

**Breast cancer and the medical encounter: Experiences,  
perceptions, negotiations and transformations of identity and  
femininity**

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by

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## **DECLARATION**

I hereby declare that this dissertation submitted in completion of the degree Magister Artium at the University of the Free State is my own, original work and has not been submitted previously at another university, faculty or department.

I furthermore concede copyright of this dissertation to the University of the Free State.

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## INTRODUCTION

Breast cancer is a life altering illness that does not discriminate in terms of demographics, socio-economic status or popularity. Breast cancer is predominantly experienced by women, although it does not mean that men are not afflicted by this illness. This is a genetic illness that does not display pronounced symptoms such as a cough or infection but instead grows in the shadows until detected through physical touch of an enlarged breast lump or by a medical check-up. In this research, I only focus on the narratives of the experiences and perspectives of eight women who were diagnosed with breast cancer and undergoing treatment. These middle-class women are all undergoing treatment by the same oncologist in a medical practice in Bloemfontein, South Africa. The project looks directly at how women diagnosed with breast cancer perceive and experience their diagnosis, by possibly re-negotiating and transforming notions associated with “identity” and femininity. These two issues could possibly be questioned, given the manifold existential crises that any form of cancer poses to those diagnosed with it. I am also interested in understanding if the medical encounter influences the individual in re-negotiating and transforming her identity and femininity. This will be reflected in how the individual perceives, experiences and interacts with the medical personnel.

Due to the similar background that the research participants, I expect to find shared commonalities in the form of perceptions, knowledge and understanding of the illness and its treatment. This thought is also influenced by the theoretical underpinning of social constructivism and existentialism. By implementing this paradigm, I will look at how societal norms, values and beliefs influence the individual’s understanding and outlook on her illness, her perception of the self, her perception of femininity and the her experiences related to the medical encounter. By prompting the research participant to share her experiences in the form of a told life-journey, allows for unique perspectives to emerge, producing rich and value-bound findings.

My interest in conducting this research can be associated with the current diagnostic growth of breast cancer in developing countries – including South Africa – where breast cancer can be understood as an epidemic that would benefit from more in-



depth research. According to Boyle (n/d, in Smith 2011, p. 1) who heads up the international prevention research institute in Lyon, France: “the incidence of breast cancer has tripled in the past 30 years and is expected to double again by 2030 with most of the burden falling on low and middle income countries”. Narratives of breast cancer are mainly confined to first-world countries, where state-of-the-art treatment and successful results are relatively common.

The focus of this project is on eight women diagnosed with and undergoing treatment for breast cancer in Bloemfontein, which is situated in the Free State Province in South Africa. Each of the research participants are from middle-class background, thus highlighting their privileged access to private health care in order to treat breast cancer. Given the history of segregation and apartheid, South Africa is known to have a dual health care system (Van Rensburg, 2004: 77) which means that there is a huge discrepancy in health care facilities and services when comparing the wealthy and the underprivileged. The research participants represent the privileged section of the population as each of these participants is able to afford and access private medical health care.

The theoretical grounding of the project focuses on a qualitative research design which integrates the theoretical understanding of social constructivism, social existentialism and phenomenological thinking. Due to the narrated experiences of the participants, I will rely on the theoretical frameworks of Alfred Schütz, Peter Berger and Thomas Luckmann. Although there are many debates surrounding the topic of “identity”, I decided to incorporate and apply the theoretical structure of the “re-conceptualisation of identity”. This theoretical structure allows me to find and apply more specific terminology than to opt for the term “identity” (Brubaker and Cooper 2000).

The research is presented in six chapters. The first chapter situates the project within a theoretical context. In this chapter I deal with relevant theorists and paradigms. The second chapter presents a literature review focusing on various aspects concerning breast cancer, the medical encounter, the social impact of the illness, and the current perceptions and understandings related to the illness. The third chapter focuses on understandings and perceptions of breast cancer, gender,

femininity, and identity. In the fourth chapter, I explain the relevance of the narrative to this study and the methodological trajectory that I followed.

Chapters five and six represent the findings. These chapters are embedded in the theoretical framework of Brubaker and Cooper (2000) in which they re-conceptualise the term “identity”. Chapter five focuses on the issues surrounding “identity” and femininity, whereas chapter six looks at the medical encounter. Within these two chapters, I give the research participants a voice, allowing them to represent their own thoughts, feelings, perceptions and experiences, in as far as their breast cancer journey is concerned.

I propose and intend to answer three research questions. These questions are as follows:

- How does the individual perceive and experience breast cancer?
- How is identity perceived and negotiated after the diagnosis and during and/or after the treatment for breast cancer?
- How does the medical intervention influence negotiation, perception, and transformation of identity and femininity?

Much awareness has been given to breast cancer and shortly before the end of this research, public attention flared up even higher when the celebrity, Angelina Jolie announced her preventative double mastectomy in February 2013 (Payne, 2013). This revelation by the actress has sparked an increase not only in awareness but also in medical health care. Dr Jacobs (2013, in Harp, 2013: 1), an oncologist from London, states: “the amount of women having breast cancer screenings has doubled since Jolie’s announcement” in England. This increase in breast cancer awareness can also be confirmed by Friedman (2013, in Lohn, 2013: 1) who founded the non-profit group FORCE (Facing Our Risk of Cancer Empowered) and who states: that “two weeks after Angelina’s announcement, FORCE’s website and hotline spiked four-fold”. This phenomenon has been dubbed the “Angelina effect” which highlights the fact that even “one of the world’s most genetically blessed women turns out also to be genetically cursed” (Crabb, 2013: 1).

This study is focused on the lived experiences and narration of ordinary women diagnosed with breast cancer. To emphasise the deeply emotional and existential

experiences that coincide with the fight against breast cancer, I share the following poem with the reader. "Poems share the fundamental constituents of (a rendition) in that they likewise feature a sequence of incidents, mediate and shape it from a specific perspective and present it from a particular point of time" (Müller-Zettelmann and Rubik 2005, p. 148).

The poem '*The darkness within*' by Donna Peach (2013) explores the intricate and emotional understanding of cancer. If cancer had a voice, it might have expressed itself in the following way:

"I, I am poison, the enemy within  
Death, hiding in life  
A faceless adversary lurking in molecular darkness  
I live in bone and flesh  
I live in blood and cells  
Stealing light, stealing laughter, stealing time  
The most precious thing of all  
I feed on toxins and chemicals  
The food you eat, the air you breathe  
I feed on innocence and purity  
Young and old, weak and strong, beggars and kings  
But even the strongest tremble when they hear my name  
I am the ultimate mirror  
I rip away the lies and the trivial worries  
The burdens that don't count, the arguments that didn't matter  
I leave you naked and weak  
Viewing the world in a whole new light  
Look me in the eye and know yourself for who you truly are  
Human. Fragile. Mortal  
In my arms mundane things becomes precious and precious things become  
irrelevant  
I conquer my victims cell by cell  
And those I touch live a different time  
When every minute counts and every word matters  
And every day above ground is a victory against me

But there is a way to freedom for those who would defeat me  
A path through the darkness for the strong and the brave  
A pound of flesh may buy your life  
Or a draught of poison, to fight fire with fire  
Be strong  
When I have drained you  
Be brave  
When I have taken your courage  
Be honest  
When you want comforting lies  
I am a dealer of death  
But to some I give the gift of life, lived to the fullest  
Those who defeat me learn the true value of time  
And those stolen hours seem cast in gold  
That wisdom, the enlightenment snatched from the grave  
That wisdom is my only gift to you”.

# Chapter 1 – Laying a Theoretical Basis

## 1.1. Introduction to Qualitative Research

In this research project, I aim to understand the personal testimonies of women diagnosed with breast cancer. I employed a qualitative research design to capture information through in-depth interviews. Within my analysis of the collected information I intend to formulate themes through the finding of commonalities and differences. Throughout this dissertation, I will deal with issues such as “identity”, the relationship between self and illness, the sick-role (labelling, categorisation and stigmatisation) and femininity. Emphasis will also be placed on the participants’ perspectives, reconstructions and narrations of the medical encounter.

This chapter will focus on the ontological and epistemological context of the research and how I will apply these perspectives. I am aware that ontology, epistemology and methodology are closely interwoven and this chapter aims to incorporate: the method that I employ (methodology), the view about the nature of reality that I adhered to (ontology) and how knowledge about social reality is formed, understood, and questioned (epistemology).

How one perceives events, actions and experiences results in how the individuals recall information and facts from their stock of knowledge (Audi, 2003: 1-2). How an individual experiences a stimulus is reflected in how knowledge is constructed. For Khine (2008: 3) the epistemological value has “important implications for learning, for example, beliefs about the nature of knowledge may influence strategy use, comprehension and cognitive processing”. This view had been proposed by Max Weber and is referred to as “interpretive sociology”, focusing on “the subjective perception of the actor” (Swedberg and Agevall, 2005: 155).

An individual will comprise her knowledge and experience from within her environment which results in her adapting to different roles within her social environment. This can be seen, for example, through a female being a mother, a daughter, a sister, a business-woman, amongst other roles (Mouton 1996, in Coetzee and Graaff, 1996: 16). Within these different worlds the individual requires a different scope of knowledge, or commonly referred to as “lay knowledge”, thus allowing each person to cope and survive within her current world. The world of lay

knowledge will be the primary area of my focus as each woman diagnosed with breast cancer has her unique way of making sense of this experience. It is also important to understand that the participants' level of medical or scientific knowledge surrounding breast cancer will vary, depending on their education, their socio-economic class, media exposure and actual experience.

Due to each individual being unique in her self-understanding and knowledge, she will perceive and understand a situation differently, whereby highlighting her "subjectivity" (Whorf 1940, in Lee, 1996: 123). Each participant will have a different view, understanding and perception of her illness and the experience surrounding the treatment trajectory. Women diagnosed with breast cancer may also find commonalities and strength with one another in friendship circles and support groups by sharing experiences and expectations.

The aim of integrating the above-mentioned points into the research is to try to capture the perspectives of individuals who have been diagnosed and are undergoing treatment for breast cancer. Each participant lives within multiple realities, which may consist of personal reality, work reality, medical reality and social reality, among others (Creswell, 2007). Each individual who participates in this research project will express her views and outlooks differently. It is therefore important to understand the subjective meanings of the research participants, how they attach importance or significance to their experiences and, if possible, to find a common thread that is conveyed throughout each of the narratives.

This research project focuses on gathering the participants' understanding, knowledge, perceptions and experience of their illness and in particular, thoughts surrounding the themes of "identity", femininity and the medical encounter. This information was obtained through the establishment of close, intimate and trusting relationships and the minimisation of distance and estrangement between the individual and me. My aim was to build these trusting relationships, in order for each participant to communicate or relay whatever was on her mind. Once such relationships were built with one another, the in-depth interview could assume a more natural flow.

For the purpose of this study, I will focus solely on the interpretivist and social constructivist paradigms. A scientist uses the interpretivist approach to comprehend

a social world that a participant has constructed. It is important to remember that the individual is “constantly involved in interpreting and reinterpreting [her] world which is seen [within her] social situations, [her] personal actions and [the] actions [of others]” (Blaikie, 2007: 124). The interpretivist view will play a central role to the research undertaking. This will be reflected in how the individual views herself, her diagnosis and her medical encounter. I am aware that I will interpret and view each narrative from my own frame of reference and constructions, as cultural and societal influences will play a role in how I perceive, read and understand the narrated life-stories. I am also aware of biases and thus will closely monitor and actively reflect on my drawn conclusions and thoughts.

It is the opinion of Giddens and Griffiths (2006: 152) that social constructivists aspire to understand how an “individual [within] society perceives and understands reality”. It is therefore their outlook that reality is created through “social interactions” with others. The aim of a social constructivist is to “analyse the processes that are concerned with the concept of social reality” (ibid.: 152). I will integrate the social constructivist paradigm as the dominant viewpoint and thus this position will be reflected throughout this study. Each individual in the research project will reflect not only on her experiences surrounding breast cancer, but also on how this illness impacts on her understanding and interactions with others and in turn, how others view and interact with her as the diagnosed individual. This circular process will influence how the individual understands her constructed reality, how she perceives the illness and its (immediate and long-term) consequences.

Methodology is seen by Blumer (1969: 24) as the “study of principles” that underlie a particular “scientific inquiry”. Within the methodological description one must be aware that the concept of methodology has “indefinite boundaries” and flows into various philosophical areas of “logic, epistemology, and ontology” (Braugh, 1990: 1). The philosophical assumption consists of an analytical investigation into “theories of knowledge, beliefs, opinions, perceptions, errors, imagination, memories, inferences, and abstractions” (Flick et al. 2004: 89). There is however a debate on how these above-mentioned assumptions are categorised and applied. For the purpose of this research project, I will rely on the view by Husserl (n/d, in Durfee, 1976: 18), that states that these above-mentioned assumptions are forms of “phenomenological enquiries”, which are understood as the basis of “mental functioning”.

In order to conduct this research it is firstly important to understand how an individual constructs her knowledge within her social interactions. These social interactions will reveal how the individual views her diagnosis, the medical encounter and the process revolving around her re-negotiation of “identity” and femininity. Depending on the participant’s cultural and societal understandings, she may base her opinions and perceptions upon given values, norms and beliefs.

I will continue this chapter by looking into specific domains of phenomenology, with the focus being on stock of knowledge and the life-world, experiences and intersubjectivity. I will then proceed by expanding the view of existential sociology and social constructivism. This section will take into account one’s understanding of the existential self and the self in society, rationale for implementing the social constructivist paradigm into this research project and the role of language. I will conclude this chapter by looking at reflexivity from a personal perspective, as well as a reflection on the chosen theoretical framework.

## **1.2. Phenomenology**

Within the research project, I will implement the social constructivist point of view, while integrating a phenomenological stance. This stance will focus on the subjective understanding associated with the “meaning-comprehension” of the life-world in individuals diagnosed with breast cancer (Flick et al. 2004: 67).

The term “phenomenology” is seen by Kant (n/d, in Bidney, 1973: 109) as comprising of firstly the “phenomena” and secondly the “noumena”. The “phenomena” is represented by “the appearances of reality in consciousness”, whereas the “noumena” symbolise “things-in-themselves that are independent of consciousness”.

There have been a variety of terms used to describe the different domains of phenomenological health and illness, which include “the lived experience, embodied experience, and bodily distress” (Ember and Ember, 2004: 126). The underlying concept of phenomenology is that it aims to explore how “life-worlds emerge from micro-processes”. These micro-processes emerge from social interactions that



materialise from the “common-sense knowledge of the participant” (Alvesson and Sköldbberg, 2012: 78).

According to De Muralt (1988: 7-8) “phenomenology” is defined as “concrete logic” but Schütz (1970: 55) is of the opinion that:

“All social sciences take the inter-subjectivity of thought and action for granted. That fellowmen exist, that men act upon men, that communication by symbols and signs is possible, that social groups and institutions, legal and economic systems and the like are integral element[s] of our life-world. This life-world has its own history and its [own] special relationship to time and space”.

Interpretations allow for objects to appear and thereby the essence is revealed. This can be applied to how each individual perceives, understands and experiences within her life-world. It is human nature to see the world and the things that happen within it as “independently existing”, but we “habitually fail to remember that they are constituents of our [variegated] cognitive-cum-volitional-cum-emotional experiences” (Durfee, 1976: 21-23). The consequences of this thought can be seen plainly as each individual understands and perceives her interactions, emotions and experiences uniquely to others. When viewing the uniqueness of interactions, emotions and experiences the individual understands herself as existing independently of others. I therefore aim to understand these unique perspectives that each individual has surrounding her illness, while taking into account that these phenomena are shaped by socialisation, her interactions and inter-subjectivity, as well as her external world.

Phenomenology can be seen to have its limitations and according to Doran and Croken (2010: 87) “phenomenology operates on the level of sense and understanding without paying attention to the critical control of rational judgment”. This thereby highlights internal and external influences, cultural and societal understanding and biases that could play a role in how the individual understands her life-world.

### 1.2.1. Stock of Knowledge and Life-worlds

Each individual experiences and constructs her knowledge and life-world within her own frame of reference, understanding and perception (Potter, 2003: 13). This view is expanded on by Berger and Luckmann (1966: 36) who state that:

“The reality of everyday life is organised around the here of my body and the now of my present. This here and now is the focus of my attention to the reality of everyday life”.

It is the opinion of Max Weber (1984, in Bruun and Whimster, 2012: 102) that knowledge is created through meaning and is seen to be “tied to the categories ‘ends’ and ‘means’”. The category of “ends” refers to the achieving of a particular goal for either knowledge, experience or an object. “Means” on the other hand highlights the search of obtaining what was strived for. Meaning is sought to validate an issue, topic or action in order to achieve a particular goal. By acquiring knowledge the individual not only understands, but appreciates each thought, action and experience at a higher level. The Weberian position views each life as laden with meaning and significance that can be “experienced as objectively valuable” (ibid.: 102-3). The value that is placed within the “sphere of one’s own individuality” relies strongly on what the individual deems ideal and meaningful (ibid.: 102-3).

The phenomenological aspects surrounding the individual’s life-world are important. The social interactions that the individual has experienced will influence how she perceives her diagnosis, her identity and femininity, the medical encounter, her support structure and how she interacts within her social environment.

As this research focuses on women who have been diagnosed with breast cancer, it is imperative that I delve deeper into the understanding of the concept of “knowledge”. According to Rogers (1983: 55), routine or habitual knowledge is related to “useful or skilled knowledge” whereby allowing the learnt knowledge to be transformed into standard or automatic knowledge. Within this study habitual knowledge will revolve around the individual’s perception, understanding and knowledge surrounding her diagnosis and her ability to comprehend the medical encounter.

Depending on the individual and the length of the treatment trajectory, certain elements of information and terminology may become standard or automatic knowledge. When applying the process of automatic knowledge, the individual does not consciously need to produce much mental or cognitive energy, as the information around that particular activity is already present. This may be the case with some of the participants, as the illness may have been experienced indirectly through a family member, a friend or the media.

An individual's stock of knowledge can be categorised and broken down into six properties according to Potter (1996: 53):

“Firstly, it is socially derived ... secondly, it is socially distributed ... thirdly, the social distribution of knowledge is itself part of the stock of knowledge at hand. Fourthly, stock of knowledge is built upon and expressed in everyday language. Fifthly, this knowledge has an open horizon of meaning ... and lastly, stock of knowledge is not a neatly and logically ordered storehouse of information and typifications”.

