However, Louw (1994:33) also argues that sin and illness should both be subjected to God's merciful dominion. Thus, Christ said with reference to the blind in John 9:3: 'Neither this man nor his parents sinned,...but this happened so that the work of God might be displayed in his life.' The purpose of illness should therefore not be to discover all one's sins but rather a total renewal so that in faith one can subject oneself entirely to the mercy of God (Louw 1994:34). In terms of the above statements, it may be fair to ask whether: the New Testament embraces as well as rejects the connection between illness and sin.

The Bible reflects a pre-industrial and pre-technological world. Life expectancy in biblical times was shorter than in modern Western societies. Without effective medical care, illnesses were often fatal because they were untreatable (Craffert 1999:1-10). Though in today's world treatment of many of these illnesses are common and therefore a person's life may be extended (Philibert
As the life of Cancer patients is extended physically, the need for quality in spirituality may arise. The patient may need an all-inclusive spiritual construction of illness to set the patient free from the restrictions of socio-religious constructions of illness where, for example, illness is attached to their own personal sin.

Many people rely on religious traditions to provide some underpinning for social norms, and one can see this in the dominant discourse of illness as linked to personal sin. Aldredge-Clanton (1998:67-80) found that people living with Cancer might feel burdened with guilt, perhaps feeling that they have caused Cancer to invade them. Others may feel guilty because they believe that God has brought on Cancer to punish them for their sins.

Rossman (1985:123) tells of how theology taught her that disease is the result of sin. Her pilgrimage with Cancer left her with two extremes in relating to others. On the one hand, people put her on a pedestal because of how well she was ‘handling’ this invasion from Cancer in her life; on the other, she was treated as a leper because people were afraid of her because she had Cancer. Both these attitudes left her isolated with Cancer, because they both failed to deal with her as a person who had Cancer. One reason for others being afraid of those who have been invaded by Cancer might be because they do not know how to deal with what they think is that person’s impending death (Rossman 1985:124).

2.3.2 Death

Death can be seen as defining life and is therefore important in these discussions. The biomedical definition of death is ‘the permanent cessation of functioning of the organism as a whole, even though individual organs may continue to function for a time’ (Hunter 1990: 260). The death of a ‘person’ is not seen as biological but more as a psychological, social, philosophical and theological concept. Permanent absence of consciousness and cognition are the criteria of a ‘nonperson’.

According to traditional Christian theology, death is regarded as the ‘separation of body and soul’ and it is from this that the related belief in the soul’s immortality stems; another Christian view of death is that death itself is a ‘consequence of sin’. This view sees death as a divine punishment. But a modern theology of death emphasises the multidimensionality of death, including the possibility of its being a ‘natural’ conclusion of life (Hunter 1990:261).

A pastor (Lubbe 2001) discussed some faith issues that patients and their families experience. One of the issues he came across was people who tell the ill person: ‘You should not lose Faith.’
This can lead to conflict between the reality of the situation and the person or family’s belief system. The family might be hoping that the patient will be cured. They might see trusting in the Lord and hoping for a miracle as their only choice. In this instance, accepting that the patient is going to die can be seen as ‘lacking faith’. Pastor Lubbe has families who are not ready to let go, either of the person or their hope. This in turn can cause the patient to believe there is nobody that he/she can talk to, leaving him/her alone with his/her fears and thoughts.

2.4 THE STORIES THAT WOMEN LIVING WITH CANCER TELL

What is most important is people’s own perception of their illness. Remen (quoted by Moyers 1993:345) states that in others’ being there for Cancer patients, listening to them, and validating their stories, new opportunities of living with Cancer may open up to them. The greatest thing you can give someone who is ill, according to Remen, is one’s attention. It is a form of nurturing to send the message that no one knows their stories better than the patients themselves do. By listening a caregiver can convey the message that the patient are living a story that is theirs to tell (Frank 1998:207-210):

Telling one’s own story can help move a person through a particularly difficult situation by providing some critical distance. When a story is well heard, it becomes something that the teller and listener can talk about and reflect on. When experience becomes an object for what is now a mutual involvement, the teller gains some distance between what is being lived and what is being told. Only at this distance can actions...be perceived as possibly having alternatives, thus making change imaginable.

These ‘stories’ that Frank (1998) talks about consist of a person’s illness narrative regarding his/her experiences in living with Cancer. The person, the family as well as the medical personnel all play a part in these illness narratives (Weingarten 2001:114). Frank (1998:200) identified three narrative structures. These can be seen as skeletons on which stories of illness are fleshed out. The stories are not material to analyse, but should rather be viewed as relationships to be entered into.

The Restitution Story: The restitution story is narrated from the sidelines, because the ill person communicates what the physicians and nurses say. This narrative represents the triumphant optimism of medical science, thus the commitment to the idea of a possible cure. If restitution is not the reality of the patient, he/she may be marginalised by telling this story (Frank 1998:201).
The Chaos Story: Patients talking from this point of view may be unable to render their lives as having a beginning middle or end. Their stories can trail off in a formless sequence of 'and then' contingencies. When these stories are denied, it can only lead to an intensification of the suffering of whoever lives this narrative (Frank 1998:202).

The Quest Story: The quest story arises where illness is seen as being lived as a quest, something to learn from so that this information can be passed on to others. It is not that the person who is living through the illness is glad to be ill, but that he/she is grateful for how it has changed him/her and his/her life. Thus, these stories are about illness leading to new insights (Frank 1998:203).

The above narratives can be intertwined. It can be important to hear which of the stories a patient is telling on a given day, so that one can know where that patient is at that specific time. ‘My strong assumption is that people tell the stories they need to tell in order to work through the situation they are in’ (Frank 1998:206).

Weingarten (2001:116), who was herself invaded by Cancer, found that Frank's classificatory scheme of illness narratives made her realise that her thoughts, feelings and even her silence made sense. She lists three other types of illness narratives that also helped her understand her own illness narrative. The first of these was the Stability Narrative, where the illness is no better, but it is also no worse. The second kind of narrative is the Progressive Narrative. Because this narrative focuses on 'improvement', it is much easier to find an audience to tell this story to. The third kind of narrative is the Regressive Narrative and the most difficult to find an audience for. The reason for this is the fact that this narrative tells of the person not getting better (Weingarten 2001:121). She is of the opinion that the latter narrative can produce isolation, because in the telling of this story the person risks being stigmatised or even marginalised. She states that a 'culture that values a progressive illness narrative, tolerates a high stability narrative and shuns a regressive narrative', which reveals a great deal about its morals and norms (Weingarten 2001:122).

By telling and re-telling illness stories, people can give illness a voice. Being ill can require giving up the old self, 'the person you used to be'. Illness can therefore threaten the way that people know themselves as well as how others know them (Weingarten 2001: 112). The ill should then search to find a way to be somebody else, the next viable 'you'. Through telling his/her own illness story, a patient might find that 'next you' (Price 1994:182-183).
2.5 DISCUSSION

In this chapter I set out to give the reader some background on the social and socio-religious construction of illness and death with reference to constructions of Cancer in Western society and how these constructions constitute people's attitudes towards Cancer patients as well as the illness.

The literature that I have consulted focuses on a Euro-American view, which I found applicable to what I heard during conversations with participants here in South Africa.

I found that many of these dominant social and socio-religious constructions do not leave space for the multiple realities of living with Cancer or new possibilities of care. I opted for a postmodern social construction of reality where the participants themselves create new possibilities by telling their stories, new possibilities for their own unique way of living with Cancer as well as the care that they would prefer.

2.6 CONCLUSION

It is clear that Cancer affects people's lives at various levels, and that each person living with Cancer will perceive his/her experience differently and therefore would respond differently to those experiences. When it comes to care, I would argue that it may also be different for each individual, especially in terms of what he/she prefers care to be.

In Chapter 3, the stories of the participants and their families are documented. The stories tell how they lived with Cancer (some longer than others), how Cancer affected their lives, the turmoil and despair, but they also tell of hope and joy. The participants and I talked about the experiences surrounding the treatment, their family's involvement and spirituality. These conversations went on to look at the specific care that the participants received. The participants and I also talked about what their preferred care would have been had they been asked.
CHAPTER 3

DOMINANT THEMES IN CARE

3.1 INTRODUCTION

In this chapter, I invite the reader to join me in the re-telling of the stories that the participants shared with me. By having these conversations with the participants, I have grown as a person. My ideas about Cancer have also been extended to include hope and resilience. I would like to thank all the participants for telling their stories and in so doing giving their experience a voice. The conversations were in Afrikaans and the transcriptions were translated to ensure access to more readers. The translations were verified with the participants.

Earlier in the research, I mentioned the comments of Aldredge-Clanton (1998:2-5) regarding counselling of people with Cancer. She is the chaplain co-ordinator at the Baylor University Medical Centre in Dallas. She is also a pastoral counsellor who focuses on counselling Cancer patients. In her book *Counseling People with Cancer*, she addresses many aspects that play a role in the life of a person living with Cancer. In her view, pastoral counselling for a Cancer patient can be useful when it allows the person to tell his/her unique story. In her ministry, she found that patients were enthusiastic to tell their stories because of the opportunity if offered to be heard and understood. The fact that their stories could have value for others gave them hope that there was a purpose in their struggle with Cancer. Some patients even found that telling their story brought order and purpose into their lives.

Some of the stories they told were long and some were short, some elaborate and others concise. This is an indication of the perceptions of the person telling the story of his/her own experiences. The participants only told the parts of their stories that they were comfortable sharing with the research study and me.

3.1.1 Introducing the participants

Five women living with Cancer (Naomi, Erika, Henriëtte, Kyla and Hester) volunteered to participate in the project, sharing their stories of care and Cancer with me. The children and husbands of Hester, Naomi and Kyla also shared their experiences with me. Chris and Hester were the only couple who joined each other in the conversation with me. When given the choice whether they
would prefer 'pseudonyms', all but one couple wanted their own names used in the study. In an
effort to enhance confidentiality, I do not identify the pseudonyms as opposed to the real names.

3.1.1.1 Naomi's story

I met Naomi through a family member. Naomi had experienced migraines since she was 16 years
old. These became so severe in her adult life that she had to undergo tests. She was diagnosed
with Chondro Sarcoma grade 2, located behind her left ear. At the time she was working full time
and had a family and household to think about. Her daughter Karla was 15, her son Henk was 17.
During treatments, her husband and children always knew what was happening. She now thinks
that her husband was perhaps hit the hardest by Cancer's invasion in their lives. She experienced
him as being quiet and withdrawn during the course of the treatments.

Karla shared her first impressions regarding her mother's illness with me. She said: 'My father
fetched us from a tennis tournament in Bloemfontein. We could tell something was wrong
though...he told us that our mother was ill, but it was our mother who told us that it was
Cancer....that was the worst moment for me.' For Henk, his mother's illness taught him to 'live for
what makes you happy'. Naomi told him that life is too short and 'not to do things that you do not
want to do, or to do it for someone else's sake'. Naomi felt he should follow his heart and do what
he prefers. He never really thought of his mother as sick 'because she didn't see herself as sick'.
Henk has the greatest admiration for his mother.

3.1.1.2 Erika's story

Erika regularly went for mammograms. She was diagnosed with Adenocarcinoma in the left breast.
There is no family history of breast cancer, except for a cousin whom she is related to by marriage.
She recalls that her sister was more shocked to hear the news than she was, after which her sister
immediately went for a check-up. She said: 'I have a “fighting spirit”...I had lots to deal with at that
specific time.' Her sons were only 7 and 11 at the time. She had her children and husband to think
about as well as a household to look after, an 'illness that can kill you' and she was running a very
busy day-care centre. Erika had to choose whether she wanted 'to live with the broken pieces of my
life or to look up and go on with my life....I chose to live my life'. She felt that she needed to be
strong, that if she was not, everything would fall apart. Cancer is a 'hard reality' and she felt out of
control. However, she decided to fight Cancer with God's benevolence. This reminded me of
Frank's (1991) ideas regarding the 'fight' metaphor.
The 'fight' metaphor Frank (1991:83) wrote about captures something of what it is like living with Cancer in one's life. Frank never personified Cancer for the purpose of beating it, though. On the contrary, he saw Cancer as being part of himself. He was still Frank, tumours and all. This realisation brought him great relief and now that his Cancer is in remission he views this ordeal as being over. For Erika this is different, and I suspect that it would also be different for other individuals. Erika is of the opinion that even though Cancer is in remission, the ordeal will never be over, instead she is 'living with Cancer' every day.

3.1.1.3 Henriëtte's story

Henriëtte's family was used to Cancer as a part of their family's life. However, even a history of Cancer in the family did not make it easier for Henriëtte when in September 2000 she felt a lump in her breast. She immediately made an appointment with the physician. The physician did not expect the lump to be a problem, seeing that it did not appear to have the same qualities as a malignant tumour. However, she went for a mammogram, after which the physicians decided to do a biopsy. The results came back positive and a partial mastectomy was done. She is a married working mother with a son of 17 and a daughter of 14.

3.1.1.4 Kyla's story

In the beginning of 1989, Kyla felt a lump in her breast but was not concerned because no one in her family had previously had Cancer. A year later, at the age of 60, she noticed that the lump had become bigger. After visiting her physician, she had an immediate total mastectomy. Members of the Cancer Association's Reach for Recovery division visited her in hospital and supported her. After her recovery, she joined them and started 'reaching out' herself to others in the same situation. The important thing for her was 'how you handle Cancer' or 'what you make of it'. Like Kyla, other women also find it valuable to have conversations about their experiences with other women who have also had mastectomies (Westlake & Selder 1990:128).

Kyla's story resonates with that of Weingarten (2000:22), who speaks about others creating hope for the person who is ill. This is evident in the reaching out of women to women in Reach for Recovery. Kyla is still going for check-ups twice a year.
3.1.1.5 *Hester and Chris's story*

Hester felt the first lump in 1983. She remembers that it was the same year when the movie 'Terms of Endearment' was released. The heroine in the movie also found a lump and Hester knew in her heart that this would be the same for her. She was diagnosed with Hodgkin's disease. Hester and Chris received the diagnosis in August, but they went ahead with their engagement in September. They had already been together as a couple for four years when they received the news. Friends advised Chris to re-think the decision to marry Hester, because it was not wise to marry such a 'sick' woman. However, Chris stayed with Hester and postponed the wedding for a year and a half so that she could go for chemotherapy and then get strong again. Hester mentioned that she wanted her hair to grow back before the wedding. They got married and six years later they had Francois, who was a 'miracle baby from Jesus', because the chances were slim that they would be able to have children. During her pregnancy she felt another lump and the physician felt that she should start chemotherapy directly after the birth. But she decided to breast-feed the baby first, which for her was a very rewarding experience. Ten months later, she started chemotherapy. Then she felt a growth for a third time, and had to undergo chemotherapy for a year and a half again. Since then she has been 'clean', and they pray that it will stay that way.

After her first series of chemotherapy, Hester decided against further treatment no matter what, but then her maternal grandmother died of Cancer. This experience made it clear to Hester that dying of Cancer is a terrible death. This led to a personal struggle: she knew that she did not want chemotherapy but she also did not want to suffer like her grandmother. Her grandmother was one of seven children, of whom six had died from different forms of Cancer. Hester's sister has been more cautious with her own health since Hester was diagnosed. Hester's mother died from Cancer nine weeks before this conversation. Her mother felt the growth during Hester's first chemotherapy and feared that her news of Cancer would intensify Hester's experience of the treatment. Hester had the experience of being both the patient and the person supporting a patient. She knows what it feels like to be in a position where one only wants to make things better for the person who is ill, but cannot. However, she says she also knows how much it means 'just to have someone there with you, someone who knows what you are going through'.

The themes identified from the literary study and conversations I had with patients at the Pretoria Academic Hospital resonate with the stories told by the research participants. These were, firstly, communication between the woman living with Cancer and her family; secondly, communication between the woman living with Cancer and the medical system; and, thirdly, the woman living with
Cancer and her spirituality. The first two themes are discussed here, weaving them in with the stories told by the participants. The third theme is discussed in Chapter 4.

3.2 COMMUNICATION BETWEEN PEOPLE LIVING WITH CANCER AND THEIR FAMILIES

Communication, for the purposes of this study, means the ways in which people living with Cancer relate with (mostly) their families, how everyone involved deals with Cancer as part of their family system and how that affects their 'speaking to one another', the flow of information, the sharing of emotions and thoughts regarding Cancer.

3.2.1 The relationship between the participants and their families

For the most part, the participants in this research project had transparent relationships with their families. From the beginning of Cancer’s involvement in their lives, they involved their husbands and children as well as some friends and other family members. The communication channels were open and the participants felt that they could share their thoughts and feelings freely with their family members.

