

THE VALUE OF NARRATIVE PRACTICES IN PASTORAL CONVERSATIONS

Witnessing women's stories of breast cancer

By

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DECLARATION

I declare that this research on **THE VALUE OF NARRATIVE PRACTICES – WITNESSING WOMEN’S STORIES OF BREAST CANCER** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

Nicole Dickson

Date

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I dedicate this research to the women who have been willing to entrust their stories to me for this research. I am in awe of your courage and determination. This research has been woven from your narratives.

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ABSTRACT

The purpose of this research is to explore how narrative practices can be meaningful in pastoral conversations with women living with breast cancer. A theoretical collaboration between narrative therapy, feminism and pastoral theology has been used in order to facilitate meaning-making, to give 'voice' to local knowledge, and to co-create a more holistic understanding of the experiences of illness narratives and breast cancer. The methodology of this research is 'interdisciplinary' and uses qualitative, co-participatory action research and reflexivity as its research design. Conversations with the co-researchers explore illness narratives, breast cancer, spirituality and faith, life-giving relationships, femininity and body image, socially constructed discourses and pivotal moments that enable alternative stories. Values of respect, curiosity and listening have been upheld in order to provide a safe place for the co-researchers to give voice to their stories and experiences of breast cancer in a way that supports the researcher position of 'witness'.

KEY TERMS

Breast cancer, narrative practices, feminist ideas, pastoral theology, hope, faith, spirituality, stories, externalization, discourses, meaning-making, witnessing, voices, alternative stories, definitional ceremonies.

“Open my heart that Compassion may be my companion;

Where I meet pride, humble me;

Where I meet anger, calm my fears;

Where I meet injustice, cause me

To act in love’s way.

May I be as gentle as the doe,

As fearless as the lion,

As faithful as the dog.”

From Psalm 17

‘Psalms for praying. An invitation to wholeness’

Nan C. Merrill

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CHAPTER 1:

INTRODUCTION TO THE JOURNEY

*“Tell me a fact and I’ll learn.
Tell me a truth and I’ll believe.
But tell me a story and it will live in
My heart forever”*
- Indian Proverb -

1.1 MY STORY

My interest in this research has grown out of personal experiences of pain and illness (although not cancer) and the assumptions and fears which I, as a woman, have towards breast cancer.

My life was introduced to the struggle of living with disease and illness when our 22 month old daughter, Courtney, was diagnosed with insulin dependent diabetes mellitus, ‘diabetes’. As a mother, my discourse of what constituted a picture-perfect life and future for her was devastated and the life-binding reliance on a needle began. An erstwhile healthy toddler was suddenly labelled ‘diabetic’, ‘ill’, ‘sick’ and people’s ignorance and avoidance made living with such a life-threatening illness very lonely. Spiritually I was challenged by those who encouraged us to have enough faith in God for her healing and to rely on Him instead of medication. I was also challenged to consider my faith journey and my picture of God. Did I believe God was a punishing God? Did I believe God had a plan for us through this illness?

My personal story of pain and disease emerged during my son, Luke’s, first year of life. A niggling pain in my right hip gradually worsened until I was limping and unable to walk. X-rays showed nothing unusual and physiotherapy made no improvement. An orthopaedic appointment and a CAT scan labelled my pain “avascular necrosis of the right femoral head”. This, in a language I could understand, meant that a lack of blood supply to the femoral head, for whatever reason, has caused a part of the bone to decay or die. The specialist suggested an immediate hip replacement

operation – I was 34 years old and felt totally at the mercy and knowledge of medical science. I learnt many things during this time. I learnt about living with constant pain. For almost two years, pain was a debilitating, daily companion. This fed a sense of failure as a woman, a wife and mother. There were basic activities, such as picking up my children, which I was not able to do. I was angry with my body for finding yet another way, after two difficult pregnancies, in which to let me down. Now, in 2011, I find myself again forced to confront my body and change. This time I am having to learn to live with the constant muscular pain of fibromyalgia.

Why Narrative?

At the same time that my relationship with physical pain started, I was studying and volunteering at our local church's pastoral care centre. Part of this involved participating in a narrative therapy training programme. My personal journey with narrative therapy has a very simple foundation. I love books; all books. I love stories and tales from childhood and the memories which books hold for me. I loved the bedtime stories read to me by my mother and my grandmother and I loved the stories of family history and memories shared by them of a time past. Their stories of '*when I was young...*' filled much of the knowledge and imagination upon which my early childhood was formed. It is therefore no surprise to me that I have been very inspired by the narrative assumption that all life is constituted of stories and socially accepted discourse. Parry & Doan (1994:211) state that "*we dream in narrative, daydream in narrative, remember, anticipate, hope, hate and love by narrative.*"

Why pastoral?

Reading the Bible, especially well-loved and familiar parables told by Jesus, has a whole new meaning after being introduced to narrative therapy. I am more aware of how Jesus listened to people. Jesus showed respect to many different people. Jesus was the voice of the downtrodden and hurt. Scripture records evidence of the man Jesus confronting and resisting oppressive discourse. He used parables and metaphors that challenged many of the discourses of the time. He spoke of alternative stories and ways of freedom, connectedness, equality, respect and genuineness. The Bible expresses how Jesus tried to teach his disciples a different way of being by exposing discourses of power and extolling a life of servant hood. Jesus teaches that it is possible, in collaboration with Father, Son and Holy Spirit, to

stand against the voices that silence us and to challenge that which robs us of the abundant life promised to us in the New Testament.

Why Women?

I am particularly involved with women and children who seek assistance from the Pastoral Care Centre where I work. As a woman, wife and mother, I feel a strong identification with the many roles women participate in. I am witnessing how gender discourses formed in a dominant patriarchal society play an ongoing part in silencing and minimising women's voices and wellbeing. I work daily with the pain and broken lives that form part of our community. I am constantly touched and in awe of the ways women overcome fear, pain, hurdles and it is to these women that I turn to further my learning and understanding of living with illness and pain.

In conclusion, I am surrounded, at the Pastoral Care Centre, by an amazing structure of support, prayer, spirituality and care, not only for those who walk through our doors in need, but also for the team of dedicated caregivers and listeners. My study of secular models of psychology has been profoundly influenced by narrative therapy, especially in the context of pastoral care. For the past seven years I have worked towards holding together narrative, theology and pastoral ways of being with others. This research is a testament to each and every pastoral conversation I have ever had.

1.2 RESEARCH CURIOSITY

My research curiosity is twofold. Firstly, as a pastoral therapist, I was curious how narrative therapy could be integrated into a pastoral context in a way which might add meaning to pastoral conversations. Secondly, based largely on my own experiences as a woman, a Christ-follower and a sufferer of and a witness to illness, I became curious about how spirituality and faith are affected by the presence of life-threatening illness. I wondered how the presence of illness might affect the faith relationship with God and how pain and suffering are experienced within this context (see section 4.5). This was to form the basis for my research question detailed in section 1.3.

1.3 RESEARCH QUESTION

My research curiosity (in 1.2 above) and a statement by Henderson, in her article 'Matters close to the heart' in Moessner (Ed) (1996:207-221) which states that the word 'cancer' is one of the most frightening medical words a person can hear, with the common myth that the diagnosis is equivalent to a death sentence, led me to the following research question:

How can narrative practices be meaningful in pastoral conversations with women living with breast cancer?

1.4 OBJECTIVES OF THE STUDY

In an attempt to answer the research question, the following research objectives were formulated, namely:

- To explore the value of narrative practices and ideas in the context of pastoral conversations
- To acknowledge a more integrated voice of illness in which the sufferer shares expert knowledge.
- To explore how illness and suffering are understood by followers of the Christian faith
- To understand how the presence of breast cancer might affect the experience of faith.
- To explore the role of spirituality and faith in re-authoring alternative stories of illness and breast cancer.
- To understand the societal discourses of breast Cancer, including my own.
- To understand and acknowledge the effects of breast cancer on a woman's body image, femininity, sexuality and other life-giving relationships.

An additional objective of this research process is to be a witness to the stories and experiences of breast cancer. Weingarten (2000:402) believes that discourses regarding illness and health are able to silence voices and isolate "sufferers" from family and support. She speaks of the "nuances there are to being a compassionate

witness to the stories and lives we journey with" (2000:402). Witnessing is discussed in 1.9.6 below. The witnessing process will be assisted through the collaborative approach between the theories of narrative practices, feminism and pastoral theology as well as the voices and experiences of the participants.

Collaboration, for the purpose of this research, will be understood as a process whereby two or more voices work together to create or weave an intersection of common goals through shared knowledge.

1.5 LITERATURE REVIEW AND CONTROL

This research report makes use of both a literature review and a literature control. Terre Blanche et al (2002:17) believe that a research project does not exist in isolation but *"builds upon what has been done previously"*. A literature review, therefore, serves as a summary of the findings of significant studies and it also serves to question discourses operating covertly in the literature, and in the researcher and participants' responses (Reinharz 1992:150). A literature review also offers new ideas, examples of successful research projects. The purpose is, therefore, to convey what knowledge and ideas have been established on a topic, and what their strengths and weaknesses are. I initially undertook a literature review in order to understand the bodies of theory that this research will use and to be familiar with stories of illness and breast cancer already written.

This research also chose to embrace a literature control. De Vos, Strydom, Fouche & Delport (2005:264) suggest that a literature control should be woven throughout the study as part of the process of research writing. Whilst a literature control serves similar functions to those of a literature review, rather than offer a separate summary of research findings, a literature control becomes an integral part of the body of this research. The literature control can therefore be reviewed and become part of the process of meaning-making, as it is being discovered or considered, and in the context of participants who have the personal stories and experiences being researched. Janesick (2011:51) suggests that the *"researcher's willingness to research the literature in an ongoing fashion helps him or her to better understand the unexpected twists and turns of interview data and better positions the researcher*

for the next session". For this purpose, chapter 2, which might normally contain a separate literature review, has been integrated into the body of this research.

1.6 RESEARCH DESIGN AND METHODOLOGY

As mentioned in paragraph 1.3 above, the purpose of this research process is to be a witness to women's stories and experiences of breast cancer through a collaborative approach between narrative, pastoral and feminist ideas. The purpose is therefore conducive to a research paradigm which embraces qualitative, co-participatory and reflexive research. Heitink (1999:225) proposes that "*practical-theological*" research is action research. He states that, because pastoral research presents aspects that touch not only on theology but also on social sciences, a "*interdisciplinary approach*" should be encouraged. Qualitative, co-participatory action research and reflexivity will now be discussed.

1.6.1 Qualitative research

Qualitative research is an approach which is less formalised than quantitative research. Janesick (1994:217) suggests that qualitative research adds value to research because:

Somehow we have lost the human and passionate element of research. Becoming immersed in a study requires passion: passion for people, passion for communication, and passion for understanding people. This is the contribution of qualitative research.

(Janesick 1994:217)

It is not based on fixed and rigid procedures but focuses, instead, on meaning, experience and understanding. This research approach gives the researcher an opportunity to interact with groups or individuals whose experiences are being studied. This emphasises the trust and empathy between the researcher and the participants. The significance of qualitative research is rooted in its preparedness to interpret subjective meaning-making and its reluctance to generalise research findings, because of the unique way in which people make meaning of their experiences. Mouton (1996:168-169) describes qualitative research as a holistic focus on understanding social phenomena in context, rather than explaining them. As a result, qualitative research usually holds rich descriptive data, focusing on an

individual or small group of participants as well as an insider approach where meanings and self-understandings are reconstructed (Neuman 1997: 418-421). One of the basic principles of qualitative research design is, therefore, to set up situations through which the researcher can become familiar with the topic of research in natural settings. For this purpose, participants are selected for any research and also play a role in the interpretation of results. Outcomes, therefore, become a collaboration between participants and researcher.

Collins et al (2000:38) write that the design of this research tends to develop as the research process develops. The design is simply a general guideline which allows this researcher some level of flexibility as this research progresses. Rubin and Rubin (1995:42-43) advise that research design for qualitative research cannot entirely be planned in advance as *“design changes as you learn from the interviewing”*. It is, therefore, non-linear and cyclical and uses “logic in process” which indicates an ambiguous and sometimes messy research procedure from which subtle shades of meaning emerge (Neuman 1997:330-331). In concluding, I hold on to the notion of Steier (1991:163-185) when he suggests that qualitative research strongly affirms that researcher and researched are inter-dependent in the research process.

1.6.2 Co-participatory action research

We cannot know for people what is good for them. We also have to know with them. To be ethical, the participation of the people about or for whom we do research is of primary importance at all levels of research

(Kotzé et al 2002:27)

A literature study of Heitink (1999), Lartey (2005), Morgan (2000), White & Epston (1990), Cook & Alexander (2008), amongst others, indicates that practical theological research, narrative research and feminist research are frequently conducted through models of participatory action research. The characteristics of action research include the participants taking part in research, ordinary and everyday knowledge, empowerment and the fostering of awareness. Action research indicates that meaning is not created on anyone’s behalf in therapy; rather, participants are responsible for the process of co-constructing alternative and richer stories. O’Brien (2001:2) defines participatory action research as the process of

“learning by doing”. He maintains that it is a dual commitment to study a system and to concurrently collaborate with members in order to facilitate change. Morgan (2000:116) calls this collaboration *“consulting your consultants”* or *“co-research”*. The ‘consultants’ in this research are the women who have personal experiences and stories of breast cancer. The ‘co-research’ aspect of this research involves documenting knowledge and experiences of breast cancer in ways that will be life-giving and respectful to the participants and be able to benefit others. This knowledge will be documented and shared through interviews and conversations as well as in any other way considered collaboratively meaningful (such as letters, certificates, declarations etc).

1.6.3 Reflexivity

It is in the space that exists between the having in common and the not having in common that the possibility for true dialogue can occur and the generative conditions for real listening, talking and learning exists.

Heshusius (1996:122)

Reflexivity seems to occur in a space where the participants and the researcher can begin to generate new meanings and examine them for possible preference. In this way, alternative knowledge or new stories become available to participants. In this research, this means declaring my own knowledge and experience which I bring to bear on the research process. I am required to constantly reflect and recognise my own role in this research process. However, the concept of reflexivity is more than merely reflecting. It is a process in which ideas can bounce off other ideas; aspects of experience can come to the fore, so that people can begin to notice and examine previously held assumptions. For Zimmerman & Dickerson (1996:115), a reflexive position can occur when people find they have some *“space to consider, think over, examine and explore their own thinking...to wonder about multiple possibilities for understanding their experience”*. For the duration of this research process I will rely on the understanding of Collins et al (2000:38) that the *“relationship between this researcher and her subjects of inquiry is structured in a way that gives them the opportunity to voice their personal experiences”*.

1.7 POSITIONING

I have used the term 'positioning' to indicate the three frames of reference that I bring to this research, namely narrative practice, feminism & pastoral theology. Each position will be explained in the following paragraphs.

1.7.1 Narrative Therapy Position

Narrative practice invites the challenging of discourses and the re-authoring of stories in ways that respect the participants and allow me to co-research and document their experiences. This position is aligned with the role of "*compassionate witness*" (Weingarten 2000:394) which invites subjective and contextual knowledge to be created by the real experts – the women who actually have the stories and experiences of illness and, in the context of this research, breast cancer. Chapter 2.2 explores narrative practices more extensively.

1.7.2 Feminist Position

This research embraces a feminist-centred perspective as it unfolds within a set of assumptions which believes that women and men live their lives in a world in which gender is still marginalised. Neuger (2001:1) believes that these dynamics are at the heart of much of the distress and pathology that is brought to pastoral care environments. A feminist position attempts to give a voice to women and holds that women express and experience themselves differently from men (De Vos et al 2005:7). Reinharz (1992:258) maintains that projecting this research in the researcher's own voice is more authentic when the researcher has lived experience of the research topic. Whilst I cannot lay claim to personal experiences of cancer, I can use my voice as a woman and as someone who lives with illness and pain. Feminist theory is discussed in greater detail in section 2.3.

1.7.3 Pastoral Position

I am a follower of Christ, serving and ministering in a pastoral care centre. I do my research as a member of a Christian community whose "*normative ways of being in the world*" are shaped by the "*images and metaphors*" of biblical narrative accounts

of God's presence in the world. (Gerkin 1986:48-49). A detailed discussion on pastoral theology takes place in section 2.4.

1.8 RESEARCH DATA

Whilst the term 'data' is regarded as an element of quantitative or modernist research, I have retained the term here in order to create a familiar and shared understanding of meaning between reader and writer. The data, in essence, will be the personal stories and experiences that each participant and myself brings to this research.

1.8.1 Selection of participants

I invited participation from a group of women for a specific purpose, namely to explore meaning-making in living with, and surviving, breast cancer and in order that I might be a compassionate witness to their journey of pain and illness. This resonates with Rubin and Rubin (2005:vii) who maintain that qualitative research should choose participants who are "*knowledgeable about the research problem*". This research is, therefore, a culmination of a journey with women who have stories and experiences of breast cancer.

1.8.2 Data Collection process

Research conversations were conducted over a period of 15 weeks. These were undertaken as both individual conversations and group conversations. Conversations were recorded and transcribed in order that the meaning making be that of the participants. By using a co-participatory, collaborative research process it was hoped that dominant power discourses regarding breast cancer, illness, spirituality, faith and gender experiences could be deconstructed and explored in a way that was life-giving to the participants. The participants were invited to collaborate and verify information produced from the conversations.

1.8.3 Data

Data was primarily collected from research conversations with participants. Conversations of a more structured nature were included for the collection of history, illness and background information. Semi-structured and unstructured conversations

also took place during this research journey. Participants engaged in individual and communal conversations in the hope of thickening alternative stories in their experiences of breast cancer.

1.8.4 Reporting the research

Rubin and Rubin (2005:246) describe the final step in the research as putting the information into a report that is *“inviting, accurate, thorough, convincing and rich”*. This research report has been compiled according to principles of qualitative and co-participatory action research. This included the use of the taped and transcribed conversations, session notes, creative expressions, letters and journal entries of my own as well as two of the participants.

1.8.5 Outsider voices

In order for this research to be reflexive, other voices and perspectives were invited into the body of this research. It was collaboratively agreed that an illness like breast cancer invites changes into life-giving relationships with others. In order to create a space for inclusivity, and with the permission of the participants, ‘The Husband’ and ‘The daughter’ were invited into one-on-one conversations.

1.8.6 Self-care during this research

Self-reflections and research-process reflections allowed me to check how I was doing during this research process in the following ways:

1. Monthly narrative group supervision is a required form of accountability for the team at the pastoral care centre. I was able to use this time to revisit practices and values.
2. Regular meetings with my supervisor encouraged my accountability with regards to time frames and drafts and assisted me in keeping track of the aims of this research and the quality regarding the research process.
3. I continued to hold my spiritual life accountable to a spiritual director on a monthly basis in order to maintain and deepen my personal, ongoing relationship with God during this time.

1.9 CONCEPTUALISATION

Conceptualisation refers to the description of terms as they are “*used in relation to this researcher’s project*” (Leedy & Ormrod 2005:56).

This research focuses on women and, for the ease of reading; the female gender will be referred to throughout this report. The omission of men is not intended to imply disrespect for, or a negation of, male cancer and illness experiences.

The following terms are conceptualised in the section below - voice, stories, conversations, meaning-making, participant, co-researcher and witnessing.

1.9.1 Voice

In relation to feminist theory and narrative therapy, ‘voice’ is the ability to find language that validates the research participants’ own experiences. Finding a voice suggests encouraging people to appreciate that when they use their own words to describe their own experiences, no one has the right to take the legitimacy of that story away from them. Voice is discussed in greater detail in paragraph 2.3.1 and 2.5.2 below.

1.9.2 Stories

Narrative practices maintain that lives are constituted of “*multiple stories*” (Morgan 2000:8). The term ‘story’, in the context of this research, refers to life events and experiences. Accordingly, the term ‘storyteller’ refers to the research participants. The term is not intended to marginalise the value of the experiences shared. Stories are explored in more detail in paragraphs 2.2.2 and 2.5.1 below.

1.9.3 Conversations

In the context of this research, conversations refer to the natural flow of communication, in a conversational relationship, in which the research participants impart their ‘expert’ knowledge and stories in response to my research.

1.9.4 Meaning-making

Nadeau (1998:14) describes meaning as the effort to understand the significance of an event and ‘what my life means now’ in relation to that event. This research uses

the concept meaning-making as it refers to understanding the experience of breast cancer. This is conceptualised in more detail in Chapter two, paragraph 2.1.1.2 on Social Constructionist theory.

1.9.5 Participant and Co-researcher

The terms participant and co-researcher have been chosen to refer to the women who participated in this research. Co-researcher is aligned with the practices of co-participatory action research and narrative practices. The participants are the real experts in the experiences of breast cancer and bring with them local knowledge and lived experience. These terms will, at times, be used interchangeably in this research report.

1.9.6 Witnessing

Witnessing is a term I borrow from the work of Weingarten (2000, 2001, 2003) and one which I will use to convey key elements of being in the presence of another. Weingarten (2003:192) believes that elements to witnessing are listening carefully, responding thoughtfully and acknowledging the other's pain.

1.10 ETHICAL CONSIDERATIONS

As this research involves the participation of people and a collaboration of their stories, it is of vital importance that sound ethics form the foundation. Kotzé et al (2002:21) has a picture of what ethics should look like and feel like in any research journey:

When we choose to ethicise the dynamic process of “doing ethics” becomes more participatory and transparent. Ethicising is not something unseen that some people sometimes do for or about other people. To ethicise is to do everything in participation with the others, or rather, with everyone participating. This implies that all who are involved, implicated or possible affected by ethicising in any given situation become participants in the process. Together we have to negotiate what is a good life for all the participants in each and every specific situation. To live is to ethicise, and to live is to participate in an ethicising manner.

(Kotzé et al 2002:21)

In order for this research journey to embrace Kotzé et al's (2002:26) participatory ethicising, all the research conversations with the participants had to be transparent in terms of the aims and hopes for this research and the hopes for their participation in making meaning of their experiences. All the participants were asked to complete an informed consent document. This document is attached as Annexure A.

Kotzé et al (2002:30) maintains that a researcher should not hold a 'privileged position' of knowing:

This different way of being in the world that guides our research and counselling work is the realisation that no one has a privileged position of knowing, be it scientific, religious or any other way. We are in this together. The more we participate in such a way that the voices of all, especially those who have been previously silenced, can be heard, the more we can research and co-consult, in an ethical manner, an ethical, just and ecologically sound world to live in.

(Kotzé et al 2002:30)

In order to work ethically, this research provided space for each participant's voice to be heard. This research report also contains collaboration on all stories and experiences.

1.11 CONCLUSION AND OUTLINE OF THIS RESEARCH

This chapter set out an introduction to the research journey by providing my research curiosity, the purpose of the study, a research statement and the decision to incorporate both a literature review and control. It explored the research design and methodology of qualitative, co-participatory action research and reflexivity and provided my three frames of reference in terms of theoretical positioning. It provided the research objectives, research data, conceptualisation of some of the key terms and an ethical overview. A brief outline of the following chapters is as follows: Chapter two contains a scaffold of the theory used in this research, namely narrative practices, feminism and pastoral theology. Chapter three introduces the participants of this research and includes the voices of illness, breast cancer and the women participants. Chapter four explores the research findings and the birth of new meaning. Lastly, chapter five will reflect on this research process, the findings and the learning's of this research.

CHAPTER 2:

A SCAFFOLD OF THEORY

“We do not view ourselves as expert at scientifically assessing client problems and then intervening. Instead, we strive to be experts at exploring client’s frames of reference and identifying those perceptions that clients can use to create more satisfying lives.”

De Jong and Berg (2002:19)

2.1 INTRODUCTION

This research draws on the values and ideas of narrative practices, feminism and practical theology. I have chosen to use the term ‘scaffolding’ to indicate the role of the theory of narrative practices, feminism and pastoral theology in supporting this research. The term ‘scaffolding’ is used by Michael White in his work on narrative therapy (2007). Scaffolding is a term used originally by the Russian psychologist Vygotsky (1986) in his work on early childhood development. He believed that adults and caretakers structure children’s learning in ways that make it possible to move from what is known to what is possible for them to know. Adults and caretakers break down the learning tasks into manageable portions in order to facilitate learning. White (2007:272) suggests that it is the ‘scaffolding’ which *“encourages the child to ‘stretch’ his or her mind and to ‘exercise’ the imagination”*. For the purposes of this research the scaffolding will be constructed of the theory of narrative practices, feminism and pastoral theology which will support the objectives of the witnessing process.

It is difficult, within the scope of this research, to include a comprehensive understanding of the bodies of theory used. Instead, an overview of the theories of narrative practices, feminism and pastoral theology, as they relate to this research, will now follow. I have chosen to include some of my reflections and thoughts, as they pertain to this research, in text boxes throughout the next three chapters. This is in line with the function of a literature control which invites a review or consideration of knowledge throughout the research journey.

2.2 NARRATIVE PRACTICES

Narrative practices refer primarily to the ideas and practices of Michael White, David Epston, and other practitioners who have built upon this work. In essence, the narrative researcher is a collaborator in the process of discovering richer or ‘thicker’ narratives that emerge from different descriptions of experience, thus destabilizing the hold of negative or ‘thin’ narratives (White & Epston 1990). Narrative practices draw on social constructionist theory for many of its ideas and assumptions.

2.2.1 Social constructionist theory

There is no single feature which identifies social constructionist theory. Rather, there are *“things you would absolutely have to believe in order to be a social constructionist”* (Burr 1995:2). Social constructionist’s main premise is that *“the beliefs, values, institutions, labels, laws and the like that make up our social realities are constructed by the members of a culture as they interact with one another from generation to generation and day to day”* (Freedman & Combs 1996:16). There is great emphasis on the importance of relationships and social interaction. In fact, Gergen (1994:264-269) maintains that every act of meaning can be regarded as a relational act. In this way, knowledge is constructed between people. Implied in this understanding of social constructionism is the effect that various discourses in society have on the personal lives of people (Kotzé & Kotzé 1997). Social constructionism invites people to have a *“critical stance towards taken-for-granted knowledge”* of the world (Burr 1995:3). This should include distrust and questioning of dominant culture positions that permeate families and society today. The importance of socially constructed knowledge implies that language, meaning-making and discourses are also inherently social processes. These concepts are fundamental to narrative practices.

2.2.1.1 The social construction of language

Language provides the basis for all our thoughts and gives us a *“system of categories for dividing up our experience and giving it meaning”* (Burr 1995:44), so that our ‘selves’ become the products of language. Language produces and constructs our experiences of ourselves and each other. In this light, language is a place where identities are built, maintained and challenged. It can also, however, be

a place where entrapment, restriction and oppression occur. This research is curious about the language of breast cancer and how it influences the experiences and identities of the participants and the meaning they ascribe to breast cancer.

2.2.1.2 The social construction of meaning-making

Frankl (1988:85-95) describes meaning-making as finding a purpose to life, death and suffering, creating a future hope and living for one's values and ideals. Cotter et al (1994:7-8) suggest that *"we assume that our primary vehicle for organising meaning is the narratives and stories we socially construct to provide ourselves with a sense of coherence, meaning and identity"*. Stories organise our experiences temporarily; they connect our past to our future by providing continuity; they serve as a guide for the future and, because they are evolving, ever-changing social constructions, they are flexible enough to fit unexpected events into our lives in order to make sense of it.

2.2.1.3. Meaning-making as prescribed by discourse

Discourse refers to a system of thoughts that become institutionalised and are then perpetuated and maintained as an instrument of *"truth and domination"* (hooks 2000:7) A discourse can be described as a social commentary that creates certain meanings about what is acceptable or not. They are generally dominant, culturally created ideas. Zimmerman and Dickerson (1996:61) argue that discourses take the form of *"taken-for-granted realities"*. Discourses may also be defined as a set of meaning systems in language (Kotzé and Kotzé 1997:33). These meaning systems are used as a source of power by individuals believed to have knowledge, such as people in authority. Societal discourses often operate invisibly and shape the personal discourses of people's lives and their identity.

Burr (1995:48) describes discourse as *"a set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events. It refers to a particular picture that is painted of an event"*. In line with this, Narrative creates a sense of *"what is true"* (Gergen 1994:189) and, because of this, the potential for abusive and prescriptive social practices exists when our stories are socially accepted and institutionalised as *"truth"* (Burr 1995:122).

Discourse describes the ways a system of language and relationships has become institutionalized among a particular group of people. It provides a way of being for those who belong to that group. A discourse is embedded in the customs, manners of speaking and relating, institutions and written documents of a culture.