I am interested in understanding how knowledge allows for new routines and/or habits to be formed after the diagnosis of breast cancer and how the experience of this illness impacts on daily functioning. The forming of routines and habits is scientifically known as “habitualisation” which allows for “new categories” to be made through “observing others and their actions” (Alvesson and Sköldberg, 2012: 26-27). Within this research, none of the participants faced the breast cancer illness without prior knowledge to the illness, or as Kant (1881: 232) states from a “tabula rasa” perspective. Each individual diagnosed with breast cancer had varying degrees of knowledge surrounding cancer and breast cancer in general. This knowledge may have contributed to a better understanding of physical, psychological and emotional aspects to the individual's personal diagnosis.

### **1.2.2. Experiences**

It is the opinion of some that women experience stimuli differently from men and this is contributed to historical and societal factors (Ellison and Douglas, 2010: 23). The point that men and women experience stimuli in different ways is partly to be

ascribed to different ways of socialisation and exposure to different cultural norms. Depending on the different forms of socialisation, the individual encompasses “divergent capacities and divergent experiences of the world” (ibid.: 23).

I am aware that societal norms and values will play a part in how the diagnosis is understood and thus how the individual aims at overcoming her illness. As Babbie (2010: 41) states “all our experiences are inescapably subjective”, as what one views or hears creates “different physical realities”. Each individual will view and understand her diagnosis differently and depending on previous experiences, such as having experienced the illness through another, will create a different outlook on how she copes physically, mentally and emotionally. It is important to remember that influences of society and its norms, values and beliefs influence how the individual understands a situation and the decided route of action that may be taken. Crotty (2005: 58) states that:

“Each one’s way of making sense of the world is as valid and worthy of respect as any other, thereby tending to erase any hint of a critical spirit. On the other hand, social constructionism ... shapes the way in which we see things [even in the way in which we feel things] and gives us a quite definite view of the world”.

Each individual is placed within her own sense of reality whereby allowing experiences to “shape our sense of self” (Freeman and Mathison, 2009: 14). This view therefore highlights the validity of each individual’s claim to knowledge according to the “shaping effects of culture and location” (ibid.: 14). The uniqueness of each experience that the individual has with the illness will contribute not only to her stock of knowledge, but also to her self-understanding and life-world. This uniqueness will also highlight the different attitudes (optimism or pessimism) towards the diagnosis and how negotiation of identity and femininity is accomplished.

It is the opinion of Crotty (2005: 45) that “experiences do not constitute a sphere or subjective reality separate from ... the objective realm of the external world”. Therefore when the individual was diagnosed with breast cancer she may have felt periods of isolation and loneliness. But this state of isolation and loneliness was overcome when confiding in a family member, friend or a relying on a strong sense

of religion. Being able to find comfort in others may help the individual understand the experience better.

Each person has a “unique perception of reality” which leads to or allows for “varying lifestyles”, thereby producing or creating “different perceptions of reality” (Tischler, 2011: 5). It is important to realise that if one wants to understand another’s point of view “one must stop looking at the world from a perspective based solely on one’s own individualistic thought processes” (ibid.: 5).

When applying the concept of inter-subjectivity, Schütz and Luckmann (1973: 68) are of the opinion that the “life-world is not my private world nor your private world ... but rather the world of our common experience”. For the purpose of this study I seek to understand how each individual perceives her life-world and where possible to point out any commonalities and differences in experiences and perceptions surrounding illness. I am aware that reflecting on particular experiences may make the participant feel uncomfortable or become emotional. As seen by Van Manen (1990: 73), it is important to reflect on these sensitive experiences, thereby “discovering or re-discovering” different aspects. Within this research project, the experiences of the participants are an invaluable source. I aim to understand how the diagnosis and treatment trajectory impacts on their lives and how they experience, understand, perceive and re-negotiate their “identity” and femininity.

### **1.2.3. Inter-subjectivity**

Subjectivity falls into a sphere of “attitudes, opinions, and points of view” (Babbie, 1989: 45). Inter-subjectivity can refer to several individuals sharing rather similar views on a particular topic. By considering a topic such as breast cancer, one would agree that each woman diagnosed with breast cancer will share certain experiences. These experiences may include aspects such as shock when diagnosed, existential uncertainties, side-effects to certain treatments and having to come to terms with the physical changes. It is thus the opinion of Tymieniecka (2010: 195-197) that the concept of inter-subjectivity is seen to be:

“[The] recognition of the other as being similar to me is ultimately the experience of inter-subjectivity ... The body of another signals intentional acts

and it also expresses a content of thought through the spoken language. This more generally expresses conscious life, which again provides other perspectives on the way things are, which leads to recognition of the epistemological value of inter-subjectivity ... The communicative aspect is the inter-subjective fundament which, in objective, normative and subjective matters, can make possible every speaking and acting subject to reach an agreement when it comes to objective as well as normative controversial matters”.

Consciousness allows a person to be aware of surrounding stimuli, thus enabling the individual to perceive, understand and experience. Each experience is placed within an “ego-relatedness” (Vaitkus, 1991: 46). This “ego-relatedness” can be explained when a unique experience is perceived and understood in totality only by the individual (ibid.: 46). Inter-subjectivity can only be recognised through understanding that consciousness permits one to comprehend the world in which one lives. Experiences and knowledge allow the individual to make connections within her life-world. These connections highlight self-understanding within the context of the experience. Consciousness enables the individual to understand or comprehend what has happened and therefore allows for memories to be made. Thus, how an individual comprehends and memorises an experience will be reflected in how she expresses her narrative. Due to my focus being on a personalised illness experience, the participants will draw knowledge from their perception and understanding and therefore express their rendition in a subjective manner (ibid.: 46).

### **1.3. Existential Sociology**

Existential sociology is grounded within central themes such as “the nature of the individual, the central role of passions and emotions in human life, the nature and responsibilities of human freedom, and the irrational aspects of life” (Kotarba and Johnson, 2002: 3). The three main questions an existentialist aims to understand are firstly “how to live”, secondly “how to feel” and lastly “what to think about one’s situation” (ibid.: 4). In order to be able to answer any of the above-mentioned

questions, one must be aware of the experiences that an individual has and how these experiences have impacted on the individual's life.

For this research project I will implement Ritzer's (2011: 205) definition of existential sociology which states that it is "the study of human experience-in-the-world [or existence] in all its forms". One of the prominent features of experiencing in the world is "change" (ibid.: 205). Existentialists understand that within each individual's life-story, change is a constant element. It can thus be said that no one individual's social existence is un-dramatic or scripted, but instead, that each event allows the actor to write, produce and act within her own social setting. Before being diagnosed with breast cancer each participant continued with her life as a healthily functioning individual. It is not to say that she did not have her daily challenges but she proceeded through life mostly overcoming these challenges and embracing the unexpected joys within her day-to-day context. After being diagnosed with breast cancer, women may experience changes not only to their health, but to their overall well-being which can influence elements within the physical, emotional, psychological, spiritual and social aspects of their lives.

I am aware that when implementing the social existentialist approach to the research, each participant becomes the centre of my focus. I aim to understand the life-world and experiences of each participant whereby seeking to understand how "identity" and femininity are re-negotiated and transformed. I place a strong importance on the individual's experiences and how these experiences influence her understanding and knowledge. In contemporary society, being labelled as ill is sometimes seen as a weakness. When a woman is diagnosed with breast cancer, she is not only seen as having an illness, but she also has to come to terms with the physical, psychological and emotional implications of what the illness and the treatment trajectory will do to her physical appearance.

Social existentialism focuses on the potential of humans seeking "self-fulfilment through the social encounter in which the 'I' and 'You' blend into a communion of mutuality" (Glicken, 1974: 116). The ultimate search for "fulfilment through life" allows people to seek and understand the "resolution of social meaning". It is the opinion of Weiss (n/d, in ibid.: 116) that social existentialists believe that "through the human encounter each person who is sent or thrown into the world fulfils her life in

and through others with meaning and dignity". This is the way to achieve courage and at the same time to re-affirm one's standing within one's environment. This thought can thus highlight that life is episodic and always changing, thereby allowing for new interpretations to be made (Lyman and Scott, 1970, in Kotarba and Fontana, 1987: 9).

One can combine the thoughts of a social existentialist and social constructivist. Gold et al. (2010: 521) are of the opinion that:

"The existentialist perspective enables us to explore meanings and choices in relation to work relationships and development. Using this perspective alongside a constructionist approach further enhances the scope to explore some of the influences on relationships and inter-relationships".

Social constructivism allows for the analysis of the "ongoing and relational acts between people ... this reinforces the importance of examining the social and local context in which people are located" (Gold et al. 2010: 521).

### **1.3.1. The Existential Self**

The existential self is seen to incorporate "an individual's unique experience of being within the context of contemporary social conditions and this is most notably marked by an incessant sense of becoming an active participant in social change" (Ritzer, 2011: 206). The individual must integrate her sense of embodiment and becoming into situations of everyday life (ibid.: 206). Embodiment encapsulates the attributes of "feelings and perceptions" within the life-world. The feature of becoming is situated in "the real social world of being effective and coping" (ibid.: 206). When looking at the existential self, Kotarba and Fontana (1987: 11) added an additional two elements which are: the situational and reflexive self. In their view, the situational self is "always dependent on its immediate contexts for a sense of grounding and belonging". The second element is that the "self is reflexive because it is aware of itself. It is the focal point for the social, biological, cognitive, affective, and interpretive dimensions of being". Therefore they are of the opinion that the existential self can be defined as the following (ibid.: 11):



“The self is existential because it is in an incarnate self, filled with rational thoughts, sudden emotions, deeply felt anxieties, biological urges, and cultural elements. The self is in society because it is a self-embodied-in-the-world, therefore it is studied in its natural settings, in its interacting stance, and in its experiential confrontation with society”.

### **1.3.2. The Existential Self and Society**

There are two prominent factors that link the self and society, firstly one’s culture and secondly the individual’s expected roles. Depending on one’s culture, certain themes and roles become ingrained as being socially acceptable and thus result in determining the individual’s “personal identity” (Kotarba and Fontana 1987: 228-229).

When focusing on the life of an individual there will be instances when certain experiences and events challenge the individual’s outlook and self-view (Kotarba and Fontana, 1987: 227). When an experience or event threatens the security of the self, a sense of meaninglessness can result. In the case of meaninglessness, the individual may “seek social forms that can assist in reconstructing the self and in eliminating the threat” (ibid.: 227). Meaninglessness in breast cancer patients may be alleviated or overcome by confiding in family, friends, joining support groups or even finding or consolidating religion. Obtaining person-centred or spiritual support can allow the individual to create a unique connection, whereby finding mental and physical strength to overcome her affliction.

Within this research project it is vital that one understands the role that existentialism plays in the lives of the individuals. The different aspects of how a participant views her life and how she answers the question of “who am I?” will influence each participant differently.

#### **1.4. Social Constructivism**

The key feature to social constructivism is that “reality is not self-evident, stable and waiting to be discovered but instead it is a product of human activity” (Rogers and Pilgrim, 2010: 15). Within the social constructivist understanding there are three main themes. These themes revolve around the following points: “reality is not rejected as an epiphenomenon of human activity ... reality is being viewed, in whole or part, as a product of human activity ... and power relationships are inextricably bound up with reality” (ibid.: 16).

In this research undertaking I will implement a social constructivist view on women who have been diagnosed with breast cancer. The aim of the research is to understand how each individual creates, understands and perceives her reality. Additionally, I seek to recognise how society influences the re-negotiation and re-construction of identity and femininity within the culturally accepted norms, values and beliefs. Depending on the cultural understanding, I may determine if the individual was subjected to any forms of labelling, categorisation or stigmatisation through her illness experience.

According to Roberts and Watkins (2009: 294) “a person’s sense of reality depends on how the mind constructs knowledge and reality”. The unique characteristics (physical, emotional and psychological) of the individual are a strong determinant in how meaning is given to her reality and life-world. For Gergen (1999: 60), social constructivism combines factors from both the individual and society “while the mind constructs reality in its relationship to the world. This mental process is significantly informed by influences from social relationships”. But for the mind to construct reality and be influenced by social relationships, Roberts and Watkins (2009: 294) hold the opinion that each person’s reality is “constructed through people using language” within multiple “interactions at all levels of social life”.

Language is an integral and interrelated element to social constructivism (Cain, 1995: 24). Cain’s idea is based on the thought that social constructivists “treat change more as a matter of altering language practices than as a matter of social intervention and emancipation” (ibid.: 24). Language is an important element within the research, as what the individual reveals verbally is my primary area of interest.

Each rendition will be analysed through word choice and each word will convey meaning to what was experienced, perceived and understood from the illness experience. Wells (2011: 55) states that when the researcher views a narrative from a social constructivist approach, “the narrator’s identity may vary in relation to her context but the narrator and the narrative are inseparable from the social context of which they are a part”. According to Shay (1994: 4-5)

“Our mode of listening deteriorates into intellectual sorting ... grabbing words from the air and sticking them into mental bins ... passages of narratives bear a different order of meaningfulness than any categories they might be put into”.

Therefore it is important not to impulsively classify the narrated experience, but to always be conscious of the type of listening that is required for the purposes of an intellectual project. As with most forms of communication, both the participant and I have to show the appropriate amount of reciprocal engagement in order to understand what is being revealed.

#### **1.4.1. Rationale for Choosing Social Constructivism**

The underlying commonality in constructivism is seen to be influenced by “biases, frames, theories, accounts, narratives and conceptual frameworks of various kinds” (Bellamy and Perri 6. 2012: 57). Certain understandings can be seen to influence how the individual is manipulated into certain actions when placed within a particular situation. This also brings forth how previous experiences impact on the individual and how she may act or react under similar circumstances or conditions. Social constructivism can be understood and defined as “the social interactions that led to shared understanding ... and to the development of practices based on those understandings” (ibid.: 57).

Gergen (1985, in Velody and Williams, 1998: 160) defines social constructivism as “the explication of the processes by which people come to describe, explain, or otherwise account for the world [including themselves] in which they live”. The above mentioned definition also considers the hermeneutic view incorporated into “social constructivism” which brings the focus on how an individual comprehends, interprets,

explains and establishes an activity in itself. The hermeneutic view as seen by Ritzer (2011: 283) is a “branch of sociology concerned with human understanding and interpretations”. When applying a hermeneutic approach to social events, the investigator aims to “examine a participant’s understanding of the events from the standpoint of her specific historical and cultural context” (ibid.: 283).

For this research project, I will gather, interpret and present findings from within a social constructivist point of view. Creswell (2007: 20-21) describes social constructivism as attaching meaning to experiences, objects or things and as a result, meanings are varied and diverse, thus it is important to look for the unique and intricate viewpoints that have been experienced. The subjective meanings that are attached to the experiences are socially, culturally and historically created through beliefs and values that are recognised as norms.

The social constructivism framework will help to enable the understanding of the narrative process, thus allowing insight into the individual’s world in which she lives, works and interacts. The purpose of conducting this research is to understand how meaning is attached to and influenced by the illness experience. I am particularly interested in seeing how identity and femininity are re-negotiated and transformed. I am also interested in seeing if the medical encounter which includes the treatment trajectory, influences or aids the individual in her re-negotiation of “identity” and femininity. The language and description the participant uses to recollect and attach meaning to her past experiences will help me add validity and essence to this project.

#### **1.4.2. The Role of Language**

It is my opinion that an individual may learn to cope with her illness by narrating, through language, certain emotions to others. The use of language to narrate an experience – especially an experience that may present a threat (physically, psychologically or emotionally) – can be viewed as being potentially therapeutic. The therapeutic value in expressing one’s fears, uncertainties and doubts to another may bring a better understanding of the overall experience. This understanding can encourage the individual to plan or prepare herself physically and mentally for the

challenges related to breast cancer. One may understand one's situation better through the verbalising of one's fears and qualms to a family member, to a friend or to a religious leader.

The metaphors that are contained in narratives reveal "strong therapeutic values" and may allow the communicator to give "meaning to her lived experiences" (Dwivedi, 2000: 31-32). Language can be implemented in a non-invasive manner, therefore allowing the individual to "reach [certain] depths" while still confronting certain aspects of a lived experience (ibid.: 31). Revisiting challenging experiences allows the individual to revisit issues that were avoided or even missed. This can give the individual a greater perspective and perhaps more insight into what was overcome in the past. Each participant in this research project will have her own understanding of her diagnosis, but I will work with the assumption that within the initial diagnosis the most common reaction was disbelief and shock. Therefore it is also my opinion that the topic of diagnosis is going to be the most likely platform from where the individual will begin her narrative journey. I do not intend to cause any discomfort (emotionally or psychologically) by asking the individual to relive her illness experience, but instead I aim to understand her experiences with regard to her overall breast cancer journey.

For Bissell and Traulsen (2005: 73), each person is involved in interactionism, which is achieved through language. This thought is expanded on by Schütz (1972, in ibid.: 73-74), who states that:

"It is the world of cultural objects and social institutions into which we are all born, within which we have to find our bearings, and with which we come to terms. From the outset we, the actors on the social scene, experience the world we live in as a world of nature and of culture, not as a private but an inter-subjective one, that is, as a world common to all of us, either actually given or potentially accessible to everyone; and this involves intercommunication and language".

In order for me to partake (ask questions and listen) in the communication process, it is important that I do not allow for judgemental notions to hinder the relationship. The language I used was closely monitored, so as to avoid inflicting emotional harm or indicating insensitivity towards their experiences. Each research participant

understood and used language that best fits her current emotional state. It is therefore important to comprehend that certain words, metaphors and tones may be used for the purpose of exaggerating or highlighting particular areas within the narratives. It should be noted that even though I spoke the same language (English) as the research participants, there is a chance that misinterpretation can present itself. A participant might have meant something different to what was understood within our contact sessions.

## **1.5. Reflexivity**

The purpose of including a reflexive section is to highlight “transparency and address ethical issues and power relations between [the] researcher and [the] researched” (Etherington, 2004: 37). I aim to provide “information on what is known as well as how it is known” through exploring and representing the “blurred genres of experiences”. These experiences are vital within the project as this will add “validity and rigour ... by providing information about the contexts in which [information] was located” (ibid.: 37).

### **1.5.1. Self and Reflexivity**

My assumptions, interpretations and personal views will play an integral part within the study being undertaken. According to Dewey (1910, in Lee, 2011: 406)

“Reflection forms the basis of a disciplined mind: an ability to look at matters deliberately; to gather and judge evidence; to balance analysis and synthesis, the concrete and abstract, experiential and experimental [scientific] thinking”.