In an effort to include her sons, Erika’s husband went to their school after she came out of surgery to inform them that their mother was doing well. Erika said: ‘They felt included in the situation.’ It also made them ‘knowing witnesses’ of their mother’s illness: ‘They saw me as “living life and not death”.’

For Kyla, the support of her husband and two daughters was very important. Her husband was the one who cared for her and always accompanied her to the doctor’s appointments. However, because she is a very private person, neither her husband nor her daughters have yet seen her scars. Communication, according to her, was very strained and therefore she feels that communication, especially between herself and her husband, could have been ‘better’. When I spoke to Kyla’s husband, Jim, tears ran down his cheeks and I could tell that the experience of his wife’s being invaded by Cancer had been very difficult for him. He told me: ‘I was late on the morning that Kyla had the operation. I was caught in a traffic jam and arrived just as she came out of surgery. I cared for her and looked after her in those “bad” times, when she felt sick after the treatment….I would make her tea and something to eat when she did not have the energy to do it herself. We even picked out a wig together after her hair started to fall out.’ With admiration in his voice, he said: ‘It is only my wife’s courage and strength that has carried her through this struggle
with Cancer.’ Kyla’s husband believes that support and care are the most important things that one can give a person living with Cancer.

Because communication – in this situation, the sharing of emotions and feelings – was difficult in Kyla’s and Jim’s relationship, Jim and I spoke about the kinds of thoughts that he would have wanted to share with her had the communication channels been more open. He said: ‘I would have liked to tell her that I do not foresee the worst, but that if it is bad news that I would be there for her, always. I know that Cancer can come back, but hope that it will not.’

Hester and Chris also battled to keep communication channels open. This had not been a problem before, but they felt drained and vulnerable by the third set of chemotherapy. They discovered that each one found a ‘corner to withdraw into’ with personal emotions and fears. Now, in hindsight, they feel that this was the ‘wrong’ way for them to have dealt with the situation. But at the time they felt they were ‘protecting each other’ from their own thoughts and fears. However, these attempts just contributed to the emotional stress they experienced. What they wanted was to ‘help each other’, but they were too drained at times. ‘We now think that feelings and emotions should be discussed, so that there are no misunderstandings about what each person is thinking or feeling.’ Hester feels that by discussing each other’s thoughts and feelings one ‘can share in each other’s experiences as well as feeling emotionally lighter.’ They agreed that it is not as if one always wants advice, but that sometimes what one wants is ‘emotional relief’. Talking about communication brought them some sense of what was troubling them at that stage.

Cullinan (1990:141) writes about a ‘pretence awareness context’ – this occurs when both the people involved are fully aware but both pretend not to be. Closed awareness occurs when the one person does not know the other’s view or thoughts on his/her experiences. Pretence awareness can contribute to the erosion of the marriage/relationship itself. So, when either the husband and/or the wife does not know what the other is thinking or feeling, and pretends to be unaware of the other’s struggles, he/she could remain alone in his/her own suffering and pain.

Naomi’s son Henk experienced his dad as having an irrational fear when it comes to his mother. This was evident in his father’s trying to keep any sort of stress from Henk’s mother and leads to irrational conflict in the father-son relationship. This fear is also something Henk encountered in the rest of the family – a desire to protect Naomi from stress and even from Henk’s high-spiritedness.
3.2.2 The support the participants received from family and friends

Suffering can bring a gift: when someone manages to break through the wall of pain of the person living with Cancer, to provide love and support. This means being there to lend a hand by taking care of the household, arranging suppers and anything else that the family may need.

Naomi raised her children to be independent and this served them well when she was diagnosed with Cancer. In her situation, the family had a big 'support group' of family and friends. Though the children were not dependent, Naomi felt that 15-year old Karla was at a sensitive age and they discussed the idea of whom Karla would want as her 'other mother' if something should happen to Naomi. The conversation stands out as very precious in their relationship. Naomi related the conversation as follows: "Who do you think will look after you the best?" I asked Karla. We slowly went through my list of close friends, and Karla chose the biggest "shopper" – I am not a person who likes to shop! Naomi said, laughing. 'The friend that she chose does not have children of her own, she is modern, she goes to the gym....I was surprised that Karla chose her. I spoke to her and asked her if she would be there for Karla should she need it. She felt honoured at the request.' Conversations like these between mother and daughter were kept light and full of humour. 'I would joke with Karla by saying things like: "Even if I do hold on – you can always go shopping with Aunt Altrina".'

The support Hester and Chris received from their friends and family carried them through the difficult times of treatment and being very ill. Friends would phone just at the right time. Having friends, even though they could do nothing to restore Hester’s health, was emotionally strengthening. Hester and Chris would like the friends and families of people living with Cancer to know that one should not say 'tell me if I can do anything'. They should just do it. Hester and Chris felt too proud to ask for help. They thought it would be interpreted as saying: 'We are not coping.' They have friends who phoned and told them that they were bringing food over, which was helpful to Hester and Chris. They appreciated the practical care. Chris also shared with me the frustration that he experienced when people told stories about other people that they knew who had Cancer; the problem with this was that those patients had died. Chris felt that this was not considerate at all. Patients and families, like Hester and Chris, can often feel discouraged, especially during the first stages of the illness. It is then that they can do with hearing positive stories about anyone who had gone through the same experience (McDaniel, Hepworth & Doherty 1997:5). Karla found support from outside the family from friends who had gone through the same experience to be the most valuable.
3.2.3 Preparing for the unknown

One of the things that Naomi tried to prepare her children for was that physically she could be
different after the surgery. She wanted them to be aware that she could change from what she was
before Cancer physically took hold of her. She also wanted them to know that she as a person and
as a mother would stay the same. She fell silent for a while during our conversation: ‘I didn’t always
know what to prepare them for otherwise.’ Tears flowing, she told me about the financial
implications and the worries that surrounded her illness. As a working mother, she was not
financially prepared for what happened. Luckily she did have an insurance policy in place, but she
believes that women should always be prepared for the unexpected, financially as well as
emotionally.

3.2.4 Humour as a coping strategy

Humour as coping strategy might be useful for some people, but Frank (1991:69-71) is of the
opinion that patients who use humour, cheerfulness and bravery to cope have to deny their own
humanity to receive the support and care they may need. Some patients deny that being human is
normal, so that becoming ill raises the possibility that death is lurking around the corner. Western
society praises patients with words such as ‘courageous’, ‘cheerful’ and ‘optimistic’. When a patient
jokes or smiles, family and friends approve. So when patients talk only about recovery and act
cheerfully it makes the patient and the people surrounding them feel good. The problem is that this
can lead everyone to believe, no matter what the reality of the situation is, that the ‘sick person is
going to be fine’. This can be harmful for the patient in the long run in the sense that when the
patient does want to look at the seriousness of the illness, he/she may find that family and/or friends
are not easy to talk to. At this point, so-called ‘negative emotions’ may be viewed as ‘depression’
(Frank 1991:64-65).

An example of a positive use of humour comes from Naomi’s story. Naomi always tried to keep the
atmosphere and topics regarding Cancer and her illness light by introducing humour during serious
discussions with family and friends. This strategy proved to be very valuable for her, as well as for
the rest of the family. Humour has always been a coping strategy that Naomi has exhibited in
dealing with previous crises in her life.
3.2.5 Having family members accompany one to treatments

Treatment time spent in waiting rooms, clinics and hospitals can be valuable time when it is spent with either family or friends. The participants in this study all experienced having a family member or a friend accompany them to radiation and chemotherapy as beneficial both to them and the person supporting them. This was especially true when the participant's children went along, because they felt included and important.

Henriëtte's children accompanied her to radiation and chemotherapy, so that they could see what was happening to her at all times. For Naomi, treatment times proved to be valuable time spent bonding with family or friends. She had a friend who came to stay with her and her family for a few weeks to lend a helping hand: 'She accompanied me to the therapies and was also a buffer between the medical world and me. She protected me and saw to it that I received the medical attention I needed.' This friend was the 'somebody' that Naomi needed to stand up for her. Hester's son, Francois, accompanied her and Chris to the chemotherapy so that he could see and understand that it was the medicines in the intravenous drips that made his mother sick and that she was not mad at him if she did not seem to feel like talking. He even helped with caring for Hester during the sessions of chemotherapy, cleaning her arm, or calling the nurses. For the participants, these actions spoke of love, support and genuine care.

3.2.6 'Sharing information' versus 'not sharing information'

I heard stories of information being shared and also of information being withheld by the participants. One of the participants only recently started keeping information from family members. She believes that because they cannot do anything about the situation, they should not be informed. However, she does not experience a sense of isolation when she keeps her illness and her pain to herself.

On the other hand, keeping information from children whose parents have Cancer might be potentially destructive. Children invariably do have some sense of what is transpiring. Therefore, by informing children of the facts and assisting them to understand, one can help them and create a sense of greater safety (McDaniel et al 1997:15). This is what Hester and Chris did from the start. They told Francois what was happening to his mother from the time that he could understand and made him part of the process. They are of the opinion that for Francois to be informed helped him
to accept Cancer in their lives. When he was eight, he came to Chris and said that he knew why his mother got Cancer – because ‘now I can help other children whose mothers are sick’.

Kyla mentioned that she kept her fears and thoughts to herself: ‘I did not want to be a bother to my husband or my children nor did I want them to worry.’ She thought that sharing her story or illness narrative with loved ones could be dangerous and therefore impossible. According to Griffith and Griffith (1994:51), it is due to fears such as these that these narratives can become destructive for the person holding on to them. There are stories that cannot be shared without taking the risk of triggering the alarm for others, and it is this ‘alarm’ that governs the degree of intimacy in people’s conversations and relationships.

Henriëtte is sure that sharing information with her children lessened their uncertainty: ‘My children and parents were all shocked by the news. My father was in the process of recovering from an operation. It was an uncertain time for our family. The children were worried that I might die, but they stood by me and helped me wherever they could.’

### 3.2.7 Staying ‘strong’ for each other

Most of the participants in the study told stories regarding staying strong for their families and therefore keeping the families’ worlds from tumbling down around them. Karla said that she did not want to cry in front of her mother for fear of causing her mother to feel ‘down’. Karla wanted to protect Naomi after the first operation. One of the reasons was that Naomi’s face was paralysed on the one side and people stared at her. Naomi taught Karla that she should not let it bother her and that she should learn to live with it just as Naomi did. Karla said: ‘My mother is a strong woman and that is what kept me strong as well.’ With a shrug of the shoulders, Henk noted: ‘I never really thought of my mother as sick because she didn’t see herself as sick or as having Cancer. I have the greatest respect for her.’ The physical changes in Naomi were difficult for him because they presented the evidence to him that she was really ill. It was small changes in his mother that affected him and reminded him that everything is not well: ‘The time I got worried was when my father gave us the letters that my mother wrote to us before her surgery. I am not used to her having a sentimental side.’

Francois, Hester’s son, told her that he did not like her bald and drew pictures of her with long black hair. Hester commented: ‘I think it is the result of me being so negative about my hair loss. I never
felt good about myself.' For Hester, it was important to look good, so that no one could tell that she was ill.

Erika had this to say on the subject: 'I found that my mother, but especially my mother-in-law, needed me to comfort them. I decided that for my husband, children and the rest of the family I should stay positive. It was up to me to carry everyone else through this time of tribulation.' She believes that this kept the family from worrying and being overcome by anxiety. Henriëtte agrees with Erika: 'I do believe that the children stayed positive through my illness because I stayed positive. I also tried to share only the positive things with my family.'

3.2.8 ‘Stolen childhood’

Karla, Naomi’s daughter, went through a ‘bad patch of acting out’. She and her mother spoke about what they thought caused this bout of unruly behaviour and together they wondered whether it was related to Cancer’s being in their lives. Karla experienced growing up much faster than she would have normally. She experienced pressure from her mother to be ‘more aware of what I am doing, to do it right and to think of the consequences thereof’. She thought it was Naomi’s way of preparing her for ‘a life without my mother’. Moreover, she found herself being careful not to ‘stress my mother out. Cancer robbed me of me being a “carefree” teenager. This has also been mainly an emotional battle for me. I would not have survived this illness experience if I did not stay positive’. Cullinan (1990:145) states that because of adolescents’ developmental need for gradual emotional withdrawal from the family, they may respond by acting out when, once again, Cancer demands from them emotional intimacy with the family.

Francois, Hester’s son, said: ‘Having Cancer around is not fun but I still help other children when their mothers are sick.’ I asked him what he thinks it means to his friends to be able to talk to him or have him talking to them. After a short silence, he said that he thinks ‘it is nice for them to know that someone has gone through this already’, that someone else has been through a similar experience and survived it. Chris and Hester felt that it is unfortunate Francois had to grow up with Cancer as part of his life. They said that Cancer stole Francois’s ‘childhood’ from him, but: ‘He grew up to be a very loving and considerate young boy. We believe that he also grew up knowing that life is what you make of it and that a person’s faith is very important.’
supported me in all the decisions that I made regarding the treatments, as well as in the way I decided to deal with Cancer. A decision that we made together though was to have the second mastectomy. I was always comfortable about the mastectomies, I never felt self-conscious about the fact that I did not have any breast. My husband never pressured me to go for reconstruction. He left it for me to decide whether I wanted to have reconstruction done and when I wanted to do it. After I decided that it was time for reconstruction, I decided on the size of my new breasts myself again. For Erika, her sexuality was not linked to having breasts. Both she and her husband saw the mastectomy as functional. She never experienced her sons as being embarrassed by her appearance. “I was “breastless” for five years before I decided to go for the reconstructive surgery....’ She laughs when she says: ‘After the reconstruction, people would tell me that the new breast seemed to give me more self-confidence and I would say to them: “It takes more self-confidence and courage to be without breasts in our society where the norm is having breasts”.'

The experience of having a double mastectomy was much more traumatic for Kyla. Her relationship with her husband changed dramatically, especially after the second mastectomy. ‘I decided not to have reconstructive surgery, even though I felt scarred and humiliated. It was my body and I didn’t want any more surgery’. I asked her whether if her husband had ever talked about reconstruction, she would have considered it. ‘No’ she replied, and after a moment of silence she said: ‘He never asked though.... I felt like “less of a woman” and that had a negative effect on my sexual desire. I felt ashamed and afraid that my husband would be disgusted with my physical appearance now. I never discussed these agonising thoughts with him. One afternoon he asked me if we should “leave the sex” and all I said was that it was “fine”....but it was not only the intimate relationship between us that Cancer stole from us, it was also the “hugs and kisses”.’ I asked her about this and it emerged that it was not really ‘fine’. She was pensive for a while, battling with her emotions, after which she said softly, tears in her eyes: ‘I could not be myself because of the physical scarring, so at the time I was happy to let go of the intimate relationship between us.’ Kyla felt disfigured by the mastectomy. She felt that she did not want her husband to do ‘something’ that he may feel uncomfortable with, like having sex with a disfigured person.

Cullinan (1990:138-139) discusses sexual functioning after surgery and the fact that a woman’s sexual self-image, attitudes and behaviour can actually change after the loss of her breasts to Cancer. A study done by Taylor et al (quoted by Cullinan 1990:140) of 209 breast Cancer patients found that the more radical the surgery, the more negatively affected the women and their marital relationships were. However, according to their study, women who had had reconstruction were
'better adjusted'; but there were also indications that mastectomy patients perceived a decline in their spouses' sexual interest. Kyla's story touched me deeply – the sadness of the reality that Cancer had invaded a healthy sexual relationship between two people and destroyed the closeness that had once been part of their life, leaving each of them alone to battle regrets about the past, unable to talk about this loss.

3.2.12 Is emotional growth and/or life-enrichment possible?

I wondered whether emotional growth or life-enrichment are possible, having heard stories in this regard. The participants and I pondered the question during our conversations.

Erika thought that she herself had grown emotionally as well as spiritually because of how she and her family handled Cancer's intrusion into their life. She was not the only one changed. She thought that her husband had 'changed for the better'. Her sons also now know that life is not without struggles and that these can be overcome.