My reflection:

There are societal discourses about breast cancer that I bring to this research and which I hope to understand through co-participative conversations. These include the understanding that breast cancer is an illness that requires great strength of the sufferer to fight it; breast cancer is life-threatening and breast cancer brings life-altering changes to the body and, along with it, changes to body image and the identity of women

2.2.1.3.1 Medical discourses

Medical discourses refer to the socially legitimised way in which medical practices regard and treat the ill. Medical personnel are trained to treat the physical body in a predominantly modernist model of care. The focus is on symptoms rather than emotions, often with little regard for the suffering of the person or the meaning of illness to the person. This process “*dehumanises the ill*” and often compounds their distress (Kleinman in Frank 1998:xi). As discussed in section 2.2.1.2 above, meaning is made through storytelling and, if physicians do not listen to the stories of their patients, Frank (1998:201) suggests that they may, in fact, hamper the meaning-making process and intensify the isolation because when “*people have no story to tell, they are isolated in their suffering; they can achieve no critical distance from their pain*”.

My reflection:

My own discourses assume that the nature of medical care is focussed around the breast cancer as a disease which needs eradicating, often through radical scientifically researched medicines and surgery. I’m wondering if medical personnel cares for the unseen part of the patient - the emotions, mind and soul?

2.2.1.3.2 *Discourse and the body*

Narrative practices attempt to present a less 'pathologizing' view of the world by shifting focus from what is wrong in people to what is strong in people (Eron & Lund quoted in Duvall & Béres 2011:24). It is important to be aware of how words, behaviours, uses and practices of scripture and tradition participate in constructing the body. Illness involves the body's fragility and this, for Foucault, (1984:83) introduces the body as a site of power struggles. Bordo (1989:13-33) also suggests that culturally mediated messages and behaviours create unhappiness with the body. Discourse views the physical body in various ways: the practice of medicine, images of beauty, definitions of gender, norms of sexual practice and the habit of lifting up a woman's appearance as a surface to be decorated and a currency to buy love, acceptance, and success. Whilst it is true that breast cancer can occur in men, this research will specifically address the phenomenon of breast cancer in women in keeping with the overall theme of pastoral care conversations with women.

My reflection:

At the outset of this research I had my own assumptions about how breast cancer might affect a socially constructed image of sexuality, femininity, womanhood and health and how women might accept these images as their own. I imagined women to feel 'de-feminized' and as if the essence of their physical womanhood was lost and, because of this, I was curious to understand the role that women's breasts have in the context of femininity, sexuality and body image.

2.2.1.3.3 *Religious discourse*

In choosing to include a discussion on religious discourse in this research, I am choosing to mention only those that I have encountered in the literature, in my own life and in conversation with the participants. As a result, it is selective in nature. Traditional Christian religion suggests that we need to pray and believe, and God will give us our heart's desire (Bouwes 1996:92). The unspoken assumption is that miraculous healing from disease is included in our heart's desire. This discourse of faith places the church, the believer and the ill and hurting in vulnerable positions. If healing can only be obtained through faith, it prohibits the ill from procuring self-care and nurturing as doing so may illustrate a lack of faith in God's ability to heal. In the

Christian bible, healing by God is seen as a restoration of the right relationship between God and man/woman (Mark 5:25-30, Psalm 147:3, Matthew 8:8, Luke 8:50). It may be assumed, therefore, that not receiving healing lays the blame on the person's relationship with God.

My reflection:

As a practising member of a Christian faith community and as someone with my own experiences of living with an illness, I have experienced the religious discourses of others such as 'God doesn't give you more than you can handle', 'have enough faith', 'illness is a punishment for sins'. I know the worthlessness I experienced as a result. I am curious about the experiences of others and wonder how, if at all, they have forged some of their own faith stories in legitimized discourse.

The discourses discussed above suggest a few which marginalise or hamper a meaning-making process for women's stories and experiences of breast cancer. This research remains aware, however, that discourse may also facilitate positive meaning-making by providing a secure frame for the creation of subjective meaning.

2.2.1.4 Deconstruction of discourse

Monk et al (1997:95) defines deconstruction as "a process in which discourses are exposed and people's positions within them revealed". Discourses are rarely challenged and over time become 'the way it is' or 'what I was taught'. Discourses are also influenced by prevailing practices of culture and society. White (1991:21-40) advocates the practice of questioning and challenging social discourses that are considered "given" or "taken for granted". Deconstruction may be considered a way of 'undoing' systems of meanings. In narrative practices, deconstruction occurs when meanings of experiences are examined. Deconstruction questions the understandings of the discourses that are 'given' or 'taken for granted'. It also assists in mapping and understanding the effects of the problem on the person. Deconstruction therefore encourages an understanding to grow around the problem, its strategies, influence and the way it works in a person's life.

Deconstruction, as a construct of narrative practice, takes place through questioning, externalisation as well as the researcher's stance of respectful curiosity.

Questions encourage various dimensions of the problem to be explored. Unstated or unknown cultural assumptions and discourses may be revealed through asking of questions which aim to investigate the problem saturated story (in the case of this research, the problem saturated story is breast cancer). Externalisation will be explored in paragraph 2.2.3.3 below.

In concluding this section on deconstruction, this research explored the effect of a diagnostically labelled illness such as breast cancer and the effects of discourses relating to health, body-image, femininity and religion on the meaning-making process for the participants.

2.2.2 The significance of stories

Narrative practices pay particular interest to stories in the midst of dominant cultural discourses. In the South African context, the desire to re-story many of the narratives of Apartheid and the disempowerment of the past has been collaborated with the help of narrative ideas. Kotzé and Kotzé (2001:2) state that *“daily encounters with suffering, hunger, malnutrition, unemployment, rage & anger, crime, violence, rape – all these issues are not extraordinary but ordinary to many counsellors, caregivers and pastoral therapists in South Africa”*. Hudson (1999:19) speaks of how stories allow us a *“personal encounter with the pain of our shattered and fragmented community”*.

Stories have the power to shape our reality in that they construct and constitute what we see, feel and do. The stories we live with grow out of conversations brought about in relational, social & cultural contexts (Morgan 2000:5-8). The point of the 'story', according to Duvall and Béres (2011:52), is *“an invitation to the therapist to participate in and witness the unfolding of the story”*. In line with the intention of this research, Frank's (1995:115) 'Quest Narrative' comes to mind. He suggests that *“quest stories meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest”*. Important to this research is Frank's notion that a quest narrative *“affords the ill person a voice as a teller of her own story”* (Frank 1995:115).

Duvall and Béres (2011:37-40) suggest that stories are “*organised units of experience*” evolving from a story containing a beginning, middle and ending. They see storied therapy as a metaphor of a ‘three-act play’. White and Epston (1990:10) clarified the purpose of a storied metaphor as follows: “*In striving to make sense of life, persons face the task of arranging their experiences of events in sequences across time in such a way as to arrive at a coherent account of themselves and the world around them*”. The story metaphor is also shared by De Shazer who suggests:

The conversations that therapist and client have can be seen as stories, as narratives. Like any story, each case or each session has a beginning, middle and a sense of an ending. Like any story, the conversation is held together by the patterns involved, by the plot. Like many stories, therapy conversations deal with human predicaments, troubles, resolutions and attempted resolutions

(De Shazer 1991:92).

Duvall & Béres (2011:26) suggest that “*the therapeutic conversation, as the container that holds the story, needs form*”. The premise for this metaphor is that a conversation is more productive when there is a guiding framework or ‘map’ to help develop meaning and a sense of purpose. Their ‘three-act play’ metaphor provides me with another scaffold, alongside the theory, to use for this research conversations. The three acts are briefly discussed next, starting with ‘setting the stage’.

2.2.3 Setting the stage

Duvall and Béres (2011:41) view ‘setting the stage’ as Act One in their ‘three-act play’ metaphor and it serves to announce what the story is about and what is most important to talk about. They suggest that this sets the “*agenda to begin the therapy session*”. For the purposes of this research, Act One is focused on the position and agency of the researcher and co-researchers as well as the stories of breast cancer.

2.2.3.1. Researcher’s position

Discourses or socially accepted ‘norms’ can position us in our relationships with other people. Monk et al (1997:304) define positioning as “*the process by which discourses place people in relation to each other – usually in a position of power*”.

Dinkin (2005:23) consolidates this researcher's position for me when he says:

When I am engaged in narrative counseling, I try to speak as naturally as possible, using everyday words. I seek to avoid judging, diagnosing, explaining, telling people what to do about their problems, or taking on the air of a professional counselor. I believe in caring for people by conversing with them so that they can discover how their stories will help or hinder them. A conversational approach is less stressful and more interesting than a problem-orientated approach to counseling. Instead of ending a counseling day drained of energy, I find that I am energized and inspired by the stories counselees and I create together

(Dinkins 2005:23)

Duvall and Béres (2011:7) appear to concur with Dinkin's position when they refer to narrative practices as a "*therapy of witnessing and acknowledgement*". They maintain that researchers are guided by a "*desire to witness people's stories, which involve both pain and possibilities*", and an acknowledgement of the hopes and values of those we meet with (Duvall & Béres 2011:8). This researcher's position is therefore essentially one which centres the client and collaborates meaning by providing space for involvement, ideas and desires. Weingarten (2003:22) also uses the term 'witnessing' or "*compassionate witnessing*". She proposes that bearing witness is a systemic process of meaning-making, where a person's ability to witness depends on their willingness to assume the risks associated with authentic connections. She writes that the position of witnessing demands vulnerability. This is supported by Harvey (2002:94) as he writes that without vulnerability, witnessing is a hollow, disconnected experience. The therapist/researcher works to be a curious, compassionate and interested advocate on behalf of the client (Neuger 2001:55) and, in fact, sessions are not "*fact-finding missions*" but rather, conversations that encourage the telling and retelling of stories and experiences and the co-authoring of possible stories moving into the future (Duvall & Béres 2011:45).

2.2.3.2 Participant's position of agency

The concept of agency is related to the undertaking of "*conscious choices about how to position oneself in relation to ideas, practices and experiences*" (Arkwright in Cook & Alexander 2008:133). Monk et al (1997:304) suggest that the form of power

developed in the modern world, rather than being repressive, is a product of relations and subjectivities.

Agency operates everywhere to produce truth, reality, and normality. It is the intention of this research to acknowledge all participants as experts of their own lives and experiences and, as such, to position them as the storytellers with local knowledge of breast cancer. Agency can therefore be defined as *“the extent to which individuals can act for themselves and speak on their own behalf”* (Monk et al 1997:301).

2.2.3.3 Developing storylines through externalisation

From the outset, narrative practices see the problem as being separate from the person through the process of externalisation. White first wrote about the practice of externalizing conversations in 1984 (White 2007:23). It is probably one of the practices that most sets narrative practices apart from other models. White (2007:10) writes that many people seek therapy believing that the problems in their lives are a *“reflection of their own identity”*. This leads people to believe that the problems of their lives are a reflection of certain truths about their nature and their character and, in essence, that these problems are internal to their self or to the selves of others. Operationally, narrative practices involve a process of deconstruction and meaning-making achieved through questioning and collaboration with the clients. So-called strengths or positive attributes are also externalized, allowing people to engage in the construction and performance of preferred identities and alternative stories.

For the purposes of this research ‘breast cancer’ was viewed, through the lens of externalisation, as something outside of the identity of the participants. Externalisation characterises the way the problem speaks, tactics of power it uses and strategies employed by the problem in order to establish dominance. White (2007:28-29) writes that externalizing has the effect of *“reducing power”* of the problem. Externalizing conversations, therefore, assists people with giving *“expression to a range of experiences of life that they previously had not had the opportunity to express”*. Parry and Doan (1994) suggest that the outcomes of the externalization of problems include reducing the sense of failure people have in response to not having solved the problem and unity against the problem.

Externalizing conversations are considered part of a deconstructive practice in that it challenges the 'truth' of problems existing **in** persons (my emphasis). Assumptions are created by discourse. Zimmerman and Dickerson (1996:75) believe that exploring discourses is not about merely replacing one truth with another but, rather "*questioning how we accept certain conditions, situations, and events as 'realities' in life*". The intent is to 'unmask' these 'realities' so that a clearer sense of the influence of the discourse can be discovered. This resonates with this research intention of providing a platform in which stories and experiences of breast cancer can be explored, thickened and shared.

2.2.4 Embarking on the journey

Duvall and Béres (2011:42) view embarking on the journey as Act Two of their 3-Act play metaphor. White (2007:4) adds:

When we sit down together I know that we are embarking on a journey to a destination that cannot be precisely specified, and via routes that cannot be predetermined...and I know that the adventure to be had on these journeys is not about the confirmation of what is already known, but about expeditions into what is possible for people to know about their lives.

(White 2007:4)

As a means to facilitate movement in conversations and therapy, White (2007:4) introduced the idea of the zone of proximal development ('ZPD') into narrative practices. The zone of proximal development is a concept developed by Russian educational psychologist Vygotsky (1986). It refers to the "*difference between what people can achieve individually and what they can achieve with assistance from someone else*" (Duvall & Béres 2011:67). Rich dialogue is a key feature of the zone of proximal development and conversation provides fertile ground for this development. One of my main roles, as a 'witness' in this research, is to be able to offer an environment which facilitates a zone of proximal development to the co-researchers through the research conversations.

In order to thicken alternative stories and to be able to acknowledge sparkling moments, the conversation needs to be 'scaffolded' by the use of metaphors, an

understanding of the landscape of identity and pivotal moments. These concepts will be discussed next.

2.2.4.1. Metaphors

Metaphors are used regularly in narrative conversations. According to White (2007:31), they are generally borrowed from particular discourses that invoke specific understandings of life and identity. Metaphors can shape peoples view of themselves and the view of the problem or story they share. In narrative conversations, metaphors are used to create stories about reality. Griffith and Griffith (1994:193) believe that a metaphor “*contains within it implicit, unstated assumptions about what is real and what is not*”. Metaphors can also be used to grow understanding or deconstruction of social discourses that can wield power over the minds and bodies of people who live within them. For this research, this refers to the women participants living with breast cancer.

2.2.4.2 Landscape of identity

Landscape of identity is a term used to refer to a person’s experience of meaning within a narrative. Theoretically, it includes personal characteristics; desires and preferences; goals, purposes and intentions; philosophies, values and beliefs and a commitment to a way of life and a way of being. White (2007:106) terms the landscape of identity as being that of “*filing cabinets of the mind*”. He writes that each one represents a category of identity that is culturally relevant. In our western culture this may include internal categories like needs, instincts, desires, drives, dispositions, personality traits and intentional categories like purposes, aspirations, quests, hopes, dreams, visions, values, beliefs and commitments. White states that into these filing cabinets of the mind, people file a range of conclusions about their own and each other’s identities. The intention of this research is to create a richer awareness of meaning-making amidst living with breast cancer.

2.2.4.3 Discovering Pivotal Moments

Zimmerman and Dickerson (1996:57) suggest that ‘unique outcomes’ are “*contradictions to the problem*”. They may be possibilities which have always been present in the client’s experience; they may have been lost, not attended to, not

storied in memory or simply not 'storied'. Often these unique outcomes or contradictions "*pop out*" in the course of conversation about the problem.

Literature sources indicate that words such as 'aha moments', 'sparkling moments' and 'pivotal moments' are also used to refer to moments in a conversation when a simple question "*cracks open a door, shining light on possibilities only thinly imagined*" (Duvall & Béres 2011:xiii).

Duvall & Béres (2011:143) describe a pivotal moment as being "*a short duration of time in a conversation where a shift in understanding occurs in a manner that can be experienced as quite startling and surprising to the person, like an aha moment*". As this sparkling moment is a mere moment of time, situated in the present moment of the research or therapeutic conversation, it might be the "*most fertile ground of change for people*" (Duvall & Béres 2011:122). These moments draw the person towards strongly-held values or preferred ways of being in the world. Duvall & Béres (2011:129) also consider these moments to be pivotal because people undergo a "*shift in meaning during the experience*" which can result in a different view of themselves, others or situations. However, pivotal moments are also "*vulnerable & risk disappearing quickly if they go unnoticed and are not acknowledged*" (Duvall & Béres 2011:129). This notion is shared by Zimmerman & Dickerson (1996:57) who suggest the importance of noting these moments and calling "*attention to their existence*", less they be lost.

Whether referred to as 'sparkling moments', 'unique outcomes', 'aha moments' or 'pivotal moments', this research was aware that these opportunities could be experienced by the participants sharing their stories and experiences of breast cancer. This research engaged in conversations around alternatives and ways in which the participants had stood against the threatening implications of breast cancer.

The third and final act of Duvall and Béres (2011:82) 3-Act play metaphor is that of thickening alternative stories. This is described in the following section.

2.2.5 Thickening alternative stories

Thickening alternative stories is what Duvall and Béres (2011:82) consider the final act, Act Three, in their 3-Act play metaphor. Re-storying or re-authoring conversations occur when participants begin not only to notice but to also recount events, actions and behaviours that fit better for them than those the problem story has recruited them into. This new or preferred story becomes richer or 'thicker' as characters other than the problem are included and become part of the participant's re-authoring context. Narrative practices acknowledge the problem story but also seeks to discover the alternative story which highlights survival, strength and practices which have enabled the person to fight back and even overcome. Witnessing women's stories and experiences of breast cancer in this research invites new ideas, alternatives and re-authoring of preferred stories to be considered.

To reach an understanding on a dialogue is not merely a matter of putting oneself forward and asserting one's own point of view, but being transformed into a communion in which we do not remain what we were.

Hans-George Gadamer (1994:379)

In this research, opportunities to thicken alternative stories are explored through re-authoring conversations which include letter writing, definitional ceremonies, outsider witness practices, taking-back practices, exploring of rites and rituals and reflexivity. What follows is an explanation of each concept and its relevance in this research.

2.2.5.1 Re-authoring conversations

Monk et al (1997:20) consider re-storying as "*self-redefinition*". It involves becoming reacquainted with an ability to stand up to a challenge or to do something differently and refers to "*developing an alternative story*" (Monk et al 1997:305). Re-authoring also highlights areas of resistance to a problem story. These conversations invite people to continue to develop and tell stories about their lives, but they also help people to include some of the more neglected but significant events and experiences into their dominant stories. The term 'reconstruction' is also used by Monk et al (1997:210) when challenging dominant discourses and becoming aware of new or forgotten possibilities and, according to Harker, quoted in Monk et al, (1997:212) this is a "*writing and rewriting of self as an ongoing process throughout life*".

This research explores and facilitates a 'reconstruction' process in which the women have an opportunity to highlight, focus or remember a richer and thicker story of their experiences of breast cancer. The practices of letter writing, definitional ceremonies, outsider witness practices, taking-back practices, exploring of rites and rituals and reflexivity scaffold this exploration and are now discussed.

2.2.5.1.1 Letters

One of the most powerful ways to increase the effectiveness of the narrative conversation is to write letters, or short notes, to participants after a conversation. The conversation moves to a new level of awareness when the phrases, quotations, and references to parts of the conversation are included in a letter. Dinkins (2005:117) highlights that a *"more meaningful story unfolds ...as the story shifts from an oral to a written narrative"*. Seeing the story in written form brings the story alive in the present moment. The time between a narrative conversation, reading a letter and the next conversation, is as full of possibilities for re-storying the participant's alternative story as the conversation itself. I was able to write letters to several of the participants in response to some of the research conversations. I have included a couple of the letters in Annexures B and C.

2.2.5.1.2 Definitional ceremonies

Thickening of landscapes of identity and re-storying can occur for the participant by including practices of definitional ceremonies and rituals. Dykstra (2005:212) writes:

As we begin to sense the implications of our interconnectedness to each other, we can become overwhelmed. But we are helped by observations of meteorologists who note the "Butterfly Effect" – the flutter of butterfly wings in one part of the world can create vibrations that in turn cause massive weather changes in another part of the world. One small movement can create great change. Communities need to be reminded that small just actions can contribute to big changes in the entire organism.

(Dykstra 2005:212)

The literature frequently uses words like definitional ceremonies, rites and rituals in the same context. White (2007:165) believes that such ceremonies *"acknowledge and 'regrade' peoples' lives"*. He credits the origin of definitional ceremonies to Barbara Myerhoff (1982, 1986) and her work with a community of elderly Jews in Venice, California. White (2007:180-181) suggests that she provided an *"antidote to*

the effects of the isolation” experienced by this group. Myerhoff (1982:267) herself suggests that:

Definitional ceremonies deal with the problems of invisibility and marginality; they are strategies that provide opportunities for being seen and in one’s own terms, garnering witnesses to one’s worth, vitality and being.

(Myerhoff 1982:267)

White (2007:165) suggests that definitional ceremonies can mark important learning’s and pivotal moments of transition. Structuring conversations as definitional ceremonies provides a context for rich story development. This research included several forms of definitional ceremonies in order to mark learning’s and pivotal moments with the participants. These were outsider witnesses, taking-back practice, reflexivity and a closing ceremony and ritual. They will be briefly described in the following paragraphs and described in greater detail in section 4.9.

Outsider witnesses

One of the ways in which definitional ceremonies acknowledge people’s lives is by the telling or performing of their stories before an audience of carefully chosen outsider witnesses. In this practice a person is invited to tell their experiences in a particular way. This account is listened to by an outsider witness group. This group then re-tell the account they have heard. This re-telling is listened to by the person who, in turn, is invited to re-tell the account of the outside witness group. It is not the place of outsider witnesses to form opinions, give advice, make declarations, or introduce moral stories. Rather, outsider witnesses engage one another in conversations about the expressions of the telling they were drawn to, the images the tellings evoke, about any personal experiences that the telling resonated with and about how their lives have been touched by the expressions. Outsider witness tellings not only support and encourage the preferred new stories being told, they also add richly to the account of them and to the account of the effect of those claims in the lives of others.

I was able to include an outsider witness experience (as detailed in chapter 4, paragraph 4.9.1) as part of a taking-back practice for the participants.

Taking-back practices

Taking-back practices are about identifying something in another's story that has made a significant contribution to the researcher's life. White (1997:144) draws attention to the part that *"this work plays in us becoming better listeners"* as well as the possibilities that invite me to *"develop more compassionate relationships"* with myself as a result. In chapter 4, paragraph 4.9.2, I share the experience of giving something back to the research participants and how this was received by them as part of a taking-back experience.

Rites and rituals

Rites of passage are considered *"rituals that people go through in order to progress to the next stage of life"* (Duvall & Béres 2011:28). Events such as marriage, birth, death or times of crises can be marked by rituals or ceremonies. Weingarten (2003:233) believes that an experience of closeness and unity ensues in *"shared ritualisation"*. Rituals composed of metaphors, symbols and actions represent a quest for meaning and structure and a need to be with others in a shared experience. As *"therapy itself is a rite of passage"* (Duvall & Béres 2011:68) and intends to prepare a person for managing the complexities of life, this research was mindful and curious of ways in which the women have marked their journey with breast cancer and how, as a collaborative research group, we might seek to ritualise the journey in some way. This research's experience of rites and rituals as celebration is detailed in chapter 4.

The role of reflexivity

In narrative practices reflexivity works against the traditional flow of power in a therapist-client relationship in that the therapist is not the one reflecting on the client. Narrative practices often invite the client to be a part of the reflecting process in terms of sessions or conversations. Monk et al (1997:147) suggest that it *"creates an atmosphere of respect and a real valuing of the client's knowledge and abilities"*. Reflexivity is defined as the *"activity of reflecting on a power relation in order to understand it better and to break from its taken-for-granted influences"* (Monk et al 1997:305). It is the intentional checking and cross-checking of accuracy, the way in which recording of sessions are done and the questioning the client on whether an accurate recording of stories has been made.

For this research journey, the co-researchers were invited to reflect on their contributions to chapters 3, 4 and 5 before the submission of the final draft of this research report to ensure that their conversations, information supplied and the reflections added by myself have been correctly described. Duvall & Béres (2011:5) suggest that reviewing and reflecting on notes, themes and phrases is a *“therapy of witnessing and acknowledgement”* and acknowledges efforts and initiatives whilst attributing significance to the co-researchers.

In terms of this research, the concept of reflexivity refers to the notion that I also bring an influence to the ‘witnessing’ position that I seek to have. Hall suggests that the process aims to make visible this researcher’s *“human influence in the process of selecting, interpreting, analysing and reporting data”* (1986:28). I need to declare the knowledge base and frame of reference that I bring to this research process. It also takes cognisance of my need for conversations with my supervisor in order that my own understandings, assumptions and discourses are recognized.

2.2.6. Conclusion

As discussed in paragraph 2.1 above, narrative theory is a prominent scaffold in this research and it will support the participants with its practices and values of respect, curiosity and client-centredness. A discussion of the scaffold of Feminism follows in the next section.

2.3 FEMINIST THEORY

Feminist theory shares certain values and practices with narrative. Neuger (1996:3) writes that feminism requires a *“commitment to the belief that each individual life must be understood in the context of the power arrangements and rules of the dominant culture”* and that the construction of theory and practice must also listen carefully to each individual marginalised voice. Christ (1980:1) believes that:

Women’s stories have not been heard. And without stories there is no articulation of experience... If women’s stories are not told, the depth of women’s souls will not be known.

Christ (1980:1)

Feminism is, according to Neuger (1996:92):

A set of political assumptions and commitments that have to do with the transformation of a culture that disadvantages all women, women and men of colour, gay men and lesbians, women and men who are disabled, children and the aged and those who are not on the dominant or ruling side of the culturally determined value-laden split.

Neuger (1996:92)

Feminist values that inform my research are the notions of finding 'voice', the importance of relationality in which to do this and the emphasis on community. These are each discussed in greater detail hereunder.

2.3.1 Finding Voice

"Hearing another into speech" is a term commonly 'heard' in feminist writings.

She must learn again to speak. Starting with I. Starting with we. Starting as the infant does, with her own true hunger, and pleasure, and rage.

Marge Piercy 1982 "Unlearning to not speak"

When a woman is denied the opportunity to name and interpret her experiences, it is not surprising that a central metaphor for describing this is 'loss of voice'. Belenky et al (1986:18) writes that:

We found that women repeatedly used the metaphor of voice to depict their intellectual and ethical development; and that development of a sense of voice, mind and self were inextricably intertwined.

Women's stories throughout history have strong elements of suppression, silence, and unworthiness. Greenspan (1983:233) writes:

The simple process of women sitting and listening to each other's' stories respectfully and with an ear to the shared strengths as well as the shared ordeals had some very powerful therapeutic effects. Our relationship to everything – our bodies, our work, our sexuality, the men and women and children in our lives – emerged in a thoroughly new light. Together we saw that the old terms used to describe politics, relationships, sexuality, power and language itself were an outgrowth of male experience and had to be reinvented from our own point of view as women. For many of us, the overwhelming sense was of seeing the world through our own eyes for the very first time.

(Greenspan 1983:233)

Feminist theory has played a large role in questioning assumptions of gender and power relations and the issue of language and voice has long been a hallmark of the feminist movement. Non-dominant groups are not only deprived of language but are also denied voice. Most works in feminist counselling have focused on the importance of helping girls and women to gain access to their own voice. Neuger (2001:68) believes that it is not just a matter of being able to tell one's story; rather, it is the *"empowerment of hearing oneself speak and learning to believe in the truth of that long-denied voice, language and narrative"*. Corey (2005:348) also suggests that feminists recognize that *"women are searching for a connectedness with others"*. Although a primary aim of feminism is to understand gender inequality, politics, power relations and sexuality, there is a great emphasis on the promotion of women's rights and interests. Rich (1983:35) writes:

When I speak of an end to suffering, I don't mean anesthesia. I mean knowing the world, and my place in it, not in order to stare with bitterness and detachment, but as a powerful and womanly series of choices: and here I write the words, in their fullness: powerful; womanly.

(Rich 1983:35)

A feminist perspective attempts to give a voice to women and holds that women express and experience themselves differently from men (De Vos et al 2005:7). This research created the opportunity for the participants to share, in their own voices, their experiences of breast cancer. The way in which this was accomplished was by offering each participant a compassionate witness in the form of the researcher. In order for this to be successful, the notion of relationship becomes of utmost importance. Relationship, using Neuger's (2001:233) term 'relationality' is explained next.

2.3.2 Relationality

Feminist theories are also interested in the notion of relationships. Neuger (2001:233) calls this 'relationality'. Her reason for this is her focus on the origin, function, nature and role of relationships and relating in women's lives. She suggests that women have a unique tendency towards, and skills, at building and maintaining relationships which can be seen as morally valuable and familially necessary. Neuger also believes that a focus on women's ability and tendency to be committed to co-operation, care and the nurture of relationships is important for

reclaiming the value of women's lives and culturally given roles. It may be necessary for women to be connected as they seek to develop strategies of resistance and transformation. If women are going to participate in communities of resistance and solidarity in ways that give them new options for justice and empowerment, they need to be clear about what kinds of relationships are healthy and positive and what kinds are exploitative and destructive. Hess (1996:64) talks of the necessity for women to have relationships of *"hard dialogue and deep connection"*. These relationships require honesty and authenticity in order to provide communities of real care and transformation. This research created a relational understanding between myself and the participants through one-on-one conversations and also between each other through group conversations. The ensuing sense of relationality with each other, through the sharing of experiences, meant that community was formed. The importance of community is detailed hereunder.