I am aware that my research undertaking is not a topic that I can understand through introspection. I thus placed myself within the sphere of breast cancer, which was achieved by becoming familiar and confident with the subject material, consulting experts (such as an oncologist) and expert literature, as well as finding and interviewing women who were diagnosed with this illness. This made me a part of the research by giving me insight, understanding and higher knowledge on the topic of breast cancer. It can be seen that my relationship with the participants was

intimate, as sensitive issues surrounding their illness were discussed in depth and at length. I am also aware that this relationship can cause me to become biased within the analysis of the information and in writing up the findings. This thus highlights my subjectivity, as I was the one who researched the literature, designed the interview schedules (Appendix C), conducted the interviews and analysed and wrote up the findings. According to Davies (2008: 4), reflexivity is defined as “a turning back on oneself which is a process of self-reference” and I have implemented this thought throughout my research.

The participants and I were involved in the reflection process. Each individual in the research project would have to examine her own experiences surrounding her diagnosis of breast cancer, how she perceived and experienced the diagnosis, the medical encounter and how identity and femininity were re-negotiated. In order for the research to accurately capture what I experienced, I kept a journal to document the activities or interactions with participants. These activities and interactions included: non-verbal observations during interviews and how emotions (micro and macro expressions) were revealed, the handling of findings, how I interpreted and analysed the findings, how assumptions, emotions and personal views emerged during the interpretation of findings and personal interactions with the participants. A strong point made by Cheng (2010: 76) is to continuously reflect on “what I know and how I know it”. These two reflexive questions were considered in the course of collecting field work, as well as during the period of writing up and finalising the findings.

It was my aim for each individual to partake in the reflexive process by reflexively going over the illness experience and not necessarily to relive and re-experience the challenging times of the breast cancer ordeal. Within this reflexive activity, the individual may discover certain aspects that may have been overlooked or purposefully unacknowledged. Overlooking or not acknowledging certain experiences within the breast cancer journey could be seen as a self-protective mechanism in order to overcome the shock of being diagnosed with breast cancer and having to face the ensuing medical encounter. By reflexively going over the breast cancer journey, I hoped to understand the research participants’ experiences by asking specifically designed questions in the interview, listening to their responses and delving deeper into a particular experience, to afford these

participants the opportunity to expand on their current experience. This also gave me a clearer understanding on how the individual sees and projects herself within her narrative.

### **1.5.2. Theory and Reflexivity**

Within this study my theoretical focus is on the social constructivism, social existentialism and the phenomenological approach. These approaches fit well with the chosen topic of research, despite the fact that they also hold some epistemological biases and a very specific point of departure when doing research. When viewing the critiques surrounding the social constructivist paradigm, Holstein and Gubrium (2008: 54) mention the “Alan Sokal” affair. This manuscript brought constructivism into the public eye whereby making “ridiculous claims about the public world” (ibid.: 54). Consequently, this brought critics to the conclusion that social constructivism is an “arbitrary” paradigm whereby there is “no fact, only interpretations” (ibid.: 54). The critiques conclusion was that “calling something a social construction was presumed to be equivalent to denying its existence ... and many equated social construction with the dangerous denial of real problems” (ibid.: 54-55). However, not all critics categorically dismiss this paradigm and some argue that “all ideas are equally valuable and that they cannot be tested against the empirical world” (ibid.: 55). Despite its shortcomings, social constructivism is still deemed to be a worthy approach to be followed in this research, especially given its stance of trying to make sense of the constantly changing reality that human beings constantly face, and more so in the context of an adverse event such as a diagnosis with breast cancer.

The critical view of social existentialism can be understood as “refusing to engage in the problems of the world”, which could be attributed to an individualistic outlook, thus leading “to a lack of concern for other people” (Panza and Gale, 2008: n/p). But currently, existentialism has found a new focus in giving a “voice to the situations of oppressed people, such as women” and promoting the “well-being” of humanity (ibid.: n/p). An illness experience is a lonely and largely individual ordeal. Cancer, in all its forms, carries within itself the potential to eliminate all future aspirations of



people. In view of the overarching research question, an existential approach is thus very appropriate for the general aim of this study.

My decision to apply these three approaches to the research was to aid my quest in understanding how women diagnosed with breast cancer re-negotiated their identity and femininity and if the medical encounter influenced this negotiation.

Even though the theoretical focus on constructivism and existentialism is seen as how an individual integrates, understands and externalises her given and known society, it is also important to understand how society influences the individual's norms, values and beliefs, especially during a time of profound and dramatic change in the individual's life. This theoretical approach was not just convenient, but a perfect fit to this project, as how a woman negotiates who she is, is strongly influenced by her immediate context and her personal construction thereof.

## Chapter 2 – Literature Review

### 2.1. Biographical Disruption

When looking at the biographical disruption from a sociological framework, my aim is not only to understand how an illness disrupts a person's health, but also how the illness ripples through the totality of one's life. According to Bury (1982: 169) an illness can cause a significant disruption to an individual's life, thereby prompting the individual "to rethink her biography and self-concept". This rethinking or reassessing of one's life can be beneficial, as this act can help an individual to re-negotiate and transform where she feels comfortable to belong (physically and psychologically) and who she has become (spiritually, emotionally and physically).

When working around the understanding of the biographical disruption Bury (1982: 170-175) identifies three main themes. These three themes are seen to comprise of "onset and the problem of recognition", "emerging disability and the problem of uncertainty", and "chronic illness and the mobilisation of resources" (ibid.: 170-175). When an individual is diagnosed with an illness, the immediate focus is on the consequences and significance of that particular illness. This focus is reflected on the impact that the illness can or will have on the individual's everyday roles and relationships (ibid.: 170). The gravity of the diagnosis (its prognosis), the estimated time of treatment, the diagnosed individual's everyday responsibilities and the level to which the sick-role is viewed as "legitimate" are aspects that could be grouped under 'onset and the problem of recognition' of the illness (ibid.: 170).

When looking at the "onset and the problem of recognition" of breast cancer one must remember that this illness is not just a traumatic diagnosis, but that it can have profound implications on an individual's mental, physical, spiritual and emotional understanding of who she is. For Charmaz (1991: 61) the meaning of an illness can "shape an individual's experience and stance towards it". Thus, how an individual recognises, not only who she is, but who she will become, can influence how she engages in the medical encounter and the actual treatment trajectory. This highlights the individual's self-understanding towards the illness, whereby allowing her to physically, psychologically, emotionally (and even spiritually) prepare herself for change or a biographical disruption. It is the opinion of Charmaz (1991: 61) that "the

relative significance of [an] intrusive illness turns, in part, on the structure of ill people's lives". This form of change is unique to the individual and her environment, but my opinion is that each individual diagnosed with breast cancer will undergo some form of identity transformation and re-negotiation.

Once the initial shock of the diagnosis has been accepted the next theme is "emerging disability and the problem of uncertainty" (Bury 1982: 172). This encompasses how the individual understands and accepts the labelling of the illness and also the treatment trajectory. The medical encounter should encourage the individual to search for information, make sense of her illness and try to integrate it into her immediate environment. In other words, it is a form of empowering the individual to regain her health while still obtaining knowledge (ibid.: 172-175).

Depending on the individual and her cognitive capabilities, knowledge surrounding breast cancer can either be seen as a beneficial coping mechanism to greater understanding or an avenue that is actively avoided. How the individual approaches knowledge can influence how she sees herself, her prognosis and her overall medical encounter. This thought can be linked to Schütz's (1970: 24) view of "zones of relevance", whereby one's understanding and need to attain more information to understand, maintain or overcome an issue (in this case an illness), allows the individual to "make [her] world cognitively manageable". These zones of relevance can influence the diagnosed individual's projected and actual treatment trajectory. How each treatment (and its consequences) is approached and how each side-effect is felt will directly influence and ripple through the individual's life-world. This ripple-effect can prompt the individual to either seek different forms of support or it can disrupt the individual physically, psychologically, spiritually or emotionally. Therefore the impact that the treatment trajectory has on the individual's life can be linked to the individual's curiosity or avoidance in obtaining further knowledge and understanding around her diagnosis, but also on how the initial knowledge was conveyed to her by various practitioners and other medical personnel.

After the individual has gained, understood, and implemented this knowledge into her life-world, she moves to the last theme, being the "chronic illness and the mobilisation of resources" (Bury, 1982: 175). This theme aims at promoting the "best quality of life" for the individual by employing a health strategy within the confines of

her impairment. According to Bury (1982: 175-178) coping should be seen as “a means of determining the ways in which individuals maintain or recover a sense of self-worth ... it also involves maintaining a sense of value and meaning in life, in spite of symptoms and their effects”.

Even though women diagnosed with breast cancer may recover physically, psychologically and even emotionally, they still need to readjust to their altered and transformed selves. According to Charmaz (1991: 194) individuals may languish for their past selves, whereby in reality “recapturing [their] past [selves] may remain elusive”. Therefore how an individual re-negotiates her self-concept after having gone through a breast cancer diagnosis and treatment may result in various forms and degrees of disability, which can be seen in that many women find it hard to cope with their day-to-day routines. Earle and Denny (2005: 128) point out that the main view of a disability is most commonly seen from a medical perspective. Thus it is my opinion that having a disability (albeit in this case, a temporary state of disability) not only separates the individual from society but puts forth her illness as her defining characteristic. Thus I am of the thought that the life-long experience that is left with a woman after a breast cancer diagnosis leads not only to the re-negotiation and transformation of her self-concept and self-image, but also the readjustment of her life, which can include values and beliefs. This thought thus integrates with the theoretical work of Brockmeier and Carbaugh (2001: 146) who state that the “experience of breast cancer is thus a biographical disruption of physical and emotional integrity, threatening death, marking women’s lives, and changing their sense of personal and social identity”.

As my focus is on the personal testimonies of women diagnosed with breast cancer, I would like to understand how this illness has brought about a biographical disruption. For Kelleher and Leavey (2004: 190) the implementing of a narrative “makes it possible to give meaning to disruptive events that change not only the course of life but also who one is”. According to Hydèn (1997, in *ibid.*: 190) the implementation of an illness narrative “knits together the split ends of time, to construct a new context and fit the illness disruption into a temporal framework”.

Some argue that one can add another dimension to the biographical disruption. This contribution includes the dilemmas for the self and identity. According to Chamaz

(1994, in Kelleher and Leavey, 2004: 13) “the self consists of several personal identities” and these identities need to be re-negotiated to incorporate the illness into daily activities and social interactions.

There are varying debates around the topic of the biographical disruption, but according to Weitz (2010: 131) how “the individual responds to [her] illness [highlights the] seeking [of] meaning and explanation for [her] condition”. This intellectual seeking of meaning and explanation can shift. This shift can be seen to encompass the overall understanding of a biographic disruption to the “biographical fracture and biographical flow” (ibid.: 131). This thought thus sheds light on how the illness causes a temporary shift in everyday life. This viewpoint by Weitz (2010) holds merit, but I am of the opinion that the labelling of how an illness disrupts the individual’s life-world holds value, but precedence should be given to the type of illness and to what degree this illness affects the individual’s life-world (and the duration of the affected time).

An illness such as breast cancer can have a permanent physical and psychological impact on the individual’s life-world. Currently there is a high probability that medicine can cure an individual of breast cancer, but only after an extensive treatment regimen. The treatment trajectory encompasses many side-effects, which in the case of this illness can result in the loss of (a) breast/s and hair, the burning of veins, blackening of nails, radiation burns on sections of the chest and neck and five year-period suppression of the hormone oestrogen. Some of these side-effects will have a permanent physical effect on the person who underwent the treatment. It is thus my opinion that breast cancer is not a temporary disruption, but an illness that will mark the individual throughout her life.

In this research project the biographical disruption can be seen to encompass the entirety of the participant’s present and future life. This disruption can firstly influence the individual’s understanding and view of breast cancer, daily routines and roles and the degree of information that is sought in order to better comprehend her diagnosis. Secondly, a biographical disruption can be attributed to the treatment trajectory. Common treatments are surgery, chemotherapy and radiation or according to Brockmeier and Carbaugh (2001: 145), the “slash/burn/poison trilogy”.

Depending on how the side-effects of the treatment trajectory impacts on the individual, Earle and Denny (2005) are of the opinion that certain relationships and social interactions may be disturbed. This disruption can be seen from both the individual's perspective and from her social environment. The individual may withdraw from certain relationships and groups for the purpose of self preservation (protection against labelling or stigmatisation and the lessening of exposure – in social relationships and groups – to germs because of her compromised immune system). The social environment is seen to include family and friends and the wider community where interactions take place. Once the individual is diagnosed certain family members or friends may withdraw from the breast cancer patient. This withdrawal can be seen to reflect aspects of insecurity and not being able to cope with the illness and its implication, even when the diagnosis is not directly related to their own bodies.

Due to the transformation of the body (partial or full mastectomy and the suppression of oestrogen) and how the individual views herself, certain perceptions and understandings may have to be re-defined. To summarise the “biographical disruption” I will use the thought of Brockmeier and Carbaugh (2001: 146) who state that a breast cancer experience is a biographical disruption of the “physical and emotional integrity, threatening death, marking women’s lives, and changing their sense of personal and social identity”. The theme of a biographical disruption holds relevance to this research undertaking and this is underscored by Frank (1995: 54), who is of the opinion that women diagnosed with breast cancer engage in a notion of “repair work on the wreck”. This thought can be represented as a “continuous endeavour to manage [a breast cancer diagnosis] by regaining ontological security and the continuity of self-identity: fundamentals that have been seriously threatened” (Orgad 2005: 66).

## **2.2. Disease and Illness**

Oakeshott (1978, in Kleinman, 1988: 3) poses the statement that “whatever is real has meaning”. Therefore how people understand illness and what it represents is all determined within the cultural context in which it occurs (Walsh 2004: 95).

Before one can appreciate and classify illness or disease it is important to first understand what health is. According to the World Health Organisation (WHO) (1978, in Singer and Baer, 2007: 63-64) health is “not merely the absence of [an illness] and infirmity but complete physical, mental and social well-being”. Within this definition one can highlight that “the boundary between health and illness is dynamic and fluid” and therefore not a fixed state (Brockmeier and Carbaugh, 2001: 176). Each person will fluctuate between health and illness throughout their life-span. Depending on varying factors such as diet, living arrangements, and financial means the individual may succumb to various illnesses within her life-span. This is not to say that breast cancer can be avoided by life-style choices, but rather to say that no human being goes through life without experiencing some form of disease or illness. I am aware that this thought is seen along the lines of common sense, but depending on the individual and her beliefs, understandings and perceptions, she may believe that her breast cancer diagnosis was part of her life-style choice. This can be seen to include cigarette smoking or an unhealthy dietary consumption.

A disease is understood as: “what the practitioner creates in the recasting of illness in terms of theories of disorder ... and seen through the theoretical lenses of their particular form of practice” (Kleinman, 1988: 5). The meaning of disease and cancer can be explained in the following rationale made by Rosenberg (1986, in *ibid.*: 3):

“The meaning of disease is the mechanism that defines it; even in cancer the meaning is often that we do not yet know the mechanism. To some, however, the meaning of cancer may transcend the mechanism and the ultimate ability of medicine to understand it. For such individuals the meaning of cancer may lie in the evils of capitalism, of unhindered technical progress, or perhaps in failures of individual will. We live in a complex and fragmented world and create a variety of frameworks for our several ailments. But two key elements remain fundamental: one is faith in medicine’s existing or potential insights, another personal accountability”

Disease, maladies and illness are considered synonyms in English literature, but for this research project I aim to clarify the terms; “disease”, “malady” and “illness” according to their specific understandings (Winkelman, 2009: 36). Each of the

following definitions is aimed at specifying the context, meaning and use of the word within this research.

When deconstructing and defining “malady”, Gert et al. (2006: 141) are of the opinion that maladies are to encompass:

“A condition of an individual, other than her rational beliefs and desires, such that she is suffering or is at significantly increased risk of suffering some nontrivial harm [death, pain, disability, or loss of freedom or pleasure]”.

Now that one understands the defined understanding of malady, Scadding (n/d, in Caplan et al. 2004: 92-93) is of the opinion that to define a “disease”, one must consider the following:

“The sum of the abnormal phenomena displayed by a group of living organisms in association with a specified common characteristic or set of characteristics by which they differ from the norm for their species in such a way as to place them at a biological disadvantage”.

Lastly, the meaning and understanding around “illness” is “fashioned out of culturally available images and symbols as well as the more personal language of individuals and families” (Barnard 1995, in Brockmeier and Carbaugh, 2001: 146). Therefore an illness is referred to as to the “literalisation [treating the signs and symptoms of the illness] of phenomena whose experience is always culturally, socially, and psychologically mediated and hence open to interpretation” (Lambek and Antze, 2003: 2). For this study I will rely on Kleinman’s (1988: 3) definition of “illness” which states that an “illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disabilities”.

In order to aptly describe the trajectory of having breast cancer, it is therefore important to distinguish between an illness and a disease. According to Walsh (2004: 95) an illness is “experienced as disvalued changes in states of being and social function”, whereas a disease is viewed as “abnormalities in the structure and function of body organs and systems”. This research is therefore much more focused on studying notions of illness experiences, than the mere onset of the disease: it rather delves into the intricate subjectivities of those diagnosed with the illness, cancer.



### 2.3. Medical World and Treatment

The medical world involves many different aspects but the main and underlining point of medicine is to treat diseases. According to a biomedical approach, when the body does not function optimally the individual seeks medical advice and assistance to overcome her ailments. When viewing the medical system with regards to cancer Stewart and Kleihues (2003: 127) are of the opinion that “the majority of cancers are preventable”. It is therefore thought that the prevention of cancer is achieved by firstly “reducing exposure to cancer-causing factors” and secondly by promoting regular check-up thus allowing for “early detection at a stage when curative treatment is still possible” (ibid.: 127).

The treatment success and overall survival rate for women diagnosed with breast cancer all depends on the “extent of the cancer”. The extent of the cancer is based on the tumour and how “large, diffuse, and multicentric” it is. Depending on the type of tumour, the axillary lymph nodes<sup>1</sup> need to be checked and monitored to “indicate the risk of relapse from metastatic disease” (Stewart and Kleihues, 2003: 193). Once the oncologist has a more comprehensive understanding of the type and grade of the tumour s/he can devise a treatment plan for the patient. According to the Cancer Research Association in the United Kingdom (2012: 1) the most common and standardised breast cancer treatment plan would consist of “surgery, radiotherapy, chemotherapy, hormone therapy, and biological treatments”.