'My whole family's perspective on life changed,' said Henriëtte. The same experience was true for some of the other women. Westlake and Selder (1990:130-131) reported on the positive impact that 'having Cancer' has on some people living with Cancer. The change came for either the Cancer patient and/or one or all the family members. Westlake and Selder (1990) reported a re-evaluation of the Cancer patient and/or one or all the family members' lives and a reprioritisation of their expenditure of personal time and energy. The only certainty for the Cancer patient and/or one or all the family members is 'the here and now' and the opportunity to engage more completely in the nature and the experiences of being fully human and alive. Henriëtte's family now realises that one can never be certain of anything in life: 'My husband shares more of his feelings with me now....our relationship has improved because of Cancer in my life.' Another aspect of her life that turned out well for Henriëtte was that her relationship with her sister improved, she said they 'grew closer to each other....it is wonderful.... As our values changed, the family became emotionally close'. Henriëtte does not make long-term plans, she takes it day to day, she lives for the moment. She appreciates life and does not take anything for granted – 'I give the love and the kisses now, not later.'
3.2.13 Uncertainty and medical check-ups

A very important aspect that came to light in many of the conversations I had with the participants was the waiting time before the next medical check-up. Kyla’s husband told me that the weekend before each doctor’s appointment he and Kyla would be ‘living in separate worlds and the world that I was in was one of uncertainty’. They could not speak to each other. His thoughts were always about ‘what are the doctors going to tell him today’. I asked: ‘Why do you think you each kept your thoughts private?’ He replied: ‘I did not want to upset her.’ He thinks that she must have thought that he was not interested. I wondered whether he wanted to protect her, and he said that it was a possibility.

Henriëtte stated that only after the treatment had been completed, did the reality set in of ‘what really happened and of what I had gone through. Emotionally it will take a long time to recover….it is a process’. Uncertainty reverberates through her and her family’s life each time that she has to go for a medical check-up. The fear of the illness recurring is a major source of uncertainty for patients. Medical check-ups can reactivate fears and previous concerns (Westlake & Selder 1990:129-130). Karla, Naomi’s daughter, is living with the question of what will happen if the tumour grows again. However, she also says: ‘I don’t really want an answer.’

For Erika, the uncertainty that accompanies her annual test once a year is evidence of the fact that she is ‘living with Cancer’. For Frank (1991:2), also living with Cancer, recovery meant wanting to put the whole experience behind him, but he realised that Cancer does not permit that to happen. For him, just like for Erika, the reminders come each time he has a doctor’s appointment. Uncertainty before each check-up seems to be a common denominator for the participants and their families.

3.2.14 Deconstructing professional help

Professional help was suggested for some of the participants – either for them or for a family member. Some participants found this ‘help’ useful but others did not. Hester and Chris’s son Francois experienced a ‘bad patch’ and they took him to consult a psychologist. The psychologist diagnosed separation anxiety, which the parents then addressed. In retrospect, Hester and Chris wanted to address two more aspects in the therapy as well. The first was that they had needed an opportunity and space to talk about their religion and faith, and the therapy did not provide space for talks like these. In some Western religions, authentic religious experiences involve private
intrapersonal dialogues with a personal God that is private. Therefore, patients do not bring their conversations with their personal God into the therapy room. These conversations are then kept outside the awareness of the therapist unless the latter asks (Griffith & Griffith 1994:58-59). Hester felt that her needs on a spiritual level had not been met by the therapist who did not address the spiritual issues and therefore she did not seek further professional help, even though she felt that she needed it.

The second issue was that they objected to the therapist’s question ‘If dad was on his way out?’ meaning ‘Is he leaving?’ ‘We felt evaluated and violated as well as misunderstood,’ Chris said, shocked. ‘I was going nowhere and resented the question, which I saw as implying that our relationship was a failure. Emotionally this experience has put more stress on our relationship, planting thoughts in our minds to wonder about. This was not what we needed at that time.’ The incident scared them, but they could not see a way to discuss the misunderstanding with the psychologist. ‘We did discuss it among ourselves and came to an understanding that our relationship was strong and that we will come through this stronger than before.’

3.3 THE DOCTOR – PATIENT RELATIONSHIP

Farrow, Cash and Simmons (1990:2) argue that the skill with which a physician communicates information to patients and families can be seen as the most powerful tool at his/her disposal in helping people cope with illness. This is where the education of the patient and family should start. By giving information, a physician can help reduce the patient’s uncertainty, strengthening the doctor-patient relationship and altering the patient’s perception of his/her illness from total hopelessness to hope.

I asked the participants about their experiences with their physicians and other medical staff.

3.3.1 Experiences of medical staff and physicians

Naomi said that in dealing with physicians, she experienced ‘being just another patient most of the time. I felt as if I was just part of a process, out of control and without any choices’. For the most part, she felt that there was a lack of communication between her and her physician. ‘I was just the physician’s tumour’, she said, disillusioned. ‘There was a total disregard for my life and me. When I told the oncologist that I did not want the treatment, he replied by saying: “You only have one chance, and we are going to do everything to save you”.’ After her last surgery, she asked the oncologist when she should come back for a check-up and he responded: ‘You will know when to
come in.' When she asked him what he meant, he said: 'When you lose another bodily function.' This was an indication to Naomi that the tumour could grow again and that she would have to go back to see him. She experienced most of the medical staff as believing that there is only 'one way they should handle you as the Cancer patient as well as only one way that I as the patient should handle Cancer'.

Erika's experience with medical staff was mainly influenced by the care she received from two female medical staff members. The one was a young woman at the X-ray department who 'looked as if she could be caring, but who kept a distance'. She did not show any understanding at all towards Erika in the trauma that she was experiencing. On the other hand, the woman doing the scintigram was warm and sympathetic. Erika said: 'I called her my Angel, because by that time I was worn out. She explained to me what she was about to do, and it really helped.' The reader will remember Farrow et al's (1990:2) statement that it is important for the medical staff and physician to convey the right information to the patient in a sensitive way in an effort to reduce his/her uncertainty. Erika's experience with chemotherapy speaks of a different approach. The doctor did not take the time to communicate to her what her prognoses was or what the treatment entailed: 'The first time I went for chemotherapy, I thought that the doctor or medical staff would explain the process before they administered the chemotherapy, but they did not. All I needed at the time was for someone to prepare me for what was going to happen.'

In hearing a talk given to another patient on chemotherapy, as being 'nothing too serious', Frank (1991:73) felt disturbed. He had heard the same talk a few months earlier, before his treatment and then he experienced the reality. Frank (1991) thought that the patient had a right to know that the treatment was more than 'not too serious' in order to do some realistic planning for the time ahead.

Hester and Chris's belief and trust in the medical world was shattered by the fact that Hester had 'to show the physician where the lumps were. We experienced the oncologist as a knowledgeable physician but, as a person, cold, impersonal and unsympathetic'. She found the oncologist uninterested in helping her on an emotional or spiritual level. They came to realise that physicians were there to cure Hester and that she had to 'go look for the rest somewhere else'. Tronto (quoted by Dixon 1999:237) states that even the most prestigious medical doctors tend to 'care' less for patients' emotional and other than medical needs. Hester experienced the nurses as the ones who gave her advice. The third time that Hester felt a lump, the family waited three weeks for the results. The previous two times Hester and Chris had
waited only two days for the results. The family interpreted the 'no news as good news', but the tumour was malignant and she had to start a third series of chemotherapy treatments. Chris called these the 'atom bombs' of chemotherapy. The nurse told her to be prepared to lose her hair quickly and to take alternative measures, like getting a wig or scarves. Hester appreciated this care and preparation immensely. She did start to lose her hair by the seventh day, and by the tenth she was bald. She experienced this as a loss and could not understand why, because she was not a 'vain' person and looks 'were not everything to me, yet being bald affected me negatively. I did not enjoy wearing the wig at all, which made this experience even more traumatic for me'. When she started the chemotherapy, the physician told Hester that the treatment should last twelve months, which Hester and Chris prepared for emotionally. After twelve months of treatments, they went on holiday as a way of celebrating the fact that 'it is all done'. When they returned, Hester went back for her check-up appointment and the physician told her that she should return for more sessions of chemotherapy. 'We were devastated, we felt that the physician should rather have prepared us for the worst possible scenario from the beginning as far as treatment duration was concerned,' said Chris.

During this time, Chris had to inject Hester, for 22 months, three times a week, and this became an emotional hurdle in their relationship. Hester went into early menopause and this made 'handling Cancer' even more intolerable, seeing that once again the physician had not prepared her for this: 'I sometimes felt too exhausted and therefore was not willing to carry on anymore.'

3.3.2 People-oriented physicians and medical staff

Naomi experienced one doctor as more human-oriented and caring. He explained to her 'what was going to happen' all the time. At the radiation department, the staff introduced the apparatus and shared information with whoever accompanied Naomi. This involved the visitors in the treatment process and benefited Naomi and the visitors in their understanding of what was happening.

When Erika decided on reconstruction, she listened to the physician who told her about a plastic surgeon 'whom he and his wife were very happy with'. Just the fact that the doctor was talking from a personal point of view helped to deconstruct the 'expert' viewpoint that was portrayed earlier. Erika recalls that the best advice she received was from people who had dealt with Cancer themselves. Frank (1991:104) had a similar experience, and said: '[T]hese friends seemed able to look at me clearly and to accept what they saw....Human suffering becomes bearable when we share it.' This made me reflect on Reach for Recovery's volunteers. All the women from the
organisation had fought the grip of Cancer and therefore had first-hand experience. Who better then to advise and assist others?

For Henriëtte the physician who took the mammogram was ‘wonderful and caring’. After an extensive examination, the physician himself came to her to give her the x-rays and results and to tell her that he had already spoken to her doctor who referred her. Henriëtte’s doctor phoned her immediately. By then the doctor had already arranged an appointment with the surgeon. This surgeon is a man whom Henriëtte praises for the way in which he treated and informed her. The morning of the surgery she had a ‘premonition’ that the growth was going to be malignant and she felt prepared for the worst. Even though Henriëtte thought that she was prepared, she was still in terrible shock after the results came back, revealing Cancer: ‘I just “cut out” and did not want to speak to anyone. I just didn’t want to hear it.’ Henriëtte thinks that this reaction helped her protect herself against the shock of the reality of Cancer. After the surgery, the surgeon spoke to her and her husband, informing them of what exactly had happened in surgery and what the next step was going to be. He also contacted Reach for Recovery of the Cancer Association, who sent a volunteer to advise Henriëtte on ‘practical care’ for women after surgery. She experienced the medical personnel as professional and efficient: ‘I had an oncologist who understood and who really spent time with me,’ she said. Though the oncologist never gave her a choice in treatment, she always described to Henriëtte exactly what she was going to do and what the treatment entailed. Henriëtte appreciated this, seeing that she wanted to know the details of what was going to happen to her.

Kyla and her husband were also very impressed with the treatment they received from the physicians and medical staff. They were comfortable to leave the decision-making to the physician, regarding the treatment, guidance and direction during this time. They felt that they were not in a position to make their own choices because of a lack of knowledge. They wanted the decisions to be made for them. Kyla’s husband experienced the medical staff and physician as caring, as they explained the treatment procedures as well as what Kyla and Jim could expect to happen. Before every appointment and examination, Kyla and her husband were very stressed. The physician always calmed them and they appreciated this tremendously. Kyla said: ‘The one thing that the physician did not prepare me for sufficiently was the long-lasting physical side effects; for example, I must be careful of what I eat, my stomach is very sensitive now. The doctor told me that the chemotherapy would destroy the “good” cells as well.’
3.3.3 The medical staff's dealings with the participants' children

For Karla, who accompanied her mother to radiation, the 'experience was terrible'. She thought that the medical staff was very impersonal. 'They ordered us around and didn't even call my mother by her name.' Karla would have wanted someone of the medical staff to talk to them as the children of the parent who has Cancer and for the staff to be more sensitive to everybody's emotional needs.

On the other hand, Henriëtte experienced the surgeon as warm and caring, speaking to the children, explaining to them what was wrong with her. Because the children were uncertain and worried about her, Henriëtte invited them to accompany her to radiation and chemotherapy. At these times the medical personnel spoke to them and explained to them what the treatment entailed. The oncologist even told them what to expect, for example, her hair falling out, that she would be weak and sick and that they could be there to help and support her if they wanted.

3.4 KNOWLEDGE / POWER RELATIONSHIPS

Erika said 'Physicians are the ones with the knowledge and they use this knowledge to obtain power over the patient. The patient's 'only' role is to co-operate with that what the physician is prescribing.'

3.4.1 Dependency

Erika sometimes experienced being the patient as being 'disempowered and vulnerable because I felt and was dependent on others'. Such a situation can lead to a power relationship between the sick person who is weak and the caregivers who is healthy: 'Sometimes the "expert opinion" felt like abuse to me, the people taking care of me demanding that I do and say what they wanted me to.' Erika offers an example of 'a nurse who felt that I should cry, that it was not normal if I don't cry, she carried on and on until I cried. I felt victimised by her attitude and the treatment I received.'

For Frank (1991:56-58), power was in the hands of the physicians. Decisions and treatments were delayed until the physician's arrival, thus everybody had to wait – the patient, nurses and residents – for the physician. So, when he/she did arrive, the physician commanded centre stage. This means that when the physician leaves, the patient then can relate to visitors the information the physician gave. The patient is constantly reminded of how little he/she knows and then assumes that the physician knows all. Frank (1991) recalls a female patient asking too many questions during a visit. The physician thought this to be inappropriate and accused the patient of trying to 'control' her
treatment. The physician stated that the patient should remember that he was ‘in control’.
However, Griffith and Griffith (1994:73) write:

Clinicians should strive to establish egalitarian relationships within the therapeutic
conversation, while openly acknowledging the power differences between clinician,
patient, and family members....

Hierarchies of power are evident in the medical world and therefore also in human relationships like
the physician-patient relationship. These hierarchies can silence patients, making them non-
dominant participants in their own care and treatment. By establishing an egalitarian relationship
within the physician-patient relationship, with mutual respect and acknowledgement for each other’s
ideas, thoughts and feelings, each person can actively participate in the decision-making process.
The patient becomes an active partner in his/her own care and treatment. It is the physician’s
responsibility to regulate the flow of knowledge, seeing that

possibility of knowledge can shift power....Possession of expert knowledge is
toxic for dialogue when its presence in the relationship silences the voice of one of
the participants.

(Griffith & Griffith 1994:77)

3.4.2 Agency

Agency refers to a sense of making personal choices in dealing with illness and the health care
system. Therefore it is the active involvement in one’s own care (McDaniel, Hepworth & Doherty
1992:1-11). In Erika’s situation, I wondered about the kind of agency she experienced regarding her
treatment. Erika started informing herself about this thing called ‘breast cancer’ as well as the
treatments. She read and found information on the subject so that she knew what was happening to
her as well as what to expect. When people start seeking information, it could be that they are
actually trying to reduce their uncertainty (Westlake & Selder 1990:128). For Erika this meant
looking at pictures of women with only one breast. She experienced this as shocking but thinks it
also empowered her to think for herself (Graham 1996b:173; Bons-Storm 1996). Farrow et al
(1990:5) are of the opinion that through knowledge patients are able to maintain a sense of control
over the events taking place in their lives. Erika believes that knowledge empowered her; it helped
her to make informed decisions and to accept the mastectomy. She says: ‘Accepting the
mastectomy was not that difficult for me. I think it is because I had a choice; I decided what I wanted
for myself.’ Choice can turn the worst of situations into an experience of value. In having a choice of
how one experiences illness, one becomes more than a victim. However, Frank (1998:138) sees the choices available as limited.

### 3.5 THE 'GAPS' IN CARE IDENTIFIED BY THE PARTICIPANTS

All the participants thought that the most important gap in the 'care' they received was in the medical field. For instance, Naomi felt that there should have been someone to support her children and the rest of the family. The provision for social support for their spouses, children and family can be an important component in relieving women's uncertainty (Westlake & Selder 1990:128).

Naomi had her own way of handling Cancer. For her it was 'private between the physician, the treatment and myself. I am not the "type" of person who likes to go to support groups or psychologists, even though I was told that it would be the right way of handling this crisis in my life. People should not be treated the same, since we are not. What I needed was more direction and information surrounding the Cancer treatments available.'

Henriëtte, Hester, Erika and Kyla were also concerned about the lack of information they had received regarding the side-effects as well as the long-term effects of the treatments. Women who received adjuvant treatment in the form of chemotherapy or radiation therapy found that not knowing about the side-effects of those treatments caused uncertainty and anxiety. The ability to predict the occurrence and duration of side-effects appears to reduce the uncertainties and to assist patients in managing their lives better (Westlake & Selder 1990:128-129). Henriëtte said that she thinks that the surgeons should know how to deal with women with breast cancer specifically. The physician should be more aware of the psychological effects of this kind of trauma in women's lives.

During our conversations, the participants and I wondered about 'negotiated care'. By 'negotiated care' we mean that the person who receives care should be asked what it is he/she wants or needs. In these discussions, we wondered whether one person should be assigned as a facilitator of a care network, and then to have a caregiver assigned to the person living with Cancer and his/her family. This person can then function as the advocate for the person who is ill. For the purposes of this study, a pastoral therapist can be the facilitator, facilitating communication between the carers and patients, their families, physicians and the rest of the medical world. Farrow et al (1990:4) mention situations where a social worker assists the patient and family after the patient has been diagnosed. The patient can then be encouraged to bring other than social problems to their attention. Farrow et
al (1990) established that only in such situations do patients discuss their confusion around the treatment.