2.3.3 The importance of community

Feminist literature appears to concur that it is important for women to be in groups that help them resist and reshape destructive personal and cultural narratives. Without the support and challenge of healing communities, re-authored, alternative narratives are often too fragile and too 'thin' to be sustained when a woman takes them back into the dominant discourse of culture and, often, family. Communities and groups that work to hear and elaborate the new and alternative narratives help the woman to make this new narrative a viable part of her life story. With an added narrative voice, this research believes that the participants were more likely to continue to gather evidence to support an alternative story than allow the problem story (the experience of breast cancer) to be centralised again.

2.3.4 Conclusion

I am a feminist in as much as I believe that women have as much calling from God to live full and fruitful lives as men do. Carmody (1995:1) terms this *"moderate feminism"* and defines it as a *"commitment to the complete equality of women and men in the possession of humanity"*. In this research I have elected to invite participation from women, whilst acknowledging that men have their own stories of cancer. Indeed, even breast cancer.

This section of chapter two has briefly explored the feminist ideas of voice, relationality and community that inform this research. The focus now turns to the third theoretical scaffold of this research – pastoral theology.

2.4 PASTORAL THEOLOGY

The third scaffold of theory that supports this research is pastoral theology. This research has elected to use the term ‘pastoral theology’ rather than ‘practical theology’ as it is in keeping with the element of pastoral care that defines this research. I acknowledge, however, that pastoral theology is embraced within the greater context of practical theology. In essence, pastoral theology is the application of theology to everyday life. Woodward and Pattison (2000:xiii) define practical theology as:

a place where religious beliefs, tradition and practice meets contemporary experiences, questions and actions and conducts a dialogue that is mutually enriching, intellectually critical and practically transforming.

(Woodward and Pattison 2000:xiii)

Doehring (2006:111) believes that, at its simplest, theology is a “*way to talk about people’s deepest values*”. Bondi (1995:17) says it well when she suggests that pastoral theology is about the “*messy particularity of everyday lives examined with excruciating care and brought into conversation with the great doctrines of the Christian faith*”. It is the ‘giving of voice’ to the fact that listening to, and telling stories lies at the heart of all human experiences and which forms a part of the fabric of pastoral theology. Miller-McLemore and Gill-Austern (1999:10-13) suggest that pastoral theology “*grasps the complexities of lived faith*” which encompasses care within “*a wider social, political and religious context*”. Miller-McLemore (1999:81) describes pastoral theology in the following way:

It disturbs as well as comforts, provokes as well as guides. It breaks silence and calls for radical truth telling; it names shame and guilt, calls for confession and repentance, and moves vigilantly towards forgiveness and reconciliation, knowing that both are even more difficult to effect than people have hoped.

Miller-McLemore (1999:81)

Clinebell (1984:26) believes that the overarching goal of all pastoral theology and care is to “*liberate, empower and nurture wholeness centred in spirit*” (1984:26).

I am of the opinion that women's stories and experiences of breast cancer form part of the complexities of living a life of faith. I believe that spirituality and faith form an integral part of life and illness narratives. It is a concept not encouraged in much of the theory on narrative practices and feminism which were consulted for this research. I hold on to the bodies of literature by Griffith and Griffith (2002); Cook & Alexander (2008) and Frank (1995), who use spirituality and faith stories to thicken illness narratives. I would like to suggest, therefore, that a scaffold of pastoral theology brings a differential to this research for the following three reasons - spirituality, faith and embodiment. These are briefly discussed hereunder.

2.4.1 Spirituality

Griffith and Griffith (2002:14) describe spirituality as “... a commitment to choose one's relatedness with all that is. With this commitment, one attempts to stay focused on relationships between oneself and other people, the physical environment, one's heritage and traditions, one's body, one's ancestors, saints, Higher Power or God”. The implication here is that spirituality places relationships at the centre of awareness; whether they are interpersonal relationships with the world and other people, or intrapersonal relationships with God or other nonmaterial beings. It is these intrapersonal aspects that are important considerations when we offer another a relationship of care. This research brings curiosity about the effect of breast cancer on the experiences of spirituality of the participants.

2.4.2 Faith

Faith, in the context of Christianity, is based in and on the work and teachings of Jesus Christ. Faith is an act of trust or reliance. Rather than being passive, faith leads to an active life aligned with the ideals and the example of God. It sees the mystery of God and his grace and seeks to know and become obedient to God. To a Christian; faith is not static but causes one to learn more of God and grow. Fowler (1995:11) quotes Smith's definition of faith:

Faith is a quality of human living. At its best it has taken the form of serenity and courage and loyalty and service: a quiet confidence and joy which enables one to feel at home in the universe, and to find meaning in the world and in one's own life, a meaning that is profound and ultimate, and is stable no matter what may happen to oneself at the level of immediate event.

If faith is indeed about the making of meaning in the world, as suggested by Smith (in Fowler 1995:11), then I bring to this research a curiosity about how the presence of breast cancer might affect the experience of faith.

My reflection:

I take cognisance of the various denominations that collectively share a faith in God and acknowledge that research participants were drawn from women who are Christians practising their faith at a local congregation of the Methodist Church of Southern Africa.

2.4.3 The importance of Embodiment

Anderson and Foley (2001:38) suggest that our *“engagement with the Holy - similar to our engagement with virtually every aspect of life – is mediated through word and gesture, body and song, architecture, poetry and movement”*. This resonates with my own understanding of embodiment as the unifying of the body, mind and soul.

Brockman (1974:50) describes people as:

Basically spiritual being[s]. [She] is more than physiological and psychological processes. The search for meaning and purpose, aspiring for creative fulfilment, and the development of an ethical system are as much a part of the person as are [her] motions and bodily processes. Indeed, the search for meaning is fundamental to the process of becoming fully human.

(Brockman 1974:50)

In this way, pastoral theology can lift up the body as a site of resistance and hope. Dunlap, in Miller-McLemore and Gill-Austern (1999:145) believes that the body can be seen as a starting point for spiritual growth. She writes that through bodies there can be extraordinary communion with others. Healing touch can be a starting point for connection with others, and thus the arena for connection with God. Our bodies continually remind us of our mortality and of our limits as physical beings. A deep appreciation of our fragility as creatures opens the awareness that each breath is by the grace of God. We are reminded that we are all equals in our vulnerability and the inevitability of death. Our bodies can also be sources of solidarity with the suffering. The body at risk is a profound point of connection with the powerless of the earth.

I believe that it is within the context of spirituality, faith and embodiment that pastoral theology indeed brings an element of difference to this research. One of the ways to thicken this element is through the use of pastoral images. An introduction to the pastoral images used in this research follows.

2.4.4 Pastoral Images

Over recent time many images and metaphors have been used to describe pastoral theology. The pastoral images which resonate with me and the purposes of this research are Dittes' (in Dykstra 2005) 'ascetic witness' and Hanson's (in Dykstra 2005) 'midwife' image. An explanation of both images is described next.

2.4.4.1 The Ascetic Witness

Dittes, in Dykstra (2005:137), portrays pastoral theology as an act of witnessing to the fullness of life. He suggests that the witness witnesses:

Life experiences, the harried pilgrimage of a soul that has too often scurried in shadow. The rhythms, negotiations and rules of the conventional world are suspended in favour of an alternative world. For both the counselor and the counselee, life is moved out of the marketplace into a sanctuary.

(Dittes in Dykstra 2005:138)

This image is very much like Weingarten's (2000:392) term 'compassionate witness'. She suggests that we are always witnesses. *"People speak, we hear, whether we choose to or not. Events explode in front of us, whether we want to see or not. We can turn on television, see people in moments of extremity, and know their fate before they do"*. Therefore, she believes that witnesses assume risks. There is the risk of grasping, even for a second, the experience of another. There is the risk of staying with the other until another's reality circulates conterminously with one's own. There is the risk of attempting to share what one has learnt from a perspective that is at once one's own and another's. This is an aspect of this research that I needed to be cognisant of. The risk involved in being a witness to the participants and to their vulnerability amidst the pain and experiences of breast cancer is, as Weingarten (2000:393) suggests, that faithfully representing their stories and *"shaping words until sensation is rendered so vividly that the witness re-witnesses that which she has opened a way for others to witness as well"*.

2.4.4.2 The Midwife

Hanson (in Dykstra 2005: 200) suggests that midwives and pastors have much in common. Both are in the “*practice of tending births, the physical and the spiritual*”. Both share the intent to, “*attend people in a process*”. I am intrigued by her suggestion that she attends to “*people in travail, in any kind of tribulation or anguish, as God does the miraculous work of delivering new life in its myriad forms*”. Midwife images are substantial in scripture (refer to Genesis 35:17, Exodus 1:16-21, Deuteronomy 32:18, Psalm 22:9-10, Psalm 71:6, Isaiah 66:9, Galatians 4:19, Revelations 12:2) and, in the words of Julian of Norwich, in Colledge and Walsh (1978:295-297), they evoke for me a sense that: “*As truly as God is our Father, so truly is God our Mother*”.

Laurel Ulrich (1990:12) quotes a wonderful line from an 18th century midwifery book, “*There is a tender regard one woman bears to another, and a natural sympathy in those that have gone thru’ the pangs of childbearing; which doubtless, occasion a compassion for those that labour under these circumstances, which no man can be a judge of*”. For me, this resonated with the feminist idea of ‘hearing into voice’ and with my hopes of being a compassionate witness to the voices of the women who are the real experts in their stories and experiences of breast cancer.

My reflection:

Hanson (in Dykstra 2005:157) writes that in order to be a good spiritual midwife, it is necessary to have “experienced rebirth, to have passed through some sort of spiritual travail oneself”. Whilst my experience of living with pain and illness is not necessarily one of cancer, I do consider myself to be in a continual process of spiritual rebirth because of the presence of illness and pain in my own life. I also feel a connectedness, by virtue of my shared lived experiences of womanhood, to encourage, listen and support women into birthing, through giving voice to, their stories of breast cancer.

Hanson (in Dykstra 2005:157) also maintains that death is a very present reality in the birthing process. She suggests that there are aspects of dealing with death that

can be gleaned from midwifery. The first is the reality that with every birth there is a kind of death for the woman. She is no longer who she was as a pregnant woman. She delivers new life in herself too for now she is a mother and she is changed. In our Christian journey there is the reality that every day is a death and resurrection. We die to the old, sinful self and rise to newness of life in Christ.

Secondly, with birth there is the possibility of death for the baby. As some of the participants were receiving treatment for breast cancer, the possibility of illness and death silencing their voices was very real and did, in fact occur. Chapter 3 (refer paragraph 3.4.6) and chapter 4 (refer to paragraph 4.5.5) speaks to this loss.

Pastoral theology gives birth to the practices of pastoral therapy which enable the witnessing of stories to take place. Clinebell (1984:50) describes pastoral therapy as a way of *“doing theology”* and of living out the commissions of the scriptures. Pastoral therapy will briefly be explained here:

2.4.5 Pastoral therapy

Clinebell (1984:109) defines the pastoral therapist as a person who helps people to *“grow in the depth and vitality of their spiritual life”* and acts as an incarnate Christ in the lives of *“Hurting, hoping people”* (Clinebell 1984: 50). The role of the pastoral therapist is to create an environment in which people can tell their stories, feel their pain and their joy, and then discover their competencies and their faith in *“God who is the author and the finisher of all our stories”* (Dinkins 2005:39). I suggest that the hospitality, relationship, the practice of wonder and holding on to hope are important concepts for the practice of pastoral theology. They are, therefore, also important considerations for this research and are described next.

2.4.5.1 Hospitality

Henri Nouwen (1972:71-72) defines hospitality as:

The creation of a free space where the stranger can enter and become a friend instead of an enemy. Hospitality is not to change people, but to offer them space where change can take place. It is not to bring men and women over to our side, but to offer freedom not disturbed by dividing lines. It is not to lead our neighbour into a corner where there are no alternatives left, but to open a wide spectrum of options for choice and commitment.

Dinkins (2005:20) is of the same opinion when he writes that conversations are “*opportunities for hospitality*” (2005:20). Pastoral therapy is, therefore, the establishment of a trusting relationship in which participants can fully explore their spiritual and faith practices and their underlying beliefs (Doehring 2006:84).

Rather than shying away from spiritual issues in the context of pastoral conversations, I support the idea that pastoral therapists should create the space for people to feel comfortable enough to open up. However, I need to guard against the possibility of the participants experience with a personal God being limited by what Griffith (1995:124) refers to as either proscriptive constraints – that this God-talk is not to be spoken here – or by prescriptive constraints – that God can and should be spoken of here but only in a certain way. Essentially, Doehring (2006:84) concurs when she maintains that participants need to trust pastoral therapists not to impose religious and spiritual practices and meanings upon them. Empowering victims is an “*essential ingredient of pastoral care*” (Doehring 2006:84). In the context of pastoral theology and care, and therefore also in the context of this research, being hospitable must include listening to the voices of the participants and acknowledging their experiences.

Another important element of hospitality to consider important to this research is that of listening. This research draws on Bonhoeffer's (1954:97) writings about listening in the Christian community:

The first service that one owes to others in the fellowship consists of listening to them. Just as love to God begins with listening to His Word, so the beginning of love for the brethren is learning to listen to them. It is God's love for us that He not only gives us His Word but also lends us His ear. So it is His work that we do for our brothers and sisters when we learn to listen to them. Christians so often think that they must always contribute something when they are in the company of others, that this is the one service they have to render. They forget that listening can be a greater service than speaking.
Bonhoeffer (1954:97)

This resonates with Anderson and Foley (2001:53) who maintain that people are happy to “*explore intimate stories with trustworthy people who will hear those stories*”.

It makes sense that if I welcome the participants and offer a space in which their stories and experiences of breast cancer can be shared and heard, then an element of relationship forms. As suggested in section 2.3, paragraph 2.3.2, relationality, in feminist practices, provides a platform for stories and experiences to be shared in safety. Whilst this also holds true of pastoral therapy, an added dimension to pastoral relationships exists in acknowledging the presence of God in our midst. This dimension of relationship will be described next.

2.4.5.2 Triune relationships

In pastoral conversations, the storyteller and the listener depend on the presence of the Holy Spirit as the third party in the conversation. The words of Jesus in Mathew 18:20 (The Message) say “*When two or three of you are together because of me, you can be sure that I’ll be there*”. Dinkins (2005:35) suggests that the Holy Spirit is the third participant in the conversation. In the presence of the Holy Spirit, pastoral conversations greatly relieve the therapist and can prevent them from “*over-functioning*” (Dinkins 2005:38). The therapist can invite mystery, and expect unknowing creative imagination and the process of dialogue to be stimulated and aided by the invisible but dynamic work of the Spirit. Pastoral conversations are for the purpose of alleviating suffering in persons and to facilitate the healing power of God through stories created during the conversation in the presence of the Holy Spirit. In this way, the therapist enters the conversation without a specific agenda for the conversation but as a way of being the incarnational presence of Christ for others. This research acknowledges that all the research conversations took place in the presence of the mystery of God.

By being aware of the mystery and power that Christians attribute to God, the invitation exists to practice what Griffith and Griffith (2002:1) call the practice of wonder. This is described in the next section.

2.4.5.3 The practice of wonder

Griffith and Griffith (2002:1) describe the heart of pastoral therapy as the “*practice of wonder*”. They see this as a practice or a skill which can be useful for opening conversations to the spiritual and faith domains. The practice of wonder occurs within “*curiosity, wonder and openness to the being of another*” (Griffith and Griffith 2002:27). With regards to this research, this includes stories which surprise and release me from the assumptions I have about collaborating with women from the same faith community that I belong to. I cannot assume that all Methodist women will experience breast cancer in the same way and I am reminded that each participant will bring to the conversations their own images of God.

Learning to practice curiosity, wonder and openness in the presence of another’s stories and experiences of pain and suffering is perhaps an invitation to reach out to hope.

2.4.5.4 Holding on to Hope

Hope is difficult to describe and define. Words such as expectation, desire, anticipation, promise and convictions come to mind. Yancey (1990:210) writes that “*Hope means simply the belief that something good lies ahead*”. For Capps, in Dykstra (2005:156), a working definition of hope is “*projections that envision the realizable and thus involve risk*”. He maintains that hope is a projection in that it envisions “*a future that is technically false and unreal, as it does not exist, yet it is profoundly true and real, as it expresses yearnings and longings that not only exist but are often more real than the objective world. When we hope, we envision eventualities that are not yet realities*”. For Lester (1995:59), hope is rooted in time in that it has roots in the past which are acted out in the present but shaped and identified with the “*future dimension of human temporality*”. For this reason he suggests that there are two different hopes. The first is hope that is rooted in the future; transfinite hope which encompasses the mystery of the spiritual and an anticipation of eventuality. The second hope is finite hope; the hope that is rooted in the present and which is defined by what is manageable and accessible.

I have found Weingarten’s (2000, 2010) work on hope very meaningful for this research. She uses the concept ‘reasonable hope’ in a similar manner to Lester’s

finite hope. She defines reasonable hope as something both sensible and moderate which directs attention to that which is within reach rather than what may be desired but unattainable:

Reasonable hope's objective is the process of making sense of what exists now in the belief that this prepares us to meet what lies ahead. With reasonable hope, the present is filled with working not waiting; we scaffold ourselves to prepare for the future.

(Weingarten 2010:7)

Weingarten (2010:8) names five characteristics of reasonable hope, which, she suggests, taken singularly or together, illustrate the construct. Reasonable hope is relational; consists of a practice; maintains that the future is open, uncertain and influenceable; seeks goals and pathways to them; and accommodates doubt, contradictions and despair. Yancey (1990:209) is of the same opinion with regards to reasonable hope. He suggests that people without reasonable hope must *"still find a source for hope; like bread, it sustains life"*. This research is curious about the understanding of hope, in the midst of experiences of breast cancer, for the participants.

There is another understanding of hope and it is one in which I, as researcher, have a contribution to make too. Yancey (1990:208) says, of some of his findings on hope, that *"courageous hope cannot be taught. But it can sometimes be caught. We can seek ways to awaken courage in suffering people"*. For Weingarten (2010:8) there is a sense that caregivers co-create hopefulness with those we journey with. She suggests, therefore, that hope, as a verb, is also the act of doing hope. She defines this as the responsibility of the community to do hope with those who are hopeless. Lester's (1995:64) concept of 'finite hope' resonates with 'doing hope' and focuses on the expectations and anticipations that we have with regards to actions and achievements. In this context, Lester (1995:64) suggests that *"Hope is a verb"* and it can be regarded as *"a shorthand term for an expectation about goal attainment"*. In concluding this section on hope, I share Weingarten's (2000:402) thoughts that *"hope is too important – its effect on the body and soul too significant – to be left to individuals alone. Hope must be the responsibility of the community"*.

2.4.6 Conclusion

In concluding this section on pastoral theology I again draw on Hanson's (in Dykstra 2005:207) image of pastoral therapists being in the business of *"assisting God in birthing new life in people and in their relationships with self, others, and God"*.

This seems to be an appropriate way of supporting the witnessing objective of this research.

In the following section I suggest a collaborative scaffold of the values and practices of narrative practices, feminism and pastoral theology.

2.5 FORGING A COLLABORATIVE SCAFFOLD

It is my opinion that each of the theoretical scaffolds, namely narrative practices, feminism and pastoral theology, have common threads which collaborate well in a therapeutic pastoral setting and, therefore, for the purposes of this research. The common threads which will be discussed are the importance of stories, helping women to find a voice, relationships, the challenging of dominant discourses and the positioning of agency. Each aspect will be explored in the sections below.

2.5.1 Stories in narrative practice and pastoral theology

"God made man because He loves stories"

– Elie Wiesel (as quoted in Dinkins 2005:11)

Narrative practices maintain that each person is constituted in stories. Stories give direction to our lives. Purnell (2003:74) writes that the sharing of stories in pastoral conversations helps people tell of their experience of living. Story-sharing is the primary means of pastoral theology and *"when you walk with people into the spaces of silence and/or chaos, you are walking into the space into which the voice of God breaks in fresh ways"* (Purnell 2003:74). In this way, a pastoral setting can be experienced as a context for inviting the re-telling of life stories as well as Biblical ones. Meteyard, in Cook and Alexander, (2008:96) suggests that people are constituted in stories by a God who is a storied God. The Bible should be encountered as a narrative with an *"unfolding plot"* and developing characters within the biblical story - *"there are a great variety of stories. Some merely entertain us;*

others teach us what is right and good or warn us of danger....but there are also stories that are basic or foundational: they provide us with an understanding of our whole world and of our place within it" (Meteyard 2008:96).

According to Lartey (2003:58), the primary function of pastoral theology is to "encourage people to make sense" of their experiences; to disclose Christian "meaning in life"; to encourage people to engage in their "own conversation with the Christian tradition". Anderson and Foley (2001:40) add that there is also a need to discover "God's presence in the human saga". They suggest that "ordinary life is transformed when we recognize that our stories bear the presence of God" (Anderson & Foley 2001:40).

The importance of story is perhaps the most evident in the "portrayal of a life" (Goldberg 1991:62). It is safe to suggest that narrative practices and pastoral theology share the importance of stories. The sharing of stories is, however, only possible through the use of 'voice'. This element of collaboration is discussed next.

2.5.2 Helping women find a 'voice'

The term 'voice' is frequently used in feminist, narrative and pastoral theology literature and it encompasses more than merely a willingness to speak. Voice, according to Neuger (1996:95), also refers to the ability to find language and models that validate one's own experience. 'Voicelessness' can be understood as the inability to speak or write about central concerns. It is also a feeling of powerlessness to speak and sensing that there is no one out there to speak for us.

For Weingarten (2000:391) the themes of her professional work have been the themes of her personal life – silence, voice, witnessing and hope, and in the gift of being able to be a witness to her dying mother that she experienced the complexity of voice and silence. Weingarten (2000:392) shared that through this witnessing she came to see voice not as an individual's achievement of self-knowledge but, rather, a "possibility that depends on the willingness of the listeners that make up the person's community". In her opinion, "voice is contingent on who listens with what attention and attunement. Voice depends on witnessing". The realization is that in capturing a memory in words, for witness and storyteller alike, it can "no longer haunt you,

push you around, bewilder you, because you have taken control of it – you can move it wherever you want to” (Weingarten 2000:393). For Bons-Storm, (in Ackerman & Bon-Storm 1998:23),

Women have to hear the sound of their own voice in groups or in conversation with another person to whom they give authority. We practice speaking out, the act of “raising one’s voice”, in a safe context... A woman has to become convinced that she has something to contribute...Pastoral theology should uncover these new stories. A woman needs an image of the Divine which will encourage her to raise her voice

This research provided an opportunity for the women participants to tell their stories of breast cancer to me, a woman, and in the process make their voices heard about their local knowledge of breast cancer. In this context, local knowledge refers to the understanding of expert knowledge that the co-researchers bring to this research. The sharing of voice allows for relationships to be formed and, in so doing, for community to be constituted. The importance of relationship is described next.

2.5.3 The importance of relationship

Each of the three scaffolds of theory highlights the importance of relationship for ‘voices’ to be heard and for communities to receive the voiced stories. Weingarten (2000:394) describes therapists as “*compassionate witnesses*”. They are men and women who have “*made a commitment to listen with open hearts and minds to the stories of those who have been physically, mentally, emotionally and spiritually assaulted. They have made a commitment to feel in the cells of their bodies what it is like to be touched against one’s will, to be penetrated beyond one’s ability to imagine a way to make it stop. And, they have made a commitment to try to render those experience to others on behalf of their clients*”.

If it is in the construct of relationship that voices can be shared and heard, then it must also hold true that it is in the same construct of relationship that social and religious discourses can be deconstructed and explored.

2.5.4 Challenging of dominant discourses

The Bible is full of instances of Jesus challenging some of the dominant discourses and voices of His time; of His invitations to embrace alternative stories; of the way

He engaged people of all walks of life in a respectful, curious way; of his encouragement of people resisting oppressive voices (Refer Mark 2:27, Luke 13:15-16, John 8:4-5, Matthew 23:26, Romans 12:2 and 2 Corinthians 3:16-18). In much the same way today, narrative practices deconstruct social and Christian discourses. The deconstruction of dominant discourses is a feature of the three scaffolds of theory and, therefore, links to this research in terms of what the women experience and story around breast cancer. I am conscious of the fact that not all discourses can be deconstructed in the scope of this research and that the ones included are those which the participants and myself brought to our conversations. I also acknowledge that not all discourses are understood to be negative. The conversations explored how the women embraced the label of breast cancer, how it affected their self-image and femininity and how they experienced 'voice' in its midst.

Deconstructing and exploring the effects of discourses, by assuming a narrative stance of 'not-knowing', places the position of power in the hands of the participant. The next paragraph describes the positioning of power which forms part of the theoretical collaboration.

2.5.5 Positioning of power

Narrative practices maintain that the therapist is not an expert in another person's life. However, it acknowledges that I can still be influential as a facilitator of the research conversations. Narrative values of respect and curiosity reinforces my own desire to be a Christ-follower who provides shelter for the wanderer (Is 58:7), who, with curiosity, takes up a stance respectful of the person (1 Peter 2:17) and of humility (Phil 2:3, Is 38:9-20, Col 3:12-15). Narrative practices encourage me to be honest about my own context and beliefs whilst respecting and being curious about those of another. This teaches me the value of another's culture and to be curious about another's experience and presence of the Divine, rather than imposing my own ideas of God. Osmer (2008:84) suggests that this is a spirituality of "*sagely wisdom*" which "*puts aside the quest for certainty*" and "*learns to live with uncertainty*". This research focuses on placing the agency of knowledge and power into the hands and the voices of the real experts and knowledge holders – the participants.

The following section explores some of the challenges that a collaboration between narrative practices, feminism and pastoral theology could bring to this research.

2.5.6 Collaborative challenges

Smith (2006:18) suggests that postmodernism is a *“fresh wind of the spirit sent to revitalise the dry bones of the church”*. There are, however, some potential challenges to a collaboration between narrative practices, feminism and pastoral theology that this research will need to take into account. Some are the challenges are one that I have come across in the literature review and others have been voiced by peers. Below is an explanation of some potential challenges that might be relevant to this research.

2.5.6.1 One of the major voices of critique between Christian perspectives and those of a postmodern secular world is around the understanding of truths and absolutes. Narrative theory appears to challenge the existence of essential truth, including the existence of God, and the concept of absolutes.

Narrative practices, however, do not necessarily question existence but instead questions the meaning-making process constructed in language. Narrative theory therefore makes visible the assumptions that have guided meaning-making and it is therefore about how we know what we know and not about whether the things we know exist or not. During the course of this research it was not, therefore, my intention nor my role to question the participant’s beliefs in God but rather how the participants were able, in the context of an illness such as breast cancer, to make meaning of their spirituality and faith.

2.5.6.2 The deconstructive nature of narrative practices could have the potential to challenge a person’s faith in God. One of the central assumptions of narrative practices is to deconstruct taken-for-granted ideas and beliefs in order to assist in the recognition of preferred stories. One of the main challenges of deconstruction to Christianity is therefore what to deconstruct and what not to. In scripture, Jesus is noted as having challenged dominant discourses. He challenged and exposed the religious leaders and the Pharisees for their values, interpretation of scripture and behaviours towards the marginalised in society (refer Matthew 23:4-12 and 23-25,

Luke 22:25-26, Mark 6:30-31, Mark 10:45 and John 18:10-11). He articulated alternative ideas and practices of freedom, connectedness, equality and respect (Refer Matthew 5:3, John 5:19 and 2 Corinthians 12:9). McLaren (2004:90-91) writes that *“Jesus represented good-news in the face of ruling powers, as a revolutionary leader who deconstructed oppressive authority, freeing people from dehumanizing and oppression that come from all the ‘powers that be’ in our world including religious powers”*.

This research hoped to deconstruct some of the illness discourses present in an experience of breast cancer without challenging the participant’s spirituality or faith stories.

2.5.6.3 Christianity teaches that God has one right path for people to follow. Narrative practices, on the other hand, may appear to encourage independence from the authority of God in a person’s life by the invitation to re-author your own life and, in so doing, undermine the authority of God in a person’s life. This may seem especially true in instances where people’s faith stories have been built around discourses which suggest marginalisation and oppression. Narrative practices aim to make these discourses visible and replace them with alternative discourse as a measure of liberation. This can be seen in the way in which Jesus came to ‘set his people free’ and could, therefore, enrich and thicken faith stories.