The side effects experienced from cancer treatments can be seen through three different stages. The acute or early side-effects are determined shortly after treatment is concluded and it comprises of nausea, vomiting, diarrhoea, a drop in blood count and sores in the mouth. Long-term side effects continue for months or years after treatment. They include nerve damage and fatigue. Late side effects are seen months and/or even years after the treatment is completed and they may encompass the issues of infertility, heart and lung problems, and/or cataracts (Kelvin and Tyson, 2011).

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<sup>1</sup> Axillary lymph nodes – “the lymph glands of the axilla that help fight infections in the chest, armpit, neck, and arm and drain lymph from those areas. The 20 to 30 axillary nodes are divided into the lateral group, the anterior group, the posterior group, the central group, and the medial group” (Farlex, 2013: 1).

### 2.3.1. The Medical Encounter

When consulting with a physician there are two primary functions involved in the consultation, namely open communication and the physical examination. If these two functions are successful the physician will proceed by implementing a third function, namely medical tests. The first function of open communication is where the individual verbally explains the ailments or discomforts by which the doctor may ask questions to narrow the field of inquiry. The second function may include a physical examination in which the physician looks at the body to confirm a diagnostic idea. If the physician finds certain abnormalities, the third function is implemented, which is the undertaking of medical tests to confirm a lump or active cancer cells. The communication from patient to physician is seen as subjective (and often deemed less important than the rest, thereby de-legitimising the voice and views of the patient), whereas the physical examination and medical tests are more objective (Heath, 1986).

It is the opinion of some that there are various aspects involved in understanding the medical encounter. Bale (1950, in Friedman, 2011: 323-324) developed an analytical scheme which focuses on understanding “the process and structure of communication” between the doctor and the patient. According to theorists such as Hall et al. (1988) and Roter et al. (1988), there are five mutually exclusive categories. These categories include: “information giving, question asking, social conversation, positive talk, and negative talk” (Friedman, 2011: 327). Questions asked by the physician are usually “closed-ended questions”, thus allowing the doctor to narrow the field of inquiry. Patients on the other hand rely on “open-ended questions” to inform themselves and understand their situation or diagnosis better. Physicians attempt to build a partnership between themselves and their patients, using what is commonly known as social conversation, thus allowing for a stronger engagement in the medical dialogue. It is thought that negative talk is rare between a physician and a patient, but it is important to remember that negativity can be transferred or expressed in other ways such as body language, tone, and eye contact (ibid.: 328).

The physician’s diagnostic conclusion can be stated in various ways and according to Peräkylä (1998: 305-306) there are three distinct ways in which to relay the findings to a problem. Firstly, the findings can be relayed by the “plain assertion” as

seen in “I am sorry to say but you have breast cancer” (ibid.: 305). Secondly, findings can be relayed by “diagnoses incorporating inexplicit references to the evidence”, such as “after examining your breast and determining there is a lump that causes you discomfort and pain, it seems to be breast cancer” (ibid.: 305). Lastly the findings can be relayed by “explicating the evidence of the diagnostic conclusion”, as seen in “breast pain and a lump therefore it must be breast cancer” (ibid.: 306). When diagnosing the individual the physician must show empathy and be open to further discussion on the concluded diagnosis. By allowing the individual to inquire further about her diagnosis, Peräkylä (1998: 307) states that a form of respect in “treating the patient as an understanding recipient” is created.

The prognosis of breast cancer is an extensive process whereby “much of the investigation of the variables [are] associated with the risk of relapse and factors predicting the treatment response” (Glare and Christakis, 2008: 124). The actual treatment response and overall prognosis for both bilateral<sup>2</sup> and unilateral<sup>3</sup> breast cancer is based on the “patient’s age and tumour stage at diagnosis” (Singletary et al. 2004: 631). When focusing on a treatment plan the physician tends to focus on the past, the present and the future.

The past of the individual may shed more light on the probability of the individual having breast cancer. The physician works primarily in the present and future, while devising a treatment course by either ordering further tests or referring the individual to a specialist. It is vital for the individual who has been diagnosed to accept the diagnostic conclusion (either from a trusted physician or after seeking a second opinion) and thus co-operate with the doctors to partake in the devised treatment plan (Stivers, 2006). Depending on the medical institution and doctors, some breast cancer patients can be subjected to and viewed as just being subjects in the institutionalised “regime of medicalisation” (Klawiter, 2008: 75).

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<sup>2</sup> Bilateral breast cancer – A cancer that occurs in both of the breasts (Farlex, 2012: 1).

<sup>3</sup> Unilateral breast cancer – A cancer that occurs in one of the breasts (Farlex, 2012: 1).

### 2.3.2. Medicalisation

Medicalisation is defined as “a process by which non-medical problems become defined and treated as medical problems, usually in terms of [an] illness [or] disorder” (Conrad, 2007: 4). There has been much debate about the medicalisation of society and according to some there are two main views surrounding medicalisation. The first view looks at the “professional dominance thesis”, which focuses on “doctors as [the] main agents of medicalisation, and a critique of professional aggrandisement and medical imperialism” (Pescosolido et al. 2011: 174). The second view looks at the “processes, complexities, and consequences of how things are actually made medical [rather than legal, religious, and personal]” (ibid.: 174). This point is more conducive to the phenomenon of medicalisation which focuses on social construction (Conrad and Schneider 1980a, 1992, and 2005, in ibid.: 175). Therefore, medicalisation is emphasised by the understanding that “beyond the profession of medicine to entities such as big [pharmaceutical] suppliers of hospital equipment and technologies: patients [are] increasingly acting as consumers of biomedical goods and services”. This thus highlights the point that medicalisation and all that surrounds the medical profession rests on “economic interests and motivations of multiple and varied actors situated in different institutions of society” (ibid.: 175).

Both these views hold advantages and disadvantages, but Pescosolido et al. (2011: 175) are of the opinion that these two debates of medicalisation are seen more along the lines of being “open and empirical”. Conrad and Schneider (1980, in ibid.: 175) have incorporated the “professional dominance thesis” and the “definitional, jurisdictional and institutional understanding” to bring forth a simpler and more concise understanding of medicalisation. They simply highlight medicalisation to be seen along three levels:

“The conceptual [the use of medical language], the institutional – where organisations use the medical approach to address particular problems, legitimating and institutionalising medical arrangement – and the physician-patient interaction” (ibid.: 175).

It is the opinion of Cheng (2010: 63) that an individual's self-identity is shaped by "socially and culturally constructed health care ideologies". These ideologies influence how the individual who has survived breast cancer will interact with people and thus how others will respond to the patient. These interactions will allow for both positive and/or negative interpretations and meanings to be made. It is therefore an important aspect for the health care provider to encourage the patients to be more empowered and better informed, and that the health care provider is more "responsive to the patient-consumer empowerment" (ibid.: 63). In the current understanding and perception of breast cancer one is able to see that this illness has been transformed. This transformation can be seen to have taken place through the social understanding of medicalisation. Among the middle-to-upper class population, breast cancer is seen as an illness that can be overcome (as witnessed by international celebrities who were diagnosed, and treated, and who survived the illness). It does not hold the same stigma as in the early twentieth century. According to Ehrenreich (2001: 45) "breast cancer was a dreaded secret, endured in silence and euphemised in obituaries as a long illness".

When engaging in the medical encounter, Stewart and Kleihues (2003: 271) highlight the point that each patient (who has access to a well-functioning medical health care system) will have a "uniquely structured treatment scheme" that caters specifically for her form and grade of breast cancer. The treatment methods used to treat breast cancer are usually very "aggressive" and depending on the specific regimen, some women have to undergo "surgery, radiation, and chemotherapy, as well as five years of hormone therapy" (Klaeson and Bertero, 2008:185).

### **2.3.3. The Voice of the Patient**

After reading various personal testimonies of women diagnosed with breast cancer, it is clear that the most common first response to an actual breast cancer diagnosis is shock and disbelief. According to Delinsky (2001: 3-4) a common coping mechanism to the initial diagnosis is to collect information and to learn more about the illness. This can be seen in the following two statements. The first statement is made by Lambert (2000, in ibid.: 2) and the second statement is made by Wood (1997, in ibid.: 4).

“I knew pretty much nothing about breast cancer – except that I didn’t want it! By learning everything I could, I started to calm down, sort things out, and actively make decisions. Knowledge is power. It definitely makes you feel a little bit more in control of your life”.

“I wanted information immediately. I wanted to know which treatment plan was right for me ... I sought the advice of trusted family, friends, doctors, and breast cancer survivors, so that I could be my own best advocate”.

What I found in newly diagnosed breast cancer patients was that after the initial shock wore off, the majority of these women sought information through books, the internet, family, friends and medical staff to broaden their knowledge and to regain some form of control over their illness. This form of control can assist the individual from being placed into the sick-role, a role they often do not want to fulfil. According to Teghtsoonian and Moss (2008: 288) the sick-role is defined as “the segregation of ‘the sick’ from the ‘non-sick’”. When referring to the sick-role within the context of breast cancer, “the sick-role co-constituted the imperial authority of surgeons, along with the isolation and obedience of breast cancer patients” (ibid.: 288). This points not only to a form of involuntary disempowerment on the part of those diagnosed with breast cancer, but also to the overbearing medicalisation of the illness and its consequences.

After obtaining a better self-understanding of what breast cancer is the next step entailed a search as to what treatment method would best suit the diagnosed individual. A strong medical merit is usually given to the initial surgery which generally allows to completely remove the cancerous tumour. This can be seen to include either a lumpectomy or a (partial or full) mastectomy of one or both the breasts. Losing a breast – and even both breasts – is a traumatic experience and even though the patient may opt for this treatment plan, it may have upsetting effects in other social roles and expectations, such as within the intimate confines of the couple.

The next form of treatment is chemotherapy, which is a drawn out process of usually eight sessions expanding over three week intervals. Each session lasts for three to four hours of sitting in the hospital chemotherapy lounge with an IV (intravenous drip) attached to the arm. Chemotherapy affects each individual differently: some

individuals cope rather well with few side-effects, while others are severely affected by the medication and suffer the full spectrum of side-effects. After being diagnosed with breast cancer, women viewed “time” differently (Abel and Subramanian, 2008: 132). The understanding of time became important to breast cancer patients through the acknowledgement and realisation of mortality and that life seems to be shortened and punctuated. Abel and Subramanian (2008: 120) quote one of their participants as stating:

“My relationship with time changed so dramatically, an hour became so interesting, whereas before time either flew or there [was too much] time in the day”.

Due to the uniqueness of each person, support groups can be understood as either a place of safety and emotional support or seen by Ehrenreich (n/d, in Abel and Subramanian, 2008: 161) as the “handmaidens of the medical establishment”. In light of this research, my focus is not predominantly on support groups but rather how the individual copes with her diagnosis and if attending a support group becomes a beneficial part of her path to recovery. In Ehrenreich (n/d, in *ibid.*: 66), a breast cancer survivor, describes her experience of a support group and the benefit it had on her:

“I found myself opening up and talking, and it felt good. I started doing things and making gestures and everything ... And we were just talking. That helped, and that’s what I needed”.

It is the opinion of Delinsky (2001) that it is important not to misplace one’s sense of humour. This thought can be confirmed by Barbara Moro (1999, in *ibid.*: 119) who states that: “after the upset of learning I had cancer, I decided that my humour, my faith, and most of my entire attitude would be how I could take control”. During and after the treatment process there are many aspects that change an individual physically (mastectomy, hair-loss and scarring), psychologically and emotionally, but it is thought that humour can help alleviate anxiety and stress. According to Carol Dine (1980, in Delinsky, 2001: 207) “humour was [the] most important [aspect] in helping me survive this [breast cancer] ordeal”. These participants from the studies of Delinsky (2001) and Abel and Subramanian (2008) shed some light on how their experiences affected them through their personal breast cancer experience. These

snippet extracts not only broaden the voice of the patient, but also – and more importantly – prevented these women from being seen as just subjects in the world of medicalisation. However, it should be stated that these voices emanate from a specific cohort of diagnosed women: mostly middle-class women from Western countries who have access to efficient health care systems.

#### **2.3.4. Impact of the Breast Cancer Diagnosis**

According to Han et al. (2004: 82) the younger a woman is when diagnosed, the more severe the impact of the diagnosis will affect her. Kroman et al. (2000: 474) state that “women who are diagnosed with breast cancer in their early twenties and thirties seem to have a poorer prognosis than women diagnosed in middle age”. This is due to the probability of recurrence which diminishes their overall survival rate. The most influential part of being diagnosed at a younger age, according to Breast Cancer Care in the United Kingdom (2012: 7) is the realisation of mortality and the choices the individual faces surrounding her future. Within these circumstances the individual may have a young family and her primary concerns are with her children and their future.

The impact of being diagnosed at a younger age places a higher level of stress on the individual, as women in their twenties and thirties are commonly thought of as healthy, ambitious and ready to start families. With this diagnosis, life altering questions are asked and the answers can impede upon future aspirations. Some of these questions can impact on relationships, the choice to start a family and the individual’s overall future plans due to the chance of recurrence or metastasis<sup>4</sup>.

When a diagnosis of breast cancer is made, Oktay and Walter (1991: 61) are of the opinion that there are four main themes that are disrupted. These themes are seen to include: “achieving independence, fertility, developing intimate relationships and developing a place in the adult world”. This thought is confirmed by Schover (1994: 177), who conducted a study on breast cancer; he revealed the impact that this

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<sup>4</sup> Metastases – “is an active process by which tumour cells move from the primary location of a cancer by severing connections from the original cell group and establishing remote colonies. Because malignant tumours have no enclosing capsule, cells may escape, become emboli, and be transported by the lymphatic circulation or the bloodstream to implant in lymph nodes and other organs far from the primary tumour” (Farlex, 2012: 1).



illness had on sexuality and body image. The disruptions included diminished sexual functioning, self-esteem, attractiveness, acceptability in society, loss of reproductive opportunities and fear of rejection (given our societal ideals of beauty). Therefore the impact of having one's future threatened at a younger age can have life altering changes.

The broader impact of being diagnosed with breast cancer at a young age is that family members such as sisters, daughters, and mothers have a "significantly higher chance of developing breast cancer as well" (Dite et al. 2003: 454). Therefore a diagnosis of breast cancer – be it at a young or older age – is a devastating illness to accept personally and beyond.

### **2.3.5. An Oncological Perspective**

It is imperative that the oncologist is aware that "he or she will have to share some of the emotional burden of the illness [from their] patients and relatives" (Fawcett and McQueen, 2011: 109). How the physician reflects and implements his/her treatment regimen echoes his/her ability and skills. Patients only reflect over the treatment trajectory as either being successful and the doctor knew what s/he was doing, or the treatment trajectory failed and thus the doctor does not know what s/he was doing (ibid.: 109). Patients and those close to them could easily judge the doctor according to the outcome of the treatment and even the severity of side-effects. When an individual is diagnosed with cancer, the oncologist is the face and voice of the entire surgical team and his/her sole purpose is to cure the patient of this illness that is damaging the health and functioning of the human body.

When a patient is officially diagnosed with breast cancer, she may exhibit an array of emotions such as anxiety, shock, and fear (Fawcett and McQueen, 2011: 112). This reaction is usually linked to the unknown. No one can accurately predict the outcome of the treatment, but it is important to discuss the procedure and possible treatment methods on a regular basis. It is the opinion of Fawcett and McQueen (2011: 112) that giving strong precedence to introducing the medical team to the patient allows the patient to "accept the news and accommodate to it", whereby reducing the risk of hostility and gaining the patient's "trust and confidence".

According to Stern (2006: 25), “medical accountability” is defined as the physician having a “responsibility to [the] patient [in] fulfilling the implied contract governing the patient-physician relationship, to colleagues, to the profession for adhering to medicine’s time-honoured precepts, and to society for addressing the health needs of the public”. The doctor is responsible for putting forth three key pieces of information. This information can be seen firstly, that the doctor is to “name the [illness]” by locating the specific problems; secondly, the physician “assesses the patient’s condition” by running tests and connecting the given symptoms, and lastly, the specialist “gives background information about the [illness]” which includes the aetiology, prognosis, and aspects of the treatment trajectory (Peräkylä, 1998: 304).

### **2.3.6. South Africa’s Breast Cancer Statistics and Studies**

According to Bray et al. (2004: 229) in today’s day and age women are at a higher risk of being diagnosed with breast cancer in “developing countries”. The increase of Westernisation in developing countries leads to changes in “dietary habits and exposure to exogenous oestrogen”. These changes can be linked to “environmental determinants” rather than a solely “genetic factor”, which can be confirmed in the previous study on migrants by Bray et al. (2004: 229). Some are of the opinion that “Africa, Asia and most of central and South America reveal low incidence” rates for breast cancer (ibid.: 230). However, Albrecht (2006: 4) is of the opinion that South Africa must anticipate a strong rise in incident rates “due to migration to cities and [an] increased life expectancy”.

A document in 2006 titled “Overview of the South African cancer research environment as a basis for discussion concerning the activation of CARISA (Cancer Research Initiative of South Africa)” by Albrecht, highlighted the startling point that cancer research and awareness was of little precedence in South Africa.

When reviewing the breast cancer statistics for South Africa, Albrecht (2006: 44) found the incident rate for a developing country like South Africa in 2006 as: new cases estimating 33 per 100,000 of the population and mortality rate at around 18 per 100,000 of the population. These figures surrounding the “mortality/incident ratio [are seen] to be the same in South Africa as in the [rest of the] world, [but Albrecht is

of the opinion that] an extra 54,507 cancer diagnoses would need to be made per annum [for South Africa to reflect the correct statistics]" (ibid.: 13).

What I found while conducting the literature review was that South Africa still lacks the ability for full co-ordination of different provinces concerning its breast cancer statistics. Organisations such as CANSA (Cancer Association of South Africa) are working tirelessly on promoting awareness for breast cancer and thus have utilised many avenues: internet sites, magazine articles and awareness activities such as cancer month and the cancer "Shavathon", to educate the public. The CANSA "Shavathon" promotes support by encouraging communities to either "shave, spray, or stencil" their hair (CANSA, 2013).

This lack in sharing of statistics thus makes a diagnostic forecast non-existent. According to Albrecht (2006: 14) in South Africa there are "no available data to monitor the progress of all efforts against cancer with any certainty except for age-adjusted incidence of mortality". The unreliability of data may be attributed to "under-reporting especially in terms of the Black population group in South Africa" (ibid.: 14). When reviewing the national cancer registry, Albrecht (2006: 3) found that in six out of the ten most common cancers, "the mortality rates were significantly higher than the incidence rates", which clearly indicates a lack of reporting. Much effort to find an estimation or approximation for breast cancer incidence and mortality rates for 2012/3 has borne little results.