3.6 CONCLUSION

When one re-tells other people’s stories, their personal story enters into conversation with the collective stories already in circulation. The hearer can then place his/her story alongside those of others (Graham 1996a:177). My hope is that the stories the participants told through this research report might resonate with the experiences of others.

It was evident from the conversations that Cancer took away the participants' lives as they had known them. They had to adapt to a new way of life with limits and became used to living with Cancer 'as a family member'. One participant said: 'The patient and his/her family are never without Cancer in their lives.' Cancer stole their identities; some of the participants became 'their illness', leaving them powerless in the hands of the 'medical world' of technology and science, 'experts' and knowledge. Some of the participants found that they could not share their illness and experienced feelings of regret. Others stayed positive and kept a 'presence' of wellness turned to the world, while others shared their emotions as well as emotions freely. Cancer wreaked havoc in some families while in others it brought them together. Love, support, hope and humour were words used by participants describing their lives living with Cancer.

In Chapter 4, I pay attention to Spirituality and Cancer, the role that spirituality plays in the lives of people living with Cancer as well as their families. The participants and I discussed their preferred pastoral care and the implications for pastoral therapists. Graham (1996a:53) argues that care should not only be in the hands of the 'pastor' but can be put back in the hands of the community. She talks specifically about the 'communal context of the regular gathered Christian congregation'. This implies that caring can also come from church members, as part of their 'everyday activities' of being there for each other. The question that may come to mind is this: If care can be done by any Christian, what is the role of the pastoral therapist in such a situation? As the researcher, my answer would be that the pastoral therapist would be the person who would commit his/her time to the patient and his/her family in assisting them with information gathering and planning. He/she can also be someone who can provide training for church members who would want to care for the sick. The pastoral therapist can assist the caregivers in helping the patient spiritually, bringing the patient into contact with the right medical resources, which can present choices to the patient and his/her family regarding treatments as well as general information regarding Cancer.
Farrow et al (1990:12-13) identify a willingness to allow the patient to express whatever religious beliefs he/she may hold as well as share in that experience to be an important aspect of care; they state that some patients receive comfort and courage from religion. Thus, in using a participatory way of 'doing spirituality', I was reminded to be sensitive to the practical consequences that traditional theological perspectives and belief practices may have for the participants that I had conversations with (Kotzé & Kotzé 2001:7). I wanted to respect their preferred spirituality at all times. For some of the participants there were stories that they were afraid would trigger emotions of shame, fear, sorrow and the like. Hence, for a person and his/her family to be able to share those stories that they are afraid of, a pastoral therapist should create a space of safety that does not ordinarily exist in spontaneous everyday conversations (Griffith & Griffith 1994:68-69).
CHAPTER 4

SPIRITUALITY AND PASTORAL CARE

4.1 INTRODUCTION

In Chapter 2, I discussed social and socio-religious constructions of illness as well as how some of these played a role in the lives of the participants and their families in Chapter 3. Some participants viewed Cancer as a 'death sentence', while others were told that their sinful ways were the reason that Cancer was in their lives.

In this chapter, I look at the role of spirituality in general and touch on the biopsychosocial model used in the medical field. Next, I focus on what I have heard from the participants regarding pastoral care, against the background of what the literature regarding Cancer patients says about pastoral counselling. Lastly, I discuss narrative practices of pastoral care in the light of the participants' stories and their views on what they perceive as their preferred care. As I attended to the participants' stories as narratives, while valuing and listening to them as stories, I also analysed the levels of support they received on various levels (Jensen 1984:222).

4.2 THE PARTICIPANTS' VIEWS ON SPIRITUALITY AND CANCER

Johnson and Spilka (1991:21) show that, according to research, between 64% and 90% of Cancer patients consider religion to be important. I noticed from the conversations with the participants in this study that spiritual care seemed to be important to all of them, but in different ways. Some needed emotional and spiritual support from pastors and their congregation, while others only needed to believe in God's helping hand. We also touched on what their preferred pastoral care would have been had they asked for it or had been asked what they wanted.

Naomi said: 'My faith experience is my own; it is unconventional and casual. I believe that God’s angels carried me through the operations. I found support in my family and friends.' When she was faced later with a decision about giving someone a chance by employing that person in her firm, Naomi experienced the Lord as saying to her: 'I gave you a chance, who are you not to give this man a chance?' This man with his 'naive' religion became one of Naomi's religious role models. Henk, Naomi's son's, does not view 'God' as only 'one entity'. He believes that God helped him by keeping him calm in the face of being overwhelmed by Cancer. This is evident to him from his
sense not being overly anxious, seeing that 'it was not a “realistic emotion” to have in the situation that my family was in’.

Erika told me: ‘During the chemotherapy treatment I was physically weak and went into a comatose state. While I was in this comatose state, I had this vision of standing at a bridge and a man asked me why I did not ask the devil for assistance, to which I replied: “Satan, I will never bow to you.” At that stage, after coming out of this comatose state, I believe my condition started to improve.’ Erika’s minister, who visited her in hospital, used the metaphor of God’s hand and suggested that she should go and lie down in His hand. ‘The morning before the surgery I said farewell to my breast and I made sure that I did not sign for a mastectomy, after which I envisioned myself lying down in God’s hand.’ After the surgery, when Erika had to make the decision about whether to have a mastectomy because the growth was malignant, she signed the form immediately. ‘After the second operation I had a sense that God was telling me that He has a “plan with me”. This made me feel calm and at peace with what had happened.’

Henriëtte received a book of spiritual teaching from friends. ‘I was reading from this book and the message that touched me was that if it is God’s “will”, it will be so. I knew then that the growth was going to be malignant.’ She saw this premonition as preparing her for the worst. ‘I believe that my faith carried me through this time of suffering. My children also experienced this to have been a time of being strong in their faith and realising that there is “Someone” bigger than them and their problems. I hope that by telling others about my spiritual journey, I will be able to help them in theirs.’

Kyla stated that because she already had a relationship with the Lord, it was easier for her to accept Cancer and treatment. ‘I told my minister that I was in God’s hands and that God only wants what is best for me. I have put all of my faith in the Lord.’ With a smile she told me of the time when she asked the Lord to add just five more years to her life: ‘He gave me ten years and I am hoping and praying for another five years. I am indeed blessed.’

Hester and Chris view themselves as active Christians: ‘We have always had a devoted relationship with Jesus.’ Though they were active in their church, there came a time during the chemotherapy that they withdrew from church life because they were too tired and emotionally drained. What puzzled them was that nobody even came to see what had happened to them. For them, on the other hand, it was too difficult to ask for help. This was terribly disappointing to them. They said: ‘It
felt as though the congregation did not even miss us, we felt unimportant.’ Apparently the congregation thought that they had left to go to another church and this hurt them as well.

As discussed in Chapter 3, care does not necessarily need to stay with a minister or the pastoral therapist but can also be found in the community (Graham 1996a:53). I wondered then whether, in Hester and Chris’s situation, the community of care had not failed them. I received an answer from Hester, who said: ‘I have learnt from this experience that it is people outside of Cancer’s grip that should do the “caring”.’ As a couple they experienced the biggest gap in ‘care’ on a spiritual level. There was no one to talk to about their ‘faith struggles’. ‘It felt to me as though Hester was hoping that I could give her the spiritual “care” that she needed, but at the time I myself felt emotionally drained.’ Chris said, adding that he also felt that he was not ‘trained’ to do this: ‘I needed help – spiritually as well.’ When he said this, they looked at each other, silent for a moment, and after a while Hester said: ‘We shouldn’t have pulled back...it just became more difficult the longer we were alone in this spiritual void to free ourselves from it.’ ‘When people learned of Hester’s struggle with Cancer,’ Chris commented, ‘they relied on us to “counsel” them [people would need Hester or Chris to guide and comfort them], and I believe that this was the reason why we withdrew. It just became extremely burdensome to share our struggles with others.’

4.3 THE PARTICIPANTS’ VIEWS ON DEATH

For Naomi’s children, death is a long way off. Her family see her as healthy, because at present she appears to be doing ‘well’. Only when her health starts deteriorating again does she think the reality of Cancer will again set in. She is a practical person and thinks about things in the short term. ‘I had discussions with my children, telling them that I would always be there for them, maybe not physically but in spirit,’ she said on a light note. Without being melodramatic, Naomi said: ‘I do think about Cancer and dying and I have accepted it. I am a person who likes being prepared and Cancer gives me that chance – to prepare my loved ones and myself for the end. I have always thought that I would not grow old and now I know that I will not. So, having Cancer in my life, I know that I will die from Cancer. It is a blessing that I have time to get all my affairs in order as well as the time and opportunity to say good-bye.’ True to her ‘organised self’; she wrote letters to her children before her surgery, making sure that if she were not to survive, each child would have a letter addressed especially to him/her. However, she never really thought about dying. Her thoughts centred more on the fact that she would be ‘losing bodily functions’. In an effort to protect herself from the reality of death, she kept away from other patients and their families, and the negativity of
their situations. She did not want to become part of 'the Cancer patients and did not feel part of those who were dying'.

Quite early on in the treatment, Chris talked to Francois about death. As a couple, Hester and Chris did not know what God's plan was for them and Francois, but they wanted to prepare him for Hester's death. 'I can die any time because I know that Chris and Francois would be all right. I would like to be able to protect them from the suffering that is involved when one dies from Cancer though,' Hester said calmly.

Suffering was also a common theme that emerged repeatedly in the conversations with the participants. Hester sees each day as a gift from God: 'Dying does not weigh on my mind every second of every day; I do not dwell on the fact that I might die. I saw my grandmother die from Cancer though, and the reality of the experience touched me profoundly. What was evident for me is how Cancer strips away all that is human, laying the suffering bare for everyone to see. Dying is not the problem; it is the suffering that I am afraid of.'

One participant felt comfortable sharing her fearfulness surrounding suffering and death only with her husband and a close friend. She had also experienced the death of someone who had been invaded by Cancer, and seeing the suffering she decided that she does not want to suffer in the same way. 'I decided to ask a friend if she would help me die when the suffering becomes too bad,' she explained. Her husband's view differs from hers when it comes to death, especially euthanasia. However, during our conversation, she said she believed that 'when the time comes he will respect my wishes'. She did not share her decision with the rest of her family.

Henriëtte pointed out that the one thing about having Cancer that frightens her the most is the suffering: 'I think it is a horrific way to die....I am not sure whether I will be able to face that....dying slowly frightens me.'

In an effort to get her affairs in order Henriëtte revealed her fears regarding the possibility of dying to her husband. At that stage, he did not want to listen or discuss it. She believed he had to, though, so she persisted in talking about these fears until he started to listen. She also talked to her children about these fears and the possibility of her dying. She said: 'I assured them that they would be looked after and that I will always be with them in spirit.' Naomi also used the two weeks before her first operation to 'sort through my affairs in an effort to get everything in order. This was also the time that I wrote the letters to my children'.
4.4 THE ROLE OF SPIRITUALITY AND CANCER

Each participant's personal relationship with God is a unique experience. Each person sees God through his/her own lenses, coloured by the way they were brought up, their own beliefs and specific situations. Each one relates to his/her own personal God, and therefore spirituality, in his/her own special way. For all of them, spirituality played a very powerful role at the time when they needed it most.

Spirituality can mean different things to different people. For some, prayer and their religion are what they see as their spirituality. A question one can ask is whether religion and prayer are likely to become important support systems for the individual and/or his/her family when physical problems are compounded with feelings of isolation, separation, dependency, and helplessness. Johnson and Spilka (1995:183) report on a study undertaken by the American Cancer Society's Reach for Recovery support group with 103 women, all of whom had had mastectomies. They found that caring was repeatedly associated with prayer. Prayer represented a form of control that identified the individual with power sources higher than themselves. In the midst of the stressful conditions related to their illness, their relationship with God became crucial. When the women were asked whether their religion had helped them in dealing with Cancer, only two out of 103 women replied that religion was irrelevant (Johnson & Spilka 1995:183-195). The rest indicated that religion had played an important part in their handling of Cancer in their lives.

Studies done in the United States have shown that during times of physical and emotional illness, religion may be used as a means of coping with the stress that accompanies illness. According to surveys, 50% of patients had spiritual needs and half of those thought that those needs had not been met during their stay in hospital (Koenig, Bearon, Hover & Travis 1995:153-155).

The Christian point of view of healing is that God is part of the process of healing or wholeness. Even if God is not seen as acting to heal, a religious person may still feel that the spiritual dimension is important. A patient may see healing as coming from God who, in the midst of pain and uncertainty, promotes growth and wholeness. Prayer, for Woodward (1995:97), is the area where theory and practice meet. Prayer also played an important role in the life of a woman whom Vanderzee (1993:62) calls Meg. Meg described her relationship with God as that of a friend with whom she can pray, talk, scream, and cry out her pain. She was not afraid to direct her grievances directly to God because she knew she could trust Him, no matter how she feels.
Naomi, a participant in this study, does not see herself as a traditional Christian. Her relationship with God was informal—‘I see Him as my friend’. When she was diagnosed with Cancer she told God that this was going to be too difficult for her to handle and asked Him to help her in the fight against Cancer. She said: ‘Because of this direct relationship that I have with God I never feel that I am alone.’

Erika used prayer, Scripture and gospel music in her struggle with Cancer. ‘I fought Cancer with God’s help. Prayer was part of my life... we as a family have always been religious people. I was scared and needed support. Our minister came to see me just before the surgery. He read from Hebrews 12:10-11, which talks about the “no chastening seems to be joyful..., but painful...”. This verse did not console me; what it did tell me is that I was being punished for my sins. I found this also to have been some of my visitor’s opinions [viewing illness as punishment for sins]. The tone in her voice changed when she said: ‘It felt as though others were judging me. They told me that I should think about the sin in my life and that before I can receive healing I should confess my guilt.’ During her recovery she used gospel music and praise to help her to gain her strength: ‘I was reading the works of Merlin R Carothers ‘Power in praise: How the spiritual dynamic of praise revolutionizes lives’ he writes: ‘Only God is qualified to judge, and He has already declared that we are holy and without a single fault in His eyes when we are covered by His love.’ This made Erika strong against attacks from ‘confessional verbal abuses by people who interpret the Bible directly’.

Frank (1991:87) argues that the confessional thinking that ‘I must have done something wrong’ might only lead to regrets and feelings of guilt. So being ill can be seen as a balancing of faith and will. The quality of acceptance is what Frank (1991:87) calls faith. Frank views illness not as a test of faith but rather as an opportunity to use this illness experience and make life meaningful. Erika said: ‘I decided to manage my sickbed, deciding whom I was going to see and who not.’ She added: ‘Scripture played an important role in my struggle. When my oncologist warned me about my hair falling out, I prepared for it by going to my hairdresser the next day and I had my hair cut short. I thought this would help to make the ‘falling out’ less traumatic. Matthew 10:30 “But the very hairs of your head are all numbered” was an important verse for me and the wonderful thing is that I did not lose my hair. Faith became my biggest gift.’

During the conversations with the participants on the subject of medical care, I became aware that in the medical world, spirituality seems to have not been included in the biomedical model or the biopsychosocial model. The biomedical model leaves no room for the social, psychological and behavioural dimensions of illness but was the cultural imperative to be used in the training of
Western doctors. These limitations have just been overlooked (Engel [1977] 1992:317). It became evident to Engel ([1977] 1992) that a model that only understands the determinants of disease and arrives at rational treatments does not suffice (Engel [1977] 1992:318-325). It has become obvious that a therapist has to deal with biological as well as psychological problems and a physician with psychological as well as biological problems. For a treatment model to be sufficient, it has to take into account a patient's social context, the complementary system devised by society to deal with the disruptive effects of illness, the physician's role and the all-round health care system. The biopsychosocial model (Engel [1977] 1992) was introduced in the hope of overcoming the limitations of the biomedical approach. The biopsychosocial approach communicates the idea that all problems are biological, psychological and social. This model leads to increasing collaboration between medical providers and psychosocial specialists. An egalitarian relationship based on mutual respect between the medical system and the rest of the health care system should then be central to functional collaboration (McDaniel 1992:280). McDaniel sees herself as a member of a medical family with special talents, each member providing alternative perspectives. This relationship should be seen as a partnership of two or more practitioners who respect each others' skills and can communicate in a way that will enhance the care of mutual patients (McDaniel, Hepworth & Doherty 1992:40). However, I wondered where a patient's spirituality fitted into this biopsychosocial model. The question that I asked was whether there is a place for spirituality in this model. What I am proposing is care for the total human being, that is, medically, socially, psychologically as well as spiritually. But it should also be the type of care that the patient prefers at that specific time in the illness.