It was the intention of this research to participate in growing an awareness of the socially constructed nature of meaning-making and a connectedness to love and hope amidst the stories of breast cancer.

2.5.6.4 Traditionally, Christians are conditioned not to question their faith. In the gospels, however, we read how Jesus questioned interpretations held sacred by those in power and how he honoured the poor, marginalised and powerless. Church in this post-modern world can benefit from acknowledging that much of church hierarchical culture, gender roles, power practices, church services and Bible exegesis was part of a culture of inheritance rather than derived from scripture and the teachings of Jesus. Hart (2001:46) suggests that thoughtful questioning of some of the basic tenets of faith can be useful, saying *“It is important that doubts about*

truth not be judged or discounted offhand, as some Christians tend to do...It may just mean that the person doubting is a little more honest”.

This research acknowledged that narrative practices have the potential to challenge structures of power within organised religion of Christianity. It was not, however, within the scope nor the purpose of the research to challenge foundations of faith and religion.

I hold on to a statement by McLaren (1998:194) who writes that *“postmodernism invites an exploration of more than facts – values, purpose, meaning, mission, passion, wisdom, faith and spirit”* as the intention of the collaborative scaffold of theory.

2.6 CONCLUSION

This chapter explored three scaffolds of theory, namely Narrative practices, feminism and pastoral theology and also introduced a fourth scaffold; a collaboration between narrative practices, feminism and pastoral theology. This chapter also chose to highlight some of the potential challenges to the theoretical collaboration before the research commenced. My role in this research has been compared to the images of Weingarten’s ‘compassionate witness’ and Hanson’s ‘midwife’ with the objective of collaborating with the participants on alternative or thickened stories of breast cancer.

Chapter three introduces the research participants and co-researchers. They are the voice of illness, the voice of breast cancer, the voices of the five co-researchers and the voices of significant others who were also included in this research.

CHAPTER 3

MEETING THE PARTICIPANTS

*“The opportunity to tell one’s own illness story as one wants to tell it
– in one’s ‘own voice’ – is a kind of grace”*

(Frank 1995:134-135)

3.1 INTRODUCTION

Chapter two provided an understanding of the scaffold of theory used in this research, namely narrative practices, feminism and pastoral theology. A collaboration of the theories was suggested as an additional scaffold and for the purpose of supporting the objectives of this research. Chapter three introduces all of the research participants and co-researchers. I suggest that they are the voice of illness, the voice of breast cancer and the voices of the women who shared their stories with me. By externalising the voices of illness and breast cancer this research sought to bring a distinction between the participants and the illness dominant story. In the process, it was hoped that alternative meaning-making would take place and thicken the re-storying process. Some ‘significant other’ voices are also introduced.

The voice of illness will be introduced in the following section.

3.2 THE VOICE OF ILLNESS

Illness happens in a life that *“already has a story, and this story goes on, changed by illness but also affecting how the illness story is formed”* (Frank 1995:54). Arkwright, in Cook and Alexander (2008:127) believes that the *“helping professions have constructed the self in deficit terms”*. Many modernist theories about illness appear to be focussed on psychopathology, negative causal factors, labelling of pathological behaviour and identifying destructive processes. As a result, the Diagnostic Statistical Manual of Mental Disorders (commonly known as the DSM-IV) creates a deficit, symptomatic and non-socially contexted account of self. Frank (1995:5) maintains that modern medicine separates illness from health and sickness from

wellness, as illness experiences are overtaken by technical expertise, medical language and prescribed treatment. He argues that illness and disease aren't necessarily passive in the body. Instead, he suggests that the ill person has a choice to turn illness into an illness narrative.

Illness is significant in separating the person, at least for a time, from a state of wellness. Marinker (1975:82) suggests that illness expresses itself in potentially three ways. Firstly, illness appears as a *"feeling, an experience of 'unhealthy' which is entirely personal, interior to the patient"*. The second expression is through medical science, in the form of doctors, who pathologize illness by what they can see, touch, measure and smell. In this way the medical professions imbue illness with a physical 'face'. Thirdly, illness speaks in a mode that is external and public. Marinker (1975:83) believes that illness is *"a social role, a status, negotiated position in the world, a bargain struck between the sick person and a society which is prepared to recognise and sustain"*. I would like to suggest that a fourth expression of illness exists in the way illness integrates into the life story of the individual. Frank (1995:6) writes that a postmodern experience of illness begins when *"ill people recognize that more is involved in their experiences than the medical story can tell"* and this might invite the person to reclaim her own story.

Illness wounds people, not only in body, but also in 'voice'. The 'voice' is not only a metaphor for 'mind' and expressions of the 'spirit', as discussed in chapter 2, paragraph 2.3.1, but it is also a physiological organ of the human body. Martin Buber (1958:6) suggests that the body *"does not use speech, yet it begets it"*. It is this notion that leads Frank (1995:xi) to focus on the idea that a person living with an illness is able to choose to turn illness into an illness story and, in so doing, transform it into an experience. In this way the illness that *"sets the body apart from others"* becomes the *"common bond of suffering that joins bodies in their shared vulnerability"*. The ill, and all those who suffer, need to become storytellers in order to recover the voices that illness and its treatments rob.

I believe that an important purpose of illness narratives is to integrate illness into the larger context of life. These illness narratives are produced intersubjectively in conversation as people produce stories about the causes and effects of their illness

that connect it in direct ways with their constantly evolving life story. Frank (1995:182) believes that the embodied stories have two aspects; firstly, the personal aspect which serves to give the body a voice in order that the body and its changes may become familiar and, secondly, illness narratives have a social aspect in that narratives and stories are told to another.

To Frank (1995:184), the wounded storyteller is a *“moral witness re-enchanting a disenchanted world”*. He has named three broad types of stories that the ill person tells. In any illness, all three types of narratives are told. These three narratives intertwine and no one takes precedence over the other. Frank (1995:76) likens the three narratives to *“patterns in a kaleidoscope”* in as much as, for a fleeting moment, colours produce a pattern before the tube shifts and another problem emerges. Each illness narrative is now discussed.

3.2.1 The voice of restitution narratives

These narratives assume that anyone who is ill wants to be healthy again. Contemporary culture treats health as the normal condition that people ought to have restored. People want to hear stories of restitution to former health. The plot of the restitution story is one that says, ‘Yesterday I was well, today I’m sick, but I will be well again tomorrow’. The storyline may be thickened with information of tests and their interpretation, treatments, outcomes and competencies of the physician. Frank believes that western culture is obsessed with cure and medicine. The restitution narrative therefore talks about ‘fixing’ what is ‘broken’ in a very mechanistic way. Metaphors such as ‘good as new’ are at the centre of restitution narratives and a reminder that the story is about ‘health’.

3.2.2 The voice of chaos narratives

These stories are full of chaos and imagines life will never get better. Events are told as the storyteller experiences life - without sequence or discernable causality. Chaos stories are anxiety provoking and full of vulnerability, futility and impotence. The teller of chaos stories is the wounded storyteller. Frank (1995:101) maintains that the wounded storyteller cannot tell their stories in words. Instead, chaos stories are told on the edges of a wound and on the edges of speech. Chaos is told in the silences that speech cannot penetrate or illuminate. The challenge of encountering

the chaos narrative is how not to steer the storyteller away from her feelings. The challenge is to hear the story of what is not being said. In White's (2000:35-58) words, this is the *"absent but implicit"*. The person who has lived chaos can only be responsible to that experience when distance and the passing of time allow reflection and some narrative order of temporality. Exercising responsibility requires a voice and the chaotic body has no voice. This voice can only speak about the chaos from outside of the chaos. To deny a chaos story is to deny the person telling the story and people, who are being denied, cannot be cared for. People can only be helped out when those who care are first willing to become witnesses to the story. An overview of Frank's quest narrative will be discussed next.

3.2.3 The voice of quest narratives

Quest stories meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey which becomes a quest. The quest is defined by the ill person's belief that something is to be gained through the experience of illness. The quest narrative affords the ill their most distinctive voice and most published illness stories are quest stories. Metaphors of quest stories may be likening illness to a journey. Frank (1995:116) writes that Nietzsche described his pain as having the dog-like attributes of being faithful, unobtrusive, shameless, entertaining and clever. *'I can scold it and vent my bad mood on it, as others do with their dogs, servants and wives'*. This naming and externalising of illness offers a new or alternative relationship to illness. Frank (1995:127) suggests that quest storytellers speak of their own bodies, including details of pains and disfigurements. The quest narrative recognizes ill people as responsible moral agents whose primary action is witness.

My reflection:

I was aware that, in light of Frank's three types of illness narratives, each participant's story would differ from each other's even though the voice of breast cancer was common. This was indeed experienced. At times it caused a tension within me as I needed to recognize that certain participants saw breast cancer through a different narrative to how I saw it and the illness quest in my own life. I was very aware that my own meaning-making could potentially hi-jack this research when different ideas were shared.

Frank, in Krippner et al (2007:33), suggests that ultimately, each narrative “*deserves to be honoured in its time of telling*” and that “*one listens to ill people’s stories not in order to fix them by doing something ‘therapeutic’ but rather to honour them*” (Frank in Krippner 2007:35). This understanding supports Weingarten’s ‘compassionate witness’ (discussed in 2.2.3.1.) and stands before me as a reminder of my role in the illness narratives of this research.

In the next section I introduce the voice of breast cancer and some of the medical names and terms used during the research conversations. I named the voice of breast cancer as one of the participants in this research according to the narrative practice of externalisation (refer paragraph 2.2.3.3). I sought to do this by introducing breast cancer in the first person. An introduction now follows.

3.3 THE VOICE OF BREAST CANCER

I am a malignant tumour that starts in the tissues of the breast and I can grow and invade surrounding tissue or spread to other areas of the body. I have two faces. Sometimes I am called Ductal carcinoma when I start in the tubes (ducts) that move milk from the breast to the nipple. This is my most common name. The second name I use is Lobular carcinoma when I start in the parts of the breast, called lobules, which produce milk.

I can be invasive or non-invasive in the human body. Invasive means I have spread from the milk duct or lobule to other tissues in the breast. Non-invasive means I have not yet invaded other breast tissue. When I am non-invasive the doctors say that I am ‘in situ’. Mostly, I am sensitive to the hormone oestrogen. This means that oestrogen allows me to grow. Sometimes I can have oestrogen receptors on the surface of my cells. When the doctors find these receptors they call me oestrogen receptor-positive cancer or ‘ER-positive’ cancer. In some women I go by the name of ‘HER2-positive’ breast cancer. HER2 refers to a gene that helps cells grow, divide, and repair themselves. When cells (including cancer cells) have too many copies of this gene, they grow faster. Doctors and scientists believe that I am more aggressive when I am HER2-positive and then I have a higher risk of returning than when I am not HER2-positive.

I develop in four stages in the human body. If I progress at level I, II or III then the doctors treat me with chemotherapy, medicines that kill my cells; radiation therapy to destroy my tissue; surgery to remove me (a lumpectomy removes the breast lump; mastectomy removes all or part of the breast and possible nearby structures); or with hormonal therapy when my ER-positive cells are present. If I have grown to level IV, there is very little that the doctors can do to get rid of me besides improving the symptoms I cause in the person. After treatment, some women use medications like tamoxifen in order to try and curtail the effects of oestrogen, which helps me to survive and grow.

3.4 THE VOICES OF THE WOMEN

“The pedagogy of suffering means that the one who suffers has something to teach”

Frank (1995:150)

Several studies have described the ill as storytellers (Frank 1995; Hawkins 1993; Kleinman 1988). Frank, in Krippner et al (eds. 2007), suggests that attention should be less with the patient – the object of medical attention and intervention – and more with the ill person – the person struggling to negotiate a life lived in deep illness. Griffith and Griffith (1994:63) suggest that having a ‘voice’ can be a code-phrase for *“expressing who I know myself to be”*. It is with this understanding that I invited the participants to introduce themselves in their own words and voice.

3.4.1 Moira

“My name is Moira Keymer and I feel very privileged to have been part of this research. Cancer entered my life 5 years ago and with it came a whole lot of new challenges, new friends and new enemies, along with a whole range of new insights and learning’s. The journey has taken me into places of consolation and desolation but in the end of the day there is one thing I have really learnt to do and that is to pick up Gods calling cards. He goes before and comes behind and is ever present. When fear comes to bite me I am learning to look for His calling card and find His presence”.

3.4.2 Tania

“My name is Tania Landers and I am a breast cancer survivor. I have been a primary school teacher for the past 22 years. I was diagnosed in 2005 when I was 37 years old. When I found out I had cancer I was married to Gavin and we had two children, our daughter Hayley aged 6 and our son aged 4. I have now been clear of cancer for 6 years and we have since added our “miracle” daughter Gabriella to our family. Cancer did not rob me of my life, but gave me a new perspective and gratitude for my life”.

3.4.3 Lynda

“My name is Lynda and I am, by the grace of God, a cancer survivor. Through my journey with cancer I have discovered much about myself and especially my relationship with our Saviour. Would I choose this path again? Honestly, YES. I do not believe I would have the same insight into just what it means to have a real and deep relationship with Jesus, or with others, if I hadn’t walked this road. To be solely dependent on His Grace is extremely humbling. Has it always been easy? No, it has not, but I have done this alone. I am privileged and consider myself chosen to walk this path for HIS glory alone. What an amazing gift.”

3.4.4 Noriko

“My name is Noriko Solomon. I am a 34 year old woman, wife and mother. I am a Christian and I love the Lord. As of 2011, I am also a cancer sufferer.”

3.4.5 Karen

“My name is Karen Heath and I am a woman living with cancer. Being diagnosed with Breast Cancer four years ago changed my life in many ways, and you go through stages, from shock to suffering and finally to a sense of renewal and gratitude and contentment. When you are diagnosed early Cancer doesn't make you sick, but the healing of it sure does, and the sense of it never leaves you. Cancer is something that stays with you forever, but once you are over the worst - the operation, the chemo, the radiation - you carry on and make the most of every day because you are one of the lucky ones, you have had a wake-up call!

You realize that there are no guarantees, life is precious and you have to make the most of every minute because you had cancer, and it could have been worse - we all know people who have died from it - and tomorrow it could make its way back into your system, because nothing you did put it there in the first place. Surviving Cancer makes you want to be a better person, to help others who are going through it, to do what you can to pay it forward in gratitude to God for letting you be one of the lucky ones, and to thank and love the people around you who stood by you and propped you up on the days when you just couldn't do it yourself."

3.4.6 Jennie's story

Jennie's story was never shared as she passed away before we could start our conversations. I have included her name, nevertheless, as a way of respecting her intention and as a reminder of her life as a fighter of cancer.

3.4.7 The voice of a significant 'Other'

In order for this research to be reflexive (see 2.2.5.1.2), I invited significant 'other' voices to be a part of this research too. These voices came from conversations with people from outside of the participating group of women. The voices came from conversations with a husband and e-mail conversations with a daughter. I asked them to participate in this research process because each has their own story to tell about the experience of living with breast cancer, either alongside a wife or a mother. Consent for their participation was first obtained from the research participants.

3.4.8 The voice of a male cancer sufferer

The last 'other' voice which has been included is that of André, a minister and my spiritual mentor who lost his own battle with cancer in 2010. I have included an insight on hope (paragraph 4.5.7) from a poignant e-mail shared with me two weeks before his death. I had his permission and his willingness to be part of this research.

3.5 CONCLUSION

This chapter introduced the voices of illness, breast cancer and the women as participants in this research.

I believe that people tell stories not just to work out their own changing identities but also to guide others who will follow them. Storytelling is for another just as much as it is for oneself. Frank (1995) suggests that it is in the reciprocity of storytelling that stories have an element of testimony as well as serving to thicken and enrich the person's self-story.

Chapter four is a reflection on the research conversations, problems encountered and the meaning-making experience for the co-researchers and myself. It leans on Hanson's metaphor of 'midwife' (in Dykstra 2005:157) and describes a 'birthing journey' as the image for witnessing stories of breast cancer.

CHAPTER 4

THE BIRTHING JOURNEY

“Allowing our wounds to become the womb where new life is conceived.”

Julian of Norwich

(in Dykstra 2005)

4.1 INTRODUCTION

Chapter three explored the voices of illness, breast cancer and the women who participated in this research journey. In this chapter I reflect on the stories and experiences encountered by the participants, and I, in our conversations together and how these became part of the ‘birthing’ process of making meaning of our experiences of breast cancer. ‘Birthing’ is an image used by Hanson (in Dykstra 2005:200), and described in paragraph 2.4.4.2, in which she likens the role of pastoral therapists to that of a midwife who attends to people in distress as ‘new life’ is being born. This image will be used throughout this chapter. I begin this journey by discussing the preparation for the birthing of the stories.

4.2 PREPARING FOR THE BIRTHING JOURNEY

Ronnie Kaye, in her book *Spinning Straw into Gold* (1991:17), shares two lists that she compiled after working with breast cancer patients for five years. The first list is her understanding of the issues that surround having breast cancer. These include death, body image, sexuality, differentness, communication, self-worth, recurrence, femininity, isolation, fatigue, treatment concerns, side-effects and relationship problems. The second list is what Kaye discovered to be common feelings that may be part of a woman’s response to breast cancer. These include fear, grief, depression, envy, powerlessness, vulnerability, guilt, betrayal, self-hate, anxiety, anger, sadness, loneliness, shame, resentment (Kaye 1991:17). I have used these thoughts and feelings to inform some of these research conversations.

In order to prepare for the birthing of meaning-making, the research conversations took place over a period of about fifteen weeks and for usually an hour at a time. During this time an average of five separate conversations took place with each participant. Initial conversations were semi-structured for the collection of illness information. The conversations that followed were unstructured. These unstructured conversations were initially prompted by questions which I brought to the sessions and about aspects of breast cancer that I was curious about. As all the participants were working women, there were occasions where the flow of conversations was interrupted. Conversations were recorded and transcribed for accuracy and transparency.

The research conversations were concluded by two group conversations, in which narrative practices of outsider witness groups and creative definitional ceremonies were included. These were arranged to suit all of the participants. The group conversations encouraged each participant to review the content as well as the meanings ascribed to their experiences. We were also able to reflect on the meaning-making process of this research journey and collaborate on a meaningful way to end our time together (refer paragraph 2.2.5.1.2 on definitional ceremonies).

In the following section I discuss some of the 'labour pains' which I, as researcher experienced during this research process.

4.3 LABOUR PAINS

I experienced some stumbling blocks as this research started and I have chosen to use the term 'labour pains' to describe them in an attempt to create a flow with the metaphor of 'midwife' which was discussed in detail in chapter 2, paragraph 2.4.4.2. A brief discussion of these labour pains now follows.

4.3.1 Meeting with inadequacy

Once this research proposal had been approved and initial meetings with my supervisor undertaken, the enormity of the process ahead of me loomed large. I had no personal experience of breast cancer and my frame of reference was limited to the stories of others and through literature and information pamphlets.

Would I be able to do this research in a way which didn't marginalise the actual, lived experiences of the participants? Whilst I was able to draw on and relate how my own journey with illness and pain had grown my sense of differentness, it was, nonetheless, not breast cancer. Self-doubt crept in as I wondered whether this research would indeed bring any meaning to the participants or if this was a self-seeking journey for the purpose of academic measurement or achievement.

4.3.2 Trying to connect

Another area of concern was connecting with potential participants. The 'women living with cancer' support group at the pastoral care centre was going through transition and I met with resistance from the person heading it up. If it wasn't going to be possible as a group research project, then I had to consider individuals who would be willing to participate. Once the first call had been made, to Lynda, other participants were suggested and we were ready to start.

4.3.3 Issues of time & control

Time to meet and time to consolidate soon became another concern. The reality was that each participant was a working woman, a family woman and, in some instances, still in an ongoing relationship with her breast cancer treatment. My own health, work at the centre and time as a wife and mother also meant that there were times when alternative arrangements needed to be made.

4.3.4 Coming full-term

What sustained me through this time of self-doubt and inadequacy was a firm belief in the importance of illness stories and the unheard voices that live with them. This validated, for me, a sense that this research could have deep meaning. I referred often to a sentiment from Wikan (in Mattingly & Garro 2000:232). She writes that –

Women's storytelling is haphazard, often interrupted, disturbed, distorted by children, visitors and other family members making their claims felt. There are false starts, unfinished endings, musings, hesitations, interruptions, and so on. In consequence, you often get only the beginning, or the middle, and so it's back to the beginning again, since we have lost track. Storytelling in natural settings has this contingent quality: it is part of life; it takes place in a world of urgency and necessity, a world of multiple compelling concerns. Telling a neat narrative, nicely structured around an ending that gives meaning to the whole thing, is a luxury life does not afford too many of the world's inhabitants.

This quote invited me to acknowledge that this research was taking place amidst the busyness of life and that it might well mean embracing interruptions.

From the stories and experiences of the women participants, certain themes of meaning emerged. In the next section I will explore these themes.

4.4 THE BIRTH OF MEANING

Several of the themes of meaning documented in this chapter were produced in response to areas of curiosity which I brought to this research. These were either as a result of the literature review for this research or as a result of being a woman who lives with the fear of encountering breast cancer. Other themes of meaning were spontaneous responses given by the participants and indicate ways in which each woman made meaning of her own experience of breast cancer.

Once the conversations with the participants were transcribed, I was confronted with a multitude of possible meanings and this was, at times, rather overwhelming. However, upon further reflection, groups of meanings emerged spontaneously and became the themes of meanings discussed here. Due to space restrictions I have elected to share the experiences and themes of meaning of the participants under common headings rather than as separate stories for each participant. This has meant, however, that not all the participants are mentioned under every theme.

4.4.1 The Illness Story

This section introduces the discovery of breast cancer into the participants' lives and what the experience of diagnostic procedures, doctors, the news and the treatment journeys were like.

4.4.1.1 In the beginning...

My curiosity was around the circumstances in the participants' lives that led to a diagnosis of breast cancer. I assumed that something necessitated each participant's life-changing mammogram.

Karen decided to have a mammogram before she started a new job. Noriko's check-up was also the result of starting a new job and fulfilling the required medical check-up. *"I was declared fit but they found something in the x rays and suggested that I follow up with the GP, who referred me to a cardio-thoracic surgeon. He recommended a CT scan before seeing me"*. Moira's mammogram was done before she left on a long-planned holiday, as a matter of routine.

4.4.1.2 The experience of diagnostic procedures

'It is just so undignified doing all these things with your top off' - Karen

Each of the participants expressed the sheer amount of tests that were usually conducted in one day as overwhelming. Tania remembered, *'Blood tests, bone scan and then they give you radiation and inject, wait an hour, then go back. Then I had to go for x-rays and I felt overwhelmed.'*

4.4.1.3 The waiting game

'For me it was the waiting. I was always waiting' - Tania

One of the biggest frustrations voiced by all the participants was the waiting - the waiting in-between the procedures; the waiting for results; the waiting; period. Karen put it like this, *'...waiting is nerve-wracking. It's the worst part of the day – the waiting'*. Tania believed that *'the waiting was the worst part of the initial experience'*. For Noriko, the waiting continued throughout this research as she waited to hear whether or not she would be part of a new test protocol in South Africa: *'I'm in limbo, and just want to prepare myself for whatever is coming. I like to plan my life, and I like structure. I have a lot of ifs and maybes because of the cancer. I'm feeling anxious as my treatment is on hold, waiting for this'*.

4.4.1.4 Receiving the results

'He just said that your tests are in and you have breast cancer' - Karen

Henderson, in Moessner (1996:209) believes that one of the *"most frightening medical words a person can hear is the word "CANCER"*.

A common myth about breast cancer, as with most cancers, is that the diagnosis is equivalent to a death sentence.” I was interested to learn that three of the participants had discovered breast cancer’s presence through telephone conversations with their medical professionals. For Moira, the possibility had existed at the time of the mammogram and the telephone call was merely confirmation. For Karen, this news was not what she had anticipated, ‘The disbelief - cancer was such a big scary thing...Your whole world turns upside down. I’m going to die. He [gynaecologist] just said your tests are in and you have breast cancer. I only remember writing down the telephone number he gave me’. Noriko remembered ‘part of me was having an out of body experience. In my mind I have two views – one right there [in the hospital ward] and one looking down on me and the doctor.’ Tania recalled feeling sick when she received the news. ‘When she told me, I just cried. I thought that’s the end. It was more than just an overwhelming experience. I can’t do this. I’m just going to have to die. I’m not strong enough to walk this road’

The husband’s voice

‘What life would be like without her? – I prefer life with her.’ - Gavin

Gavin, who is married to Tania, remembered, ‘It was a whole lot of things. It was shock. She was one of the lowest risk people to get cancer. No family history, all the risk factors were zero. You realize when you are confronted with the possibility of the family disintegrating and breaking down, what you have is precious and life-giving. It gave me clarity that I was happy to be married. The thought of Tania dying was heart-rending. It brought life down to right now, and what do I do with today’.

4.4.1.5 The presence of breast cancer

‘I couldn’t feel it’ – Moira

Coming out of my own assumptions and curiosity, I asked each participant if the lump was something that they could feel. Moira said *‘Not at all. It was 4 mm. If I had left it for another 2 years or 18 months I would have been in trouble. That she caught it at 4mm is nothing short of a miracle. I couldn’t feel it.’* For Karen and Noriko, the same was true. Noriko said that *‘I’ve never had a pain or ache and wondered. Never considered it.’* The news was a real blow to her.

She recalled exact dates as she remembered, *'On 07 March 2011 they did a biopsy of the breast tumour and lymph nodes. I was diagnosed with breast cancer on the 14 March 2011'. On 9 Feb 2011, I received confirmation that I had cancer in the lung. On 14 March 2011 they did a biopsy of the lung and a lumpectomy aspiration. I was then diagnosed with breast cancer.'* Lynda's experience was different. She has been diagnosed with breast cancer twice. After completing the suggested 5 years of radiation, chemotherapy and hormone therapy route, a routine mammogram was to bring bad news, *'I said to Dr B "I'm in remission, I've done my time after 6 years". After the five years you feel that is it. It's over. They discovered I was Her2 positive. It's a gene you are born with. It's not something you can change and it never goes away'.*

For Tania, unlike the other participants, her breast cancer had had a physical manifestation, *'Cancer isn't sore - everything that you read says that if it's sore it's not cancerous. Mine was sore. It was a definite lump. I thought it would go away. '*

4.4.1.6 The emotions

'I cried when I walked out of there – it's [breast cancer] just so big' - Tania.

I reflected on the work of Griffith and Griffith (2002:267) whose work with medical illness suggest that some of the emotions experienced are despair, helplessness, meaninglessness, isolation, resentment, sorrow and that, in their studies these emotions can activate recurrences or accelerate progression of illness. Noriko highlighted the sense of anxiety which was very present for her in the waiting and a *'little voice which can't quite believe that I have been diagnosed with cancer, let alone two different types'* in explaining some of the disbelief she still experiences. Tania remembers thinking, *'I had little children. I was thinking it will just go away and I won't have to do it'.*

The husband's voice

'I won't have a conversation about feelings' - Gavin

Gavin said that *'It has to find a practical outworking. I can rather **do** stuff. I would leave it to my actions'.*

Later on in our conversation he added, *'The possibility of losing Tania, I found myself almost withdrawing from her in preparation for the worst. Then the guilt of how do you withdraw in the greatest time of need. That fight was going on. I am protecting myself from any future pain or I acknowledge it is self-protection. But not something I articulate in Tania's presence'*. Gavin chose not to share his emotions with Tania because he was concerned that *'it would clutter. She doesn't need to share my journey. She needs to conserve her energy for her own journey'*.

The daughter's voice

'It was a shock and then I felt immense anger and fear' – Sandi

The thought of losing her mother *'was unbearable. Just the thought of what she was going through scared me so much and the unknown was daunting'*.

4.4.1.7 The surgical journey

'Better to deal with cancer in a radical way' - Moira

Treatment plans for breast cancer are indeed radical and, by all accounts, invasive to varying degrees. The participants each had their own experiences to share. Moira's treatment started with a *'wedge section with an immediate reconstruction. She [Dr B] said she didn't know what would follow that until they had the full pathological report on the personality of the cancer.'* The doctor's had this report by the time Moira's surgery was complete. Lynda's treatment was long, *'6 years after the original diagnosis of breast cancer I had the mastectomy and they started the reconstruction. They actually cut your stomach and they take skin and make a nipple'*. Lynda's surgery was radical. *'The cancer had corroded my whole chest wall. He [Dr] had to remove my whole sternum. It had actually grown into the ribs and everywhere'*. Karen underwent a *'Lumpectomy – three tiny lumps were removed with massive reduction because the abnormal tissue was quite extensive'*.