It is understandable that when dealing with an illness such as cancer, highlighting statistics and concrete facts (quantitative research) can be the main focus to influence and guide individuals to strive for change. Another technique is qualitative research, which can be seen as highly controversial due to its value-bound interpretations and subjectivity in reporting (Klenke, 2008). The majority of research done in and around breast cancer is based primarily within international contexts. When I narrowed the literature search within the South African context an alarming discovery was made.

Albrecht (2006: 36) declares that "cancer is not a national priority, [and] consequently cancer research is not a national priority". Of the 73 reported cancer projects conducted in 2006 only three were dedicated towards breast cancer.

Therefore, Albrecht (2006: 5) states that “cancer research in South Africa has reached a dangerously low level and needs a substantial boost”.

## **2.4. Social Impact of Breast Cancer**

It is important not to presume that this illness is “experienced in the same way or to the same degree” by all who are diagnosed with breast cancer (Klawiter, 2008: 230). There are a multitude of factors that influence how this illness is understood and perceived. These factors can be seen to: “age, race, class, gender, sexuality, family, culture, ethnicity, physical location, and religion” (ibid.: 230). It is important to take into consideration, when the participant was diagnosed (age) and if the illness is a first-time diagnosis or a secondary diagnosis. The recurrence of breast cancer (or metastases) may influence the individual differently as previous knowledge and understanding can be embedded from a previous experience.

### **2.4.1. Social Interaction and Age**

Depending on the age when the diagnosis is made certain factors such as social needs and interactions may be required. The younger the individual was when being diagnosed with breast cancer, the higher the need for social support. The diagnosis of breast cancer brings about the added pressure of maintaining normal day-to-day routines. These routines can be interrupted by the rigorous treatment regimens and depending on to the age of the diagnosed individual’s children, she may have to put her health as a first priority. This form of prioritising can create disarray within the family dynamics. According to Coyne and Borbasi (2006: 13), the distress experienced by younger women revolved around being “positive for the sake of the family”, which was emotionally draining. Depending on the age at diagnosis, the individual’s priorities may shift to different aspects surrounding her life. When a diagnosis is made in older women who have raised their children, and children are independent of their parents through age and financial stability, the diagnosed individual will seek stronger social and emotional support to cope with her daily activities such as chores, meals, and side-effects of the treatment (ibid.: 13-14).

The increase of diagnoses could be attributed to the common medical guidance that women need to only start worrying about regular mammograms and breast screenings after the age of 40. According to Johnson (2006: 23), the 1998 Breast Cancer Network in Australia states that “there is no need for young women to worry about the illness as it is a problem that affects old[er] women”.

This idea is seen to divide younger women into two distinct categories: firstly, young women “who are overly worried and feel that they are at a higher risk of getting breast cancer” (Bryan 2001, d’Agincourt-Canning 2006, Epstein et al. 1997, and Siegel et al. 1999, in Johnson, 2006: 22). This perception is commonly attributed to having a family member or a close friend diagnosed with breast cancer, whereby prompting hyper vigilance in bodily sensations. Even though the diagnosis of breast cancer in younger women is substantially lower than in older women, Friedman et al. (1998: 26), Haas et al. (2005: 847), Lerman et al. (1994: 172) and Paul et al. (1999: 398) are of the opinion that “young women actually perceive themselves to be at a high risk for breast cancer as compared with older women”.

Secondly, there are women with the common perception “who think that [breast cancer is] not going to happen to them so they want nothing to do with it” (Johnson, 2006: 22). This perception can be seen as a way of coping with the common thought of “it will never happen to me” whereby protecting the individual from any emotional turmoil (ibid.: 22).

#### **2.4.2. Social Interaction and Social Support**

An individual diagnosed with breast cancer may seek support in coping with her illness by joining a psychosocial intervention group. According to Hewitt et al. (2004: 110), these groups may vary in their styles and techniques, but the underlying focus is on supporting the individual, which in this case is finding strength and overcoming breast cancer. Each woman diagnosed with this illness will have unique experiences and knowledge, and support systems aim to eradicate the feelings of isolation and segregation by making the individual feel part of a group.

It is the opinion of Ganz (2008: 1) that psychosocial distress entails “cancer-specific concerns, such as fear of cancer recurrence, to more generalised symptoms such as

worry, troubled sleeping, fatigue, being anxious about going to the doctor ... emotional wellbeing, and quality of life". The common management of distress is seen to implement "support systems [spouse, family, friends and religion] as well as some professional resources such as nurses, social workers, community resources, and support groups" (ibid.: 1). These resources thereby enable the individual a healthier outlook and overall recovery.

## **2.5. Perception and Understanding of Breast Cancer**

Each individual is unique in her views in as far as cultural, societal, and lived experiences are concerned. The perception and understanding of a breast cancer diagnosis will vary according to the individual and no generalisations can be made.

Depending on the access an individual has to the media (television, radio and newspapers) certain facts about breast cancer can alter the way she perceives and understands her own diagnosis. Johnson (2006: 21) is of the opinion that the media plays a significant role in promoting public awareness of breast cancer and its associated risk factors. The media can also be seen as a method of empowerment for ordinary people. Awareness campaigns that utilise the media as a tool to convey their message can indirectly empower their recipients by revealing information that will encourage the individual to go for regular medical check-ups and portraying breast cancer as an illness that can be overcome.

According to Chapman et al. (2005: 248) celebrities play a strong role in influencing the public's view and understanding of illnesses. This can be seen in celebrities such as Kylie Minogue, Sheryl Crow, Giuliana Rancic, Wanda Sykes, Dame Maggie Smith, Olivia Newton-John and Christina Applegate who have all survived breast cancer.

It is important to remember that there are negative aspects to relaying messages through the media especially when reporting on the diagnosis of a celebrity. In this day and age, celebrities are placed on a higher social ladder than regular people due to their wealth and societal standing. Therefore due to a celebrity's societal standing and idolisation her diagnosis with an illness, especially breast cancer, can produce more awareness or evoke anxiety and fear in the public. According to Chapman et

al. (2005: 248) when Kylie Minogue was “diagnosed with breast cancer a 40% increase was reported in breast screenings”. By having a celebrity or public figure diagnosed with breast cancer can highlight “that [this illness] has no respect for wealth, status or ethnicity” (Johnson, 2006: 22). The media then probably influences the public’s knowledge, perception and understanding in both a positive and negative way, depending on the public’s access to this mediated information.

### **2.5.1. Accuracy of Perceptions Surrounding Breast Cancer**

A woman’s perception of breast cancer can be seen as highly “inaccurate by either: overestimations or underestimations” (Johnson, 2006: 25). These perceptions are frequently linked to the misconception that the risk of “breast cancer cannot be reduced or prevented in any way”, therefore if it is going to happen, it will happen (Tittle et al. 2002: 40). But the most common perception is that all cancers and in particular breast cancer, will ultimately result in death, especially when there is a family history of cancer. According to Hopwood (2000: 1) these over- or underestimations are strongly linked to “cultural differences and risk information”.

The most universal method in detecting breast cancer is the Breast Self Examination (BSE) which relies highly on the individual’s own perception of what is felt. This form of detection can bring forth strong feelings of anxiety and fear due to the sensitive nature of what is revealed in the self-examination, understanding (family history or direct experiences) and knowledge. According to Haas et al. (2005: 845), the perception of breast cancer can be reflected in different areas of the individual’s life which are seen to include “family history of breast cancer, no history of childbirth, and exposure to lay information”.

When looking at the accuracy of perception it is the opinion of Stiefel (2006: 26) that certain crucial elements play a role in how an illness is understood. These elements are seen to include:

“cognitive biases, individual preconceptions [and misconceptions], life experiences, cultural context, the subject’s general outlook [locus of control], as well as social biases, such as family history and related beliefs of being vulnerable, may also influence the interpretation of risk information”.

These elements can be seen as direct sources of understanding, but depending on the individual and her knowledge base, certain elements may be seen as secondary or non-existent, thus resulting in an inaccurate understanding or view of the actual illness. According to White (2009: 145), breast cancer is seen as a life-threatening illness, which has no one explanation that can highlight, or be clarified with certainty, to the specific cause. The American Cancer Society has confirmed that breast cancer is the most common cancer in women and the second leading cause of cancer death in women after lung cancer (Day, 2006: 258). Therefore each perception is created within a subjective mind and depending on one's environment, cognitive abilities and experiences, and will thus result in different degrees of understandings (from superficial to in-depth).



## Chapter 3 – Breast Cancer and “Identity”

### 3.1. Conceptualisation of “Identity”

Using identity as a construct has become popular in the social sciences and humanities. Despite this increased popularity social scientists often claim that “identity” is a complex and elusive term and that “it has no analytic value” (Wetherell and Mohanty, 2010: 3). “Identity” is seen as a “cover term for names humans impute and avow in the course of interacting with others and orienting themselves to their various social worlds” (Ritzer, 2005: 390). For this research undertaking, I will argue that an understanding of “identity” can add to our comprehension of narratives. My aim is to deal with various aspects under the broad term of “identity”. These aspects will include “personal identity” (or self-identity), “social identity”, “role identity” and “gender identity”. These terms will be adapted into the framework of Brubaker and Cooper (2000) whereby allowing for a clearer understanding of the term “identity”. This allows for differing points of view to emerge and it can thus be stated that “identity is being refashioned for the twenty first century” (Wetherell and Mohanty, 2010: 3). This interest and growth in the concept will allow for a more direct understanding and application, whereby a more accurate definition and framework will emerge.

“Identity” can be seen to refer to three broad categories within the social sciences: social identity, personal identity, and collective identity (Brubaker and Cooper, 2000). It is important to highlight the point that each of these above-mentioned categories to some degree interconnect and overlap and for this reason one cannot understand and apply identity in a simple or straightforward manner. According to Brubaker and Cooper (2000: 14) the word “identity” is an “overburdened” term. It is therefore important to distinguish between the different aspects of “identity” that I deem important in view of this study.

When trying to understand the different aspects of identity, Ritzer (2005: 391) infers that “identity is conceptualised and analysed, in large part, on one’s orienting perspective” which can be seen through three broad perspectives: essentialist, dispositional and constructionist. I am aware of the current debate surrounding identity whereby identity is understood in varying degrees (as seen by Brubaker and

Cooper 2000: 1) as either “too much [when understood in a strong sense], too little [when understood in a weak sense] or nothing at all [because of its sheer ambiguity]”.

As explained in chapter one, this research positions itself within the social constructivist and social existentialist viewpoints. By taking a constructivist or existentialist stance one’s views regarding the concept of “identity” will emphasise the “constructed, fluid, and multiple” nature attached to the concept “identity” (Brubaker and Cooper, 2000: 1). “Identity” is often seen as an attribute within the individual that takes shape over time. Brym and Lie (2010: 63) talk of this process as the “crystallisation of self-identity [which] occurs during adolescence and is just one episode in a lifelong process of socialisation”. The dynamic process of the crystallisation of “identity” emphasises the fact that an individual’s “identity” can be seen as including different dimensions, such as being a mother, a woman, a wife, and etc.

### **3.1.1. “Identity” Defined**

There are different views, definitions and understandings surrounding “identity”. It is the view of Erikson (1956: 65) that the individual continuously struggles to “attain consistency between the self she would like to be and the self she believes is attributed to her by others”. Erikson adds that identity “provides a sense of continuity and sameness throughout the individual’s lifecycle” (ibid.: 65). In this research project I will however also make room for an approach that includes that an individual’s “identity” can be altered through a traumatic event or life threatening illness (ibid.: 65).

I will rely on Côté and Levine’s (2002: 70) definition of “identity” which states that identity is in part “the sense of self providing sameness and continuity in personality over time”. According to Podgórecki and Łoś (1979: 101), each individual’s personality is “shaped within a definite social context and as a result of concrete social interactions”. It is the opinion of some theorists that “the self can be thought of as a central mechanism through which the individual and the social world intersects”

(Elliot 2008: 30). This thought is taken further by emphasising that the self arises from “human interactions and interpersonal relationships” (ibid.: 29).

In reviewing how the self interacts with societal influences, Mead (1934: 164) highlighted the point that there is “no clear dividing line ... between our own sense of self and the selves of others”. He thus proceeded to state that “our own selves exist and enter as such into our experience only in so far as the selves of others exist and enter as such into our experiences also” (ibid.: 164). When one focuses on “identity” from a sociological perspective one can therefore conclude that there is a “relationship between the self and society” (Burke and Stets, 2008: 1).

“Identity” is established through the interaction between the environment and culture and this evolution of growth brings with it a “set of meanings” that provide the individual with a standard to base her “identity” on and thus to guide her behaviour within certain situations (Chafetz, 2006: 254). “Masculinity” and “femininity” is each seen as a “master identity”, which is based on the cultural standards of meaning associated within the specific gender. These characteristics are applied by the self throughout different situations rather than being evoked within a “specific institutionalised context” (ibid.: 254).

One can therefore say that “identity” is formed through unique experiences and interactions between the individual and her given society. It must also be noted that each individual has different aspects to her inner self and identity. Burke and Stets (2008: 8) state that “the overall self is organised into multiple parts [identities] each of which is tied to aspects of the social structure”. Each individual holds different identities, which come into play when the individual interacts within society. These different identities help the individual hold different “positions or role relationships in society” (ibid.: 8).

In this research project “identity” plays an important role in how the individual understands and perceives her breast cancer diagnosis. Each experience will be unique because the individual is unique in so far as the degree to which she relates to her cultural norms, values and beliefs. Societal influences will reveal unique aspects to how the individual will cope with her diagnosis and treatment trajectory. I will not identify or categorise these women according to their illness. I will instead allow each woman to define herself by verbally expressing how she views her

“identity” and femininity. Each “identity” holds meaning for the individual and thus a woman diagnosed with breast cancer has to relate to roles such as the self as a mother, the self as a friend and the self as a wife or partner, to name but a few. Within this research the participants are not categorised or seen as just breast cancer patients. Instead it will be remembered that each individual constantly has to deal with a different self throughout her daily interactions within society, while still overcoming a breast cancer diagnosis.

### **3.1.2. Aspects of the Self and the Experience of Breast Cancer**

Within this research I will focus on different aspects of the self. These aspects are seen to include the personal, social, role, gender and survivor’s identity. I will also touch on how popular expectations regarding beauty impact on the breast cancer diagnosis. As this research project focuses on illness and the re-negotiation of identity and femininity, I aim to understand which aspect/s of the self is/are affected by a breast cancer diagnosis and the treatment trajectory. I am of the opinion that the concept of the self is what makes her unique in her self-understanding, characteristics and frame of reference. In the attempt to understand the self I will focus on aspects of the work of Brubaker and Cooper (2000) regarding “identity”.

### **3.2. Brubaker and Cooper’s Re-conceptualisation of “Identity”**

According to Brubaker and Cooper (2000: 6) the application of “[identity] depends on the context of its use and the theoretical tradition from which the use in question derives”. In dealing with the re-conceptualisation of “identity”, Brubaker and Cooper (2000) make use of five points that allow for a clearer understanding of “identity”, but for the purpose of this study I will only focus on three of these. The first point highlights that the “action – [be it] individual or collective – may be governed by *particularistic self-understandings* rather than by *putatively universal self-interest*” (ibid.: 6). This can be broken down further by explaining how the individual acts and understands “identity” (individual or collectivistic) and thus it highlights the following issues: “self-understanding and the [narrowly understood] self-interest ... particularity and [putative] universality ... and construing social location” (ibid.: 7). Although the

above-mentioned points can be seen as distinct contrasts, they are related in how an individual conceptualises and explains her actions. This point holds true for all people: when the individual or collective group is threatened – be it through illness, strife, or war – self preservation or preservation of the collective whole will become the predominant focus. This is an important issue, but will not be further discussed in this research project.

As a second point Brubaker and Cooper (2000: 7) highlight the view that “identity” has a “fundamental and consequential sameness among members of a group or category ... and thus may be understood objectively [as a sameness in itself] or subjectively [as an experienced, felt or perceived sameness]”. I will integrate and further discuss this point in the section “categorical and relational identification” following later on.

The third point focuses on the “core aspect of [individual or collective] selfhood or as a fundamental condition of social being” (ibid.: 7). This point will not be used further in this research project despite the merits thereof.

In the fourth instance, Brubaker and Cooper (2000: 7-8) see “identity” to be a “product of social or political action ... invoking the processual, interactive development of the kind of collective self-understanding, solidarity, or groupness that can make collective action possible”. I will discuss this point in the section “self-understanding and social location” at a later stage. Lastly, “identity” can be understood as an “evanescent product of multiple and competing discourse thus invoking the unstable, multiple, fluctuating, and fragmented nature of the contemporary self” (ibid.: 8). This point will be discussed further in the section “commonality, connectedness, and groupness” following later on.

Within my analysis chapters – chapters five and six – I will integrate my findings into Brubaker and Cooper’s (2000) framework, especially by referring to the three aspects highlighted above. This integration will be seen under specific headings of “categorisation and identification”, “self-understanding”, and “commonality, connectedness, and groupness” (ibid.: 2000).

### **3.2.1. “Categorical and Relational Identification”**

When looking at the term “identification and categorisation” Brubaker and Cooper (2000) refer to the individual’s environmental context. The environmental context entails how one identifies and integrates oneself into varying social environments. This term can be seen to link with the Brubaker and Cooper’s (2000) framework of “re-conceptualising identity” which highlights the “fundamental and consequential sameness among members of a group or category” (ibid.: 14).

Brubaker and Cooper (2000) distinguish between relational and categorical modes of identification. In a relational mode “one may identify oneself [or another person] by position in a relations web” which may be “a web of kinship, for example, or friendship, patron-client ties, or teacher-student relations” (ibid.: 15). On the other hand, a categorical mode of identification refers to “identifying oneself [or another person] by membership in a class of persons sharing some categorical attribute” like gender, race and language (ibid.: 15).

“Categorical identification has assumed a great importance in modern settings” and self-identification is seen as the way an individual positions herself in the normal and everyday “ebb and flow of social life” (Calhoun 1997, in Brubaker and Cooper, 2000: 15). Both modes of identification can be linked to the term of “role identity”. By defining role identity in terms of either a positioning relational web or by membership in a category provides a clearer and more diverse meaning of the word.

#### **3.2.1.1. Breast Cancer, “Categorical and Relational Identification”**

Instead of attributing those diagnosed with breast cancer with any kind of specific identity, such as “survivors identity”, this research project will explore how the eight women identify themselves relationally and categorically and how these identifications are linked to their experience of breast cancer. The analysis avoids assumptions that these women see and understand themselves necessarily in certain ways, that such presumed “identities” automatically constitute a salient dimension of their self, that their self-identification is not necessarily congruent with the external identification by others and that such identifications are employed

across all situations, and that used permanently after the occurrence and treatment of breast cancer.