4.5 CONVERSATIONS VERSUS LITERATURE ON PASTORAL COUNSELLING

In speaking with a pastor (Lubbe 2001) concerning the subject of counselling Cancer patients, I began to form a picture in my mind of the struggles that both the patient and his/her family have to deal with. This includes struggles on a spiritual level. Though Lubbe (2001) counsels the ill and finds it very rewarding, the pastor thought that there were issues and factors that hamper the counselling process and which keep it from being a truly meaningful experience for the patient. One of these issues he experienced as problematic was that a pastor could approach the counselling session as the 'expert' on religion. He could set ways of dealing with 'faith issues', and might not give any thought to what the patient might need at that point. Lubbe said: 'In my view counselling can be more meaningful in the future by just asking the patients what it is that they and sometimes
the family need from the pastoral therapist or pastor at that given point.' The pastor/pastoral therapist can also help to facilitate better communication between all the parties involved.

It sounded to me as though what is needed is that a pastor/pastoral therapist should approach a patient and the family from a 'not knowing' position. The term 'not knowing' signals moving forward to what is 'not yet known' during a conversation. Freedman and Combs (1996:44-45) describe it as 'not asking questions from a position of pre-understanding and not asking questions to which we want particular answers', in other words, staying curious about the stories that the participants are sharing with the researcher or the pastor. For Anderson (1997:64) 'not knowing' is the freeing of the therapist from having to be the 'expert' on how clients should live their lives, on what the 'right' questions are to ask and what the best narrative for the client is. Not knowing made Anderson (1997) examine her position as therapist as well as the position of others in the conversation. New meanings emerged from what the therapist learns from the client. Anderson (1997:145) calls 'not knowing' questions 'conversational questions'. These questions can lead to elaboration by the client on parts of the story he/she is telling. She is of the opinion that these questions help her to enter the client's subjectivity. Hartviksen (quoted by Anderson 1997:145) describes it as follows: 'The question is the only tool I have in my work. It is the only way that I have of wondering, of participating in the patient's life.' According to Woodward (1995:60), the most dangerous people are those who believe that they know what is best for another person. For this reason, sensitive pastoral care needs to be critical of such an approach. By being with a patient in a 'not knowing' position and asking the patient about the 'type of care' he/she wants and needs, the pastoral therapist might be more of value to the patient and his/her family.

Woodward (1995:54-60) argues that pastors/ministers have not been empowered to use their theological resources for their work within the illness culture. He states that this inability lies in the theological training of both the clergy and of lay people. Thus, if the theory of theology is difficult to put into practice and relate to experience, then there is an urgent need to explore how theology is taught and what modes of doing theology are promoted in training. An example of this inability can be seen when a pastor is dealing with a woman with breast Cancer. Many members of the (male) clergy experience some sort of aversion or reluctance to discuss matters relating to female identity and attractiveness. They attribute an unwillingness to discuss this to the shyness of the pastor, the woman's not knowing the pastor well enough, the 'awkwardness' of the illness, sensitivity on the woman's part or to the notion that the pastor is not sure whether the woman wants to discuss it with them (Johnson & Spilka 1995:183-195).
Earlier in the research, I looked at the works of Aldredge-Clanton (1998:2-5) regarding the counselling of people with Cancer. She writes about an existential crisis as coming in the beginning of the counselling process, right after the diagnosis of Cancer, when the patient might experience all kinds of psychological issues. Aldredge-Clanton (1998:6) views it as an existential crisis when the person starts to question the meaning, purpose and value of life. She sees it as being a time of re-evaluation of religious beliefs and spiritual experiences. Aldredge-Clanton offers her patients sacred images to restore feelings of self-worth and meaning in a time when they might feel lost and out of control. Cavanagh (1994:232) is also of the opinion that ‘because of the nature of Cancer, patients and their families are often in need of pastoral care and counselling at many stages throughout the process’, arguing that ministers should have some understanding of the nature of Cancer and the pastoral challenges it can present. For Jensen (1984:224), a diagnosis of Cancer can present a dramatic change in the plot of a person’s story. Thus a pastor can seek to embody the hopeful belief that the God who was active in the formative sacred stories of the person is still active in the current story.

Cavanagh (1994:236) found that ministers could find themselves caught up in the midst of problems of communications between the family members and the patient. The minister should then respond sensitively, because the patient and each of the family members might be at different levels of readiness to hear the news as well as at different levels of ability to handle the stress. Open discussions are not for everyone, as I realised when talking to Kyla. She never discussed her fears with either her husband or her children. She kept it to herself for fear of ‘upsetting them’: ‘I wanted to keep “up a good front” so that I appeared strong to the world.’ Farrow et al (1990:7-8) state that acknowledging emotional pain, providing opportunities to express and work with these feelings, can facilitate the healing of emotional wounds, to ‘normalise’ reaction, and to reduce the enormous burdens that patients and their families may carry. It can be helpful to facilitate sharing of feelings for all the family members. I asked Kyla if she, in hindsight, thinks that keeping all the emotions to herself was a satisfactory way of dealing with the situation at the time. ‘Thinking back...’ Kyla pondered the question, ‘I think I would have liked to have had someone with whom I could have shared my feelings. Not long ago a friend of mine made the comment that we will both die from Cancer; I was shocked. Though the uncertainty is always there, I do not dwell on thoughts of dying. I do believe though that Cancer will enter my life again...’ In Kyla’s situation, she believed that it could be dangerous to share her story or illness narrative with loved ones, and so she did not tell her story until now.
According to Aldredge-Clanton (1998:3-5), a patient's view of God may change when he/she is in Cancer's grip. She found that each individual's spiritual response to Cancer varies, according to the person's unique religious and cultural background and experiences. Some, in an effort to make sense of it all, may seek authoritarian religious systems. Others, who would like to have something stable in the midst of the chaos, might find peace in the faith traditions that they grew up with. There are even individuals who find traditional belief systems inadequate to deal with their experience of Cancer and therefore might explore other spiritual avenues. Aldredge-Clanton (1998:3) is of the opinion that pastoral counsellors have a unique opportunity to guide patients that are living with Cancer toward life-giving sacred images. The person's view of God as judgmental and threatening might be changed through Scripture and prayers, which talk about God as loving and nurturing. Pastoral counsellors can also guide people to face the positive and negative implications of their sacred images, affirming the life-giving images and challenging those that contribute to distress. With supportive guidance from a pastoral counsellor, patients may let go of those sacred images that hinder their well-being and rather expand familiar images that have healing potential, and then embrace new images that may hold the possibility of wholeness and health (Aldredge-Clanton 1998:28-39).

Cavanagh (1994:236-238) argues that this can be a time when some patients and families are particularly open to spirituality, but that for others religion can be a source of confusion and anger. A question like 'what kind of God will let me suffer this way?' can also confuse a minister who does not always have the answers. The minister then has to tap into the fear, loneliness, helplessness and sense of abandonment that the patients and the family might be feeling. To deal with people on that level of stress, Cavanagh (1994) proposes that ministers should step aside and make space for the patients and family to vent their anger and then step in and help them address the underlying feeling of terror.

Faith struggles as well as questions directed towards God were common in the lives of the participants. 'I would ask "why" all the time,' said Karla, smiling. These questions were all directed towards God. She believes that there are no answers, but that by asking God one can maybe find comfort in Him.

Chris thought it to be unfair that they should suffer in this way. They did not receive any spiritual support because they were too tired and proud to ask. They needed someone just to be there for them, giving care without their having to ask for it. Hester did have questions about why her hair had to fall out and struggled with God about this. 'I never complained about my hair, you know.'
Hester paused. 'I could not understand why I had to lose it. I felt so guilty for being so vain about being bald.' Chris was angry at God about the fact that they had to go through this ordeal three times: 'I thought that seeing that we already went through it twice, shouldn't there be someone else that should maybe go through it once now? I know this must sound awful but it was how I felt at the time.' Although Hester and Chris felt guilty about being angry, they believe that Jesus understands when humans get angry. Hester said: 'We are content with not having the answers to our questions. I made peace with it because the Lord does say that everything will work out for the best for those who believe in Him. Even though one does not understand.' Later on Hester and Chris would ask: 'Why us?' as well as 'Why not us?' This helped them to deal with the reality of Cancer. 'It was definitely our faith that carried us through these ordeals and is still carrying us to this day.'

When Erika and her husband decided to have the second mastectomy, others saw this as a lack of faith. However, her minister told her to look at the mastectomy as a vaccination against Cancer. 'I was thankful for this vaccination because when the results came back it showed that in about two years I would have had the same problem in the second breast. I was clinging to hope and God's grace.' In her view, God is a God of love and healing. Erika did not buy into the discourse that Cancer is a death sentence. Her experience was never that she had received a 'death sentence'. 'I believe that my religion kept me from being depressed and falling into the trap of believing that I was dying.' The children were worried that she could die, but her being positive kept the family positive. Her older son reacted to Cancer by demanding attention, whereas the younger son was more caring towards Erika. She said: 'When you have Cancer you are never free of the "discourse of death".' So Erika's dance with death continues – 'as a slow waltz of long-time friends'.

'My father died of Cancer in the early 1900's when I was 9 years old,' Kyla's husband told me. 'I saw a big healthy man wasting away due to Cancer. To this day, when I hear the word "Cancer", it frightens me.' So, when his wife was diagnosed with Cancer, he was petrified and believed that only his relationship with his Heavenly Father gave him the strength he needed to be able to support her.

For Henriëtte, like for so many people, the word 'Cancer' conjured up thoughts of serious illness. She did view Cancer as an illness that you can die from. 'So when I received the diagnosis of what was wrong with me as being Cancer, I immediately thought of it as a "death sentence".' She sees it as 'just being realistic' to think that she will die from Cancer, but also decided that she could fight Cancer.
Aldredge-Clanton (1998: 53-54) explores issues regarding hope with her patients. She states that the stories patients tell have the power to restore hope when they are linked to biblical stories, which brings the holiness of the patient's story to the foreground. A pastoral counsellor can assist the patient in reframing past stories and in rewriting future stories. Joining their stories with other sacred stories reveals that they are not alone and that there is hope in their struggle: 'Cancer is a word, not a [death] sentence.' Patients should be reminded of this fact because hope can be seen as an important weapon in the fight against Cancer (Cavanagh 1994:238).

Aldredge-Clanton (1998:80) found that some patients feel angry towards God because they feel responsible and guilty for inviting Cancer into their lives by not living 'right'. One way a pastoral counselor can help is by helping patients understand their life story not only from the perspective of their individual responsibility but also in the context of social evil. Aldredge-Clanton (1998:80) states that:

...entering into their stories, we can feel with them the anxiety of human limitations and the relief that comes from forgiving whoever...is responsible for these limitations.

Connecting patients with other individuals or groups who are experiencing the same in living with Cancer, a pastoral counsellor participates in their move from alienation to increased authenticity in relationships, helping patients to realise that they are not alone and that their experiences may have healing possibilities for someone else (Aldredge-Clanton 1998:92).

Jensen (1984:217) sees the question of 'Why me?' as either an 'expression of anger, a prelude to confession, or a lament about a belief system crumbling'. No matter in which form it is expressed, it can be regarded as reflections of a spiritual struggle. Jim, Kyla's husband, missed the guidance of a minister through the faith struggles he had. While they received support, no one really tried to work through those struggles with him. Jim said: 'I did question the Lord on why it had to happen to us. I started wondering whether God was “punishing” us maybe for “wandering off” and Cancer then as the “thing” to bring us back on track.' After contemplating his wife and his active relationship with the Lord, he decided to see the Cancer as 'cells in her body that got hurt and became mad'. Illness is sometimes viewed as a personal failure, when the question it raises is whether the patient did something to deserve this. However, guilt, excessive or realistic, cripples patients and families and the answer may lie in forgiving oneself (McDaniel et al 1997:6).

Aldredge-Clanton (1998:57) calls the time when the patient is waiting to see what is going to transpire the 'Waiting Game'. She states:
While walking with cancer survivors through the grieving process, pastoral counselors can guide them to develop hopeful future stories.

Naomi mentioned that she knew that she was going to be 'different' after the surgery and wanted to prepare her family for that. The pastoral counsellor could assist patients with the grief they are experiencing in saying-good bye to who they once were and in saying hello to the new them.

Aldredge-Clanton (1996:98-107) also attends to the physiological issues concerning sexuality and the question of 'Who am I now?', because Cancer and the treatment thereof can result in many physical changes which can have a negative influence on a person's self-image. She connects the person's story with the image of God as wounded. This image of a God that suffers with them and therefore understands their pain, she found, can bring comfort and healing to patients. Cavanagh (1994:233) believes that it is essential that the minister has an understanding of the psychological issues that some women and their husbands may experience in living with breast Cancer and that ministers are sensitive to these issues and perhaps counsel the patient/husband apart and as a couple. For Rossman (1985:125), her suffering had meaning because of the suffering of Christ.

Two of the participants spoke about this issue and said they had both had a different experience. One participant viewed herself as less of a woman, which had a negative effect on her sexual desire and her marriage. She felt ashamed and was afraid that her husband would be disgusted at her physical appearance. This was the first time that she had spoken to anyone about it. On the other hand, the other participant and her husband did not see the mastectomy as being part of her sexuality but simply saw the mastectomy as functional.

Erika, Jim, Kyla's husband, Hester and Chris experienced insufficient spiritual care. For Erika, Reach for Recovery did not mean that much, because of the fact that the volunteers did not make space in their conversations for a person's religious thoughts. She is of the opinion that patients should decide whether they would want to bring their preferred spirituality into the space of care or not. Jim, Hester and Chris stated that they had needed pastoral care in the form of someone who was there to help them through the 'faith struggles and the questions' that they had. We discussed the fact that Cancer stole 'spiritual communication' from them. In response to the question 'If you were in that situation again, who would you prefer to help you with this spiritual communication?', they all said it should be their ministers, who should facilitate the communication process between them and the 'rest of the world'.
We spoke about the possibility of a pastoral therapist's being the person to assist patients with questions on a spiritual level, opening up space for patients to voice their fears and thoughts in a 'safe environment', in short, a narrative way of pastoral care.

4.6 NARRATIVE PASTORAL CARE

I would like to use the term 'pastoral' as to mean 'caring'. 'Caring' for me is not a technique of sorts, but an attitude, a way of being. Thus, for a therapist, caring can mean being interested in others' stories and staying curious as well as being attentive to their needs and concerns. Pastoral caregivers have long stressed the importance of people's stories as theological reflection. This can only happen when the therapist opens up spaces by listening to people who narrate their stories to them. The stories that Cancer patients tell speak of the spiritual and existential struggles of these patients and their families (Jensen 1984:216-217). Jensen views the narrative approach as the most suitable vehicle to capture tragic dimensions of human existence. It is also with the narrative approach in mind that my conversations with the participants were held. By externalising (see Chapter 1) Cancer, the participants were able to state their preferred care. Graham (1996a:49) regards pastoral care as a 'shared companionship on life's journey' rather than as an imbalance within the expert/client relationship where power is in the hands of the 'expert'.

4.6.1 Pastoral care

Care can be seen as a human phenomenon which occurs whenever a person truly listens to another person, when they feel for one another, when they understand each other's struggles, when they comfort, encourage, support and help each other (De Jongh van Arkel 1999:112). Kyla said that Reach for Recovery did exactly that for her. She felt understood by the women who supported and helped her through a difficult time of illness. De Jongh van Arkel (1999:120) sees the focus of pastoral care as being care for God's people through the ups and downs of everyday life, as well as creating a caring environment in which people can develop their highest potential.

Louw (1994:62) looks at pastoral care as it 'deals with a sick person, not merely with a patient'. He believes that it is important to establish a patient's immediate need and to attend to that. This can be the need to be respected, listened to or acknowledged and understood. Pastoral care, for Louw, can also be 'embracing' someone so that it feels as if the arms of God are holding him or her. So, for example, Naomi needed the physician to see 'her as a person and not as an illness'. I wondered
whether a pastoral therapist could have communicated those feelings for her at the time and whether it would have made a difference.

Berman (1989:3) states: 'When the bad stuff comes, all the questions you have are religious ones.' This was true for some of the participants in the study. Karla, Naomi's daughter, said that her questions were all directed to the Lord.