Noriko had required treatment for both lung cancer and breast cancer. *'On 11 Feb 2011 they removed my right lung... On 21 March I saw a surgeon and he confirmed that they could take the lump out [of the breast] without having a mastectomy. They take the tumour and healthy tissue surrounding the tumour. There is the possibility of me developing a secondary tumour in 10-15 years as a result of the radiation. If I didn't have the radiation, I wouldn't live to run the risk.'*

4.4.1.8 The family history

Lynda is the only participant who has a family history of cancer and breast cancer. *'I have a sister and three cousins who also have cancer.'*

4.4.1.9 The experience at the hands of medical professionals

'She's so calm and so reassuring' - Tania

My assumption is that doctor's practise according to the teachings of a modernist medical system that diagnoses and treats illnesses, such as breast cancer, and that this is often the focus of their treatment, rather than the emotional wellbeing of their patients. Another assumption is that the care given to a woman by a woman doctor is different to that of a male doctor. My basis for this is that only another woman is likely to understand the ramifications of an illness story like breast cancer.

(All doctors have been indicated with a capital letter only as no permission was obtained by them to use their names for the purposes of this research.)

Three of the participants received their medical care from the same doctors. Moira recalled receiving caring support from her team of doctors; both male and female. *'My husband had received a sensitive phone call from Dr C enquiring after me. The two of them then had a 45 min conversation around what it was like for him to have a wife diagnosed with breast cancer.'* Lynda recalled her experience of Dr B, *'She is a great one for not telling you what you should do. She says these are your options if you want to go to somebody else and get advice. This is nice, but you would love her to make the decision. She said that if it was her body she would have it. And that was a done deal.'* Karen was also treated by Dr B, *'She is very factual, and I was told to go away and think about it.'*

Noriko's male doctor *'showed in many little ways that he cares for his patients. Encouraging you to stay strong and care for yourself. He would always examine me, and not just walk in and look at me. He went through the chart in detail, and told me what he was doing. I had a very good experience with the doctors and treatment'*. Tania remembers her doctor, a woman, being a source of care, *'She's so calm and so reassuring. Even when I was going through my treatment, she would phone me up to see how things were going at that time'*. Tania remembered waiting to see the oncologist for the first time. She remembered saying, *'I don't care how good he is, if he doesn't have a good bedside manner I'm not staying here... He was amazing. He is just such a nice man and he explained everything. The x-ray people were also fantastic. They saw from my papers what was happening. They were so compassionate – got me through the next step.'*

4.4.1.10 Encountering the unexpected moments of medicine and faith

My assumption is that medical professionals neither openly profess their own faith stories, nor use them in their interactions with their patients.

Both Lynda and Moira recall moments of faith or spirituality in amidst the context of medicine and treatment. Lynda recalls how, in meeting with Dr B and in deciding what to do, she had an amazing experience: *'I really, really prayed about it and I asked God to speak through her [Dr B]. I told her about an amazing God experience that I had – a message in which "You must just trust, you must have faith and you must go with what the surgeon says". She spoke about John in the Bible – he was the doctor and God used him – it was a wonderful conversation. It was almost like God had prepared her for me'*. Moira shared how she had woken up to the sound of the nurses singing worship songs in the ward and how she had subsequently learned that Dr B prays before surgery. She remembers feeling *'drenched in grace. In the music I found his presence'*.

4.4.1.11 Looking for help elsewhere

Karen was transparent about having explored finding help outside of her faith and conventional medicine. She shared with me how part of that seeking had been spent at a Buddhist sanctuary; using crystals purported to have healing powers and also a visit to a witchdoctor to have bones read.

She told me about her visit to the Buddhist sanctuary in Bronkhorstspruit and how the peace and the serenity she experienced there had been profound. *'At the end, you hold onto your faith and thank God for every day, and go with the medical stuff. There is no other alternative.'*

4.4.2 The Personality of Breast Cancer

'She held it between her fingers, tiny as it was.' - Moira.

I first heard the analogy of breast cancer having a personality after my colleague, Moira, discovered her breast cancer. It was an image used by her doctor, Dr B, in talking about the various forms of cancer and how each one is different and therefore requires different treatment approaches. It occurred to me that this image was aligned with the narrative practice of externalization and I decided to explore it with the participants.

Moira mentioned that at the time of diagnosis the doctors know that *'there is a cancer – they don't know what cancer, because they only get the personality of the cancer once a full pathological evaluation comes back. Once they have dissected the tumour. She remembered that 'they measured the tumour absolutely exactly. They give you the dimension – length, depth, weight – of this tumour and its profile.'* For Lynda, the second diagnosis brought with it a personality of Her2. *'It's extremely aggressive and the only thing it [Her2] knows to do is mutate. So it just makes babies and grows'*. Karen recalled that *'Dr B kept emphasizing that the cancer was small and slow growing with a pleasant personality and non-aggressive'*. Noriko was faced with two different cancer personalities. She remembered being told that *'they are both at stage 2. The doctors have a basic understanding of the lung cancer, but they don't know how it behaves all of the time because it's not common and therefore not well researched.'*

4.4.2.1 The face of breast cancer

Freeman, Epston and Lobovits (1997:3) ask two questions that I have considered over the course of this research. *"Do we dare to be playfully creative in the face of worrisome problems? What happens when we engage our imagination, humour and resourcefulness in opposition to the deadly seriousness of problems?"*

Freeman et al (1997:148) suggest that expressive arts therapy have things in common with narrative therapy and that “*similar benefits result from artistic expression of a problem as from the practice of externalisation*”. I wondered what inviting the participants to draw breast cancer would be like. The words of Carl Jung, in his autobiography ‘*Memories, Dreams, Reflections*’ (1961:223) helped forge the idea - “*Words and paper, however, did not seem real enough to me; something more was needed. I had to achieve a kind of representation in stone of my innermost thoughts and the knowledge I had acquired*”. Some of the representations of the face of breast cancer are contained in Annexure D – G.

A reflection after the creative externalisation highlighted new thoughts on breast cancer for Tania, Moira and Lynda and confirmed an existing image of breast cancer for Noriko and Karen. Moira shared that doing the exercise ‘*made me realize how cancer is. No two cancers are the same. If cancers appear in a body and then metastasize in two different cancers, they nevertheless still have their origins in the same place and they have their purpose in the same place. My cancer is only one branch of cancer*’. She had used many different colours flowing out of one spot (see annexure D) and the colour red represented her breast cancer in the mix. This was a new image for Moira.

Lynda said of her image, ‘*It looks like a monster*’ (See annexure G). ‘*All of these tentacles going out grabbing at parts of you. For me it’s [breast cancer] not a good thing – a dark place*’. Lynda found the exercise helped her to see the breast cancer as something that she wasn’t responsible for.

Tania said, ‘*Cancer has arms everywhere. It affects many things. Danger. Tentacles that get in everywhere. Not like a cold you can forget when it is over. Fingers invading everywhere*’ (See Annexure E). She added afterwards that she had never tried to think of breast cancer’s form before our exercise. ‘*You just know what it means*’. She enjoyed the experience of giving the breast cancer a face.

Noriko appeared very eager to draw the face of cancer. She later explained that it was not a new image but rather making visual one that she already had. ‘*I was lying there during radiation – thoughts run through my mind – almost like there is a little*

Pac man going on inside. I suppose I would be the game. The black line is my body, and everything inside me' (See Annexure F).

Karen never had the opportunity to draw an image but we did discuss what her picture would look like. She was very clear that it would be a black and decaying body cell.

Hinz (2006:12) believes that images can become a 'midwife' between experience and language and the externalisation exercise did appear to facilitate an awareness between the experience and language of breast cancer.

4.4.2.2 Externalising breast cancer through metaphor

*'The first thing is an awareness that you are up against a life-threatening assailant' -
Moira*

Section 2.2.4.1 details the importance of metaphors in narrative practices. During the course of this research, several metaphors were identified by the participants as being representative of breast cancer. Moira named breast cancer '*unwelcome assailant*'. She elaborated that '*Suddenly this assailant has found a presence, found a place, a foothold. It's quite subtle.* She also named her experience around this assailant. '*The very first thing that happens is fear. Fear comes and then you are working with the fear rather than the assailant. I was working with the fear, because very quickly you have to deal with that. I'm not a person who wants to live my life out of a position of fear*'. She referred to the breast cancer as an assailant for the rest of the research conversations.

Lynda has experienced breast cancer twice and she commented on how each one had been different. She named the first experience of breast cancer '*a lump*' and '*then it was gone*'. Her experience of the second diagnosis was very different. She called breast cancer '*it*' but she was very clear about what '*it*' was doing inside of her. '*I was aware that all of a sudden it took on a form, it was eating away at my bones and making a meal out of my body*'.

Noriko described cancer as *'an unwanted guest that you didn't invite. They invited themselves'*. She shared that, as a result of the cancer in her life, *'I sometimes feel that I am a spectator. I'm not in denial and I am free to talk about it [lung and breast cancer], but there is a part of me that is struggling. Not often. Sometimes a snapshot while I am driving. I never saw myself here'*.

4.4.2.3 Chemotherapy gives birth to 'illness'

'You function, but there is no quality of life while you are having chemo' - Karen

I was intrigued to read in Weingarten (2000, 2001) and Frank (1995) that the side-effects of the medication informed the realisation that you weren't well.

Each participant experienced side-effects differently but those who had experienced chemotherapy were unanimous that the chemotherapy treatment for breast cancer was the reason for experiencing illness in the way they each did. Lynda felt that, *'It's the treatment that makes you ill. They cut the cancer out – it was gone. It [chemotherapy] makes you very tired, and I do get breathless.* She recalled that the first time, *'I really was sick on that chemo. I didn't feel 100% normal until I stopped that medication'*. Karen shared that *'Chemo and radiation were absolutely horrible. Four years later I'm still trying to get back. The chemo made me lose confidence. My hair was thin, mouth sores, gaining weight, rashes. For two weeks of the month I suffered from these rashes, you start to get better and then you have to go for the next treatment. I can still remember the taste of the chemo tablets. The chemo is the pits'*. Tania remembers that her skin felt *'like paper-thin and everything is sore. You just get tired'*.

This concludes the medical aspects of the breast cancer and research journey. It is important to reiterate that this document is not able to detail the entire stories of each participant and therefore has chosen to use experiences as themes.

The next section explores the effects of breast cancer on life-giving relationships.

4.4.3 The effect of breast cancer on life-giving relationships

All aspects of life are lived in community with others. In 'Making sense of illness narratives' (2001:119), Kaethe Weingarten states that *"fighting cancer is a full-time job. It's also lonely"*. The notion that a journey with cancer can be lonely led to an exploration of five life-giving relationships, namely family & friends, husband, daughter and self to learn how breast cancer might have influenced them. The first relationship to be explored is that of friends.

4.4.3.1 The friends and family

*'Most people can cope with the fact that you are ill, but not that you have cancer' -
Maira*

Maira expressed a sentiment that the other participants shared, *'People are afraid of cancer and often they are not sure what to do with you. The cancer issue doesn't figure in conversation. In many ways it is a solitary journey'*. This resonated for Lynda, *'it [breast cancer] can become a very lonely place, if you let it'*. Tania said, *'Some people don't want to be around you. They distance themselves. You learn who your true friends are'*. There were, however, exceptions to this understanding. Maira felt that, *'It also speaks of the kind of silence that surrounds cancer and the fear. People speak about it by not speaking about it, but by speaking about how they feel about you. It makes people give voice to their love, but they don't talk about cancer'*. Tania agreed with this expression of care from others. She recalled that *'Some stepped forward. I have never felt so cared for. It was an awful year, yet the best year of my life. I have never felt so loved'*.

4.4.3.2 The husband

<p><i>I imagine that this is a very difficult relationship to bring breast cancer into. My assumptions are that it changes the dynamics of intimacy, for both husband and wife, and that breast cancer's very presence necessitates changes in the familiar marriage roles.</i></p>

Maira felt that *'I'm not sure whether it influenced the relationship, as much as influenced the individuals. Cancer has influenced me and it has influenced my*

husband, put him in touch with how he feels about me and how he feels about life in general'.

Noriko said that her husband's understanding was one of the things that comforted her. She felt *'free to feel however I feel with my illness without him imposing his feelings on me. I can be honest, and that doesn't put added pressure on me'*. Tania was very clear about what her relationship with her husband Gavin was like during her journey with breast cancer, *'Gavin and I are very different. I'm the emotional one, and Gavin is the thinking one'*. She remembered thinking, *'Whatever he is going through I don't want to know because I can't cope with his emotion right now. He was very practical and for me that was very helpful. We didn't speak about it'*.

The Husband's voice

'I could feel a sense of loss' - Gavin

He spoke of his role as being an insensitive one *'to keep her going. I would keep her doing what I thought would be the best life-giving opportunity for her. Emotionally her journey was with other people. I didn't define my role as an emotional support. I wasn't there to process emotions. I would provide practical care, pick up any slack while she wasn't feeling well, take over the house duties, keep things going... I don't think I am unemotional, but I'm not driven by emotion. Has Tania felt that she can't explore her emotional life? I think she has felt that'*.

Lynda, on the other hand, shared how her husband *'battled to deal with the cancer. He never came with me to the doctor. My husband is afraid. I can see that often he is fearful. He keeps saying please don't die'*. *I was angry at Ian because he did not support me. He never asked how I was feeling. He never came with me for'*. In a later conversation she shared some of her frustration around his reaction to breast cancer. *'He didn't know how I felt. I never ranted at him – but I just expected him to want to. This time I asked him if he wanted to come with me. It was ok if he didn't, but I wanted him to be honest with me. He didn't want to do it. I realized that if you don't tell people how you feel, they won't know'*.

I was very curious about how Gavin (Tania's husband) being a Methodist minister might have influenced their roles with regards to cancer. My assumption was that two people of faith, one being a minister, would share their struggle with breast cancer together in their expressions of faith.

Tania was amused but said that, *'Gavin wasn't my minister. Gavin has never been my minister. He's my husband. We don't find God in the same places. We lead very private lives religiously, because I think we are so very different'*. Her needs from Gavin during that time were, *'that he allows me just to be and not to try and be something that a minister expects me to be. It gives me freedom to not be religious all the time. It gives him the freedom to not have all the answers. I'm not going to go to him for counselling. That is not the roles that we need for each other'*.

4.4.3.3 The daughter

All the participants have daughters. I was curious what sharing a journey of breast cancer was like with them. Karen recalled *'My one daughter was in the UK, she is a drama queen. We told her afterwards. My other daughter was at boarding school. She was very protective of me. Noriko has a young daughter of four and she admitted trying to 'downplay and appear as normal as possible but at the same time being open and honest about my disease in a way that she could understand'*. Tania reflected on the decision that she and Gavin had made about telling their young children about breast cancer and how important it was for her that they be allowed to ask her any questions that they might have had. In one of our conversations I asked her what her oldest daughter would say about her and the journey with breast cancer. *'That I'm doing ok. I want to be a good mom and to know that I am making a difference in their lives'*.

The daughter's voice

'Going on this journey just bonded us even more' – Sandi

Sandi recalled how close she and her mom had become. *'Our relationship grew beyond words. I realized how much I needed her in my life and my girl's lives. Life without her would be unbearable. We all chose to support her and fight with her. She is a hero to all of us and everyone she crosses paths with'*.

4.4.3.4 The next generation

Karen discussed how her daughters *'live with the thought that it comes from both sides [paternal grandmother died from breast cancer]. They are so different – the drama queen went for tests to see if she had the gene, and the younger one got an insurance policy. The older one was going to have her breasts removed if she had the gene, but fortunately she didn't. The younger one has decided not to find out. I worry about them'*. Lynda shared this sentiment. She said *'it really niggles at me. If I was tested positive for the Braca gene, my girls could go and have testing done. They could make educated decisions. I have got three girls. For me it is very important to identify that gene if it is passing on. They said they would just have a mastectomy. It wasn't emotional for me because I was older. My one daughter has just turned 35, but by 40 they need to make a decision'*.

The daughter's voice

'For me, it has made me realize that if I could take a preventative choice I would without a doubt choose to have a double mastectomy. I would not be afraid or feel less of a woman because I'd at least have life. My mom is living proof of this. She is more beautiful to me than ever before'.

4.4.3.5 The body relationship

Griffith and Griffith (2002:264) believe that disease can *"transform one's body into an alien and threatening presence"* in as much as the body's predictability of function is diminished.

This was one of the hardest experiences of this research for me. I bring to this research my own image of my body constituted on its physical attributes and cannot imagine an image without my breasts in it. I wonder what breasts mean to the participants? And what the significance of the breasts are to various relationships? I decide to be aware of Henderson's caution, in Moessner (1996:219), to assess my personal thoughts and feelings regarding body image and the significance of breasts to a woman's identity and function. She maintains that this self-awareness increases the ability to work through some of one's own prejudices or stereotypes that may inadvertently prevent effective pastoral care.

4.4.3.5.1 Significance of breasts

Breasts are very visible signs of womanhood and, as a result, are simultaneously private and public. You don't have to look too far in magazines or on television advertisements to realize that, as Henderson, in Moessner (1996:215) suggests *"we are a culture focused on women's breasts as important symbols of womanhood or femininity. From even before the onset of puberty and into mid-life and sometimes beyond, girls and women are measured by themselves and by others on their breast size"*.

In our conversations, Moira expressed that the downside was that *'the cancer took out the one part of my body that I did love. I've always celebrated and enjoyed my upper body. I have breasts that have always been small, so my breasts have never drooped and I have very good boobs for a woman my age. Now they [breasts] are still ok, but the one is scarred, quite badly, even though there was a reconstruction. So I don't enjoy them like I used to'*. When I asked about 'femininity' she replied, *'I am still trying to figure out how to recover those feelings that I have about my femininity and how I feel as a woman. The fact that the cancer went there [breast] was hectic for me'*.

4.4.3.5.2 Changes to Breasts

'The gravest part in the suffering is the mutilation of the body' - Moira

Henderson, in Moessner (1996:212) suggests that: *"Nothing about the picture of breast cancer is pretty or nice. Even though facing breast cancer is an enormous crisis that may shake all the foundations in a woman's life, she can possibly emerge more aware of her femininity and her personal power as a woman – with or without breasts"*. I was curious about what the physical change was like for the participants and how it has changed their relationships with their bodies.

Lynda was the only research participant who had had a mastectomy. Each of the other participants had had the cancerous tumours removed and Moira and Karen had then elected to have reconstructive surgery afterwards.

Moira was the participant most comfortable with talking about her changed relationship with her body. She found the invasiveness of the treatments very difficult. *'It's all very traumatic physically. The scars and imperfections are there forever. The damage from radiation is there forever. There is a heightened sensitivity around the nerves and muscle tissue where radiation occurred. Now I am aware that I carry a wound in my body to remind me of my mortality'*. She suggested that it was *'learning how to live life fully with less perfection'*. She felt she was able to do that, *'By not complaining about my body and not being angry with my body, being in my heart grateful for the body that God gave me and its capacity to be on my side around overcoming. I have a tenacious spirit and a tenacious body. I need to be in a partnership with my body. I do things that make my body feel better.'*

Lynda added that she has a *'protective feeling towards my body'*. She recalled how, after her mastectomy, *'I came out of hospital and I had two scars across here. I worried more about what my husband would feel. I would have felt rejection from him. After I had the op I didn't like to get undressed in front of him. I noticed that he battled with it. If I was in the bath, he didn't look at my body. I made the right choice to have reconstruction. My boobs are not perfect, not lovely, and not even attractive without a bra. For me I just draped scarves and put brooches on. It was not about my body, it was about realizing that you can go through this and you don't look mutilated'*.

Karen admitted to struggling with her body image. *'I have new sixteen year old boobs...'* yet, *'I feel so out of touch with my body. I don't feel like me... I don't know me right now'*.

Noriko mentioned that having a lung removed had an impact on how she viewed her body. *'When I got home, I felt a sense of loss. I felt I was a shadow of the person that had walked out. I didn't recognise myself. I had changed physically but losing a breast would have affected a different part of me. I didn't want to deal with having something outward removed. I had concerns of it affecting me as a person, my marriage, so that diagnosis affected me more physically than the lung cancer'*. She added that although she had always been confident in her competencies intellectually, physically she wasn't.

The decision to excise the breast tumour has meant that one of Noriko's breasts is now significantly smaller in size and has aged in appearance. She shared, however, that this doesn't evoke any anxiety for her. In her own words, *'I'm comfortable with the scars. It is a testament of what I have been through'*. Her husband shares her sentiment. He has asked her to show the scars to a family member or a friend as a way of recognising the courageous journey she is on. One of the frustrating side-effects of treatment that she has experienced is getting acne on her face. *'I now apply make up every day'*. She said that the removal of her right lung had left her feeling robbed. *'I can't be as active as I used to be. After 5 months I still get sore, and I don't know how long it is going to take me to heal. Still discovering what a major change is was for my body.'*

Tania felt that the damage to the outward appearance of her breast was never an issue. She said that, *'I don't know if it had happened it would have become an issue, but at that stage it was just do what you have to do. I'm not very big so if they had taken one off, it would not have been that noticeable'*.

4.4.3.5.3 *Crowning glory*

'It was like looking at an alien being in the mirror' - Lynda

The loss of a breast is often not the only physical loss accompanying breast surgery. Some chemotherapy treatments cause a woman to lose all, or part, of her hair as one of the temporary side effects of the powerful drugs taken to stop the cancer growth. Henderson, in Moessner (1996:214), writes that *"it is common for women to report a sense of devastation and powerlessness as emotional reactions to the physical loss of hair. Many women initially grieve their hair loss more than the loss of a breast because it is so exposed, whereas breast loss can be kept hidden at least from the public eye"*.

Lynda remembered her first journey with breast cancer and seeing her hair all over the house. *'It was like losing a part of yourself. Especially for women, your hair is so much a part of who you are. It got thinner and thinner and eventually I cut it'*. She experienced the chemotherapy effects differently the second time around, *'It [her hair] just came out. I had little bits of hair everywhere – like man's beard.'*

When you look in the mirror you are completely bald, and you have no eyelashes and eyebrows! The first time I never lost my eyelashes and eyebrows'. She recalled that she didn't recognise the person in the mirror and that it was a strange feeling. Tania remembered 'waking up in the morning and your bed's full of it – you wash your hair and handfuls come out. You know it's going to happen, but you think maybe it won't'.

4.4.3.5.4 To cover up or not?

'For me there was no pleasure in looking ill' - Lynda

My assumption was that women would prefer to cover up the 'nakedness' of their illness. Lynda said that she went to work without a scarf, unless it was cold. She shared that, *'I thought I don't have to be a victim. I didn't enjoy looking in the mirror and seeing this faded, sick, pale thing, so it was important for me to wear makeup. I couldn't wear mascara, so I would just put eye shadow on to be as normal as possible'.* Tania, a school teacher, recalled that her daughter's response to her hair loss had been a deciding factor on how she managed her appearance. *'Mom you are not going to school with no hair'.* Tania bought a wig and wore it every day. *'It was revolting. I think also because I had just lost my hair, my head was very sensitive and to walk in the wind hurt. I'd go into the bathroom at school, take it off and scratch'.* With her daughter's agreement, she never wore it again. Tania remembered that the children in her class *'wanted to see what was underneath [the wig], so for them it was fascinating. They are so accepting. With them it was easy'.*

At the time of this research report, Noriko had not yet had any chemotherapy but it was something she was preparing herself for. *'Physically I am not looking forward to my disease being on show or being visible to everybody. Right now I look normal – some know and others don't'.* Her thoughts on potential hair loss were that she wouldn't wear a wig. *'I'm going to shave my head as soon as my hair starts falling out and I'll wear scarves to work'.*

4.4.3.5.5 Sexuality lost and found

'Physically, I had sex appeal' - Karen

An important role of the breast is that of a sexual organ. Nerve endings in the breast and nipple can be important sources of sexual pleasure and stimulation for women. As a woman I had some questions of my own in this regards. Did the participants wonder whether their partners would still find them desirable and attractive? Did they themselves still feel like sexual beings? What constitutes sexuality? How is intimacy different? Some of the responses have been included here in order to provide a thorough exploration of the participants' experiences.

Karen described 'Sexiness' (her words) as a feeling of confidence that emanates from within. *'My boobs were a part of my sexiness. I lost all sensation in my breasts – the reconstruction was good but the sensation is lost'* and that part of her 'sexiness' had been lost too. The weight gained as a side-effect of medication, has also robbed her of her 'sexiness'. Karen has been divorced for many years and she does worry about the sex-appeal she now has for forming any new relationships. Noriko remembered wondering if her physical relationship with her husband would change. There was *'no pressure on me for intimacy, and it just happened naturally'*. She also mentioned that she was still sore, at times, to be touched and that this has meant that physical adjustments have been made in order for the intimacy to be present.

The voice of the husband

In your own mind you know what is important, what is not important - Gavin.

'What is it about Tania that I love? How important is the firmness of one's body, whatever is appealing to you about the feminine? Where in this is the meaning of her being who she is, and her responding to me? The challenge was what is essential to sexuality, being feminine, what society tells you is the essence of that. How important is my body? Tania has always been quite comfortable with her body, so to have a lumpectomy etc, it wasn't the end of the world. Not something of shame. There is no attempt to hide, not talk about it, or go for corrective surgery – let's move forward'.

4.4.3.5.6 Honouring the loss

'Cancer keeps me on my knees' - Lynda

Henderson, in Moessner (1996:217) suggests that women need to honour the loss of something very sacred (the breast) and recognize the grief that is a normal response to that loss, while at the same time move towards an awareness of the holy that allows for and embraces imperfect bodies as also being sacred and sexual. It also involves redefining womanhood and femininity to be inclusive of loss.

Lynda felt that *'Cancer is big and I am reminded every day, especially now that I have had this op, my body is not what it was and I am aware of it all the time'*. For Tania, her scars are proof that she is here. *'I have a constant reminder. There is always that knowledge that cancer was there. I really find it a miracle. My baby's birthmark is in the exact same place as my cancer scar'*.

4.4.3.5.7 A surprise pregnancy

'You're pregnant' - Tania

My assumption from literature reviews and conversations with participants is that pregnancy, after breast cancer, is not possible. Tania recalled not feeling well, *'I missed my period so I thought perhaps this was early menopause, as that had been a possibility'* and thinking that *'it's only been two and a half years since my chemo, can I be pregnant if I still have all these poisons in me? I was very nervous – you read that pregnancy could trigger it [breast cancer] again, due to increased hormone levels and all that kind of thing'*. Tania admitted that she eventually stopped reading things. *'Gavin was concerned that there was going to be deformities because of my radiation and what it does to your body. And my son was convinced that I was going to have a red baby, because I had red chemo. "How do you know what colour this baby is going to be, mom?" I just knew that whatever happens I'll deal with it. Both my gynaecologist and oncologist were very positive'*.

The husband's voice

Gavin felt that having Gaby after cancer was probably the most feminine restoration for Tania. *'It was a catalyst for her own thinking in other issues of her sexuality and femininity. Her pregnancy and Gaby's birth was the peak of that journey.'*

Henderson, in Moessner (1996:218) maintains that *"Part of the bittersweet ritual of letting go of her breast, for mothers who breast-fed their children, often include reawakened memories of the specialness of breasts in their identity as a nurturer-provider"*. I asked Tania about the likelihood of breastfeeding after breast cancer. Tania's baby daughter *'fed happily for 3 months from the one side'*. Tania had breastfed both of her older children and it had been important that the new baby have the same bonding with her. She felt good about being able to achieve this.

4.4.3.5.8 A journey into menopause

'I wasn't ready for menopause' - Karen

Hormone suppression, prescribed at the end of chemotherapy and radiation, is used as a preventative treatment to shut down oestrogen production and therefore the risk of the breast cancer returning. This journey into menopause was an unpleasant experience for all the participants that required this treatment. For some of them, this was a return to a life experience previously induced by nature. For others, it was the early loss of another part of their femininity. Karen said that she wasn't sure that she was *'ready for menopause. I didn't get to build up to it or prepare myself for the end of this part of my life. I feel as if it has been forced on me'*. Noriko, being the youngest participant at 34 years of age, only has one young daughter. She shared her sadness, particularly in light of how long it had taken her to conceive her daughter, that there would be no more pregnancies. In her own words, *'We could just ignore the doctor's recommendations, but it is a risk we don't want to take. It is also not fair to have kids and then realize you might not be here. We have accepted this, and are looking at other options'*.

Tania was the exception. Her breast cancer was 'oestrogen-receptor negative' and didn't feed off of oestrogen.

This meant that she hadn't required any medication after her treatment. *'I did have to go off the pill though and I cannot have hormone replacements because it is a risk factor'*.

It appeared that breast cancer did indeed influence life-giving relationships in various ways, some anticipated and some unexpected, such as relationships with friends and family.