Due to the diagnosis of breast cancer and the treatment process taking place in the highly institutionalised field of (Western) medicine, these eight women are likely to be confronted with an external categorical identification of “breast cancer patient” (or breast cancer sufferer). Apart from organisational uses that such a categorical identification might have in a hospital setting, it comes along with other meanings that any person placed into this category is likely to be confronted with, such as being a victim and being in need of help and support. The research explores what kinds of meanings are attached to this categorical identification in different situations and how these women deal with it. Dealing with it might involve their temporary and situation-dependent refusal of this very identification in order to avoid the negative implications it most likely has for their emotional and mental well-being in turn. These women might find strength by identifying themselves with various positions in their everyday relational web – seeing themselves as friends, as mothers or as members of their church. In the case of the research participants who are themselves nurses, the external acceptance of their relational identification as nurses might even provide them with additional resources in getting better medical treatment. Thus, this research furthermore explores which relational identifications are important for these women while experiencing breast cancer and how these relational identifications are intertwined with the categorical identification (albeit a new and perhaps temporary classification) of being a breast cancer patient.

### **3.2.2. “Self-understanding and Social Location”**

This aspect is seen to encompass an individual’s mental and social space. This is understood in how the individual sees herself within a societal setting. Self-understanding and social location can be linked to the fourth point (“the processual, interactive development of collective self-understanding, solidarity, or groupness”) proposed by Brubaker and Cooper (2000: 7).

This point is also seen in how the individual perceives herself and according to Pilario (2005: 124), who expands on the view of Pierre Bourdieu's *le sens pratique* or the "feel for the game":

"One does play a game without necessarily being conscious of its explicit rules all the time. It is not only the rules which determine the player's moves but, more primarily, her sense of anticipation formed by years of physical and psychological training as well as her concrete response to the game of the moment ... beyond explicitly obeying rules or executing structures. Practice consists of improvisations and inventions at the point of urgency: one can anticipate the sense of the future within the present thanks to the fact of being born into the game. This is what Bourdieu calls *habitus*".

What is important here is that the self is not understood as just a one dimensional aspect but instead can take on various forms. This thought is expanded on by Brubaker and Cooper (2000: 17) who state that "people may understand and experience themselves in terms of a grid of intersecting categories in others, in terms of a web of connections of deferential proximity and intensity".

What was strongly emphasised with the theme of "self-understanding" is that it "may be variable across time and across persons" while still remaining stable (Brubaker and Cooper, 2000: 18). Therefore the common understanding around "identity" is that it represents thoughts of "sameness across time or persons" (ibid.: 18). This concept is most commonly referred to, as well as integrated into the theme of "personal identity".

### **3.2.2.1. Breast Cancer, "Self-understanding and Social Location"**

I will apply the concept of "self-understanding and social location" to how breast cancer individuals' view their bodily changes, how they view society and in turn how society views and accepts the individual after her diagnosis and during her treatment trajectory. This theme can be seen to highlight certain commonalities such as certain inevitable bodily changes. An individual may question herself with the thought of "who am I now?", given that her body is not the same as it used to be.



Secondly, the individual may have to re-negotiate how she integrates herself into society as this will link strongly with the first point made by Brubaker and Cooper (2000: 6) which states that an “action – individual or collective – may be governed by *particularistic self-understandings* rather than by *putatively universal self-interest*”. When the individual re-negotiates her self-understanding, common societal norms may also be interrupted. The diagnosed individual may also reflect upon her social environment and location, including people and places that may not be suitable to the individual and her illness. Such social locations may include the work environment and concomitant commitments, given the side-effects brought on by the treatment of chemotherapy or radiation. Another point that bears reference to the social location may be attributed to individuals the patient associates with. Again this will depend on the individual’s character and how her friends or associates react to and treat her after her breast cancer diagnosis and the ensuing treatment.

Lastly, society can be judgemental and in the case of a breast cancer diagnosis, women are still categorised, labelled and in some case stigmatised, because of their illness. This form of categorisation or stigmatisation may be attributed to how the illness transforms a woman physically, psychologically and emotionally and thus breaking down her confidence, her perception of her body image and her personal notions around femininity. According to Nasser (2007: 85) “breast cancer poses a threat to both survival and self-image. There is evidence that the more disfiguring the surgery, the more body image is disturbed”.

I am aware that when a woman is diagnosed with breast cancer she will focus on fighting the illness to regain her health and to avoid death. Each research participant that partook in this project made a clear and conscious statement that once the treatment trajectory is completed and the cancer is in remission, that she will continue her life and future aspirations as planned pre-diagnosis. There was thus a strong feeling of returning their lives to normal and to view this illness as an episode, not as a permanent state of affairs.

### **3.2.2.1.1. Personal Identity**

“Personal identity” is associated to the individual who sees herself as “distinct and different from others” (Burke and Stets, 2008: 32). This thought is shared by Goodenough (1963, in Wetherell and Mohanty, 2010: 66), who is of the opinion that one’s “[personal identity] represents the unique way in which an individual identifies herself”.

Each individual is not driven to fit into a labelled categorisation, but instead is motivated by her own goals. According to Kopf (2001: 6) one’s “personal identity” is “persistent over time” which can be understood – simplistically – as the individual continues through a multitude of “different and separate moments in time and which possesses a multitude of experiences”. Therefore, “personal identity” does not fade away over time, but can be “conceptualised through the sense of continuity” (ibid.: 6). Even though “personal identity” is unique to the individual, her position within society still plays a role in reaffirming the individual through constant reorganisation, maintained interaction and continued acceptance. I am of the opinion that by being selective of the types of social environments one enters into, one can promote a clearer understanding of the self, the illness, the treatment trajectory and overall perception of the self. This thus facilitates a re-negotiation and transformation of the self-concept, whereby aiding the individual in her self-understanding.

### **3.2.3. “Commonality, Connectedness, and Groupness”**

The last theme presented by Brubaker and Cooper (2000: 19) is focused on:

“Belonging to a distinctive, bounded group, involving both a felt solidarity or oneness with fellow group members and a felt difference from or even antipathy to specified outsiders”.

“Commonality” is seen to “denote the sharing of some common attribute”, whereas “connectedness” highlights the “relational ties that link people” (ibid.: 20). It must be noted that “commonality” and “connectedness” alone do not produce a sense of assemblage, but together they do promote what Brubaker and Cooper (2000: 20) called “groupness”.

Each one of these aspects can be seen to work independently, but using them in unison with one another will highlight a more beneficial and completed view of how individuals relate, understand, and integrate themselves into either a familiar or unfamiliar situation. I am of the opinion that the theme of “commonality, connectedness, and groupness could be usefully employed here in place of the all-purpose ‘identity’” (Brubaker and Cooper, 2000: 20).

### **3.2.3.1. Breast Cancer, “Commonality, Connectedness, and Groupness”**

Breast cancer patients do not actively highlight the need for “groupness”, but there is a sense of solidarity and collective self-understanding within the organised activities to heighten awareness and to raise funds with regard to breast cancer (as is the case with other afflictions). Mediatized events (such as yearly walks and the “Shavathons”), and people engaging in adventures for the sake of fundraising and awareness (such as running the Comrades marathon in pink), are becoming more widespread. During such events it becomes evident that there is an unspoken form of solidarity and collective self-understanding between current patients, those who survived and those who were (and are) affected by breast cancer. It is imperative to remember that breast cancer patients do overcome their illness and do not necessarily want to only be seen as the breast cancer survivor and thus live the rest of their lives under a metaphorical breast cancer banner.

The illness experience probably alters the individual’s previous self-concept to a certain degree, but the eight research participants were unwavering in allowing the illness to change who they were and thus aimed to continue their futures as their perceived pre diagnosed selves and not necessarily as breast cancer survivors. This pre diagnosed self will be influenced by certain experiences during the illness, but what I aim to put forth is that the individual does not necessarily want to allow the illness experience to alter who she is.

The common understanding of these themes is seen to revolve around the term of “social identity”. Again this term and its understanding are too broad for this research project. I will give a brief recapitulation of what “social identity” is regarded as within this research and how it is integrated into daily functioning.

### **3.2.3.1.1. Social Identity**

“Social identity” is understood in terms of how an individual thinks of herself within her social groups. According to Goodenough (1963, in Wetherell and Mohanty, 2010: 66), “social identity” is seen as an “aspect of self that makes a difference in how someone’s rights and duties relate to other members of a group or society”. Hannum (2007: 8) on the other hand understands “social identity” as comprising of different “parts of a person’s identity that comes from belonging to particular groups”.

Each individual goes about her life interacting with others and for most people evaluating others is done on an unconscious level. Being able to identify people or groups allows the individual to protect herself from embarrassing situations and even humiliation. Tajfel and Turner (n/d, in Hannum, 2007: 8) perceive “social identity” as including “categorisation, identification, and a means of comparison”. Comparing and categorising people and groups enable the individual to feel a sense of belonging through shared beliefs, experiences and characteristics.

### **3.3. Gender and Femininity**

Due to the illness affecting a woman’s sense of self she may have to re-negotiate aspects of her understanding of gender and femininity. Within society’s current outlook on women, her figure and outward appearance is what is perceived – perhaps superficially – to enhance her typical feminine attributes of vulnerability and sensitivity.

For Sontag (1990), breast cancer is understood as a secretive illness that threatens the individual’s life with no apparent cause or understanding. Sontag (1990) was of the opinion that cancer was seen as a mysterious illness during the nineteenth to late twentieth century, but even though current treatments for breast cancer are successful in curing the patient, the origin of cancer is still considered a mystery among medical specialists. This thought by Sontag (1990) is made relevant in the twenty-first century by Pardee (2010: x) who states that:

“The mysterious [illness] of cancer, including breast cancer, has plagued mankind since the dawn of recorded history ... [and] while tremendous

advances have taken place in our understanding of the molecular and cellular mechanisms operant in cancer, it has proven exceedingly difficult to prevent the occurrence or to halt the progress of the [illness] .... [but] the greatest challenge of finding a cure [still] confronts us”.

According to Legato and Colman (1999: 52) “cancer is on the rise” and this includes “breast cancer”. This thought allows me to highlight that women in today’s day and age that are diagnosed with this illness have to re-negotiate their self-image and perception. For Sulik (2011: 94) “the culture of breast cancer draws on the institutional strength of the existing gender system and incorporates pink femininity into symbols, messages and stories to feminise breast cancer”. She continues by stating that using the colour pink as an association to breast cancer thus “feminises [and] defines it as a woman’s illness” (ibid.: 95).

In the following section I will use the broad and commonly used terms of “gender identity”, “female identity”, “cosmetic crisis” and “survivor’s identity” to further conceptualise the nature of this research. I am using the term of “identity” in the following section, as in most literature it is not only known by this terminology, but also discussed under this title. It must be noted that in my analysis I will rework the broad terms into Brubaker and Cooper’s (2000) framework as discussed previously. This will be seen in the themes of “categorisation and relational identification”, “self-understanding” and “commonality, connectedness and groupness”.

### **3.3.1. Gender**

Gender is one of the most important “elements of our sense of self” (Tischler, 2011: 83). Physiology is seen to play a strong component in certain aspects of “gender identity”, as seen in men who are physically stronger than women and women who dispose of the physiology to fall pregnant and to breast-feed their infants. However, it is not the biology that defines the self-image of gender, but rather the cultural definition of what the self-concept of a “man” and a “woman” is to hold within the norms of that particular culture. In order for an individual to acquire a “gender identity”, she must first learn a “gender role” (Kendall, 2011: 317). Therefore a “gender role” is defined as “the attitudes, behaviours, and activities that are socially

defined as appropriate for each sex and that are learned and reinforced through the socialisation process” (ibid.: 317).

The process of socialisation begins in infancy and is established between eighteen months to three years of age, thus prompting the individual to create a sense of self-perception. According to Kendall (2011: 317) “gender identity” is defined as “a person’s perception of the self as female or male” and although the perception is individualistic it develops through interactions with others. It is the opinion of Butler (1993, in Lawler, 2008: 113) that:

“There is no identity that precedes the social ... bodies themselves are saturated with sociality as we give meaning to some characteristics and not others ... the very meanings we give to the body – for example, the fact that we understand it in terms of ‘nature’ at all – are themselves social meanings, and gender is *performatively*<sup>5</sup> produced, at least in part through the body”.

I am of the thought that the social meaning of gender can be attributed to how Western society views a woman’s figure, and especially her breasts, which are both prominent aspects that will define her sexual attractiveness. Aldredge-Clanton (1998: 97) is of a similar opinion when stating that “in our culture, breasts are a major symbol of female sexuality and beauty”.

By revealing the basis of “gender identity” and social meaning between the sexes, I am of the opinion that when an individual is diagnosed and treated for breast cancer she may experience a disruption in how she views herself, which can influence her perception of the self and her self-image. Depending on the individual and her outlook, she may view her diagnosis, and the often inevitable treatment option of a mastectomy, negatively – thus, for example producing thoughts of gender vulnerability and societal pressure to display a particular physical image. For Aldredge-Clanton (1998: 98) “a woman of any age may experience mastectomy as a disfigurement that profoundly affects her sense of self”. On the other hand an individual may view her illness in a positive light thus accepting her physical appearance and viewing her diagnosis as a chapter (that can be dealt with and

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<sup>5</sup> Performatively – “is to make something happen. The officiant is not simply making a comment but is making something happen”. These are the philosophical thoughts of J.L. Austin (Lawler 2008: 113). These thoughts were adopted by the well-known feminist writer, Judith Butler as well, and she too is of the opinion that we *perform* our gender rather than our gender being a biological given.

ended) within her life. According to Schou et al. (2005, in Kerenyi, 2007: 24) “women with breast cancer who are able to look at a situation optimistically tend to have a fighting spirit and therefore [a] better quality of life”.

### **3.3.2. Femininity**

Within this research project it is important to understand that femininity is not seen as a separate aspect to “gender identity”, but instead it is intricately interwoven into the concept of self-perception and self-image. With my focus being on women diagnosed with breast cancer, it is nearly impossible to separate the concepts of femininity and the perception of the self into neatly defined sections.

It is the opinion of Spade and Valentine (2008: xvi) that femininity is associated with gender. Certain aspects of femininity are defined and experienced throughout one’s “subculture” (ibid.: xvi). The stereotypical understanding around the concept of gender and femininity is to display “sociability, compliance with men’s sexual and ego desires and acceptance of marriage and childcare” (ibid.: xvi). These key features are the generalised, stereotypical understanding of women. This research will aim at highlighting the personal understanding of femininity from the perspective of an illness narrative.

Certain patterns of femininity are “embedded in specific social environments”, whereby revealing flexibility over rigidity in forming and understanding the specific role requirements for femininity (Connell, 1987: 846). It is the opinion of some that “a woman’s outer body [can be] interpreted as a mirror of her deep self” (Callaghan, 1994: 114). Others are of the opinion that femininity is constructed through social influences to portray one’s “appropriate surface self” (Bordo, 1989: 17).

Before one can understand femininity, it is important to pose the question “is femininity the product of nature or nurture [biologically determined or the product of socialisation]?” (Llewellyn et al. 2008: 106). There is still much debate surrounding femininity but many of these debates on “femininity inevitably involve[s] masculinity” (Alizade, 2003: 63).

When reviewing the debate surrounding femininity, two main theories emerge which are commonly seen to highlight a psychological viewpoint or a sociological viewpoint. For the purpose of this study I will rely only on the sociological viewpoint, but in order to understand this perspective I will give a brief psychoanalytical outlook as well. According to Hood-Williams and Harrison (2002: 193), the psychoanalytical understanding focuses on how “femininity is achieved through making heterosexual object choices, having a preference for passive aims, and demonstrating feminine forms of attachment to those objects (narcissistic rather than [analytic])”. Going even further to the founding father of psychoanalysis, Sigmund Freud (1915, in Van Herik, 1985: 123), who wrote that:

“It is essential to understand clearly that the concepts of femininity, whose meaning seems so unambiguous to ordinary people, are among the most confused that occur in science ... every individual displays a mixture of the character-traits belonging to [his/her] own and the opposite sex; and [s/he] shows a combination of activity and passivity whether or not these ... tally with [his/her] biological ones”.

By having a brief understanding of the psychoanalytical perspective I will now look at the other side of this debate which is situated in a sociological viewpoint. The sociological perspective aims to understand femininity by encompassing the view of socialisation. Socialisation focuses on “the process of learning how to behave in a [certain] way that is appropriate for an individual’s particular culture”, which is ultimately “governed by certain standards and values about behaviour and roles within society” (Llewellyn et al. 2008: 106).

As this research undertaking employs the social constructivist paradigm as the basis of its theoretical grounding, I will expand on the viewpoint of Llewellyn et al. (2008: 107)

“The role of nurture and socialisation in the construction of femininity, lead[s] to a social construction of gendered characteristics. Socialisation may be either a deliberate manipulation of behaviour or may be done unconsciously [by] the stereotypical behaviours being so firmly entrenched in society”.



In light of these two views on what femininity is (or should encompass), I will rely on the sociological definition of Strange et al. (2011: 528), which looks at how an individual adapts and learns her feminine traits and characteristics within her given society:

“[Femininity is] constructed by beliefs, attitudes, and reactions formed within particular cultures over time. All societies were assumed to assign certain characteristics and behaviours to those that were born female, teaching both girls and boys that females were supposed to be timid, soft, delicate, beautiful, and nurturing”.

For Ritzer (2012: 310), gender and sexuality is understood as being constructed by “socialisation and [is seen to be] infused in language, culture, [and] social structures that contour everyday life, institutional practices, and knowledge production”. The social construction of “gender identity” and femininity is not stagnant, but instead aspects of both “gender identity and [femininity] are constantly being adjusted” within societal norms, beliefs and values (Giddens and Griffiths, 2006: 465). This can be seen within the sexualisation of women in the media over the past 20 years. It is especially evident within recent movies and popular music videos where women are predominantly displayed as sex symbols and representing the personified figure of the male fantasy.

### **3.3.2.1. Femininity, Hair Loss, and Age**

When reviewing stereotypical femininity in relation to physical appearance, one of the most significant identifiers and trademarks of a woman is her hair. When an individual is diagnosed with breast cancer and undergoes her treatment of chemotherapy, hair loss is understood to be one of the most common side-effects to this treatment. According to Garnand (2012: 63) “women often associate beauty, femininity, and ‘identity’ with their hair” so when hair loss occurs, women often feel that their “beauty and self confidence” have been taken from them. Greenberg (2002: 31) is of opinion that when the individual goes for chemotherapy “the emotional and very visible alteration in her appearance ... associated with hair loss is shattering”.