The pastoral task then is journeying with, befriending and being a companion to others. Thus, pastoral care is often being with more than doing for the person in need. There comes a time when all one can do for someone is to stand by them. Resisting the impulse to rescue and save, a pastor/pastoral therapist can allow a chronically ill person's story and the therapist's own story to influence and impact on each other in mutual ministry.

4.6.2 Narrative pastoral approach

Postmodern social construction discourse (Chapter 2) insists that people with expert knowledge are not the only ones whom one listens to when decisions are made. Because a narrative approach in pastoral therapy avoids an 'expert' position and favours a 'not knowing' and 'listening' position, it is one of the approaches that possibly complies with postmodern social construction discourse as paradigm/epistemology. A narrative pastoral approach is all about listening to the retelling and reliving of stories. Therefore, with regard to Cancer patients, 'it is ministry simply to request and allow them to construct and re-tell their narrative (Jensen 1984:221). The self-narrative process should be seen as a creative process and should be appreciated by pastoral therapists/ministers as self-expression. Thus a pastoral therapists/minister should be privileged to see and participate in this human drama (Jensen 1984:224).

This human drama became real for me as the researcher in the conversations with the participants where we co-constructed their illness together and in some instances relived the experiences and emotions connected to those narratives. The narrative pastoral approach granted me the openness to have conversations with people from all walks of life and to participate in their unique spirituality. The participants stayed the 'experts' of their own stories and co-determined the content of the conversations, as happened every time I asked the participants what they would like me to know about them or their situation.

Narrative pastoral care can mean listening to the sufferer's story and creating a hospitable climate for hurtful experience to be articulated, accepted, owned and authentically lifted to God in prayer.
Erika, for instance, regarded prayer as one of the most helpful ways of coping with Cancer in her life. It can be a meaning-making and transformational process for both the people who are ill and the pastoral therapist (Vanderzee 1993:87-88). The pastoral therapist should also remember that there is always Another at work in the pastoral event, namely God, who brings new vision and creates opportunities for growth and renewal in the relationship between the patient and the pastoral therapist, who are both simultaneously subjects and objects of personal reformation and divine transformation (Vanderzee 1993:90).

4.6.3 ‘Doing hope’

Some participants found hope in the caring of others. Others needed the type of caring that should have created that hope but did not receive it. Karla said that the word ‘Cancer’ meant ‘death’ to her, though she had since found out that there is hope. ‘I’ve heard about people living with Cancer for years, I hope and believe that my mother will be with us for years to come still.’

Mickley, Soeken and Belcher (1995:215) define hope as a multi-dimensional dynamic attribute of an individual which includes the dimensions of possibility and confidence in the future outcome, active involvement from within, relations with others and spiritual beliefs.

Hope can address concerns such as future plans, relationships with others, religious concerns about an afterlife and the relationship with God or a higher power. Many studies focusing on Cancer patients have found that hope had vast implications for how patients coped with Cancer. It showed that where hope was lost, it could prevent a patient from accepting the diagnosis, complying with treatment or planning for the future (Mickley et al 1995:216-227). Weingarten (2000:20-21) sees hope as an important factor in the domain of problem-solving and coping. She found in her practice that the people who consulted her were alone in their hope, and therefore often ‘hopeless’. ‘Hope is something we do with others’, argues Weingarten (2000:22). Weingarten said to a patient that ‘it is the responsibility of those who love you to do hope with you’. So it is the family and friends of the person living with Cancer who should create hope by being there for the person when he/she feels hopeless. Therefore, I believe we can regard hope as the responsibility of the community of people who surround a Cancer patient. Hester and Chris also argued this point, saying: ‘It should be the people surrounding the family where Cancer has destroyed hope to build it up as well as to care.’
4.6.4 ‘Conversations with God’

Some religious practices describe dilemmas but prohibit the kind of conversation that would be needed to resolve the dilemma. Western religion in general regards a relationship with God as part of a person's private life. This is then kept out of the therapy, except if the therapist inquires into this relationship. But a person's conversations with his/her ‘God’ can be of great value and have great power for freeing the body (Griffith & Griffith 1994:58-59). The most important aspect of having conversations with people concerning spirituality for me was that I should remember that I cannot assume to know the ‘God’ that they are talking about just because they use languages, images or refer to rituals that I think are familiar to me. I realised that I should always be curious about what ‘faith’, ‘religion’ and ‘God’ means to them personally. Each of the participants had a different view of God; each one experienced his/her spirituality differently.

In reading the work of Griffith (1995:123-127), I became aware of the pitfalls for me as a researcher/therapist when discussing a participant's/client's religion or view of a personal ‘God’ in research/therapy, especially if the client's religion is different to my own. It dawned on me that by censoring a participant's story of his/her relationship with his/her personal ‘God’, I would only be protecting myself from other different opinions. I realised that when I invite the other person's ‘God’ into the research/therapy conversation, I should only be interested in my participant's/client's experience with his/her personal ‘God’ and that it is not expected of me to internalise this ‘God’ as my own.

When a patient finds him/herself trapped within a symptom-producing situation which constricts the patient to view the situation from an alternative perspective, a question like: ‘If God were to look at this situation, what would God see?’ can open up new insights. This can invite a person to reflect on the situation from an observing position.

I found great openness in the participants' conversations where questions regarding the participants' conceptions of God were included and were brought into the context of the research. They found their voices regarding their experiences with Cancer's intrusion into their lives and their spirituality and made those voices heard by telling their stories.

4.6.5 Theological negotiation

According to Vanderzee (1993:66), theological negotiation can lead to either spiritual growth or stagnation. This depends on how the illness is integrated into the rest of the person's life. The aim
of theological negotiation is to integrate the present crisis with past experiences and future possibilities. The process of negotiation is worked out intrapersonally, interpersonally, and/or between the believer and God through direct or indirect dialogue and prayer. A pastoral therapist's task would be to facilitate and authenticate these negotiations by encouraging a divine-human dialogue, resulting in genuine spiritual growth. The pastoral therapist should allow him/herself to be touched, moved and changed by the other's story, foster mutuality, which can generate spiritual growth, both in the therapist and in the people in therapy.

Vanderzee (1993:71) points out that even if the pastoral therapist/pastor is unable to 'help' when spiritual distress and conflict is evident, the therapist's task may be to shoulder the pain and share the praise with the person suffering, to let the person know that the therapist is aware that there are questions that have no answers, that there is suffering that has no name, that there are injustices in God's creation, and that there are reasons for patients to be angry, and that the therapist and the patient can be angry together. Vanderzee (1993) believes that people who have no disabling disorders can learn from people who exhibit other forms of wellness, because of their eagerness to tell others what it is like to live in a world of physical and social barriers, increasing dependency, treatments and frequent hospitalisations (Vanderzee 1993:79). According to Vanderzee (1993:80), the ill person only asks the pastoral therapist/caretaker to get close enough to them to be willing to risk the discomfort that the closeness generates. Thus, the therapist's willingness to feel their pain, and to hear and facilitate their story is vital. He feels that when a person who is ill is able to portray his/her pain without shame or embarrassment, others become freer to share their own anguish (Vanderzee 1993:81). This was the hope of many of the participants – that others would also feel comfortable to share their stories and experiences.

A pastoral therapist/minister should at all times understand that what was 'right' for the last patient and family could be entirely 'wrong' for the next group of people. Therefore the pastoral therapist/minister should approach each situation with: 'How do you feel I might be of help to you?' rather than 'Here, let me tell you what would be helpful to you' (Cavanagh 1994:235). Baer (1998:185) saw patients who identified themselves through their illness, but she believes that each person she visited was unique, with their own story about Cancer. Similarly, each of the participants' stories in this study was unique but also the same – they all spoke about Cancer's invasion but then disclosed their unique individual coping with the situation.
4.6.6 ‘Acceptance ethics’

Woodward (1995:42-49) states that some people can look to their spirituality or theology to explain or to give purpose to the illness experience. When their illness is seen as a punishment from God, the pastoral response needed would be what Woodward calls acceptance ethics—the need for unconditional acceptance as well as a quality of listening that may communicate their value as individuals created in the image of God, no matter what their condition.

Woodward (1995) is of the opinion that illness is constructed through language, specifically through the discourses of medicine and science. For example, in some circles, individuals or groups who wish to exert some control within the framework of social meaning are using Cancer as a metaphor for decay, pollution and disorder. The context within which people meet their illness shapes the experience and their perceptions of what is happening to them. For Woodward (1995), a focus of pastoral therapy should be to know how language shapes reality and to be sensitive about words and how they are used. Most important, within this discourse the voices of those most affected by illness need to be listened to, so that new ways of thinking might emerge and develop. Thus, the role of the pastoral therapist should be one of friendship, self-disclosure, sharing questions and feelings, attempting to integrate the experience of dying, from whatever perspective, into loving and living (Woodward 1995:108).

4.6.7 Stories: A chorus of voices

People are bound to others in their lives by their ability to express and to understand stories. But there are some stories that do not get told. These untold stories can threaten relationships, especially relationships between family members. It is not only a person’s voice that can be silenced, in order to protect a relationship, but expressions of the body can also be silenced as a person learns from public discourses the ways in which the person must live in order to compete in modern society (Griffith & Griffith 1994:41). I saw this in the stories of Kyla, Erika, Hester, Naomi and Henriétte, when they ‘stayed strong and positive’, their own voices were sometimes silenced so that their families could ‘survive’ the onslaught of Cancer.

When a patient ‘has a voice’, he/she can express who he/she knows him/herself to be. The problem comes in when the person shows him/herself as he/she is now—does he/she still fit into the relationship that he/she is trying to preserve? So people can risk losing either themselves or the relationship (Griffith & Griffith 1994:63). Being silent means being alone with what ‘you as a patient
Weingarten (2000:1-7) sees 'voice' not as an individual's achievement of self-knowledge, but rather as a possibility that depends on the willingness of the listeners that make up the person's community. Voice, for her, depends on witnessing. I chose to be a 'determined witness' in the research, by being committed to listening with an open mind to the stories of the participants and then to re-tell those stories. A pastoral therapist can also be a 'determined witness' by opening spaces for 'voices' to be heard. Isolation and loneliness can come from not sharing real fears and emotions with one's family and friends because of a fear that they will not be able to bear it (Weingarten 2000:1-14):

I withdrew myself from her because I couldn't bear to let her see me, smell me, feel me, know me as I knew myself to be, a terrified and hurt mother.

Kyla too said in one of our conversations that she thought a pastoral therapist might have been able to assist her in sharing her thoughts and feelings with her husband and daughters, and in so doing might have opened up spaces for her voice to be heard in the telling of her story.

4.7 CONCLUSION

I attended to the participants' stories as narrative during the conversations. I valued and listened to them as stories but I also analysed the stories to ascertain the support and care those participants had received, and in some situations had not received (Jensen 1984:222). It became evident that spirituality plays an important role in a person's experience of having Cancer as a family member. What emerges is that pastoral care should be negotiated with the person and family. The person should be asked what he/she needs and wants before care is given. The task of the pastoral therapist doing narrative pastoral care is 'doing hope' with the person who is ill, opening up space within conversations into which the person can bring his/her conversations with his/her personal God and find his/her voice heard and understood.

In Chapter 5 the reader can witness the voices and recommendations of the participants as well as my own voice. I pay attention to the possible contributions for pastoral care and for pastoral therapy.
5.1 INTRODUCTION

'Perhaps we can only hope that our research will clarify our vision and improve our decisions' says Reinharz (1992:195). For me as a researcher this meant changing my opinion regarding Cancer as a 'death sentence' to an attitude of 'hope and resilience' where Cancer is present in a person's life. I believe this happened because I listened to the stories of the participants; and the meanings that they attributed to their experiences changed my own attitude towards Cancer.

In listening to participants' stories, I viewed and appreciated these stories as their own unique literary creations (Jensen 1984:217). Frank (quoted by Weingarten 2001:120) writes:

The ill person who turns illness into story transforms fate into experience, the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability.

The participants' stories taught me not only how care is or how care should not be, but also what their preferred care would look like and what pastoral care to women should look like to empower them to tell their stories (see Graham 1996b:173; Bons-Storm 1996). According to Davies (1993:21), for women, telling their stories can be a way of talking themselves 'into existence', but the re-telling of their stories also meant that they are no longer the persons they were when they start out the research (see Weingarten 1997:xii).

Graham (1996b:173) states clearly that the 'feminist maxim that “the personal is political” is nowhere more true than when applied to Christian pastoral care'. Women's personal circumstances are not simply individual problems but cast light on broader structures and social causes. Appropriate pastoral care may 'promote a more proactive ministry, involving social change and political intervention' (Graham 1996b:173). However, the scope of this dissertation did not allow for these broader changes to be addressed. These changes need attention in future research, but it is my hope that the reader may identify with these stories and see his/her own life through a different lens.

This chapter reflects on the new stories the participants and I co-constructed during the course of the study. I also touch on how I was introduced to the particular research paradigm and process and the realisation that being “together” with “participants” of the study and not "subjects" was a new and exciting idea for me. I reflect on the topic of Cancer, my own voice, the research paradigm and
spirituality (in the research) and the spirituality of the participants. Reflections on how this research process developed over the course of ten months are also included in this chapter. I reflect on using the term 'conversation' as opposed to 'interview', as well as 'power' distribution during the research process. I also reflect on the suggestion of a care network that resulted from conversations and from reflections on care. The implications of the research for practical theology and future plans with the information I received from the participants and literature study are also reflected upon.

5.2 REFLECTIONS ON THE RESEARCH PARADIGM AND PROCESS

Once I had completed the research, I reflected on the process as a whole. I realised that what I wanted to achieve most with this research was to open up space for people to tell their stories of living with Cancer and to reflect on the care they had received. The participants turned out all to be women, and I became aware of wanting to open up space for them to feel sufficiently empowered to tell their stories in a way that they felt comfortable with.

In feminist liberation theology and psychology, 'empowerment refers to the relational process through which persons experience their creative, liberating power, or capacity, to survive, affect others creatively, and make a positive difference. Relational power is creative and liberating when it is being generated mutually for the well-being of all' (Heyward 1996:52). This empowerment through relational power became the focus of my commitment once I started with the conversations and learnt about the stories of these women about Cancer and care.

5.2.1 What were the research questions?

Reflecting back on my research questions, namely 'What did care look like for the persons living with Cancer and their families during the time that they were ill?' and 'If they had a choice as to their preferences for care, what would the care be?', I asked myself whether these two questions have been answered, and what the implication of the answers was for the research.

Firstly, I believe these questions have been responded to in Chapters 3 and 4. Secondly, I found that these two questions opened up space for ideas that the participants thought they had forgotten, as well as to new thoughts and ideas regarding the participants' experiences. In these spaces, sensitive issues could emerge and, once out in the open, and storied, they find an audience and therefore meaning in the co-construction process. Issues that had not been spoken of, in some instances, for years, gave the storyteller a feeling of accomplishment in telling the story in the hope that it would mean something for another patient or family member.
Participants reflected on real feelings and old emotions, wishes and regrets, but also included reflections on hope and courage. There were reflections on love, support, on sadness, on things dear to the participants, and important issues regarding care. These were issues they felt were important for them to share with the research study and myself in the hope that it would mean something to someone else. In order to open up these spaces, it was necessary for me to turn back and look at the research process. I came to understand that research can be viewed as care (Dixon 1999:233). Together the participants and I co-created knowledge through ‘participatory consciousness’, as described by Heshusius (1994:16-17).

5.2.2 Research as dance, care and participatory consciousness

Because the research process kept on changing, qualitative and participatory action research approaches were appropriate. Both of these approaches thrive on ‘elasticity and movement’ Denzin and Lincoln (1994:4); qualitative research is a process which is not rigid but elastic/flexible, a process which focuses on the socially constructed nature of reality and the intimate relationship between the researcher and the participants.

The dance metaphor for qualitative research (Janesick 1994:209) used in Chapter 1 of this study can also apply to the kind of research I co-constructed with the participants. Dance can be unpredictable; it sometimes does not turn out as planned; it allows for new combinations and strives to create meanings through movement (Janesick 1994:217). Moving, according to Zuber-Skerritt (1996:97), means changing and developing new beliefs, values, attitudes and behaviours on the basis of new information and insights.

Hughes (1996:30) describes how Wosein, a German ballet master, introduced the circle dance, which enables people to experience joy and inner peace, with the circle as a symbol of unity and the roundness representing nurturing (Hughes 1996:30). This symbol is also significant in feminist theology: Isherwood and McEwan (1993:85-87) suggest that the traditional hierarchical church model be transformed into a more favourable model in the shape of a circle (see 5.2.5). The idea of using a circle is that there would be a focal point, but no dominant authoritarian pinnacle. Therefore, care would not only be in the hands of the authorities but rather of the community enclosed by the circle.