The following section explores the role of spirituality and faith in the lives of the participants.

4.5 THE ROLE OF SPIRITUALITY AND FAITH IN TIMES OF ILLNESS

One of the objectives of this research was to explore the role of spirituality and faith in re-authoring alternative stories of illness and breast cancer. Griffith and Griffith (2002:8-9) suggest that *"Medical illnesses display the dirty laundry of religion. It is not just that an ill person's faith is challenged – can he or she keep faith alive in the face of disease, pain and disability? – But that the wisdom of following a religious tradition can become uncertain. There are many ill people who find comfort, understanding, and meaning in their relationship with their God whilst yet others feel abandoned by God, feel guilty for having become ill, or neglect their health by adhering to religious beliefs or practices. Clearly religion can both harm and heal"*.

Griffith and Griffith (2002:267-268) write that spirituality helps keep strategies that can buffer existential crisis stages centre-stage. They suggest that it sustains *"hope, purpose and self-agency. Through these links religious beliefs, spiritual practices, rituals and other expressive genres of spiritual experience can play a role in countering illness"*. In the context of illness, Griffith also maintains that *"spirituality provides human beings with a repertoire of methods to keep disease in its proper place, yielding no more influence"*.

Fowler (1995:14) believes that faith is a universal feature of human living and this research is curious to explore the relationship between spirituality, faith and illness stories.

My reflection:

I was aware that, as this research participants are all part of the local Methodist Church community, there was a common religion, an existing faith story and spiritual relationship with God in each of their stories. I was curious to discover what their image or picture of God was like. I also wondered what impact breast cancer had had on that relationship, how each participant viewed the meaning of suffering and how their spiritual relationship with God may have played a role in their breast cancer stories.

4.5.1 Images of God

'God is someone who I grew up with' – Noriko

Picturing what God is like refers to the ideas and images we have about God and deeply influences the way that we relate to God (Hughes 1985:34). I wondered how the participants pictured God as a result of breast cancer and illness and the changes it brought into their lives?

Moira's image of God was developed before cancer was around. She shared that when cancer arrived, *'my image of God was confirmed and endorsed as "the right image of God". The particular qualities and characteristics that I assigned to God from my life story came into play'*. She believes that, *'God has my best interests at heart, he cares about me. He is present not only every day and when things are going fine, but also when things are not going fine. He goes before and comes behind, and takes an active part in my life story'*. Lynda's image is of God still being in control but that she didn't see him as a *'magician with a magic wand who is just going to make me better'*. For Noriko, my question about an image of God was harder to answer. She doesn't have a picture of a person. *'I associate it more with feeling, not a picture. It's the same feeling that I get from my mom; that feeling of a cross between a parent and a friend, a warm and fuzzy feeling. It's the life I have known. God has always been a part of our lives; it's how we were brought up. That is why I have that kind of relationship – God is someone who I grew up with'*.

Tania said that, *'I have a more nurturing image of God than I previously had. I believe he is a God of love and if I can love my children and be prepared to do the type of things I am prepared to do for them, how much more is he prepared to do for me'*. She shared with me a story of abuse by her father and how that had informed her image of God until she had spent time in counselling with Rev H.

4.5.2 Did breast cancer change your relationship with God?

'I never knew how to listen to God' – Lynda

Lynda believed that her relationship with God really changed as a result of her second experience with breast cancer. *'My relationship with God made the difference. When you spend more time with God, you hear him more'*. She shared that *'I didn't make a single decision without God confirming it through somebody or something. It was about asking him for strength to cope every day, to get out of bed in the morning. It was strength to face every day, to glorify him and be positive. I just asked for a day at a time'*. For Karen, her experience with breast cancer was the start of *'going to church every Sunday. It became a huge comfort, also a way of release'*. She was intrigued at the way in which each sermon appeared to have been written for her and this brought the comfort she received. Noriko experienced a deeper insight of God's hand in her life – evidence of Him going before her in this journey in order to prepare. She said, *'The one question I have struggled with is that it must be happening to me for a reason, and I'd like to know what God wants me to do. I don't have that answer yet'*. For Tania, it was *'like a continual conversation and I had a greater awareness, a greater dependency and a reliance on God more consistently than at any other time in my life'*.

The husband's voice

'I think it just deepened my sense of gratitude' – Gavin

I was curious to explore how breast cancer might have affected Gavin's faith and spirituality in his roles of husband and Methodist minister. *'My faith journey is lived out in the presence of those closest to me.'*

I realized that I under-valued, under-affirmed, under-appreciated, under-nurtured, under-celebrated my relationship with Tania. There was a confession of that, an awareness given'. In terms of his own faith, Gavin explained that, 'My faith is not about religious experiences. I don't define my faith by how much I pray, or come to church. There is a secularization of the religious. God is in the secular, God is in my relationship with Tania. Being a husband is sacred. That is where I find meaning. I find God's kingdom in the way that I love Tania. I'd rather be human, and leave the religious stuff to other people. Even when I came into the ministry, I didn't have religious experiences, speak the religious language – if more ministers were in touch with their humanity, the ministry would be a better place'.

4.5.3 What is the meaning of suffering?

'This [breast cancer] is not God's plan for my life' - Moira

Yancey (1990:199-200) describes suffering as “*meaningless in itself, and will remain so unless the sufferer, like a miner searching for diamonds in a vein of coal, finds in it a meaning*”. The term ‘theodicy’ is used to refer to a search for God’s goodness in the face of the world’s evil by asking the central question of a theodicy: Where is God in suffering? Moschella, Pressman, Pressman and Weissman (1997) found, in a study, that the majority of the respondents believed that God had a reason for their suffering, although the reason was unclear and could not be explained. In many theological theories about suffering, two main assumptions emerge, namely that suffering is necessary as a path to God or to reveal God and, secondly, that utter estrangement between God and humanity leads to suffering (Tatman 1996:11). Louw (1985:35-36) insists that God remains faithful in suffering and that God leads us to his will through suffering. Thus the question might not be why we suffer but rather how we suffer and with whom, so that we may transform suffering into a therapeutic process from resistance towards renewal.

My reflection:

In my own life, my experience of pain is frequently a catalyst for change and growth. I realise that suffering can become a site of transformation when it is brought into the presence of the God who knows my suffering.

All of the participants agreed with the ideas shared in Moschella et al (1997) and saw suffering as necessary. For Moira, it was as clear as, *'That is how I make meaning of suffering. Suffering is for now, but we are being forged for eternity'*. She never had a sense that her journey was about being healed but, rather, that she *'had to walk a road. I didn't feel marginalized by God because God has my best interests at heart. He was going to speak to me in a special way'*. She added that, *'We have to suffer in order to apprehend not suffering. It's a spiritual law'. 'I chose who was going to partner me in my fight against cancer. I think that cancer has a profound way of usurping God's position in others'*.

Noriko remembered her frustration with the breast cancer diagnosis so soon after receiving the lung cancer diagnosis. She said, *'I felt that God over-estimated what I can manage. I believe that God doesn't give you more than you can handle, but at that point I felt he thought I was stronger than I am'*. Noriko was quite certain that she might never get the answer to whether or not illness comes from God in her life time. She was quite adamant, however, in her belief that there was a purpose for her suffering. *'If I had smoked for many years, then I might have felt it was my own choice and I have to deal with the consequences. He must have a purpose for allowing this and needs me to do something'*. It meant that *'...all of this [cancer] is not for nothing – some good will come out of it. It doesn't comfort me, it doesn't make it ok, it gives it [cancer] meaning'*. She has been seeking that meaning since the cancer happened. Eventually she shared, *'Maybe my experience will come in handy in life and in the lives of others'*.

Tania's thoughts were that without suffering you *'might live too casually. You don't treasure the good times. You don't live intentionally. I think suffering is a necessary part of life, hard or not. There were times when I thought there was something I had to learn from this, just tell me and I will try to learn a little quicker!'* It was that she wasn't going to *'crumble and die which was my first reaction when I heard I had cancer'*. She had learnt that *'I have strength, through **him**, that I don't have, and whatever comes my way, there is good in it and I will make it. In the horrible there is always something great. I have made some very special friends through their support of me and my kids. I try not be consumed by the negativity'*.

The minister's voice

'Suffering is real, and you can't always pray it away' – Gavin

One of the meaningful opportunities that Gavin's participation presented me with was being able to speak to him both as a husband and as a Methodist minister. I was therefore curious to find out what his thoughts were on suffering. As a minister, he said that, *'One of the biggest things with conflict within Christianity, in terms of suffering and healing, the reality of suffering, is that Christ frees us from suffering and healing becomes a possibility. What would God want healed? Christ and the Kingdom of God is characterized by the absence of suffering. My difficulty with that is that the journey of Christ; his message, was that in suffering he was raised. In this life there will be a victory in the presence of suffering. I'm not scared of suffering; I don't try to live absent from suffering. Suffering is part of my bodily existence, and everybody else's. For me the search would be where is God in the presence of suffering? The suffering will never negate his presence. It's not an enemy, it's limiting, obtrusive, but in all there is an opportunity to discover there is something bigger. When you discover that, you live. As I have journeyed with people you see that in the end we will all die. So, when people do die, for me to be witness to the life choices that people make in dying, has convinced me that God is present in the midst of suffering. Life is given in the presence of suffering. It's tangible. Suffering can be a great teacher. In suffering you can discover life'*.

The husband's voice

'Cancer threatened her life, but also gave her life' – Gavin

He remembered that, *'People expressed their love for her – rallied around her. This humbled her. The suffering in itself is life-taking, but it exposes the opportunity to see life greater than the suffering. Had Tania died of cancer, there would have been a victorious note. The fact that she survived it erased the victorious note. I don't expect a suffering free world'*.

4.5.4 A mention of healing:

'I had been for prayer' – Moira

Only one participant brought up any reference to physical healing. This encounter of Moira's was the one exception. She recalled *'lying there and I am thinking what if he can't find the tumour – say I have been healed? Then I had this dodgy moment. Because my tumour is so small would I ever believe that, or would I always believe that I was healed, or that he didn't find it. So I thought "Lord you have to deal with this one. I'm confused. One side of me wants to believe I'm healed, and the other is scared to believe I am healed, because I won't believe that he wasn't incompetent". Dr S actually battled to find the tumour on the sonar. I never had a sense that this journey was about being healed. I was on a journey. I had to walk a road. I don't feel marginalized by God because God has my best interests at heart. He was going to speak to me in a special way'*.

4.5.5 Thoughts on death & dying

'I don't think about death from cancer. I know it is going to happen' - Lynda

For Moira, the fear is not about dying but about the fear of suffering. She maintained that living with illness has consequences and, for her, *'The consequence is called suffering'*. Lynda chose not to *'get up every day and think it's going to kill me. I don't want to die in the near future – I want to see my grandchildren and be part of their lives. I do ask for that'*. She was very earnest, *'I don't think about dying from cancer. I don't think about how I will die. But I do ask if there will be enough time to say goodbye to my children'*. She admitted that for her, too, there was fear. *'Do you know that you are going to heaven? I wonder if my past sins are forgiven. I hope the cancer does not manifest somewhere else. I am anxious about the next scan, after them discovering the hot spot in October – I don't want this to go anywhere else'*. As with Moira, Lynda's fear is concerned with suffering.

For Noriko the reality is *'that I could die. It's a fact. If you have a terminal illness, you can die. I can talk about death, and it does mean a little bit more to me than before'*.

She added that, *'This disease is so scary because it is associated with recurrence and death. I really struggle with the possibility of not seeing my daughter grow up'*. She ended that conversation with this statement, *'Even if I had to die next year, how I live the year in between - I won't let the cancer get in between. How I deal with it, mentally and emotionally, more than physically. I live a healthy lifestyle, a balanced diet. I can do lots mentally, and that is the fight I have to fight. The doctors can fight the physical side'*.

4.5.6 When breast cancer takes a life

'She knew that she was always fighting for time' - Tania

One of the realities I recognised as I entered into this research was that breast cancer can claim lives. Indeed, one of the participants, Jennie, was re-admitted to hospital and passed away before our conversations could begin. Jennie's daughter had begun conversations with me about what it was like to witness, and live with, her mother's cancer. She declined to continue our journey after her mother's death.

Halfway through our research conversations together, Tania experienced the loss of an acquaintance that had fought a long and hard battle with breast cancer. We talked about including her experiences of that time into this research. She was very emotional and shared that, *'It feels like what I went through was a farce. I feel like I never fought cancer. I just fought chemo. How does hers figure? How do you leave children? It's been a big question week. I have more questions than I have answers. I can't believe that God would give me my baby girl to take me away from her.'* She added that *'I always had the best case scenario. It's like I never had cancer. It was something they called cancer – they cut it out, they gave me medicine, and it was over. I don't feel like a cancer patient. She knew she was sick. I just knew the medicine I was taking was making me sick. Having Gabriella was always a sign that it was over. My body was healthy, I had this baby. Surely I wouldn't have a baby to be taken away again. Yet there is no guarantee'*. She held a sadness at the loss of a mother, *'As a mother you need to be there for your children. There are no guarantees, even if you have young children. I know I can have a car accident, but this is something – why wasn't she cured? What stops me from going the same road?*

When you have an accident you don't know you are leaving your children. She did. How do you deal with it? When I asked him how the kids are? He said "they are ok, but I'm going home now to ask them if they want to see her one last time because I think she is going to die today". How do you do that? How do you be strong for the children and yet be real for what you are going through?' She went on to say that 'It's the unfairness of it all. God is father – why does he take away a mother? That has been the biggest question. What do you hold onto? Why is there no intervention at certain times? Why am I fine and she wasn't? Who decides? I don't feel angry. I'm so sad that there is unnecessary suffering'. This statement seemed to contradict her thoughts that there was indeed a meaning to her suffering (refer paragraph 4.5.3). Tania experienced it more like 'self-pity sadness'. She shared that 'There is that mother in me that cries for those children'. We explored Tania's need to be around for her children's milestones, the teenage years and the toddler years, and she shared her need to watch her own children grow up and see who they become.

There was new meaning-making around the notion that we do not always feel the same and that there are times, such as in the loss of another, that our own mortality is again faced. Tania mentioned experiencing a sense of guilt over surviving when another woman and mother didn't.

4.5.7 Holding on to hope

Weingarten (2010:11) suggests that hope confers survival advantages. I was curious how the participants experienced hope alongside breast cancer.

A letter from a Methodist minister living with cancer

'My hope is like a WASJIG puzzle' – André

André shared his picture of hope with me just a few weeks before his death.

'I admit that at the moment I am a little addicted to the WASJIG puzzles - where you don't get the picture to build (copy), but where the picture given on the box is a clue to what the completed puzzle will look like. There were some things that struck me about puzzles, WASJIGs and hope:

The first thing is that I realised that I have a certain way of approaching puzzles that sometimes doesn't work... I start with the border first so that the parameters are set.

I am searching for hope inside the parameters of my cancer and my faith - I still have those two things in my hands and will continue to hold them together, whatever the news, prognosis or outcome. The one speaks to the other and my life is now lived out in their interaction, one way or another, like it or not.

Perhaps hope is built on facing what's in front of you in the belief that it will give you what you need to face the next part of the journey. However, putting this down in words, I see that I have once again reduced hope to outcomes: "If I can... then...". Can we divorce hope from outcomes? I'm not sure that we can. Hope is about bringing our dreams into reality or having our needs met. It does require an outcome - a change in circumstance. However, it may be that hope is founded more on the PROCESS of achieving those outcomes than the outcomes themselves. As I complete each section of the puzzle I am one step closer to seeing what the final picture looks like. The parts come together in the whole. Life has given me these pieces and together with God, family and friends, I try to figure out what is happening - to find something to hold onto for the journey.

Noriko and I explored how there appeared to be two hopes in her life. The first one she mentioned included a hope that focused on the final destination she holds on to as a Christian. Hope is a *'powerful hope, not dependant on the cancer, or on how good my doctors are. The only thing you can depend on in life'*. The second hope was one in which she appeared to have a measure of control, *'If I make the wrong choices, it affects that hope. Fortunately there are things that are in my control, things that are left to free will'. Whether I am given a prognosis of 6 years or 6 months, it is still a hope that you have'*. This resonated with Lester's (1995) notion of a finite and a transfinite hope.

Tania's believed that *'Hope is the possibility of light out of the darkness. It keeps you moving forward instead of pulling you back. If you haven't got hope, how do you keep going?'* I wondered if, in light of this image of hope, the size of her hope had changed during the course of her treatment. She felt that perhaps she had just *'existed that year'*. She remembered, *'I didn't have big emotions most of that time. I was scared to feel anything. Hope had to carry on without me being truly present'*. Again, I was reminded of Weingarten (2010:7) who writes that hope can be the *"actions of one or many people"* and that hope is *"something we do with others. Hope is too important – its effects on the body and soul too significant – to be left to*

individuals alone. Hope must be the responsibility of the community" (Weingarten 2000:402).

The following section discusses some of the *"taken-for-granted realities"* (Zimmerman & Dickerson 1996:61) or discourses that were discovered during the research journey.

4.6 DISCOURSES AS BIRTHING PARTNERS

Weingarten (1995:7-22) suggests that: *"Discourse works through language and, through language it shapes what we know. In fact, a radical view of discourse holds that our conscious and unconscious thoughts and emotions, our sense of ourselves in the world, and our ways of understanding our relation to the world are constituted through language and discourse"*. Discourses, as discussed in greater detail in section 2.2.1.3, were indeed encountered during this research. These discourses were introduced into this research conversations by the participants, at various times, and were discussed or deconstructed as a matter of my interest and curiosity rather than with any intention of altering the outcomes of stories and experiences with breast cancer. Not all of the discourses discussed were experienced in a negative way by the participants. Some, in fact, scaffolded positive responses during the journey with breast cancer. In the following paragraphs, I will discuss some of these discourses, as well as the participants' responses to them.

4.6.1 'They say God doesn't give you more than you can handle' - Lynda

I asked Lynda what her response was to that. She was quite clear when she shared, *'I said enough now. Move onto somebody else. I've done my bit'*. She admitted that there were days when she found herself fighting this discourse that she otherwise chose to hold on to. Holding on to it keeps her from getting *'bogged down by the negative side of the cancer'*. Tania shared the same thought and meaning during her experiences with breast cancer. She replied *'I clung to that, even if I didn't believe it. But I needed to believe it. There was a plan and God would put people in my path when I wasn't coping'*. Discourse, as experienced by Lynda and Tania, can play a positive and encouraging role.

4.6.2 'You are being punished' - Lynda

Lynda had been told by a Christian colleague that she was being punished by God, *'he said that I must have been very bad in my life to be punished with cancer'*. She had never thought of it until that moment, *'He said that he thought that God had to teach me a lesson.'* Lynda admitted that *'That was much harder than the cancer'*. When we discussed why it was harder she felt that people have the power to hurt others far more than illness and disease.

4.6.3 'You reap what you sow' - Noriko

Noriko did believe that many actions had consequences and that *'I've always lived a healthy life'*. In as far as lung and breast cancer, she added that *'I still believe that you need to live healthily. We know that we get these dreaded diseases, no reason why. We don't have cancer in our family – I never imagined I would get it'*. After discussing how, with that understanding of people getting diseases for no particular reason, she might see that discourse as pertinent to her cancer journey, she felt that she couldn't. Lynda had experienced feelings of guilt around the diagnosis of breast cancer. *'You first think is it something I've done, did I eat wrong. You think about your lifestyle, even what you have done wrong'*. For both of these participants, this discourse had fleetingly introduced a question around their own complicity in the presence of cancer. Interestingly, this discourse then gave each a sense of agency with regards to the way forward and choices they needed to make.

4.6.4 'Out of sight, out of mind' - Tania

This thought was verbalised by Tania and Moira. Tania felt that the physical excision of the breast cancer tumour allowed her not to dwell on the presence of cancer. Moira's thoughts concurred with Tania's as she described the effects of living with breast cancer as *'I didn't think about it [breast cancer] – it was cut out and it's gone'*. Earlier, in paragraph 4.4.3.5.2 Moira made mention of the permanence of the scars and the visual reminder they were of the breast cancer. Whilst there appeared to be a willingness to acknowledge the scars as part of her journey with and survival of breast cancer, Moira preferred to think of the breast cancer as permanently gone.

4.6.5 'You have to be strong for everyone else' - Lynda

This was a sentiment expressed by all the participants. For Karen, Lynda, Noriko and Tania this was an important means of coping around husbands, family and children. Karen was very vocal about being *'the strong one in my family'* and feeling that no one else could have coped if she wasn't coping. For Tania it had been important to be strong in order to keep her children's lives as *'normal as possible'*. It was apparent, even in making treatment decisions, that life for their families didn't change much. For Lynda, this meant being strong for her husband who was struggling at the thought of losing her. She also has a sister who is living with terminal cancer. Each participant agreed that without it, they would have *'just given up'* and that, for their families and themselves, would have been disastrous.

4.6.6 'I want my life to be as normal as possible' - Lynda

Another shared discourse amongst the participants was the need for life to continue as normally as possible. For Lynda this was partly in response to not wanting to see cancer as a *'stigma or a disease'*. She said that *'Sometimes I would have to force myself to do things; to lead a normal life'*. Noriko maintained that she is not a sickly person and that breast cancer brought great frustration. *'I don't want to be Noriko – the cancer sufferer. I want to be Noriko who happens to suffer from cancer. Sometimes the concern from others implies that cancer is the first thing that comes to mind when people see me. There is more to me than cancer'*. In Noriko's case this meant choosing who to inform of her journey with breast cancer in her wider circle of work colleagues.

4.6.7 'God gives it to you for a reason' - Karen.

I have my own struggle around this sentiment and was therefore curious about the participants response to it. Karen said that *'People who survive cancer say that they are special'*. She shared that *'people said I was a lot nicer when I came out of it. I was a real bitch before, but my life has never been easy. I was tough. I was not the most compassionate person'*. She no longer saw herself that way. For Lynda it was a reason that drew her into closer reliance of God.

4.6.8 ‘My illness makes it more difficult for men to deal with me’– Noriko

Noriko was the only participant who shared this sentiment. She admitted that *‘My industry [civil engineering] is not easy to work in and when people are distracted by your gender, race or your illness, it makes it harder’*. She works in an industry in which her gender and race are an issue. It concerned her that after many years of hard work the cancer would overshadow her competence. *‘I’ve yet to be introduced to men in senior management who don’t react at all. There is always a reaction’*. She felt that breast cancer was *‘going to make other people [men] uncomfortable’*. *‘I want to be taken seriously’*.

4.6.9 ‘People expect you to be miserable’ - Karen

Karen recalled one of the biggest compliments she had (from the mother of a dancer receiving chemo) *‘She said that I am so upbeat and bubbly about the chemotherapy. I came away from there so grateful for what I am going through.’*

4.7 PIVOTAL MOMENTS

An explanation of ‘aha moments’ or pivotal moments is contained in section 2.2.4.3. For Duvall & Béres (2011:129) these moments can be considered pivotal because people undergo a *“shift in meaning during the experience”* which can result in a different view of themselves, others or situations. I had to wonder what pivotal moments could possibly come out of a life-threatening and life-changing experience of illness. These moments didn’t come out of any questions that I brought to the conversations and I was profoundly touched by the power of the ensuing moments, both for the research participants and myself.

4.7.1 ‘I’m deliberate around not empowering cancer’ - Moira

This sentiment, using different words, was shared by all of the participants. Noriko stated quite emphatically that *‘I don’t want my life to become the cancer. I don’t want it to take over who I am’*. Instead, she wanted to remain focused on who she is, on her talents, and to *‘continue to actively live. Cancer is not who I am. There is still a lot more to me, I’m able-bodied, a lot to offer and a lot to contribute. I need to focus on what I **can** do and not on what I can’t do’*.

Noriko stated that *'There are positive things that it [cancer] can add to my identity. If my experience can help somebody else in a similar situation, that is positive and how God could use me'*. Tania absolutely refused to *'give cancer centre stage'*. She managed to do this *'By not allowing it the prominence'*. Lynda used the following words, *'I never wanted the cancer to be the focal point in my life. It was something out of my control, but the things I could control – how I looked, how I behaved – for me was important. I used to make the effort, and sometimes it was an effort. But it was important for me... I think that helped me to realize that you don't have to give it so much airtime'*.

4.7.2 'I stopped waiting for life to happen' - Karen

This sentiment snuck in to our conversation when I asked Karen what the experience of breast cancer had changed in her life. As we reflected on her words, the idea grew. *'It taught me to stop waiting. I was always waiting for life to start'*. She had waited for the cancer treatment to end and then she had embraced travelling. *'Since then I have gone every year. It made me stop waiting - for the kids to grow up and my life to start. Now I say thank you God. Now I have opportunities. Travelling is doing what I most want to do'*.

4.7.3. Life is a journey

This metaphor was used by most of the participants to describe a life with illness experiences. Moira said, *'There is within me a deep certainty that life is a journey and that along the way we come to different vistas and views, and suddenly life had offered me a view, of the whole, through a body with cancer. In some ways it sharpened my awareness'*.

4.7.4 The calling cards

Moira spoke often in our conversations of *'calling cards'*. They tell her about God's presence, *'You can leave it on the ground, or you can pick it up. I'm now changed in that I am deliberate in picking up my calling cards'*. Moira said she calls them calling cards because in essence they are moments of grace, *'They are about my well-being, blessing. I don't have a divine right to any of that. So when things go well, that is grace.'*

We don't deserve it because of the darkness. Outside of God none of that is possible. Even the doctors' knowledge is by grace. God gives that. They are God's gifts'.

As a way of understanding these pivotal moments we explored, during the research conversations, how each participant had arrived at that moment of recognising that something had changed for them. Questions grew out of my curiosity and they are detailed below as the actual questions I asked.

4.7.5 What strategies were you able to use against breast cancer?

Griffith and Griffith (2002:264) suggest that *"Severe illness strikes a double blow. It stresses a person through physical pain and disability, while disabling some of the most effective mechanisms for coping with stress; communion with others, a capacity to hope, a sense of control over one's destiny, and a sense of purpose in living."* I was curious to find out what ways of coping had supported each participant. I hoped to invite the participants to be aware of some of their strengths and that they would find this process of reflecting empowering. Several strategies were indeed named and shared by the participants. They are detailed next:

4.7.5.1 Humour & laughter

Each participant recalled times of using laughter and humour and the sense of normality and relief it had brought to them. Karen recalled an experience in Dr S's rooms – *'I was lying down under the portraits of his six children...my friend C and I found this hilarious afterwards. There was this very Jewish man playing with lots of boobs and with all these children watching!! We thought perhaps they were there to keep him in line'*. Noriko said, *'We do still laugh. We are a family that loves laughing. Even with my illness, I make fun of it'*.

4.7.5.2 Work

This strategy was used by all the participants against breast cancer. For Lynda, work was *'my life saver because I have to get up every day and do something'*. Tania said that *'I think my saving grace was that I carried on working and, at the end, I just realized what a gift it was from my principal. I was determined to keep working – teaching Grade one's'*.

Noriko shared that her work, as a project manager, was very demanding and kept her from focusing on the cancer. She did, however, admit that *'I am a little nervous because I worry about my health'* and how it might still affect her ability to do her job. Moira said that she *'never missed a day at work. Not one day. Go back after the chemo, and work late if I had to'*. I remember asking Moira what it was like to keep working. She shared that *'You are so exhausted. You go home and go straight to bed'*. I found myself wondering if this strategy was a healthy one for the participants to use, but each one appeared to have done so and to name it as a way of coping.

4.7.5.3 Maintaining family routine

'I was determined not to miss out on anything that my children were doing' – Tania

This was another strategy common to all of the participants. Tania said that she *'went to every dancing eisteddfod, every concert at school. I needed normality. I needed to keep routine in order to get through and be normal'*.

4.7.5.4 Marvelling at the technological journey

'Celebrate and acknowledge the medical things that go on around cancer' - Moira

Moira brought this up in our conversations. *'One of the strategies that I did engage was to give credit and marvel at the technical journey. All these people have studied cancer with a view to putting it in its box'*. She acknowledged the medical things by inviting *'Anybody who was close to me, my sister, daughter, husband, my friend K, to come with me to a radiation session. I was ok to do that, I wanted to do that because I wanted a witness. Not to look at me, but to share the incredibly technological journey'*.

4.7.5.5 Celebrate the living

'I chose to be living' – Moira

Moira remembered thinking that, *'One day I will die and one day my boobs won't be perfect, and if that day is now, so be it. It's inevitable. Celebrate what you do have. Get on with it'*. Whilst she was doing radiation, *'my good friend K would meet me for lunch after the radiation session. It became a lunch date instead of a radiation date.'*

Cancer wasn't centralised. Friendship was centralized. It was fun'. Karen shared Moira's sentiment and had decided to 'concentrate on getting better and...take every day as it comes. I am so grateful for life and health and friends and family'.