Outside of the immediate alteration of the physical appearance after a lumpectomy or partial/full mastectomy, the treatment of chemotherapy can also be seen to produce negative effects on the individual's self-image and perception of the self. Greenberg (2002: 2–3) opines that:

“The most devastating side-effect of chemotherapy is not the nausea, the fatigue, the metabolic or hormonal changes, but it is the difficult-to-hide loss of hair. While that is the least medically important one and while it is temporary, it is, other than the loss of a breast, the side-effect [that] is associated with the greatest emotional impact, one which cannot be minimised and which has to be acknowledged and dealt with: the further disruption of the self-image”.

According to Sulik (2011: 39), when a woman rejects society's traditional understanding of femininity in relation to her breast cancer diagnosis she is “considered bad for morale”. What society deems important is that the breast cancer survivor maintains and promotes her “feminine appearance and an amiable impression” of her feminine attributes (ibid.: 39).

When looking at femininity in relation to age, Greenberg (2002: 1) states that with so much “emphasis placed on physical beauty, health, and sexuality, at least in the Western world, the finding of a breast lump is one of the most dreaded events a woman can experience at any age but particularly in the prime of her life, and worse even at a younger age”. Aldredge-Clanton (1998: 98) argues that “a woman of any age may experience [the surgical procedure of a] mastectomy as a disfigurement that profoundly affects her sense of self”.

Within the current Westernised view of what a woman should look and act like, this research aims to understand what effects the diagnosis will have on the individual. I aim to achieve this by trying to understand each participant's perspective on how she perceives and understands her illness, how the diagnosis impacted on her life and how she re-negotiated her identity (cultural norms and socialisation) and femininity. Within this research project I would like to understand how the research participants re-negotiate and transform their identity and femininity and how they accept themselves after their illness experience.

### 3.3.3. Cosmetic Crisis

As mentioned before, within today's understanding and acceptance of ideal femininity and beauty, breast cancer can be attributed to a "cosmetic crisis" and not a "major health crisis" (Rubin and Tanenbaum, 2011: 408). This view is based purely on the physical and thus viewed as a "threat to a woman's beauty and her female identity" (ibid.: 408).

It is the opinion of Datan (1989: 185) that a woman is "victimised not by [an illness], but by its cosmetic consequence: the threat of a desexualised body". When focusing on illness and "identity", the majority of the studies "treat identity as a function of illness" and consequently when an individual gets diagnosed with breast cancer it will result in drastic changes to her self-image (Pescosolido et al. 2011: 505).

It is the opinion of Shilling (1993, in Kirby, 2000: 134) that when looking at the body and illness from a social constructivist perspective, the "body is an unfinished biological and social entity which is transformed by the expectations of a society". This view by Shilling is further defined by Rubin and Tanenbaum (2011: 411), who state that cosmetic "breast reconstruction may be a strategy [to] defend against existential anxieties [stigmatisation], both for [oneself] and for others".

A different view has been taken by Charmaz (1997), who views the condition of an illness as a disruption within the perception of the self and self-image of the individual afflicted. Cheng (2010: ii) states that the diagnosis of breast cancer does not just disrupt a "woman's everyday life, but also, and more importantly, her self-identity: who she was before the cancer diagnosis and who she becomes after the diagnosis". When an individual decides on cosmetic breast reconstruction, it can be attributed to the recovery process and thus working towards obtaining a more completed appearance. This thought is reaffirmed by Rubin and Tanenbaum (2011: 405-407):

"The decision about breast reconstruction [is] rooted in patients' personal values and preferences – qualities that are already shaped by the cultural milieu – as well as in their personal valuation of the risks and benefits of surgery ... for some women breast reconstruction is linked to notions of

recovery and of transforming a once-sick body into a once-again healthy body”.

The decision to incorporate the cosmetic crisis into this project is to briefly highlight the research participants’ views, as these views are also formed by their immediate context(s). In this research project the cosmetic crisis should be viewed on the basis of a one-dimensional scale, compared to the entirety of the illness experience.

#### **3.3.4. Surviving**

Within her study, Cheng (2010) focused on the effects that breast cancer had on Chinese women and how these women understood their illness. Even though Cheng’s study shares various characteristics to the current research undertaking, there are several differences. How a woman interprets her illness, the illness experience and herself, will reflect if she has willingly accepted or avoided the term “survivor’s identity”. Within her findings, Cheng (2010: 198-199) found that the “definition and application of survivor’s identity” is challenged, as this facet may be adapted by some, but may also lead others to “silence” and feelings of “alienation”.

Due to the uniqueness of the individual and her experiences, one may revert to categorising a patient if she does not adapt to the prescribed characteristics of the “survivors identity”. When understanding “survivor’s identity”, it is important to remember, that the uniqueness of experiences and social and cultural differences will play a role in how a diagnosed individual will view herself and act within her environment. Therefore “survivor’s identity” and its characteristics are not seen as “universal across all [cultural and demographically located] groups” (ibid.: 200).

The findings produced by Cheng are reaffirmed by Kaiser (2008, in Pescosolido et al. 2011: 508), who states that while some women who have been diagnosed with breast cancer are comfortable in adopting or prescribing the term “survivor’s identity”, other women reject the term due to their personal understanding and feeling that “their illness experience had not been severe enough to warrant their adopting the survivor identity”. According to Bird et al. (2010: 167), each individual defines her understanding of “survivor’s identity” differently and therefore some women may reject the term, simply viewing themselves as “survivors”.

## Chapter 4 – The Methodological Process

### 4.1. The Narrative Approach

The term “narrative” refers to a diversity of possible activities. A narrative can be contained in “myths, legends, fables, [poems], novellas, paintings, cinemas, and conversations” (Barthes n/d, in Riessman, 2008: 4). For the purposes of this research, the concept narrative refers to a lived experience told in a “natural” form of communication that ultimately holds the purpose of broadening the understanding of who the narrative is directed to (Marvasti, 2004: 94). According to Herman (2009: XVI), the prototypical elements that constitute a narrative include “situatedness, event sequencing, world-making/world-disruption, and what it’s like”. These elements give the audience a basic understanding as to what a narrative attempts to convey. Narratives refer to processes that “rather than focusing on general, abstract situations or trends, are accounts of what happened to particular people – and of what it was like for them to experience what happened – in particular circumstances and with specific consequences” (ibid.: 1-2).

This research refers to “illness narratives”, specifically referring to the work of Arthur Kleinman (1988: 3) who reveals that an illness “refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disabilities”. I define an illness narrative as “the [rendition] the patient tells, and the significant other retell[s] to give coherence to the distinctive events and long-term course of suffering ... illness narratives are drawn from cultural and personal models for arranging experiences in meaningful ways” (ibid.: 49).

I am therefore not looking for a general story within this research but rather I am looking for the illness experience that is told within a narrative format. There are various forms in which a narrative can be structured and this revolves around what the narrator is trying to convey, the narrator’s frame of reference and the impact she is trying to make. The narrative is defined according to Andrews et al. (2009: 6) as:

“Narrative work does not examine the constructing effects of [the] individual symptomatic words, silences, or cross-textual discourses whereby all have to be placed [within] the context of an [experience]. However a narrative is itself an accumulating construction”.

Therefore each narrative that is told within this research will reveal the unique experiences and perceptions of the illness from the distinctive frame of reference of each participant. It is important to place each narrative against the backdrop of the narrator's knowledge, beliefs and culture. Atkinson and Silverman (1997, in Marvasti, 2004:95) state:

“We need to pay due attention to their [participants'] construction in use: how actors improvise their personal narratives ... how socially shared resources of rhetoric and narratives are deployed to generate recognisable, plausible, and culturally well-informed accounts”.

It is the opinion of Copley (2001: 2) that human beings “have constantly told [renditions], presented events, and squeezed aspects of the world into a narrative form”. This statement can be further enhanced by Appleyard (1999, in *ibid.*: 1):

“We tell [renditions] to ourselves; of our journey from birth to death, friends, families, who we are and who we want to be ... at each moment of our lives these [renditions] place us in space and time. They console us, making our lives meaningful by placing us in something bigger than ourselves. Maybe the [rendition] is just that we are in love, that we have to feed the cat or educate the children. Or maybe it is about a lifelong struggle for salvation or liberation. Either way – however large or small the [rendition] – the human impulse is to make sense of each moment by referring it to a larger narrative”.

This insight by Appleyard (1999) gives a broad view of how narratives are applied to everyday life. Renditions are therefore a normal way of communicating and a narrative can reveal much about any topic or subject. By using narratives, the narrator places herself within a given environment and makes sense of issues or tries to understand what has happened to her through her reflexive retelling of her experience.

There are different methods that could have been used to conduct this research, but the choice to implement the narrative as the main method of data collection is due to its potential for rich interpretations. I do not just want to understand what a breast cancer diagnosis is like in the clinical sense, but I also want to obtain the unique aspects that the diagnosed individual may have felt and experienced. By

implementing the narrative technique I aim to find common themes and differences, but also to have the original words and statements that reflect the experience of each participant. This view is supported by Riessman (1993: 2) who states:

“How individuals recount their [renditions] – what they emphasise and omit, their stance as protagonists or victims, the relationship the [rendition] establishes between teller and audience – all shape what individuals can claim of their own lives. Personal stories are not merely a way of telling someone [or oneself] about one’s life; they are the means by which identities may be fashioned”.

As much as a narrative relies on a subjective account, it is the opinion of Riessman (2008: 8) that “narratives are strategic, functional, and purposeful”. This is also true in the case of breast cancer. By encouraging these women who were diagnosed to share the personal narratives about their journey with breast cancer, one can also contribute to changing how society views this illness.

#### **4.1.1. The Illness Narrative**

An illness narrative can be defined as “story-telling [of personal experiences] and accounting practices that occur in the face of illness” (Gabe et al. 2005: 82). When a narrative is expressed, several aspects such as personal experiences, feelings, emotions and even “metaphors” are revealed (ibid.: 82). Metaphors provide the narrator with the opportunity to convey insightful and sensitive meanings that may not have been expressed in a less personal interaction, such as during a quantitative research project. Research conducted in a qualitative manner, with the aim of implementing an illness narrative, is to produce “intelligible meanings from one cultural setting for one audience to another” (ibid.: 82). Each narrative is created and fashioned within the broader cultural norms, values and beliefs of the narrator and thus conveyed from within her frame of reference. Each experience is “unique to the individual and unique to her circumstance” (ibid.: 82).

When the individual talks about her illness, she learns and gains insight by hearing herself tell her rendition which is also influenced by how others act or react to her experience (Frank, 1995: 1). Individuals who are ill often have a prevailing need to

talk and tell their story. Illness narratives are often told with immediacy, as if they are happening within the present, whereby removing the constructs of time and fusing the past with the present. By retelling a particular experience, it puts the narrator in control of what aspects to reveal, how to construct relevant meaning within the experience, and how to place herself within a certain frame of reference and mood. This again highlights the highly subjective nature of an illness narrative, but this is also where the richness of the experience lies. When a narrative is told, the audience has the opportunity to experience and perhaps identify with some of or all the revealed events. What is important to remember is that the readers of this research project will “inherently be part of the interpretive process, bringing their positioned identities and cultural filters to the interpretations” (Riessman, 2008: 111).

Within the medical world, according to Terzioglu (2008: 64), doctors often find the “illness narrative to be an untrustworthy story”. This is commonly attributed to the physician’s scientific frame of reference, whereby results are only seen in “facts and data that is obtained as a result of medical tests” (ibid.: 64). From the Western perspective, medical practitioners often hold the view that they have no use for illness narratives. Therefore, the Western medical system often does not value the narrative as a format to obtain relevant information. This often leads the patient to a “narrative surrender” (ibid.: 64). This “narrative surrender” promotes the loss of understanding and accepting of the illness and its far reaching effects.

In contrast to the above-mentioned thought, Kleinman (1988: 246) is of the opinion that the integral relationship that evolves between the patient and physician is one that reflects “learning and changes from the [illness] experience”. The patient “actively opens her life-world to her conjoint exploration” and the practitioner becomes “a moral witness, neither a judge nor a manipulator”. This relationship is not only beneficial to the patient and doctor, but filters indirectly down to show the patient’s family that their loved one is of priority. This thought by Kleinman (1988) is supported by Charon (1986, in Frank, 1995: 155), who adds that the value of an illness narrative can be used to “enhance medical care-givers’ recognition of the complexity of treatment decisions”. This recognition can allow the medical staff to become more client-centred and empathetic towards the side-effects and hardships produced from certain treatments. This is particularly relevant with regard to treatment by means of chemotherapy, where common side-effects can include



severe nausea and vomiting, fatigue and headaches. By being more client-centred, the medical staff administering chemotherapy may reassure patients by better explaining side-effects and equipping the patient to deal with the severe periods of nausea and vomiting.

The illness narratives to be used in this research are seen to highlight “inter-subjective dialogue, which articulates the illness and its effects” with an integration of “life’s issues and goals” (Mattingly and Garro, 2000: 101). It will thus be seen that “illness becomes the central element in the plot of an altered life story” (ibid.: 101).

#### **4.1.2. Narrating the Human Experience**

A narrative “records human experiences” by reflexively dealing with lived experiences (Webster and Mertova, 2007: 1). By being reflexive, the individual will reconstruct her position (psychologically and emotionally) within her ability to understand what has happened. This reflexive positioning may be understood better in the following way: a woman diagnosed with breast cancer could have initially felt victimised by her illness, but through her journey has re-established herself as not only a survivor, but as somebody who is personally stronger. It is important to remember that narratives are not joined together with “short-term elementary experiences and actions. They “pertain to longer-term or larger-scale sequences of actions, experiences, and human events” (Carr, 1991: 46). These points can be summed up in the following way (Dyson and Genishi, 1994: 242-243):

“[Renditions] help to make sense of, evaluate, and integrate the tensions inherent in experience: the past with the present, the fictional with the real, the official with the unofficial, personal with the professional, the canonical with the different and unexpected. [Renditions] help us transform the present and shape the future for ourselves and [our audience] so that it will be richer or better than the past”.

Each illness narrative in this project can contribute to a better understanding of the experience of the breast cancer illness. Although it is not the aim to contribute primarily to the narrators’ healing, there may be benefits attached to their participation in the research project. By verbalising a lived experience, the individual

can empower herself psychologically and emotionally and thus promote a sense of control over what has happened. It is the opinion of Frank (n/d, in Riessman, 2008: 113) “that [renditions] repair the damage that illness has done”. By allowing the individual the opportunity to talk about her experiences without judgement can be seen to lift an emotional burden that the illness has placed on the diagnosed individual. When talking about an illness, each “individual remembers, drawing on her experiences and knowledge to link the past with present concerns and future possibilities” (Mattingly and Garro, 2000:70).

How a society perceives and understands an illness will reflect how this illness is accepted in that particular society. This thought was brought to light by Susan Sontag (1990) who compares a society’s understanding and acceptance of tuberculosis and cancer. After much analysis and research, Sontag highlighted the point that tuberculosis was ultimately seen as a romantic illness, which prompted the afflicted individual to not only become more self-aware, but also more creative and desirable. Cancer, on the other hand, was understood as an illness that consumes the individual through the over-or-under use of energy. Depending on where in the body the illness was diagnosed, different thoughts and myths were attributed to why the individual was afflicted with this illness. These thoughts were seen to include psychological manifestations through the body, punishment for not living up to one’s potential and religious chastisement (Sontag, 1990: 143).

#### **4.1.3. The Influence of the Media on Narratives Concerning Breast Cancer**

Within the twentieth century, the media started to play a prominent role in how messages were relayed to the public. Within our day and age the media is the most prominent means to put forth and obtain information. This includes print media, broadcast media and the World Wide Web or internet. It is therefore no surprise that the majority of women in the world have heard and know of the basics about the illness of breast cancer. The media also plays a strong role in how perceptions are formed and how a diagnosis is accepted. According to Sylwester (2001: 1), “the mass media help to shape our shifting concerns and beliefs” and this is portrayed in how society views and comprehends breast cancer. Depending on how the media

portrays the illness, breast cancer can be seen as a cancer that can be either overcome, or it can be seen as an illness that compromises the diagnosed individual's future aspirations. The mass media often "exploit areas of strong emotional arousal to help shape our knowledge and opinions" (ibid.: 1). Therefore it is important that media messages on breast cancer are not only clearly understood, but that they are also factual and accurate.

Cancer is often portrayed as an illness that occurs mostly in rich and industrialised countries, but according to Sontag (1990: 71-72) this illness has been around for centuries. Cancer has been seen to claim lives through the tuberculosis epidemic, the bubonic plague and the influenza pandemic. There is no definite or accurate understanding on how long cancer has been around or the actual cause as to why an individual would suffer such a diagnosis. This thought is reflected by Sontag (1990: 85-86):

"Cancer is understood as mysterious, a disease with multiple causes, internal as well as external ... whereby cancer is presumed to lead to death".

In modern society humanity seeks to explain and justify illnesses. Therefore perceptions and experiences are morphed into theories and myths that ultimately allow a society, community or individuals to make sense and cope physically, psychologically, emotionally and spiritually with an illness.

Sontag (1990: 73-85) is of the opinion that the media use "disease imagery to express concern for social order". I disagree with Sontag and am of the opinion that illness images are seen to promote awareness and to bring to attention "specific master illnesses" (ibid.: 73-85). These master illnesses currently include cancer, Aids and tuberculosis. By making these illnesses known, the aim is to aid individuals to lead healthier lifestyles. In our current understanding and way of life, the media and all its outlets promote certain perceptions by highlighting particular knowledge. This can make people more knowledgeable, but can in part also makes them responsible for their illness, by not having led a more proactive and healthy lifestyle. This thought can be seen in the analogy of the media stating that cigarette smoking is harmful and that people's refusal to give it up can be attributed to them getting cancer.

#### **4.1.4. The Value and Validity of the Narrative Approach**

By telling and retelling renditions, people have the ability to not only explain their world, but also “to pass on their explanations [and knowledge] to succeeding generations” (Bathmaker and Harnett, 2010: 161). By sharing experiences, it allows an individual the ability to understand her past and “search out meanings for her future” (ibid.: 161). Narratives allow an individual the opportunity to create a “common identity through identification with common endeavours” already experienced by another (ibid.: 161).