The metaphor of dance gave me the freedom to get close to the participants and their stories and in so doing allowed the participants and me the flexibility to move inside the research process. In
some instances it also meant allowing my own voice to be heard during research conversations as I became a witness to Cancer's hold on women's lives and a conduit for their stories. It made me look at the participants' knowledge as gifts given to me – and I wanted to reciprocate by returning their stories to them and other people living with Cancer.

I wondered whether research could be regarded as care. Dixon (1999:233) believes that research can be seen as care when the participants have an interest in the outcome of the research. This happened in the study as soon as the problem, in this instance, Cancer, became the focus discourse in the research. According to Dixon (1999:235), caring for others' needs is the starting point for action. In my experience, as soon as the participants and I externalized Cancer, Cancer became the problem, and care the aim. Our common goal was to identify their preferred care through the stories told. Care embraced us as we laughed and cried, in the silences and the words spoken, in the re-telling of stories of care and anguish through progressive, regressive and chaos illness narratives (see Chapter 2, Frank 1998; Weingarten 2001).

When Heshusius (1994:16-17) speaks about participatory consciousness, she proposes that it is through relational selves, love and care that one comes to knowledge, not by separation. She sees this as the *self-other* relationship where the researcher lets go of concerns with the self, so total attentiveness to the *other* can be achieved. This occurred for me during our research conversations. I can now relate to the notions that a *self-other* relationship requires an attitude of openness and receptivity to create a greater wholeness and that through this experience of the self-other relationship we are all continuously changed. It was in this self-other relationship that I came to know the participants and their personal stories of living with Cancer and also took on the responsibility of bringing these stories to the reader by re-telling them. I therefore came to new knowledge by turning my attention to the participants fully and by letting go of my own perceptions and 'what I think I knew regarding their lives'.

Reflecting back on the invitation to participants, I wondered about why the only research participants were white women living with Cancer (see Chapter 1). I realised that the context in which the announcement was made was mainly a white congregation and therefore this became a determining factor for 'excluding' other cultures. The following questions arise: What about the people who do not have access to such research studies? What will the experiences of living with Cancer and stories of care be for people of other cultures? The reason why I did not include a broader population was mainly because of the limitations imposed by the academic requirements of a dissertation of limited scope. However, I came to the conclusion that the stories of these women
resonated more with my experience than I think a male participant’s story would have. This I believe has everything to do with my being a woman myself and being able to relate to issues like mastectomies, reconstruction, the loss of hair as well as the influence of these invasions on the self-body relationship.

5.2.3 Ethical considerations

I was and remain committed to an ethical way of being with the participants as well as an ethical research project. I received the information that helped to construct this dissertation; and the participants benefited by telling their stories and sharing their experiences and knowledge with the research study. McTaggert (1997:27) points out that because of the complexity of social situations, in practice it is never possible to anticipate everything that will occur, but, because of the flexibility of this research, it accommodated all the changes that occurred once the conversations with the participants started. These changes included (see Chapter 2) having only female participants and changing the title of the study from ‘Stories of Cancer Patients and their Families’ to ‘The Stories Women Tell: Living with Cancer and Care’. The aim of the study also changed from ‘care for patient and family in the terminal stage’ to ‘care for people living with Cancer’. My openness to these changes is due to my ethical commitment to keeping the participants the primary beneficiaries of the research.

Janesick (1994:212) states that qualitative researchers should allow for the possibility of ethical dilemmas and problems. Various things happened that elicited new reflections, such as using conversations and not interviews and questions about who benefits from the research.

After choosing a conversational approach I noticed that all the participants reacted with ‘so you are going to ask me questions and I will answer them’. I asked myself why this happened and wondered if it was because people are used to the ‘interview for question-answer’ style. I found that during our conversations some participants wanted guidelines from me. They prompted me for guidance, and/or specific questions to help them structure their thoughts and answers. My first impulse was to be vague because I was concerned firstly that by giving them too much guidance I could jeopardise the ‘authenticity’ of their experiences or even restrict it their responses. Secondly, I was worried that the participants might feel that I am just interested in the ‘progressive narrative’ (see 2.3). Thirdly, I wondered about a ‘power-relationship’ where I could be cast as the ‘expert,’ and, fourthly, that, if I introduced my ideas, the participants would only tell me what they think I want to hear and not be the ‘agents’ of their own stories. Oakley (1986:41) argues that the goal of inviting
participants to share information through interviewing is best achieved when the relationship of the interviewer and interviewee is non-hierarchical. I tried to explain to the participants that I would like the conversations to be more unstructured, flowing and non-hierarchical, and that they could just tell their stories in whatever manner they would prefer. However, I also realised that if structure was what they asked for at the time, it was ethical to provide whatever I could, but that I had to be transparent about my input (Elliot 1998:51). I also realised that if I asked questions during the conversations, I stayed ‘curious’ about the participants’ experiences, maintaining a ‘not-knowing’ position (Freedman & Combs 1996:44). In reflecting back on the research process, I have become aware that by asking these questions and/or by giving structure to some conversations I was co-constructing the stories and that together we were constituting the stories as ‘agents’ of these stories.

I wondered about the participants’ reflections regarding the conversational style that we engaged in during the research process. I wanted to find out whether they had any sense that my attempts at transparency, accountability and continuous reflections came across as I had intended. Although I did follow a ‘participatory action research’ approach, I could not implement the total power sharing practices proposed by Bishop (1996:64-66), where participants are involved in the development of the research questions and aims from the start of the research. I did, however, deconstruct the power/knowledge nexus to co-create a more equal relationship by promoting transparency and accountability as well as multiple reflections to ensure that the participants’ voices and stories were clear. This was even more important in the light of the claim by Bons-Storm (1996:17-18) that Dutch women felt they could not talk about parts of their lives to a pastor because they thought one ‘has to keep the door closed in order to be safe. A part of that person is lost to herself and others. That which is hidden in a closet cannot be healed or redeemed.’ I was repeatedly made aware of this when I heard the stories of women living with Cancer.

McTaggert (1997:28) states that participants in research should be involved in the research process and that the researcher should be transparent and open regarding the working method(s). One way of doing this was to incorporate reflections by the participants regarding the research process in the report. When I asked her about the process, Naomi said: ‘I felt like I had a choice in what to tell you, there was no pressure.’

Erika experienced the conversation as a place where ‘you listened and were interested in my story and in me. I enjoyed being able just to tell my story without being bombarded with specific
questions at first. The questions that followed gave me time to reflect on my own experiences and opened new avenues for me in thinking about my story.'

'The informality of the conversations was what made the situation comfortable for me. It made it easier for me to talk about a difficult topic,' said Henriëtte.

Hester said: 'I think that an interview with structured questions would have been better and easier for me.' Chris laughed: 'I, on the other hand, found the conversational style very comfortable.' Hester responded jokingly: 'It is because you like to talk and are more comfortable sharing your story with others.'

In reflecting on the reactions of the participants, I was reminded of Oakley (1986:52), who said that finding out about others' experiences is much easier done on the basis of friendship. I believe that it was within this context that we dealt with sensitive issues regarding Cancer. I also think that being open and non-judgemental towards the participants and their stories added to the conversational approach, and it also assisted the research process. I believe that this may be the reason why only some participants confided in me, telling me things that they would not dare tell even the people close to them. Zweig (quoted by Oakley 1986:52) said that being non-judgmental made him 'one of them'. I do not presume to see myself as 'one of them' even though I too have experienced Cancer's presence in my life, but only as a guest and not as my illness. However, as I listened to the participants' stories, Cancer invited itself into my life. The participants and I gave those stories voices. That is how I got to know Cancer and the hold it has on others.

5.2.4 Ethical re-telling: sharing power

In some instances, confidentiality in re-telling the stories became an ethical dilemma for me. Retelling some parts of the stories I struggled with the issue of how I was supposed to keep some sensitive information from other participants who were not to know the identity of the 'story teller', seeing that the participants will read the report. Janesick (1994:215) sees the most ethical way of retelling a story as staying close to the experiences told. It was important for me to be able to lead the reader to understand the meaning of the experiences told to me. Denzin and Lincoln (1994:15) argue that action-oriented qualitative research can create space for those who are participating in the research to speak. Thus the researcher becomes the conduit for making such voices heard. To make those voices heard was important and therefore I decided that where information was sensitive, I would not use the participants' names, but would stay close to their stories. Some of the
participants did think that openness is best, but they still wanted to keep some information from their loved ones. I realised that it was not my role to 'counsel' these participants on issues regarding openness. I asked them to trust me and therefore I should respect their way of dealing with Cancer. Dixon (1999:235) states that the researcher, being the one who asks participants for their knowledge, should value those contributions, whatever they may be.

In Chapter 1, I discussed the shift from the questions of 'who' and 'why' to a question of 'how' because of action research. The moment that I started discussing the 'how', I could not ethically remain an outsider to the stories of the participants, but entered into a caring relationship with them. This was the point where the participants became the ones that could benefit from the research (Zuber-Skerritt 1996:174). In reflecting on the question of whether the participants did benefit from this research, I turned to Foucault's (1980:81) work regarding power and knowledge. He argued that whoever has the knowledge has power and centralises specific discourses. People's stories about their experiences depend on these dominant discourses that are available to be told in their society. Thus, these dominant discourses have the power to include some stories as tellable, as well as to exclude others as marginal. Therefore one finds that some people are heard and others are not. I wondered whether the participants found that, by being heard, they may have benefited from telling their stories. I asked the participants whether they saw participating in this research as being beneficial to them in any way.

Naomi said: ‘Yes, it helped me in giving my experiences a voice. It was a kind of “catharsis” for me. Seeing that this information is going to be out in the “world” is a positive thing because I feel that others might learn from the other participants’ and my experiences.’

‘I always wanted to document my experiences, to write my own story. The goal for me is to let the medical world know that they are not working with numbers but with people with emotions and often people that are scared and confused. I believe that each woman will experience her illness in a different manner but can use this information as a guideline of what to expect from the illness and the treatment,’ Erika commented.

Henriëtte found that ‘in reading about other women and their stories I think it could be healing for me. I imagine that it would be beneficial to me to know that other women may have had the same questions that I did. I suppose it might be beneficial for others as well when they can “relate” their own experiences to mine from reading this dissertation.’
Hester and Chris felt that if their story means something to someone, they would be glad. 'I feel that the fact that people are interested in our story makes me feel that they care,' Chris added.

Kyla said: 'I feel that telling my story, especially how Cancer can steal the "intimate relationship" between a woman and her husband, was important and beneficial for me.'

As I reflected back on the statements of the participants, these words of Weingarten (1997:44) about telling her story rang true for me:

> By placing my story out in the world, by hearing from so many people that my story had resonance with theirs, I created a community of understanding with many people beyond that of my healthcare providers, colleagues, family, and friends.

In reflecting on my role, I ask myself: What was my position in the research regarding power? Power-sharing practices came into play quite early in the study when I started talking to participants regarding their experiences living with Cancer. The power shifted to me for a while as I set up meetings and provided the information and consent forms. The comments by Heshusius (1994:16) regarding participatory consciousness also assisted me in choosing the way I entered into research conversations with the participants. This is where the power shifted from me as the researcher to sharing power/knowledge with the participants. Reinharz (1992:181) writes about achieving an egalitarian relationship between the researcher and the participants through sharing practices. According to Reinharz (1992:193-194), the researcher could achieve these practices if control/power is given up in an effort to be open and transparent in the research study. Such a relinquishing of control and power might lead to shared decision-making, shared information and thus shared experiences. In an effort to protect the integrity of the participants, I encouraged them to answer only those questions or tell those parts of their story that they felt comfortable with sharing (Griffith & Griffith 1994:71). I found that by sharing power with the participants and moving away from an 'expert' position, the participants and I could create a safe space wherein sharing information and giving meaning to experiences came easily and comfortably. The informality of the conversations lent itself to easiness and openness between us. This was a very reassuring way of dealing with sensitive issues regarding their illness as well as their spirituality.

### 5.2.5 A contextual practical theology

Because a contextual practical theology approach also works from a stance of a 'turning to', I found its principles weave themselves into the research process.
Contextual practical theology focuses on praxis/action. Therefore work in the community should not only be discussed, but also put into practice (Botha 1998:137-138). As I reflected on the stories of the participants, suggestions of ways in which to deal with care for those living with Cancer came to mind.

The implication of this contextual practical theological study for pastoral care lies in the suggestion that a care network should be launched in the community, transforming it to a community of care. The network of care I want to suggest is one where any member of a church community can give care to anyone who might need it, after establishing that it is the kind of care that the person wants. Questions to ask are these: Should this type of pastoral care be a new focus of the church, and does it mean setting up a care network? Who should facilitate and organise this care network – possibly a pastoral therapist? Will the training of church members as givers of care be done by the pastoral therapist? I see this care network as a collaborative effort between the pastoral therapist, a church and its members and the people who will receive this care. Thus, action includes asking the person who is ill whether the care he/she is receiving is what he/she wants. I see this comment as a call to have someone in each congregation who can see to it that this does happen at all levels of care in a person's life.

Who has the power over care at this stage? Is there power sharing where people who are ill are asked about their ideas regarding care? Are the voices of people who are ill being heard? I believe that people who are ill should be the ones to write the programme for caring and their voices and knowledge should give direction to ‘how’ care should look. Let those that receive the care define the care programme and networks. The role of a pastoral therapist would be to make sure that those who are ill are represented on the committees that decide about the care that will be distributed by those committees.

In Chapter 4 of this study, I mentioned that Isherwood and McEwan (1993:86) argue for a new church model, moving away from a hierarchical model to a model in the form of a ‘circle’. Graham (1996a:54) also talks about ‘a diversification of practices’. To me, this means enabling more people to give care, not just the pastor/pastoral therapist, making care the joint responsibility of all who claim to be part of a Christian community.

It could be of value to ascertain to what extent care is currently negotiated in caring institutions/practices. Walker (1998:7) suggests an ‘expressive-collaborative’ model of ethics when it comes to care. The model describes ethics as interpersonal, and consequently the caregiver and
the person receiving care should negotiate care. Sevenhuijsen (1998: 82-85) argues that reflection and moral deliberation on whether the type of care given is what is needed, starts when one listens to expressions regarding care used by the providers and receivers of care.

The participants and I reflected on how to ‘negotiate’ care and how the negotiation should take place. The participants and I (see Chapter 3) spoke about the idea of ‘appointing a person’ as the ‘hub’ of a care network. This person would be responsible for organising and training caretakers to facilitate communication between the patient, family, and medical staff, as well as attending to people’s spiritual well-being by listening to what they want. The caretaker can be seen as an ‘advocate’ for the person who is ill and his/her family, by seeing to it that he/she receives the care he/she wants/needs. There is an appeal to pastors/pastoral therapists for greater involvement and participation in the community, thus a community of care (for the purposes of this study). Pastors/pastoral therapists should take a critical stance towards any ‘practice’ which does not stand for justice and fairness regarding care. Cochrane et al (1991:16,53,57) talks about ‘faith commitments’, or being there for those that need help and caring, and having those who are ill participate in the creation of these care networks.

I wondered how this role suggested for a pastoral therapist would fit in with the prophetic role of the pastor. Cochrane et al (1991:16,24,56,89) describe the role of the prophetic church as one of commitment to the oppressed and marginalised, and critical of unjust systems. They preach a ‘prophetic mode of doing theology’ where the pastor becomes the ‘enabler of prophetic words and deeds within the congregation, i.e. a facilitator of communicative praxis’. In my mind then, the pastoral therapist’s prophetic role should be finding out from people who are ill what their ideas regarding their preferred care are, then caring for those who are in need by facilitating a caring network of caregivers, promoting care and communication and training church members to do the caring. By doing so, care is put back in the community, thus creating a caring community.

5.3 REFLECTIONS ON CANCER, CARE AND SPIRITUALITY

An aspect that became visible to me was the diversity of the stories the participants shared with me regarding Cancer and care. The experiences of each of the five participants' was unique to that participant's life and situation. This raised serious questions about the application of one model or definition of care to fit all the situations of all the women involved in the study, let alone everyone else who has to live with Cancer.
5.3.1 Defining health in a capitalist society

In light of the conversations with the participants regarding the medical field, I return to the definition by Parson (quoted by Wolinsky 1980:72-75) of illness already cited in Chapter 1. In discussing the ‘impersonal nature’ of the care the participants received from some medical staff members and physicians, and becoming ‘the illness’, some questions were triggered for me relating to this definition of illness. Even though my research does not explore this important issue fully, I still want to mention the questions that I wondered about. Does this definition emphasise a capitalist construction of people, and their function in their society? What does a society centralise if it is less concerned about people who are ill and the care people receive than about getting them healthy as quickly as possible so that they can get back to producing and fulfilling their roles in the workplace and in society? Is care also capitalistic? If it is, can one argue that the care a person receives is connected to his/her social/financial status? Whose needs are central, those of the person who is ill or those of the doctor/medical system? Was some of the care that the participants in this study received ‘capitalist’ care? Is this why, when we spoke about the topic of care, most of the participants stated they would have preferred different care to the care they actually received? These questions can become a starting point for future studies.