4.7.5.6 An emotional melt-down

Karen recalled a moment of 'Melt-down'. She had experienced this moment as she sat at the Healing Well (a healing ministry at the local Methodist Church). *'I let myself go, but I needed that'. Her experience gave her 'Peace'. 'I was so busy holding onto everything, and being strong. It was a sense of relief, just sitting there crying. I can't do that often, and I don't often cry'.*

4.7.5.7 Control-freak

Each participant made mention of a part of themselves which they called 'control freak'. Karen needed the control freak because she *'couldn't be a mess because I had to cope'. Noriko agreed that it was hard not to be a control freak with breast cancer around. For Tania, her need to be ordered, structured and disciplined meant that she needed to be in control. She said that, 'I felt I still had to be everything. Perhaps it would be the last time. The cancer was not going to stop me'.*

4.7.6 Things that breast cancer has changed in your life?

Lynda realized that cancer is such a big thing – a life-changing thing. *'You are never the same again. I think I am a better person because of that. I feel different about everything. Relationships are far more important. Especially with my children and my grandchildren. You don't know what tomorrow holds'. Karen felt that gratitude is the big thing. Getting up in the morning made her grateful and reminding herself that she was not invincible. 'I am going to die at some stage – now I have that little tweak [the breast cancer]. I don't take every day for granted. I have to make the most of it'. She was more compassionate and understanding than she had been before. A surprise to her was to learn that she was actually contented, 'For the first time in my life'. I was curious how contentment grew out of breast cancer. Karen shared that 'It grew out of coping with it [breast cancer], coming to terms with life and realizing what you have got'. Karen and Tania both felt that cancer had taught them to ask others for help. Tania even suggested that 'Cancer was a gift in some ways' as she had never felt as cared for as she did that year.*

Noriko, who is still on a relatively new journey with both lung and breast cancer said only that, *'I struggle to get up in the morning, because my body is still recovering from the radiation and still adjusting to the one lung. I don't have half the energy I used to have. I feel I don't know myself any more'*. She is finding this experience frustrating. She even suggested resenting it. *'Right now I'm just travelling the journey and cross each bridge as I come to it. There are no definites'*. She added that, *'I feel unprepared. I didn't plan for this'*. She admitted to trying to see 'the silver lining' amidst the cancer in the *'little things'*. *A sense of my mortality has made me change and once it has been made clear to me, the meaning of all this, I will be able to use this to benefit others'*. Cancer has made her more mature. She describes it as *'A life-changing event where mortality comes to mind and makes you value what you have every day'*. This resonated with Frank's (1995: 115-136) quest narrative in which he suggests that *"quest stories meet suffering head on; they accept illness and seek to use it... the quest is defined by the ill person's belief that something is to be gained through the experience"*.

4.7.7 What have you learnt about yourself?

Mattingly and Garro (2000:222) use a quote by William Osler that says, *"Ask not what disease the person has, but rather what person the disease has"*. This comment struck me as placing the position of agency onto the person living with illness. I wondered what each participant would say they had learnt about themselves through their stories and experiences of breast cancer. It seemed a fitting way to turn some of the focus inwards and to learn about the women who live with breast cancer in such an inspiring way.

Lynda's learning was an ability to see things differently. She shared that she used to think that she was *'accepting of things'* because she was weak. *'I have decided that I don't have to accept negativity. I don't like being negative. God gave me a positive personality. He accepts me the way I am. It's not easy to accept compliments. I would always say it's not me, its God'*. I asked her what kind of woman God saw in her. One, she says, who *'found courage and strength even when it had to be a conscious decision'*. Moira learnt that she had *'determination to ride this out and to not let it overcome me'*.

Karen discovered that she is STRONG [her emphasis], happy, content, adventurous and having a passion for life. Tania also described herself as strong. She explained strong as being *'when the chips are down, I keep going'*. She surprised me by concluding that conversation by saying that *'I wouldn't change having cancer – makes me more aware of how fragile life is. Not to dwell on it [breast cancer], but not to forget about it. I am grateful for the gift of more time'*.

The husband's voice

'She was very tenacious' - Gavin

In her suffering she began to live, in a far more deliberate way, and 'She surprised me. Her response to cancer surprised me. I had labelled her as a bit of a princess. When we met I loved hiking and camping- that is not her. Too uncomfortable to walk, not sleep in a decent place. Couldn't understand it. I knocked her for being a princess. When she had cancer, there was tenacity in the princess, a defiance, and endurance. She chose one of the most difficult ways to cope. I have tremendous respect for her. Her cancer has changed her – her naivety, innocence - but something else fills the place'.

The next section will explore some of the rituals that the participants used during their experiences with breast cancer as a way of holding on to something life-giving.

4.8 WAYS OF MAKING MEANING ALONG THE WAY

Griffith and Griffith (2002:167) suggest that *"Rituals and ceremonies serve a special role in human life by punctuating experience into meaningful chunks of time. They highlight and illuminate important recurrences, while pointing to transition and future change"*. I was particularly drawn to an idea of Anderson and Foley (2001:23) who suggest that *"rituals are essential and powerful means for making the world a habitable and hospitable place"*. I find myself curious how the co-researchers experienced this in the midst of breast cancer.

My reflection:

I am able to reflect on the importance of rites and rituals in various parts of my own story. I recall my pregnancy journals and letters to my unborn children through difficult moments in pregnancy. I recall how I chose to ritualise important celebrations in my life with letters and photographs and even how I have chosen to document this research journey through a scrapbook of thoughts, ideas and, I hope, photos.

Most of the participants had included life-giving rituals in their experiences of breast cancer. Lynda and Karen both kept journals of their entire cancer journey. I was privileged to be invited to read Karen's and to quote some of her experiences in this document. I learnt that Karen was quite deliberate in setting rituals. She set out a reward system. She would have her chemotherapy treatment and then go somewhere for lunch, or shopping afterwards. On one such outing she chose a ring and *'I arranged with them that I would pay it off over six months [the duration of her chemotherapy treatment], and at the end of the treatment I would get it. That was what got me through'*. Karen sees the radiation tattoos as a reminder of the journey she has come through. Once her treatment was finished, her son accompanied her to have another one, a pink breast cancer ribbon on her right breast as a *'reminder of hope'*.

Before she had her lung removed, Noriko spent time making lists for the family and writing letters for her daughter to open every day of her hospital stay. *'Writing those letters was difficult'*. The sharing of this memory invited tears from Noriko. Leaving the letters for her daughter had given her peace. *'As much as I struggled, she was coping. She would speak about me, send messages or draw a picture'*. For Noriko it was these moments that kept her upbeat. She referred to them as the *'little gems in my life'*. Noriko told me about a ritual of her mother-in-law's, who also lives with breast cancer, *'My mother in law would take all her chipped crockery, when she was in a bad place, and throw it against the wall. She didn't look upset, but seemed to enjoy it. I could never understand it - until after I was diagnosed. It seemed alien. I told her that I [now] craved that experience'*.

4.9 THE CELEBRATION OF NEW BIRTH

This section focuses on the group conversations and the ways in which a sense of collaboration was experienced in finalising this research journey. Combs and Freedman (1990:xvi) believe that ceremonies are an *“Important part of life”* and that they *“symbolize important changes of relationship, both of people with one another and of people with themselves”*. The group conversation made use of three narrative practices; that of outsider witness, taking back practice and definitional ceremonies. They are described below.

4.9.1 Outsider witnesses

The outsider witness group facilitates *“healing by offering a ritual of shared experience – a meeting on common ground to question, explore, cry, rejoice, pray, socialize and support all in the context of community”* (Moessner 1996:220). In the last group conversation I asked my colleague and research participant, Moira to have a conversation with me. This invited the participants into a witnessing role of what this research journey and their stories had been like for me. This also facilitated a taking-back practice which will be discussed next.

4.9.2 Taking-back practice

Inviting the participants to hear what my experiences and learning's had been through their stories became part of a taking-back practice. White (1997:144) believes that taking-back practices are encouraging both to the researcher and the participants and he draws attention to the *“part that this work plays in us becoming better listeners, or the extent to which this work opens possibilities for us to develop more compassionate relationships with our own lives”*. The response to the conversation between Moira and I was emotional. The participants received my experiences of them as strong, courageous, tenacious women and followers of Christ. They then overwhelmed me with their spontaneous comments about what I had shared and feedback about what the research conversations had been like for them. Each participant shared that this research journey had been life-giving to them. Words such as empowering, safe place, meaningful were mentioned. Lynda said, *‘You have helped me just as much. It’s good to work through these things’*.

Moira and Tania both shared that an experience of breast cancer doesn't allow you to fully experience everything that you have lived through until an opportunity to talk and share is provided. For Karen, the realisation that someone else saw her courage and strength touched her deeply. Noriko mentioned that, as she was still at a beginning stage of her journey, the conversations had provided her a safe place to explore her thoughts and discover ways to cope. *'This has made me think about them. The discussions that we've had have given me a safe place to explore the deeper, sometimes scarier places in my journey and helped equip me for the road ahead.'*

The verbalised experiences of the co-researchers agreed with Frank (1995:133) who suggests that *"voice is found in the recollection of memories"*.

4.9.3 Living beyond breast cancer

Weingarten (2001:124) shares a thought on illness narratives, *"Yet, if there is one thing I feel I have learned from an adult life lived inside an unreliable body, it is that care not cure will keep us floating in the ocean"*

Karen's diary entry from July 2008 seemed to share Weingarten's sentiment, *'When the treatment is over, it doesn't mean the end and that things are clear and sorted – not at all. ...Life is never easy anyway'*. She recalled her last visit to Dr D. *'You don't get an all clear – you have to live in this shade of grey forever'*. Each participant is aware that the breast cancer, whilst in remission for some (Tania, Karen and Moira) and still active for others (Noriko and Lynda), is never totally eradicated from their lives. However, at the same time, there was a shared sense that life would and did carry on, despite the cancer, in a way that brings life and purpose not only to their own lives but also to the lives of those around them.

The last group conversation included a creative invitation to the participants to consider re-defining femininity despite a journey of breast cancer. Louw (1994:140) writes that femininity must be an *"indication of the uniqueness of women in the light of familiar symbols like care, love and compassion"*. To explore this notion, the co-researchers were asked to name and give voice to their thoughts on what femininity might look like for them now. Once all their words and ideas had been written down,

these were placed randomly in the middle of the conversation circle. I extended an invitation to the co-researchers to arrange and place their thoughts into something meaningful. A collaborated poem is the result of the thoughts and ideas that the participants shared. This is documented under the heading of 'The Final Say' in Chapter Five.

4.10 CONCLUSION

Chapter four has been a collaboration of the birth of meaning experienced and shared during this research journey. Chapter five will conclude the research journey with a reflection on the learning's, the meaning-making and the witnessing experiences.

Lynda's words are a fitting way to conclude this chapter. *'When people see cancer as this hopeless thing, it doesn't have to be that way. I feel there is a need to encourage people. I wish they could know God and walk that journey with him. It makes such a difference. I would rather spend every day at the chemo unit talking to people than sitting in an office. It has made me realize that people are so important. How you deal with things has an impact on your faith'.*

CHAPTER 5

REFLECTIONS AT JOURNEY'S END

"By cultivating a risky imagination we open new possibilities for being in the world"

Ackerman and Bons-Storm (1998:125)

5.1 INTRODUCTION

There is an immediate sense of gratitude for being allowed to witness the narratives of breast cancer in the lives of Karen, Lynda, Moira, Noriko & Tania and the 'other voices' of the husband and the daughter. This journey has been borne out of their commitment to *"create theory from the location of pain and struggle"* (bell hooks 1994:74) and out of their willingness to share their first-hand experiences of breast cancer. bell hooks (1994:74) suggests that *"it is not easy to name our pain, to theorise from that location, it takes courage to 'expose wounds' and to lend one's experience as a means to 'chart new theoretical journeys'"*. I am indebted to the participants, as the co-researchers on this journey, for their willingness to do just that.

It seems appropriate to pause and start with a reflection on the journey contained in this research report. Chapter one contains an 'Introduction to the Journey' and presents this research statement, literature control, this research design and methodology of qualitative, co-participatory action research and reflexivity, my positioning in this research and an introduction to the concepts of voice, stories, conversations, meaning-making, deconstruction and witnessing used in this research. Chapter two discussed a 'Scaffold of Theory' for this research, namely narrative practices, feminism and pastoral theology and suggested a collaboration of the three scaffolds of theory. It also discussed some potential collaborative challenges. Chapter three introduced the voice of illness, an externalised voice of breast cancer and introduced the co-researchers in their own voices. Chapter four focused on the 'Birthing Journey' and includes some of the labour pains I experienced, the birth of meaning, discourses as birthing partners, pivotal moments, using rites and rituals to make meaning along the way and, finally, a celebration of new birth through an outsider witness practice, taking-back practice and a

definitional ceremony. This chapter is the last chapter in this research and focuses on summarising some of this research report, reflecting on the main concepts, conversations between narrative practices, feminism and pastoral theology and some of the effects of this research on fields of knowledge, the community, the co-researchers and myself.

5.2 REFLECTIONS ON THE PURPOSE OF THIS RESEARCH

The purpose of this research journey was to explore how narrative practices can be meaningful in pastoral conversations with women living with breast cancer. This was achieved through witnessing the stories and experiences of breast cancer in women's lives, observing appropriate ethics, documenting and reflecting on all research conversations and collaborating with the co-researchers on notes and written work which form part of this report. This research was conducted within a community of women from a local Methodist congregation in Benoni. The pastoral care centre provided a safe and respectful place for the women to share their experiences and stories of breast cancer which were scheduled at times suitable to them. In order to fulfil the research question (refer section 1.3) and the aims of the research, as set out in section 1.4, this research used a collaborative approach between the theories of narrative, feminist and pastoral theology in order to witness the birth of breast cancer stories using the voices of local knowledge in a meaningful and respectful way.

In the next section I will review some of the research findings.

5.3 SUMMARY OF THE RESEARCH FINDINGS

The research question (refer to section 1.3) set out to explore how narrative practices can be meaningful in pastoral conversations with women living with breast cancer. This section on the research findings will explore the research question in two sections. The first section (section 5.3.1) will explore whether there is value in using narrative therapy in pastoral conversations and the second section (section 5.3.2) will summarise the experiences and stories of women living with breast cancer.

5.3.1 The value of narrative therapy in pastoral conversations

Theoretically, as discussed in section 2.5, there are several common threads between narrative practices and pastoral theology which collaborate well in a therapeutic pastoral setting and, therefore, also for the purposes of this research. Those common threads were discussed in section 2.5 as being the importance of stories, helping women to find a voice, relationships, the challenging of dominant discourses and the positioning of agency. I would now like to suggest that using narrative therapy in pastoral conversations is meaningful for the following reasons.

5.3.1.1 The significance of stories

Dinkins (2005:39), as referred to in section 2.4.4, describes the role of the pastoral therapist as creating an environment in which people can tell their stories, feel their pain and their joy, and then discover their competencies and their faith in *“God who is the author and the finisher of all our stories”* (Dinkins 2005:39). The centrality of story invited the participants to understand their lives through stories because God, in whose image we have been created, is a storying God. Bartholomew and Goheen (2004:11) suggest that *“God’s story”* is the true story of the world and we are invited to be a part of it. Meteyard in Cook and Alexander (2008:99) believes that the fact that God has chosen narrative as a *“major way of revealing himself to us should say that when narrative therapy focuses on the stories that influence people’s lives, they are in fact concentrating on something very deep and significant indeed!”* The co-researchers shared their faith stories, breast cancer stories and alternative stories during the research. These are explored in greater detail in chapter 4.

5.3.1.2 Giving voice to the marginalised

Narrative therapy takes a strong ethical stance against marginalising individuals and groups whose stories stand apart from the dominant stories and discourses of our cultures and societies. Indeed, Meteyard (in Cook and Alexander 2008:102) maintain that the Christian story requires that the Christian community fully participate in challenging some of the discourses of society and culture, in the way that Jesus did in stories of the New Testament. Narrative practices also seek to be respectful, non-blaming and non-assumptive and centres people as the experts in their own lives. The research was able to do this by choosing to witness and

collaborate with the voices of the research participants' stories rather than by assuming any researcher expertise.

5.3.1.3 Externalisation

Externalisation (refer to section 2.2.3.3) is an inherent part of narrative practices. Externalising language is also frequently referred to in the scriptures of the Bible. One such example can be found in Genesis 4:6-7 in which God says to Cain, 'sin is lying in wait for you, ready to pounce; it's out to get you' (The Message). Externalising language and metaphors were used throughout the research journey to separate the breast cancer from the participants and to grow an understanding of its influence in their lives. This is discussed in greater detail in sections 4.4.2 and 5.3.2.

5.3.1.4 Deconstruction of discourses

Deconstruction, in narrative terms, suggests a breaking down and a doing away with something. In a Biblical sense, deconstruction also refers to putting off the old and putting on the new in Christ. Proverbs and the Psalms use images such as "a gentle response defuses anger, but a sharp tongue kindles a temper-fire" (The Message, Proverbs 15:1) to invite a change from one way of being to another. The research provided opportunities for illness discourses, as well as Christian discourses, to be explored. See section 4.6 and 5.3.5.

5.3.1.5 The alternative story

The narrative emphasis on the alternative story, which draws on the person's survival, strengths and ability to overcome, is aligned with scripture's invitation to embrace God's extravagant and reckless love. Alexander (in Cook and Alexander 2008:117) describes God as "*a God who knows sorrow, grief, betrayal and death, and yet has turned these into a story of love, grace, joy and life. He is the God of the alternate story*". In the context of the research, pivotal moments, alternatives and definitional ceremonies were explored with the co-researchers. These are discussed in greater detail in sections 4.7, 4.8 and 5.3.6.

5.3.1.6 Narrative values

Narrative values for engaging with others includes respect, curiosity, attentive listening, questioning, acknowledging the importance of lived experience and local

knowledge and hearing into voice aligns itself with Jesus of the New Testament. Jesus accepted all people, even those who were marginalised and discriminated against. There is a parallel between Jesus' stance towards people and Narrative's open and accepting way. An example in scripture can be found in Jesus' treatment of the woman at the well (John 4:1-30).

5.3.1.7 Spirituality

For the research journey, the inclusion of spirituality into the narrative conversations and narrative ideas into pastoral conversations provided a safe place for values of respect, transparency, curiosity, attentive listening and witnessing to take place. Narrative practices such as externalisation, deconstruction of discourses, landscape of identity, discovering of pivotal moments, alternative stories and metaphors, to name only some, were collaborative in the pastoral context of the research as they invited the thickening of faith stories by their re-telling, grew images of God, deconstructed the meaning of suffering and the role of faith in times of illness, allowed for acknowledgement of the presence of God in the midst of the research conversations and positioned God as 'alongside' co-researchers, rather than as 'responsible for' illness stories. The co-researchers' experiences of faith and spirituality in times of illness can be found in sections 4.5 and 5.3.4

5.3.1.8 Collaborative concerns

I had discussed some potential concerns for the collaboration of theory (see paragraph 2.5.6) but the scope of the research journey did not invite the deconstruction of stories of faith and spirituality into the conversations, nor the questioning of an absolute truth. I suggest that this warrants further research and can be added to section 5.7.

In concluding this section, it is my opinion that the research was indeed able to use narrative ideas to bring meaning into pastoral conversations with the co-researchers. Cook, in Cook and Alexander (2008:49) believes that Christ-followers often come to therapy weighed down by expectations about how to be a certain way at home, at church, in society and within themselves. He suggests that *"Revelation of a socially constructed nature of these conforming messages can lead to a sense of liberation. This growing freedom offers an alternative view of Jesus and an alternative view of*

Christian spirituality – one of our connectedness to Love, a new knowing of fatherly acceptance and a collaboration with divine mercy” (2008:49). It is my opinion that this statement reflects the meaning that narrative practices do bring to pastoral conversations.

Section 5.3.2 now details some of the findings with regards to the stories and experiences of breast cancer expressed by the participants.

5.3.2 Witnessing the stories of breast cancer and hope

Whilst it was not the purpose of this research, nor the practice of qualitative & co-participatory action research to generalise findings or compare experiences of the participants, our journey together has indeed co-created a more holistic understanding of women living with breast cancer. This was encouraged through the use of story-telling. Narrative practices suggest that we make sense of our lives and experiences by *“ascribing meaning through stories”* (Brown & Augusta-Scott, 2007:ix) and that these stories arise within social conversations and culturally defined discourse. The research conversations provided a ‘birthing room’ for the telling of stories and the making of meaning of a life lived with breast cancer. I brought my own discourses to this research - from personal experience, literature reviews and conversation with others which I acknowledged both in the report and to the participants. The co-researchers and I explored the illness story, the personality of breast cancer, the effect of breast cancer on life-giving relationships as well as the role of spirituality and faith in times of illness. This was followed by exploring alternative stories and seeking pivotal moments or exceptions to the breast-cancer dominant story. In the following section I will discuss each of these journeys in more detail.

5.3.2.1 The illness story

These research conversations detailed not only the discovery of breast cancer in the participants’ lives but also their experience of diagnostic procedures, the medical profession, the treatment journey and the emotions. Discourses that I brought to the conversations were that medical personnel are trained to treat the physical body in a modernist model of care. The focus of modernist medical care is on symptoms rather than emotions, often with little regard for the suffering of the person or the

meaning of illness to the person. However, all of the participants experienced great care and support from their medical team with regards to knowledge, treatment and emotional care. The doctors, at times, appeared to go beyond their socially accepted, doctor-patient role by making unexpected telephone calls and even sharing religious sentiments, as experienced by Lynda and Moira. An exception to this was the way in which Karen received her diagnosis, from her gynaecologist, over the telephone.

A generally experienced sentiment around the diagnosis of breast cancer was the disbelief that something 'so deadly' could be present in the body without the participants' knowledge. The surgical procedures and treatment journeys were very different for all the participants - Lynda was the only co-researcher who had required a mastectomy and reconstruction and two of the other co-researchers had elected to have reconstruction after surgeries to remove tumours. A commonality experienced by the majority of the co-researchers was the effects of chemotherapy, and how it brought the illness experience to life. Noriko is currently on a journey with both lung cancer and breast cancer and is learning to live without one of her lungs whilst Lynda is currently living with breast cancer for the second time and has also had the added knowledge that her cancer is a Her2 gene which will never be eradicated through treatment. Karen, Tania and Moira are in remission from their breast cancer stories.

5.3.2.2 The personality of breast cancer

The idea that breast cancer might have a personality was learned of through the participants in remembering doctor conversations. The suggestion fitted really well with narrative practices of externalisation and gave birth to an unplanned research experience of asking the co-researchers to draw what breast cancer might look like. The creative exercise was well received by the participants and it introduced the opportunity to discover metaphors which the participants associated with breast cancer. (Refer to Annexures D to G).

Introducing externalising language into the stories of breast cancer invited each co-researcher to consider the breast cancer as an illness separate from themselves. In this way, a greater understanding of the strategies it used in their lives was

discovered. Morgan (2000:24) suggests that the “*problem no longer speaks to them of their identity or the ‘truth’ about who they are*” and using externalisation opened a safe space for the co-researchers to begin to take action, or recognise action already taken, against the breast cancer in various ways, as the pivotal moments and alternative stories can attest to (section 4.7). The co-researchers were encouraged to name their own experiences of breast cancer and metaphors such as ‘*uninvited visitor*’ and ‘*an assailant*’ were named. These names were important for creating an understanding of the dominant problem (in this research - breast cancer).

5.3.2.3 *The effect of breast cancer on life-giving relationships*

I brought to this research an assumption that as the participants do not live in isolation, the experience and stories of breast cancer would have an influence on all of their life-giving relationships. This research spent time exploring the relationships with significant others such as the husband, the daughter and the family and friends.

5.3.2.3.1 *The family and friends*

Discourses present in the word ‘cancer’ meant that each participant was aware of the reactions of those around them. Reactions varied from avoidance and loss of friendships to strangers providing support, care and very practical assistance. There was a clear distinction for the co-researchers between the relationships which were not able to survive the presence of breast cancer and those that had developed despite its presence. It was a shared understanding that people were afraid of breast cancer and that often, through lack of knowledge, friends chose to avoid the co-researchers rather than become part of the support team. For some, this had included the loss of important relationships. There were also times where the presence of breast cancer had invited new or unexpected people to come forward and offer life-giving support and assistance.

5.3.2.3.2 *The husband*

This life-giving relationship was explored with each participant, with the exception of Karen who has been divorced for many years. The ‘other voice’ of the husband also spoke. Reactions differed from Lynda’s husband being unable to talk about the cancer to the husbands of Moira, Tania and Noriko providing practical assistance and space to be emotional. It was also apparent that, for the majority of participants,

breast cancer had appeared not to have influenced physical, intimate relationships but had, in fact, deepened the experience of intimacy.

5.3.2.3.3 *The daughter*

Each participant is the parent of a daughter/s. The majority of the participants worried about the genetic legacy that they might leave for their daughters. Moira, on the other hand, felt that as she wasn't able to control a genetic legacy. Instead, she hoped that her actions and the choices she had made about the breast cancer would leave her daughter with a role model of living with illness.

5.3.2.3.4 *Self, body image, femininity*

I brought to this research my own assumptions about how breast cancer might affect a socially constructed image of sexuality, femininity, womanhood and health. This research journey highlighted that no two women shared the same experiences. What was shared was the notion that their femininity was partly constructed by body image and breasts. Reconstruction was not imperative to all of them. Lynda was the only participant who had required a complete mastectomy and she had chosen reconstruction. She saw the reconstruction of her breasts as more important to her physical relationship with her husband than necessary for her to define her femininity. Each participant expressed varying levels of discomfort with their new body image. Karen, who had been divorced for many years, felt very out of touch with her changed body and expressed concern over the appeal her body would have to any new relationships. Moira regarded the surgery as a mutilation of her body that was hard to accept. Tania expressed the changing shape of her already small breasts as not noticeable and, for Noriko, who also considered herself as small breasted; the changes to one of her breasts didn't evoke any anxiety.

What I hadn't anticipated was the discomfort over the loss of hair. Tania, Lynda and Karen experienced this as a traumatic and outward sign of the illness. It was evident from the conversations that not one of the participants had allowed themselves to 'look ill' and each had made unique efforts to continue to look good through items of clothing such as scarves and hats as well as make-up. Ackerman's suggestion (1998:87) that "*all perceived reality and all knowledge is mediated through our bodies... We are our bodies. Our bodies defined whether we were stigmatized or*

advantaged” seemed applicable to the participants’ experiences of themselves through the treatment part of their journey.

5.3.2.4 The role of spirituality and faith in times of illness

Anderson (1999:160) writes that “*When spirituality informs our therapy with individuals and families, the aim of care is to empower people to embrace paradox, seek justice, and glimpse the contingency of life in order to live with both feet planted firmly in mid-air*”. This sentiment was applicable not only to me as the researcher but also to the co-researchers. It was important for me to acknowledge at the outset that I bring to this research my own spirituality and faith story as a practicing Christian. I also bring the work that I do at the pastoral care centre. I cannot even consider separating this huge part of my life narrative from the work that I do nor from the way in which I care for others. I also brought the knowledge of my own illness narratives and how they have been informed and thickened by my faith story.

For the co-researchers, Anderson’s sentiment invited an awareness of the paradoxes in our spiritual and faith stories. This research acknowledged some of the discourses in our beliefs as Christians. One common Christian discourse suggests that if we have enough faith, God will bestow miraculous physical healing.

Surprisingly, this research journey highlighted that physical healing was not the main focus of the participants’ relationship with God. They acknowledged the important role of their faith relationship in order to help them survive the experience. Each woman believed that God had a purpose for them in their suffering, that there was something they needed to learn and that the cancer didn’t necessarily come from God.

5.3.2.5 Discourses as birthing partners

Several discourses or “*sets of meaning*” (Burr 1995:48) emerged during the research conversations. At times a discourse had been introduced by an outsider and appeared to marginalise or hamper the experience and the meaning-making process of breast cancer for the participants. An example of this was a colleague telling Lynda that she was being punished by God (refer paragraph 4.6.2). It was also clear that discourse was able to facilitate meaning-making by providing a secure frame for the creation of subjective meaning and, at times appeared to thicken the alternative

story of illness. An example of this was *'you sow what you reap'* (refer paragraph 4.6.3) which, after provoking experiences of questioning and guilt for Noriko and Lynda, became a reminder of the choices they were able to make in living a meaningful life despite the presence of cancer. Discourse, in this way, facilitated the thickening of stories of courage, determination and hope.