5.3.2 Care as a topic

The topic of care in the lives of women living with Cancer was the focus (Chapter 1) of my research study and grew from having dealt with illness of family members as well as a curiosity about Cancer and its effects on people’s lives. During conversations with the participants, I started to wonder whether it was my questions that opened up the possibility of ‘preferred care’ for them (Weingarten 2000:1-7). It seemed to me that the women only allowed themselves to talk about what type of care they would have liked during their treatments for the first time during our conversations. I wondered whether it was because of the medical field’s interest in illness and the body and not in the ‘person’ that they may never really have had an ‘audience’ to express these thoughts to. The next step for the participants in the ‘becoming aware’ process was a need to act as consultants to the reader by making him/her aware of what care to request. In some instances the participants suggested various possibilities of care to me. I also found my own voice during the conversations with participants regarding their experiences living with Cancer.
5.3.3 Finding my own voice

In sharing some of my thoughts with the participants, I recognised my own voice in the conversations. This brought forth more voices in myself that resonated with those of the participants. These voices opened the way for more meanings, so within each conversation with a participant more meanings were created. In learning about these women through their stories, I also discovered some of myself, through both inner-dialogue (Andersen 1993:306) and the conversations we had together.

My inner dialogue during some of the conversations started to challenge what I thought I knew about the experiences of people living with Cancer. These were thoughts I had on illness, specifically Cancer, and how people living with Cancer deal with death, and whether their knowledge of the illness assisted them in the process of leaving their loved ones behind. Do they plan for the future? My inner dialogue explored various questions on these topics. Would I want to know whether I am dying and from what? Is it a blessing to have time to get everything in order and to be able to say goodbye? What would I want if I ever fall ill? What ‘care’ would I want? I found myself being in conversation with the research study, as well as with the stories that I had been witnessing. By reflecting on these questions, I created new meanings regarding illness, death and health for myself. On the basis of what I have learnt from the participants, I have decided that if ever I became seriously ill, I would like to stay ‘me’ and not become the illness. I would want care to be negotiated with my family and myself. I would want choices and knowledge about my situation so that I can make informed decisions – as Farrow et al (1990:5) point out, by becoming knowledgeable about their illness and treatments patients might retain some control of what used to be their lives.

Hearing stories of Cancer and care helped me to question my own life priorities. Pondering what is really important in life, I questioned my foolish worrying about small mediocre problems. The research mirrored the dominant discourses of believing that Cancer is a ‘death sentence’. By being a witness to the participants’ stories, my original belief that ‘Cancer equals death’ was converted to a story of hope, resilience, love, support, truthfulness, honesty, sharing and humour, all things that I imagined would vanish in the face of Cancer. This project forced me to rethink and reassess my original beliefs about the world that I live in as well as about the people around me. I came to realise that people are much more resilient than I ever thought possible.
Oakley (1986:41) argues that where researchers are prepared to invest their own personal identity in the research relationship, it can happen that they become the ones answering the questions. This could become a valuable task for a pastoral caregiver, being comfortable in answering questions, making themselves known through their answers. Erika asked me two questions: Had I learned anything from her? Did my opinion of her change since I learnt that she is living with Cancer? My answer to the first question was that I have learnt that there is hope in situations like hers, that one can arm oneself with knowledge and in doing so be able to have some control over one's own body and treatment. Had my opinion of Erika changed? Yes, it had. I admire her strength and willpower. She proved to me that although she was living with Cancer, she had not become Cancer's victim. She fought back by informing herself, by holding on to her spirituality and what she believed in. She never gave in to the dominant discourse of 'Cancer as a death sentence'.

If I am to know myself through my narratives and the multiple stories of who I am, then this story will be just one of the many I experienced during this research process. I believe that I am at present more aware regarding the lives of people whose lives have been invaded by illness and the role spirituality plays in these participants' lives.

5.3.4 Spirituality

Discussions of Cancer's effect on the participants' lives flowed into a narrative of their own unique way of dealing with Cancer on a spiritual level and a space opened up for discussions on the participants' conversations with their own personal God (Griffith 1995:123). In reflecting on spirituality and the role it played in the lives of the participants in this study, I noticed a lack of literature on spiritual guidance for a person who is 'living with Cancer', where Cancer is in remission. The bulk of the information regarding spirituality and Cancer for a person who is ill concentrates on the 'terminal phase' of living with Cancer, and on preparing for death. Death's socio-religious constructions stem from biblical times where, as was seen in Chapter 4, death was more frequent, seeing that most illnesses were untreatable. With modern technology came the extension of life, an ability to put Cancer into remission and therefore opening up spaces for 'new' and more 'inclusive' spiritual literature for the ill person, spiritual literature that pays more attention to people who are 'living with Cancer' as survivors and who strive to enrich their lives by focusing on stories of hope and support. For a pastoral therapist, understanding the feelings and emotions of someone living with Cancer as a survivor can enrich the follow-up care that is sometimes needed.
5.3.5 Participants' spirituality

I discovered that, in each of the participants' lives, spirituality played a major role, but also that 'spirituality' was different for each individual. The way that they perceived and practised 'religion' differed. In Chapter 4, I mentioned that, Johnson and Spilka's (1991:21) research in the USA showed that between 64% to 90% of Cancer patients regarded their personal religion to have been an important aspect in their lives. The questions that the participants had were all directed towards God. Some of the participants in this study spoke about their struggles with the question of 'why' the illness had to happen to them, or, in Jim and Chris's situation, to their wives. Karla said that she thinks it is possible that God would understand her 'questioning Him', and for Henriëtte it was just normal to ask questions - for her the question of 'why' is always present in her life. The overall denomination applicable for most of the participants is that of the Dutch Reformed Church.

Since all the participants viewed themselves as Christians, I could relate to their way of dealing with Cancer on a spiritual level. I could see myself taking similar steps, holding on to a 'bigger entity' than myself, 'someone' or 'some entity' who could be in charge of the bigger picture of my life. That 'someone' for me has always been Jesus Christ and I trust in Him completely. However, I find Herholdt's (1998:215-229) statement regarding postmodernity applicable in my life when he says that postmodernity works from the point of view that humans should be co-creators of their lives and need not plug into a blueprint that renders their own efforts and creative potential sterile.

5.4 CLOSURE?

I wondered whether a researcher could be changed through the research as I experienced myself to have been changed. I found the answer in Reinharz's (1992:194) statement: 'Many feminist researchers report being profoundly changed by what they learn about themselves...revising one's worldview'.

I realised that the reader of this dissertation will give meaning to it, that each story will have a different message and be of a different value for each one that reads it. The contributions came from all the different voices that came together in this study. The dissertation also reflects all the lessons learnt from these voices. Listening to similar stories was another way for me to gain perspective and to enrich my own story (Jensen 1984:222). I do hope that for the readers reading about all these similar and also different stories, their own stories will be enriched and maybe changed.
For the purposes of this document, the research story now ends, but I would like to take this study further in starting a care network by launching a training programme for volunteers to take action in caring, by being the pastoral therapist who will do the organising and facilitating of such a care programme. I envisage different forms of care networks. Children living with Cancer have not been included in this study, because of the limited scope allowed by academic limitations, but I would argue that a care network should be established separate from others, to deal only with the special needs of children living with Cancer and their families. A care network for adults would be different. I envision a panel containing three groups: professionals (physicians, nurses, pastors/pastoral therapists), caregivers in the form of church members (in an advisory position, expanding rich resources to which the patient and family can have free access) and people who are ill (participating in the creation of the above care networks, to ensure that the care provided is the care wanted/needed). Only by such co-creation of care and the discourses surrounding Cancer and care can ethical care be ensured within discourses that promote an ethics of care.
REFERENCES


Appendix A

EXPLANATION OF CANCER CONCEPTS / TERMS


Benign tumor: A mass of cells that grows slowly, does not spread and does not threaten the survival of the person. They are usually well differentiated and have a cellular structure characteristic of their tissue of origin. They do not invade blood or lymph vessels and do not metastasize (Oppenheimer 1982:145; Friedberg 1993:23)

Biopsy: Small pieces of tissue are looked at under a microscope to see if there are any cancer cells present. Sometimes a biopsy is done by inserting a needle into the breast and drawing out some of the tissue. If the biopsy shows that there is cancer, it is important that certain tests (called estrogen and progesterone receptor tests) be done on the cancer cells. (Friedberg 1993:39)

Cancers: There are masses of cells that are able to spread from one body part to another and threaten the survival of the person (Oppenheimer 1982:12; Friedberg 1993:2). Cancer is a general term for about 100 diseases characterized by the abnormal and uncontrolled growth of cells. The resulting mass, or tumor, can invade and destroy surrounding normal tissues. Cancer cells from the tumor can spread via the blood or lymph (the clear fluid that bathes body cells) to start new cancers in other parts of the body.

Carcinomas: Malignant tumors of epithelial (surface) tissue origin. These are cancers of the body's internal and external surface linings (Oppenheimer 1982:146; Friedberg 1993:33). Carcinomas include cancer of the skin, breast, liver, pancreas, intestines, lung, prostate and thyroid gland. These cancers may be spread to other body parts via the lymphatic system.

Chemotherapy: A process to stop cancer cells from proliferating, patients are exposed to chemical agents that damage DNA (Friedberg 1993:114).
Chondrosarcoma: Cancer of the base of the skull. Treatment for this tumor is surgical extirpation, which is particularly difficult when the site of origin is the base of the skull. Preoperative chemotherapy is then recommended to decrease the size of the tumour (Williams, Krikorian, Green & Raghavan 1988:585-586).

Invasion: This is the movement of cells into neighboring spaces occupied by other tissues (Oppenheimer 1982:148,12; Scott 1979:204).

Malignant tumor: These are cancers. They are often less differentiated than their tissue of origin. They are seldom encapsulated. Growth of malignant tumors is often invasive, infiltrating neighboring tissues, blood and lymph vessels, and body spaces (Oppenheimer 1982:145).

Mammogram: This is a special x-ray which may find tumors that are too small to feel (Sikora & Smedley 1988:15; Friedberg 1993:39).

Mastectomy: Partial or segmental mastectomy is the removal of the cancer as well as some of the breast tissue around the tumor and the lining over the chest muscles below the tumor. Usually some of the lymph nodes under the arm are also taken out. Modified radical mastectomy is the removal of the breast, some of the lymph nodes under the arm, the lining over the chest muscles, and sometimes part of the chest wall muscles. This is the most common operation for breast cancer. Radical mastectomy (also called the Halsted radical mastectomy) is the removal of the breast, chest muscles, and all of the lymph nodes under the arm. For many years, this was the operation most used, but it is used now only when the tumor has spread to the chest muscles (Friedberg 1993:126).

Metastasize: This is the spread of cells to distant sites, usually via the bloodstream, lymphatic system, or through body spaces. After traveling through the blood or lymph system, cancer cells start a new tumor elsewhere in the body (Burn & Meyrick 1977:97; Scott 1979:205; Friedberg 1993:17).

Hodgkin's disease: A lymphosarcoma Hodgkin's disease is a type of lymphoma. Lymphomas are cancers that develop in the lymphatic system (Oppenheimer 1982:146; Burn & Meyrick 1977:97).

Radiation therapy: This therapy uses X-rays, gamma rays, electrons, protons, and neutrons. When a growth is malignant, surgery is often preceded by or followed by radiation therapy. Radiation destroys the more rapidly dividing cancer cells but causes less damage to the more slowly dividing
normal cells. Thus, radiation kills cancer cells and shrinks tumors. Radiation may come from a
machine outside the body (external radiation therapy) or from putting materials that produce
radiation (radioisotopes) through thin plastic tubes into the area where the cancer cells are found
(internal radiation therapy) (Friedberg 1993:114; Clark & Cumley 1978:243).

**Remission:** The decrease or disappearance of cancer symptoms, or the period during which this
occurs (Friedberg 1993:136).

**Surgically:** Tumours can be surgically removed, but there is always the danger that malignant tumours
have already metastasized (spread) (Shellwood 1977:63; Friedberg 1993:112).

**Tumours:** These are swellings that could arise from hemorrhage, inflammation, cell growth, or cancer.
The term is used to indicate or mean 'new growth' (Oppenheimer 1982:12; Friedberg 1993:22). It also
can be seen as the abnormal growth of tissue.

**X-rays:** High-energy radiation used in high doses to treat cancer or in low doses to diagnose the
disease (Scott 1979:48,70).
Appendix B

THE STORIES OF CANCER PATIENTS AND THEIR FAMILIES

Information sheet for participants and their families

Thank you for your interest in this research project. Please read this information sheet carefully before deciding whether or not to participate. If you do decide to participate, I thank you. If you decide not to take part, there will be no disadvantage to you of any kind. But thank you for considering our request.

What is the aim of the project?

This project is being undertaken as a part of the requirements for a Masters in Pastoral Therapy. This letter is designed to provide you with information on the nature and purpose of this project.

The aims of the project are (a) to have conversations with you (participants) and/or your families (b) to learn from you and your family (the participants and their families) what your (their) own preferred way of living with cancer is.

What type of participants and families are being sought?

Participants who are living with cancer and their families are given the opportunity to be included in the research project. In order to meet the aims of the project, a group of participants will be sought whose lives include living with cancer and their family’s involvement.

What will the participants and their families be asked to do?

Should you agree to take part in this project, you will be asked to give consent for the information obtained during the conversations to be used in the research project. If you decide to take part in the project, you will be asked to participate in conversations around your experience living with cancer, as well as reading the summary of the conversations and making comments, corrections and/or providing feedback regarding the summary.

Note: When the person living with cancer decides that he/she would like to participate in the project but the family would not, the family can then give the participant their permission to relate their side of the story, should that be their wish.

There will be a couple of conversations, between 2 and 4 and conversation will end only after I have consulted with you as well as my supervisor. If at the end of our conversations you still need to talk to someone I will arrange to include a spiritual leader if you so wish. I will be available to answer any questions that you may have regarding our conversations or the project.

Can participants and their families change their minds and withdraw from the project?

You and your family are free to withdraw your participation from this research project during the conversations. There will be no prejudicial consequences at all for you.
What data or information will be collected and what use will be made of it?

The information obtained during conversations will be discussed with my supervisor and used in the project in the form of a re-telling of the preferred ways that people live with cancer. With your prior consent, these sessions will be audiotaped. I will take notes during our sessions if you choose not to have them audiotaped. A summary of our sessions will be made available to you and your families at the conclusion of the conversations for review. Your comments, corrections and/or feedback will be included in the final report.

Results of this project may be published but any data included will in no way be linked to any specific participant.

You are most welcome to request a copy of the results of the project should you wish.

The information collected will be securely stored in a locked filing cabinet at my office and only my supervisor or myself will have access to it. At the end of the project any personal information will be destroyed immediately except that any raw data on which the results of the project depend will be retained in secure storage, in a sealed container, for six months. Thereafter the data will be destroyed.

What if participants have any questions?

Should you have any questions or concerns regarding this project, either now or in the future, please do not hesitate to contact either:

Michéle Harrington
Institution for Therapeutic Development
UNISA
(012) 664 5078

Dr Elmarie Kotzé
Institution for Therapeutic Development
UNISA
(012) 460 6704

This project has been reviewed and approved by UNISA.
Appendix C

THE STORIES OF CANCER PATIENTS AND THEIR FAMILIES

Consent form for participants and their families

I / we have read the Information Sheet concerning the project and understand what it is all about. All my / our questions have been answered to my/our satisfaction. I / we understand that I am / we are free to request further information at any stage.

I / we know that:

1. My / our participation in the project is entirely voluntary;

2. I am / we are free to withdraw from the project at any time without any disadvantage;

3. I am / we are aware of what will happen to all the personal information including the audiotapes at the conclusion of the project, that the data will be destroyed at the conclusion of the project but that any raw data on which the results of the project depend will be retained in secure storage for six months, after which it will be destroyed;

4. I / we will receive no payment or compensation for participating in the project;

5. I am / we are aware that all personal information supplied by me / us will remain confidential throughout the project.

I am / we are willing to participate in this research project.

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(Signature of participant(s)) (Date)

This project has been reviewed and approved by Institution for Therapeutic Development.