Having Gavin, a husband and a minister, as a voice in this research brought a new frame of reference to my understanding of the relationship between a husband, who is a minister, and his wife. It was clear from conversations with both Tania and Gavin that these were two very separate roles in their marriage.

5.3.2.6 Exploring alternative stories, pivotal moments or exceptions to the dominant story of breast cancer

It was important that this research not only focus on the breast cancer dominant stories but also provide a birthing space for acknowledging and giving voice to the ways in which the participants had stood against breast cancer. One of the important contributions of narrative therapy is the positive emphasis on the alternative story. Narrative practices are always on the lookout for the often unnoticed, unspoken story of another's survival, strength and practices which have enabled the fight back or the overcoming of a problem.

Discovering unique outcomes or pivotal moments thickens the alternative story. Morgan (2000:52) states that *"unique outcomes are anything that the problem would not like"* They can be considered a plan, action, feeling, statement, quality, desire, dream, thought, belief, ability or commitment. Several pivotal moments existed in the research journey. Each participant had made a conscious decision not to give breast cancer centre-stage in their lives (refer paragraph 4.7.1). Along with this recognition was the element of choice, of purpose and of living despite breast cancer in a way which was life-giving in some way to each one participant. Karen chose to *'stop waiting for life to happen and make it happen'* (refer paragraph 4.7.2) and Moira spoke of being deliberate in picking up her *'calling cards'* (refer paragraph 4.7.4).

In order to thicken the alternative stories, the research journey explored the strategies that the co-researchers had used against breast cancer and what some of

the learning's had been about themselves. Strategies such as humour, work, maintaining a family routine, celebrating the living, moments of emotional melt-down and keeping control were named by the co-researchers. Moira included a choice she made to *'marvel at the technological journey'* (paragraph 4.7.5.4) and to *'celebrate and acknowledge the medical things that go on around cancer'* (paragraph 4.7.5.4).

The research findings were concluded with group conversations which encouraged collaborated meaning of the research journey (refer section 4.9). This was a way to celebrate the birth of new meaning and experiences for each one of us. An outsider witness practice invited the co-researchers to experience taking-back practice and to learn what their stories had taught me and what I had been privileged to witness in them. The group conversation held the invitation for each co-research to be part of the final word through a creative and meaningful definitional ceremony (refer paragraphs 2.2.5.1.2 and 4.9.3) which gave birth to their final say in the research journey – an expression of redefining femininity (see paragraph 5.12).

5.4 REFLECTIONS ON THIS RESEARCH PROCESS AND METHODOLOGY

The purpose of this research was to witness the stories and experiences of breast cancer in women's lives. The research paradigm best suited to do this was a qualitative, co-participatory and reflexive research. Heitink's (1999:228) proposal that 'practical-theological' research is action research is encouraging of the use of an *"interdisciplinary approach"*. This research embraced not only elements of social science and psychology through narrative therapy and feminism but also pastoral theology.

A reflection on qualitative research is described below.

5.4.1 Qualitative research

Neuman (1997:328) suggests that qualitative research involves *"documenting real events"* by recording people's words and gestures, studying written documents and examining visual images. These are all *"concrete aspects of the world"* (Neuman 1997:328). I used a quote by Rubin and Rubin (1995:42-43) in paragraph 1.6.1

which suggests that the researcher should “*design changes as you learn from the interviewing*”. This research journey followed their invitation to design changes as the journey developed as a way to incorporate new learning’s and understandings from the literature control and also out of respect for the co-researchers. As five unique and individuals stories were birthed and shared, the women chose to linger or move at a place of comfort or discomfort. An example of this was Tania’s encounter with the death of an acquaintance from breast cancer (see paragraph 4.5.6). She felt able to share the grief with me and we discussed how she might feel about it being included into this research report. We learnt that it was an important inclusion into her experience with breast cancer and it enriched and lengthened our conversations together through our willingness to be vulnerable together in the face of death.

This research was able to focus on subjective meanings, metaphors, symbols and stories of the co-researchers in order to witness the stories of breast cancer. Qualitative research invited us (the co-researchers and I) to collaborate in documenting our experiences in a way which gave birth to a rich description and meaningful document of their stories and experiences of breast cancer.

5.4.2 Co-participatory action research

The characteristics of action research include the participants taking part in research, ordinary and everyday knowledge, empowerment and the fostering of awareness. Action research indicates that meaning is not created on anyone’s behalf in therapy; rather, the participants or co-researchers are responsible for the process of co-constructing alternative and richer stories. Morgan (2000:116) calls this collaboration “*consulting your consultants*” or “*co-research*”. In this way, the voices of the participants are included in the research report. This research managed this collaborative process by taping conversations, with permission, in order that verbatim words and parts of stories could be used. The co-researchers were also provided with copies of the written chapters to invite a consultative process with regards to accuracy of story, language and meaning-making.

5.4.3 Reflexivity

Reflexivity is essential to qualitative research and facilitates understanding of both the phenomenon under study and the research process itself. In this way, reflexivity is a way of finding out about myself and the research. Bochner and Ellis (2001:741) liken reflexivity to a *“personal tale of what went on in the backstage of doing research”*. For the purposes of this research, reflecting took the form of a journal and conversations with my supervisor. It also took place amidst the reading and reflecting of the transcribed research conversations and the thoughts and learning’s I received.

5.5 REFLECTIONS ON ETHICS

To ensure that Ethics were upheld throughout this research process each participant was asked to read and sign an informed written consent form at the very first conversation. The document was discussed verbally to ensure a common understanding and to discuss any concerns. The consent document detailed the purpose of this research and the level of involvement that was being asked of each person. A shared understanding of confidentiality and rights to privacy was discussed and each participant was afforded the choice of anonymity. No one chose to be anonymous. I also explained the purpose behind the taping of conversations and asked for permission to do so. Participation in this research was voluntary and the participants were informed that they could, at any time, withdraw from the process. Jennie’s daughter chose to withdraw from completing the conversations after her mother passed away (refer to paragraph 3.4.6). As no medical professionals had been approached for inclusion in this research, initials were used in order to afford them the same right to anonymity. The participants were very willing to collaborate and to participate in any way possible.

5.6 LIMITATIONS AND DIRECTIONS FOR FURTHER STUDIES

This research used the methodology of qualitative research and included the meaning-making and experiences of each of the co-researchers. There was no intention to generalise any of the findings but, rather, to create awareness, consciousness-raising of women’s experiences of breast cancer in scaffolds of

narrative, feminist and pastoral theology. The purpose of this research was to witness the stories of breast cancer in the participants' lives. I see the need for further study in the following ways:

1. To expand the group of participants to include women who do not have experiences of faith and spirituality. The co-researchers each agreed on their reliance on faith and spirituality in order to discover a meaning to suffering in the presence of breast cancer. I wonder how the experience is different for non-believers.
2. To research the illness stories and the medical experiences of women who live in disadvantaged areas and who do not have access to the same level of medical care as experienced by the participants.
3. To explore more deeply Tania's experience of 'guilt' in encountering the death of an acquaintance to breast cancer.
4. To be able to explore the use of externalisation and metaphors in a therapeutic context in illness stories

5.7 POSSIBLE EFFECTS OF THIS RESEARCH ON A WIDER COMMUNITY

Laurel Ulrich (1990:207), in her biography on Martha Ballard, a 18th century midwife, quotes the following words,

There is a tender regard one woman bears to another, and a natural sympathy in those that have gone thru' the pangs of childbearing; which doubtless, occasion a compassion for those that labour under these circumstances, which no man can be a judge of.

Martha Ballard (in Ulrich 1990:207)

One of the most important awareness's created by this research is the role of support. Support is detailed below.

5.7.1 Creating Circles of Care

One of the important roles of pastoral care is to be able to provide support and care for people in all walks of life and perhaps, in light of the voice of illness, it is important to provide safe and appropriate circles of support to people from Benoni. The co-researchers acknowledged the need for a place of safety where illness stories and experiences can be shared. They also expressed the need for basic information

focused on how to help and support someone who is living with breast cancer. This is discussed in greater detail in section 5.11.

I am also part of a circle of caregivers, supported by a supervisor, at a pastoral care centre. I believe that I need to share the experience and learning's of this research journey with the caregivers in order to encourage and inform the work that we do as witnesses to the stories and people that we encounter.

Kornfeld (1997:84) comments on Martin Buber's thoughts on the use of the most significant out circle to this metaphor:

Buber reminds us that we are in community not because we have so much in common, but because we have God in common. He painted a picture of community in which God is at the centre, and is real to us, each as individuals. We are bound up together in this relational life of salvation. Our relationship to God binds up this space between us; creates community. Buber says this community creates an invisible altar. It becomes a human cosmos with bounds and form. It is grasped, understood, by the spirit. Community becomes a world which is a house and a home - A dwelling for men, women and children in the universe.

Kornfeld (1997:84)

5.7.2 An Invitation

I have received an invitation from a specialist physician to share my experiences and learning's at a breast cancer awareness tea scheduled for 2012.

5.7.3 A collaboration

A collaboration is being formed with a local physiotherapist and a non-profit organisation in our area that offers support and education to women living with breast cancer. It is hoped that this is the beginning of a network of care for women living with breast cancer and illness stories

The effects of the research journey on the participants and co-researchers is discussed next.

5.8 EFFECTS ON THE PARTICIPANTS

Although the participants were the story-tellers of their own experiences with breast cancer, the journey of retelling and restorying did not leave them unchanged in some way.

5.8.1 The meaning of the journey

At the last group conversation I was able to share what my learning's and experiences had been during this research journey. I invited all the co-researchers to be outsider witnesses (refer to paragraph 2.2.5.1.2 and 4.9.1). It provided a very meaningful taking-back practice for the participants (refer to paragraph 4.9.2). The co-researchers shared feedback with me about the meaning of the journey and these have been detailed in paragraph 4.9.2. I have chosen words from Marianne Williamson's (1992:190-191) poem to celebrate my meaning-making of the experiences of the journey:

We were born to make manifest
the glory of God that is within us
It's not just in some of us
It's in everyone
And as we let our own light shine
We unconsciously give other people
Permission to do the same
As we are liberated from our own fear,
Our presence automatically liberates others.
Williamson (1992:190-191)

5.8.2 Story and memory as part of healing and care

It was through joining the telling and re-telling of narratives that the co-researchers and myself experienced the hospitality and community most. Welch 1990:93 points out that *"the healing possible for all of us, collectively and individually, lies in the recognition that although there is a way through there is no way out"*.

It was through the retelling and the stories that aspects of the participants' journeys were uncovered and thickened and the experience has left each one of them more aware of who they are despite living with an experience of breast cancer.

5.8.3 A collaboration of stories

At the final group meeting I asked the participants what they might like to do with their stories and experiences. The decision was both collaborative and unanimous. They need to make their stories and experiences available to others as a symbol of their journey with breast cancer. I have been asked by the co-researchers on this journey to weave some of their stories into a brochure or booklet to be used at the pastoral care centre and at other places within the community. In some ways, drawing this research to a close seemed like an ending, but the collaboration of stories is also a beginning of collective courage and hope.

5.9 EFFECTS OF THIS RESEARCH ON MY PERSONAL & PROFESSIONAL DEVELOPMENT

This research has allowed me to integrate narrative practices, feminism and theology into a collaboration of theory. In this way, it has allowed me to grow my knowledge of social construction, narrative pastoral theology and feminism in the context of illness and breast cancer stories.

I have been particularly influenced by the work of Kaethe Weingarten (1998, 2000, 2001, 2003 and 2010), Griffith and Griffith (1994, 2002) and Frank (1995) whose work and writings have been instrumental in opening up alternative ways for me to support and witness illness stories. I was fortunate to meet Kaethe in person in March 2010 and was I profoundly touched by the importance she places on being a compassionate witness in the work she does. In this research, I experienced the concept of 'compassionate witnessing' in two ways. The first was as a reminder of the de-centred position I had hoped to bring to all the encounters with the participants. It invited me to respect that the participants are the women who are 'experts' and that I am, in fact, learning from them, and not the other way around.

The second experience was a reminder that being a 'witness' means that there were times when I felt vulnerable to the emotions and experiences of the women as they relived experiences and moments of their stories of breast cancer. But, alongside this awareness, I need to hold on to the question *'How can I care for people if I am not prepared to listen to the memories of pain and to accept responsibility?'*

I hope that through listening to women who have been on a journey with breast cancer that I not only become actively involved, but that I also contributed towards finding ways of doing it respectfully and ethically. I resonate strongly with the words of Nouwen (1990:xvi) who says: *“service will not be perceived as authentic unless it comes from a heart wounded by the suffering about which it speaks”*. One of the most difficult encounters of this research was death. Death interrupted conversations and, in one case, prevented them from even starting. I was reminded of the fragility of life alongside illness as well as a sense of guilt that I didn’t start the conversations earlier and afford this woman the opportunity of having her voice heard. I had to be prepared for my own vulnerability in journeying with death and dying.

As this research draws to a close I am left with conflicting feelings. There is a sense of anger at illness such as breast cancer for the way it challenges and changes life as women know it. There is a sadness that I will no longer be a deliberate witness to the ongoing journeys of courage the co-researchers are on. And yet, there is a deep sense of gratitude and respect for the survival that each one has chosen to be a part of. I feel honoured to have been allowed to share their stories and experiences. I am in awe of the meaningful lives that each one has created despite breast cancer. The topic of breast cancer continues to hold an element of fear for me but the learning’s I now carry, both as a woman and as a researcher and therapist are invaluable to who I am and the journeys that I will continue to take with others.

In section 1.3 I wrote that *‘this research is my contribution towards being a compassionate witness in the world I live in and is one way in which I can “do hope” with a group of women in our local community who are living with breast cancer’*. That has been my biggest learning.

5.10 A FINAL SAY

The final say comes from the participants and co-researchers of this research journey - Karen, Lynda, Moira, Noriko & Tania, in the form of a poem collaborated on in the final group session together (see paragraph 4.9.3).

Redefining Femininity

I define it...

God is the only constant.

I have an invitation to find God in the secret & unexpected places;

The way was prepared for me to

Acknowledge God's hand in my life.

I have a new lust for life,

I stop waiting for life to happen.

Femininity is resourceful,

It's about my contributions

And an opportunity to be a role model

Because strength comes at a young age.

I am tenacious,

I am perseverance & determination,

I am comfortable in my different faces of 'femininity'.

What's internal is more significant than what's external.

The mask comes off

And I accept who I am.

I don't need to be beautiful,

Instead, I'm free to be me

and leave a legacy of what true femininity is -

Hope, faith, joy - LIFE

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John Kieran

<http://www.quotationspage.com/quote/36731.html>

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Annexure A

RESEARCH CONSENT FORM (I)

Background

Nicole Dickson is currently undertaking a MTh in Practical Theology at UNISA. She is investigating women's meaning-making experiences of living with breast cancer. A narrative pastoral approach of co-participatory action research will be used as a way of documenting, learning from, and giving 'voice' to these experiences. The research intends to provide a safe and respectful place for the participants and, in so doing, bear witness to cancer narratives and the re-storying alternatives. This research project is subject to ethical standards set by UNISA. This requires any participant in the research to be fully aware of what they are undertaking and their individual rights in the process.

Interviewing

The interview will be semi-structured in format. This means that there is a degree of flexibility for both the participant, and the researcher, to develop a rich and varied set of information. Unless otherwise requested, the interview will be recorded and transcribed in full. A full transcription will be made available to the participant to review prior to final consent being given to use the information in the research project. This is essential in order to ensure that an accurate re-storying of narratives occurs and that a framework of respect and confidentiality is maintained. Once final consent has been obtained from participants, the research thesis will be a public document.

Please ensure that you have read the above information then read the statements below:

- *I fully understand that I am participating in this research on a voluntary basis.*
- *I may choose to withdraw from this research process at any point and for any reason.*
- *I fully understand that I will be given the opportunity to read the complete interview transcript.*
- *Any information I do not wish to be part of the research process can be removed from the transcript.*
- *The interview transcript is a confidential document and will be stored in a secure location.*
- *All audio taping will be destroyed at the conclusion of the research process and that a copy of the final thesis document will be retained by the University of South Africa.*
- *I will not be receiving payment nor compensation for participating in the study.*
- *I will not only be participating in a research process but also in a co-authoring process of my personal narrative.*

I have read the above information and I am willing to participate in this research project.

Signature of co-researcher

Date

Annexure B

A note from Nicole Dickson

6 June 2011

Dearest Lynda

Thank you so much for sharing more of your story with me on Saturday. Our time together has left me feeling deeply moved.

One of the things you mentioned during our time together is that we all wear masks at some stages in life. We seemed to move on to areas of your story and we never had an opportunity to discuss this some more. I was left wondering what mask cancer invited into your life. Perhaps we can discuss this when we meet again.

I have also been reflecting a great deal on your conscious decision to be positive everyday; by your acknowledgement of the choice you make to be positive. I have been wondering what enables you to make this choice? Are you aware of when this conscious decision process started in your life? I would be very keen to hear your thoughts on this.

I truly look forward to continuing our conversation on Saturday

Yours faithfully

Annexure C

A note from Nicole Dickson

7 June 2011

Dearest Moira

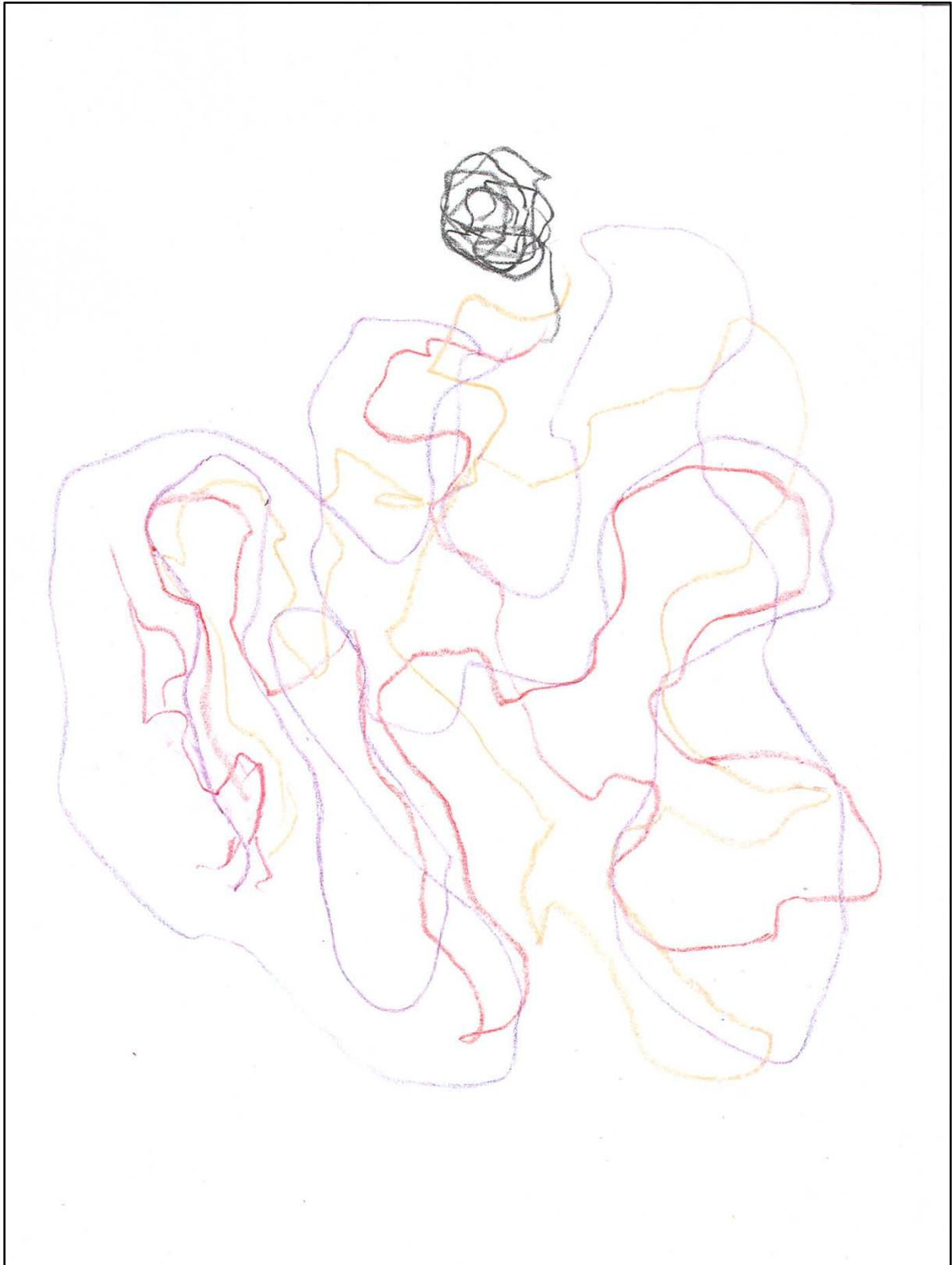
Thank you so much for sharing a part of your story with me today. Our time together left me feeling greatly inspired.

One of the things you mentioned this morning is how life presents you with a series of vistas or views and that cancer is but one of those views. I have been wondering where this metaphor for life came from? Do you remember when you first had that thought? Who else knows about this life metaphor? I look forward to exploring more of the views or vistas of your life in our next conversation.

Yours faithfully

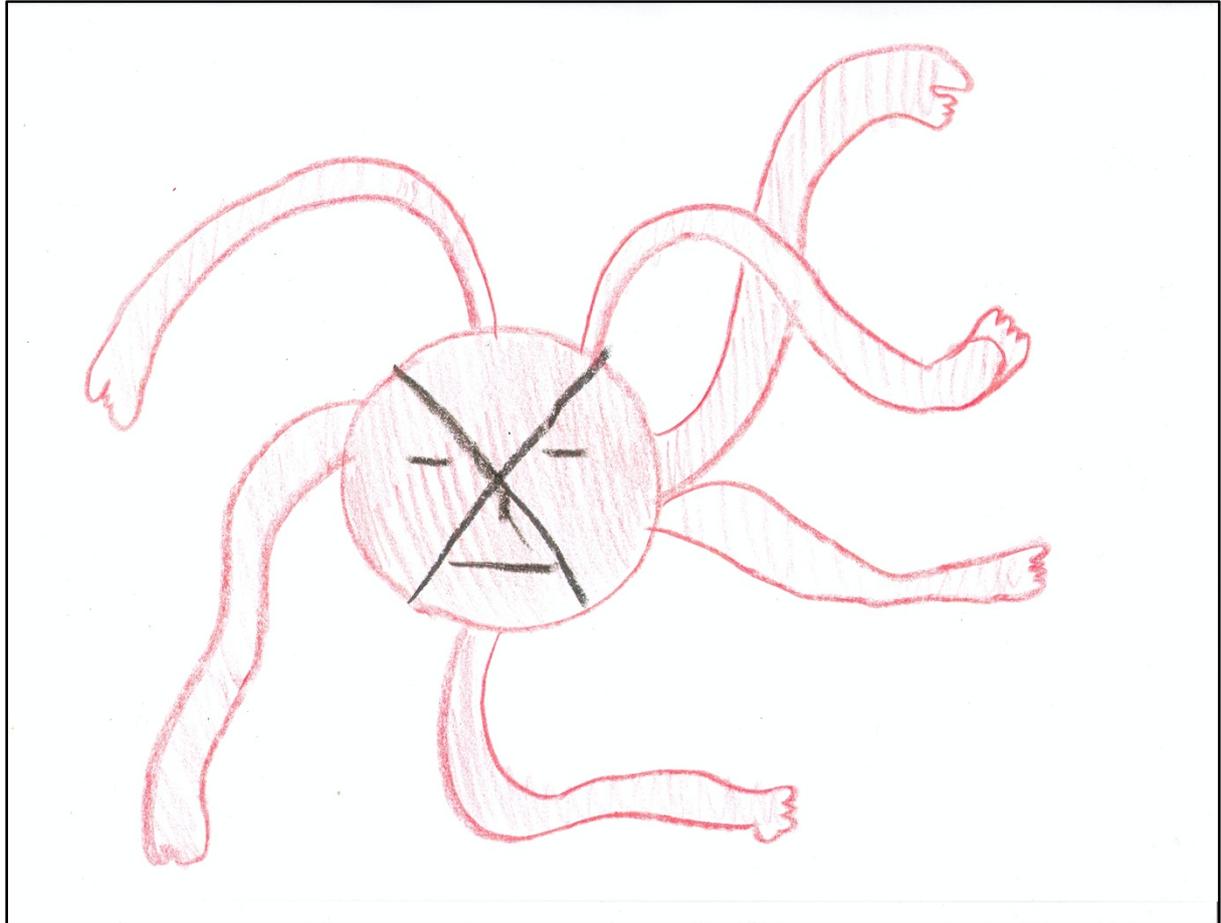
Annexure D

Moira's picture of breast cancer



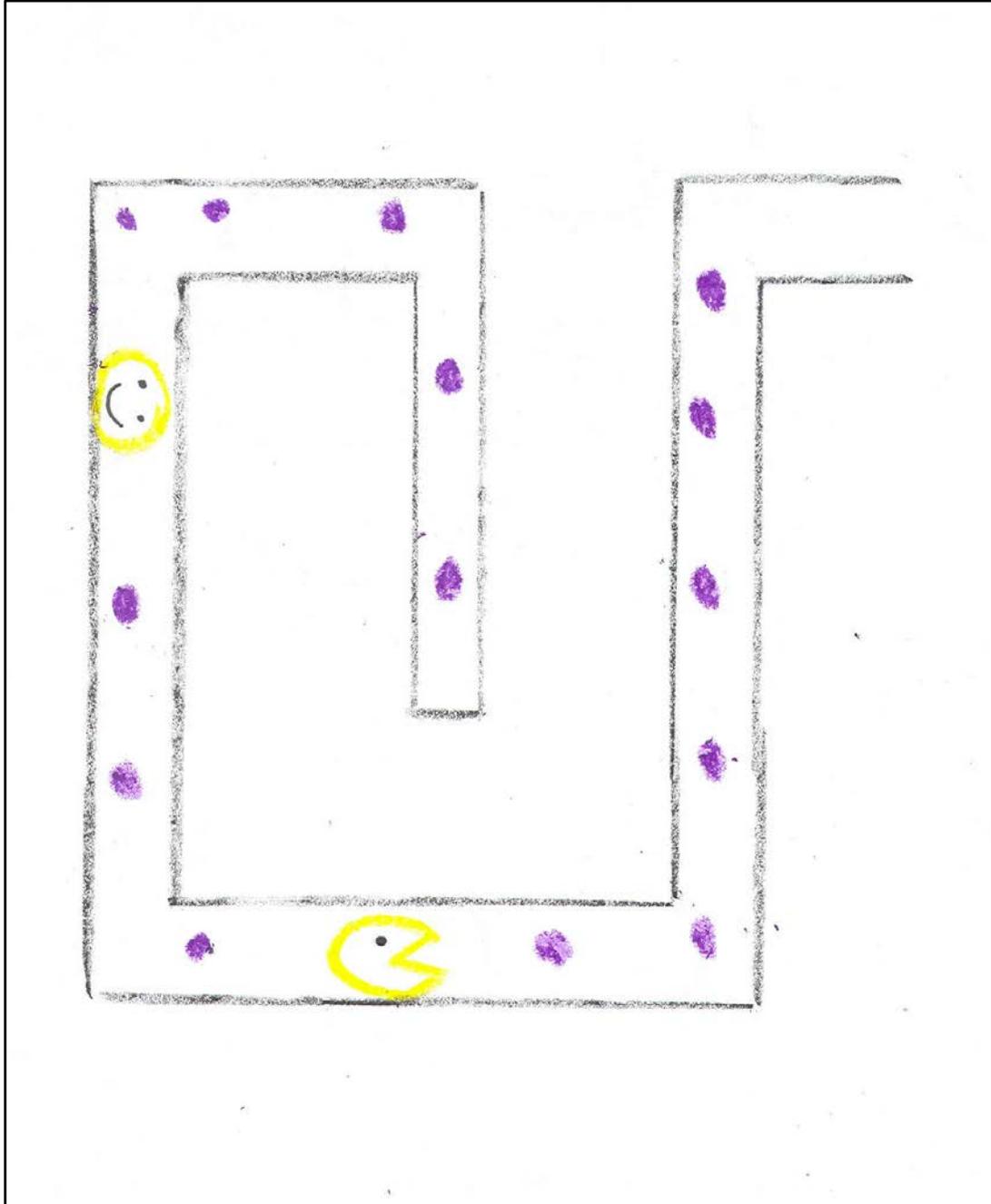
Annexure E

Tania's picture of breast cancer



Annexure F

Noriko's picture of breast cancer



Annexure G

Lynda's face of breast cancer