Depending on the individual, particular sets of previous experiences will hold more relevance than others. This can be seen in individuals who have family histories of cancers, particularly breast cancer. The family history of cancer can inform and broaden a participant’s understanding and knowledge of the illness, and depending on the outcome, can influence her perception thereof. This understanding may be brief, but due to the high rate of breast cancer diagnosis in women, it is unlikely that an individual is unaware of the illness and the repercussions of such a diagnosis (Riessman, 2008: 11).

Within this research the narrative method is seen as a valuable means to acquire the rendition of lived experiences of the research participants. According to Langellier (2001, in Riesmann, 2002: 2) the narrative comprises four themes. These themes include “the ‘narrative turn’ in the human sciences away from positivist modes of inquiry, the ‘memoir boom’ in literature and popular culture, the new ‘identity movements’ [emancipation of marginalised groups], and the ‘burgeoning therapeutic culture’ that contains an exploration of personal life in therapies of various kinds” (ibid.: 2). Each one of these themes holds value, but for this project my focus will revolve mainly around the theme of the “memoir boom” and, in part, the “narrative turn”.

According to Connelly and Clandinin (1990, in De Fina and Georgakopoulou, 2012: 20) the “narrative turn” is seen to stem from “the simple observation that humans are storytelling organisms who, individually and collectively, lead storied lives”, thus simply shifting the focus from the “event to the experience” (De Fina and Georgakopoulou, 2012: 20). Over that past 15 years the “illness narrative” has

received increased attention. This can be attributed to the differentiation of the perceived understanding between “disease ... the diagnostic entity” and “illness ... the way that disease is perceived, enacted, responded to by a person, in relationships with others” (Riesmann, 2002: 2-3). This increased attention has also highlighted the knowledge and value of the “illness narrative” in the interaction process between the physician and patient (ibid.: 3). I am of the opinion that the “illness narrative” allows me to go deeper into the topic of breast cancer. I aim to bring attention to the illness and not the disease. To put it more simply, I want to know how a breast cancer diagnosis disrupts an individual’s life and also look at how this illness is perceived, understood and accepted from the diagnosed individual’s perspective.

The “memoir boom” according to Armitstead (2001: 1) was seen to originate with “St Augustine and was given a new impetus in the 20<sup>th</sup> century by Freud’s emphasis on self-revelation”. But of late, the “memoir boom” is linked to the underlining denominator of showing a “life refracted through a particular experience” (ibid.: 1). When looking at the current understanding of the “memoir”, Smith and Watson (2010: 2) are of the opinion that this form of “life writing” enables an individual to express her life’s journey, which is commonly reflected from a past experience to her current understanding of life. This can be seen within this research project to encompass the topic of breast cancer and the unique experiences and perceptions surrounding this illness. It is also thought that the use of the narrative technique in expressing an event or illness can be understood as therapeutic. According to Smith and Watson (2010: 140), the writing and telling of a lived illness experience could promote a certain level of “healing” to occur. The thought surrounding “healing” can be attributed to gaining a better understanding through reflection (ibid.: 140).

Within the research project, the illness narrative is aimed at giving women diagnosed with breast cancer a voice. The eight voices that will be heard within chapters five and six will echo personal understandings, lived experiences and particular thoughts as to why they were diagnosed with breast cancer, to how the medical encounter influenced their outlook and understanding.

When conducting a narrative study it is important to distinguish between two levels of validity. The first level looks at “the [rendition] told by a research participant”, while

the second level looks at “the [rendition] told by the researcher” (Riessman, 2008: 184). How one views and understands the collected information and analysis is a result of inter-subjectivity. It is the opinion of Riessman (1993: 65) that one can justify the implementation of the narrative by stating the following:

“[...] the process through which we make claims for the trustworthiness of our interpretations. ‘Trustworthiness’ not ‘truth’ is a key semantic difference: the latter assumes an objective reality, whereas the former moves the process into the social world”.

For a narrative to hold validity within a research project, additional focus should be placed on four main criteria, which are: “persuasiveness”, “correspondence”, “coherence” and “pragmatic use”. Each of these themes will allow the listener or reader the opportunity to evaluate the relayed information.

The main criterion around “persuasiveness” is plausibility. According to Riessman (1993: 65), “persuasiveness” is “greatest when theoretical claims are supported with evidence from informants’ accounts and when alternative interpretations of the [information] are considered”. The underlining challenge to persuasiveness relies on the “rhetoric of writing – on literary practices – and reader response” (ibid.: 66).

“Correspondence” can be seen as the continuous relationship that I have with the participants. This relationship enables me to verify answers with follow-up questions, to take transcripts back to the individual to check and if necessary, to rectify or add to certain responses. Most importantly, “correspondence” allows me to get feedback on what the participants think about the work, while implementing all the ethical procedures (Riessman, 1993: 66).

When looking at the third criterion of “coherence”, Agar and Hobbs (1982, in Riessman, 1993: 67) highlight three interwoven levels of coherence, namely: “global, local, and themal”. “Global coherence” is seen to encompass the “overall goals the narrator is trying to accomplish by speaking” (ibid.: 67). “Local coherence” “is what the narrator is trying to effect in the narrative itself” and “thematic coherence” involves “content: chunks of interview text about particular themes that figure importantly and repeatedly” (ibid.: 67). Even though the above-mentioned criteria are seen as separate points, they must be woven together to bring forth rationality and

consistency. These three themes can be summed up in the following statement by Riessman (1993: 67):

“Investigators must continuously modify their initial hypotheses about speakers’ beliefs and goals [global coherence] in light of the structure of particular narratives [local coherence] and recurrent themes that unify the text [thematic coherence]”.

Lastly, by implementing “pragmatic use”, Riessman (1993: 68) puts forth “information that will make it possible for others to determine the trustworthiness of the work” by adhering to four basic principles. These principles can be seen as “describing how the interpretations were produced”, “making known what the researcher did”, “specifying how one accomplished successive transformations” and “making primary [information] available to other researchers” (ibid.: 68).

There is no step-by-step guide to how a narrative is evaluated. This is because a narrative is a subjective depiction of an issue or event in someone’s life. This research will not focus on any quantitative methods that mostly highlight statistical measurement or hypotheses. It depends on the reader to evaluate this project by perceiving and comprehending what I put forth in my argumentations, topics and findings. It is the thought of Silverman (2001: 129) that there is “no all-embracing list” or rules to analysing qualitative findings. I intend to interpret the collected information by carefully immersing myself in the given renditions and becoming familiar with the phenomena. The immersing style will allow me to “carefully reflect on the [collected information] and then write an interpretation by relying on one’s intuitive grasp of what is going on” (Terre Blanche et al. 2006: 323). This will also be facilitated given that I conducted all the in-depth interviews, and therefore know all the participants, and have spent considerable amounts of time with them.

A narrative inquiry comprises of “several common characteristics” (Miller and Salkind, 2002: 149). These characteristics are seen to include: the research participant and recruitment process, the interview, place and time, the theoretical procedure used, ethical consideration and the expected outcome. Within this research project, I am the sole inquirer and therefore I am responsible for “emphasising the importance of learning from the participants in a setting” (ibid.: 149). How a text is composed can result in different interpretations. For Iser (n/d, in

Riessman, 2008: 115), “meaning is not concealed within the text itself, instead we bring the text to life with our reading”.

Riessman (2008: 115) is of the opinion that the “reading process always involves viewing the text through a perspective that is continually on the move”. By continuously reviewing my findings I will not only better understand the original message brought forth, but also reveal different forms of class, race, gender, social status and cultural understanding. This will allow me to transform the “simple talk about a life affected by illness” to a fuller and completed understanding (ibid.: 115). Through analysing the narrative and the context, I will attempt to reveal these hidden dimensions and make them known to the reader.

## **4.2. Collecting the Narratives**

### **4.2.1. The Participants and Recruitment Process**

This research project focused on eight women in Bloemfontein, situated in the Free State Province of South Africa. The participants varied between the ages of 37 and 62 years. The socio-economic background of the research participants can be regarded as similar, given that they all had access to private medical health care, which is a commodity that is rather costly. Seven of the eight participants obtained tertiary education. Each participant had a sound bio-medical understanding (some participants had a higher understanding of the illness than others) of breast cancer.

Both African and Caucasian women who came from middle-to-upper class backgrounds were represented. They were all selected from a private hospital where they were receiving breast cancer treatment. In order to abide to the ethical protocol, pseudonyms were assigned to each participant (consciously avoiding a categorical system of numbers not to objectify the participants). In chapters five and six, I will represent each participant’s inter-subjective experiences in terms of her narratives.

Due to the intrusive and dramatic nature of breast cancer and its treatment, to be diagnosed with this illness is a life-changing experience. Depending on the form of breast cancer and the different treatment methods, a woman can be affected physically (through partial or full mastectomy), and can suffer other side-effects of treatment. She will also be affected emotionally, psychologically and spiritually.



Through my interactions and interviews with the research participants, I constantly attempted to fully abide to the moral principle of "*Primum non nocere*" or "First, do no harm" (Sharkey, 2008: 1).

I began the research process by looking at literature on breast cancer, which included issues around "biographical disruption" of chronic disease (Bury, 1982), on how society understands, perceives and views the diagnosed individual (Johnson, 2006), "identity" formation (Brubaker and Cooper, 2000), and issues around femininity (Brym and Lie, 2010). I obtained a broad understanding of the basic biology of breast cancer and how the body is affected by this illness. Once I had a broad understanding of breast cancer, I contacted an oncologist (Dr Jackson - pseudonym) and requested a meeting to explain the research and to enquire about the ethically correct procedure in obtaining research participants for this project.

After receiving the personal contact information from Dr Jackson, I contacted each patient telephonically and introduced myself, the research and requested a verbal consent to participate. My aim was to build a trusting relationship with each individual and to allow her to get an understanding of the project by encouraging her to ask questions concerning myself as the researcher and the research undertaking. Each individual was willing to participate in this project and was willing to set a date and time for our first meeting. During the initial telephone conversation, most research participants began to reveal certain emotional cues and understanding towards their illness, and in some cases they began to refer to personal experiences. I found that within the first attempt of contact, each individual reflected an emotional attitude that could either be placed within an optimistic or pessimistic frame of reference. In this research, I will continue to use the broad categorising concepts of an optimistic or pessimistic attitude.

Some of the women who started to explain their illness revealed a pessimistic stance, which was confirmed by negative terms such as the use of the word "suicide" or the phrase "what-if?" (a strong fear of recurrence or metastasis) – all within the introductory telephone call. The women who expressed an optimistic frame of reference wanted to meet to discuss the illness and how it affected them physically, psychologically, emotionally and spiritually. Their optimistic stance did not imply that they had not experienced troubling periods of time, but they indicated early in the

research that the illness is viewed more along the line of a period or chapter within their lives.

Each of the research participants were contacted with the aid of the oncologist, Dr Jackson, who is practising in the private medical sphere. I also had the opportunity to interview Dr Jackson, who is the primary physician of all eight of the research participants. Following ethical considerations, no personal information, except for contact details, were discussed between Dr Jackson and me concerning the individuals. All the personal information revealed in this research came from the research participants themselves. The research findings are based on a group of eight middle class women from the Bloemfontein area and the information that was collected was within a time frame of one year (2012). Each participant experienced her breast cancer diagnosis as a first time diagnosis and thus no participant suffered metastasis or a recurrent breast cancer diagnosis.

The first contact session did not begin with a systematic collection of interview findings. This session was used to become familiar with each other. This was achieved by encouraging the research participant to speak about the thoughts around her diagnosis and what impact this illness has had on her life. I explained the research project to the participant and went through the ethical considerations contained in the informed consent form (Appendix B). Permission was obtained for the interview session to be recorded for the purpose of playing back certain remarks and opinions, as well as to transcribe the conversation and to integrate personal accounts into the analysis chapters. No participant raised objections to the ethical form, the recording of the conversation or the use of their statements in the research. Once the recorder was activated and placed on the table, some participants began to reveal their experiences which included feelings, emotions, reactions, knowledge, understanding, medical procedures, treatments and expected outcomes. Other participants felt more comfortable in getting the formalities (purpose of my research and the ethical considerations) out of the way and were eager for me to begin with the interview. These particular individuals were open to participate in the research, but were more reserved in so far as the unstructured conversation that followed was concerned. Therefore, I had to be flexible in how I approached each research participant, as well as in how I approached the breast cancer topic.

The interviews aimed at hearing each individual's accounts, while still focusing on answering the basic research questions. For Terre Blanche et al. (2006: 323) "themes should ideally arise naturally from the [collected information], but at the same time they should also have a bearing on your research question". Within the analysis, I will highlight broad findings and work these findings down to themes, common trends, differences and to a conclusion. I will, where appropriate, include the voices of the individual narrators, thereby adding validity to my findings and conclusions. The analysis will be handled in two parts: firstly focusing on identity and femininity and secondly, looking at the medical encounter.

No matter the demographic particulars, race, social status or wealth, being diagnosed with "cancer" is a message that no person wants to hear. The term "cancer" clearly contains a form of stigmatisation. All the participants conveyed that the word "cancer" and the connotation surrounding this word, make breast cancer such a feared illness. This thought is shared by Sontag (1990: 5) who states that a diagnosis of cancer in today's medical understanding is similar to the tuberculosis epidemic of the 18<sup>th</sup> to 20<sup>th</sup> century (therefore, before a cure was found for it). The main point that Sontag aims to put forth is that currently medical practitioners know very little around the aetiology of cancer, which results in this illness being viewed as "mysterious" (ibid.: 5). The mystery surrounding the current understanding of cancer is seen to include the causes, progression and prognosis of this diagnosis. What makes this illness so feared is that it does not gradually show signs of manifestation but progresses in a "ruthless and secretive" manner (ibid.: 5). Therefore Sontag (1990: 6), herself, diagnosed with cancer at a stage in her life, was of the opinion that:

"Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious ... the very names of such [illnesses like cancer or AIDS] are felt to have a magic power ... and the very word 'cancer' is said to kill some patients who would not have succumbed [so quickly] to the malignancy from which they suffer".

Within this research each of the research participants was actively promoting her health by going for yearly check-ups, including in some cases, going for mammograms. Some of the participants physically felt a lump in their breast, while

others were told that a lump was detected via the mammographic scan. In all the cases, each individual acted promptly to find out about and to treat the discovered lump.

#### **4.2.2. The Interview and its Application**

Verbal communication was the only medium for gathering the research information. It is the opinion of Mishler (1986, in Kvale, 2007: 72-3) that “narratives are one of the natural cognitive and linguistic forms through which individuals attempt to organise and express meaning”. The core characteristic of the interview is to gain knowledge and thus allow the individual a broader and more comprehensive understanding to a query, issue or problem. Each individual was encouraged to talk about breast cancer, thus allowing them to broach any issue or concern surrounding their diagnosis. When a research participant started to draw to a close with her initial thoughts, I began to ask questions that were purposefully designed to highlight the illness trajectory from diagnosis to treatment.

Depending on the participant and her willingness to disclose certain issues, the interview process often resulted in spontaneous renditions, topics or issues being broached. When issues emerged spontaneously, I regarded it as of high relevance to an individual. On the other hand, renditions and topics were also elicited during the interview through specific questions. Within the interview, I directly asked participants to deal with issues, but it was up to the participants to expand on a topic.

As interviewer, “my main role is to remain a listener” (Kvale, 2007: 74). By listening one manages to “abstain from interruptions, occasionally posing questions for clarification, and assisting the interviewee in continuing to tell her life-story”. Within the interview process, I became a “co-producer through partaking in questions, nods, and silences” (ibid.: 74). The narrative interview can be seen to serve at least two purposes: firstly, to “refer to a specific episode or course of action” and secondly, it “concerns the interviewee’s life-story as seen through the actor’s own perspective” (ibid.: 74).

This research project incorporates four variations of interviewing into the collecting of information. The interviews that were used to obtain the relevant information

included aspects of the active interview (Holstein and Gubrium, 1995), the creative interview (Douglas, 1985) and the face-to-face interview (Bernard, 2006; Vanderstoep and Johnston, 2009; and Bowling and Ebrahim, 2005). These aspects will be further discussed to highlight the crucial points, which enhanced my interview schedule.

Each interview attempts to include aspects that will enhance the relationship between the research participant and me, to provide for a more active communication process, and allow for a more comprehensive understanding of the questions in order to obtain rich descriptions. I tried to incorporate the strengths of each of the chosen ways of interviewing into the collection process, in order to strive for rich findings. Rich and in-depth answers will allow for a comprehensive understanding of what a breast cancer diagnosis is like.

The active interview focuses much of its understanding on the participant and how each individual person is seen to be active in a rational and emotional manner. For Pool (1957, in Holstein and Gubrium, 1995: 14), “the interview and its participants are constantly developing”. This development highlights two forms of communication: firstly, what I aimed to gain insight into by framing specific questions and by structuring the participant’s responses. In this way I was hoping that the information would flow freely, but at the same time remain relevant to the aim and objective of the research. Secondly, how the interview was experienced by the individual would result in how lived experiences were shared. Through the sharing of lived experiences, a fuller and more complete understanding of the participants’ ordeals could be made. If the participant feels uncomfortable during the interview, lived experiences and insights will not be shared, thus resulting in a brief and bland rendition.

The main objective of the creative interview was “getting to know the real subject behind the respondent” and as such allowing for richer information to be revealed (Holstein and Gubrium, 1995: 12). The success of the creative interview to provide rich descriptions was related to provision of an equal position to the research participant and me. The promotion of an equal standing diminishes the sense of a power differentiation, thus resulting in disclosure and a creative search (Douglas, 1985: 25).

Bernard (2006), Vanderstoep and Johnston (2009), and Bowling and Ebrahim (2005) agree that the face-to-face interview technique is the most beneficial tool to the understanding of what an individual is revealing against the backdrop of her body language and tone. By seeing and hearing what the individual has to say, allows for a deeper and more comprehensive understanding. Bowling and Ebrahim (2005: 209) are of the opinion that it also allows for the researcher to “clarify any ambiguities”. In order to establish empathy and respect during the interview, I had to be able to pick up on specific cues, such as when the participant was becoming emotional, uncomfortable or overwhelmed. By creating a professional and personal relationship with each participant, richer and more value-bound information would be revealed.

#### **4.2.3. The Implementation and Practice of Ethical Boundaries**

When conducting research, it is of the utmost importance to build a safe new relationship (between the research participant and myself). When I initiated the interview process certain formalities were undertaken. These formalities included getting to know the participant on a more personal level, allowing the participant to ask questions and explaining the parameters of the research, the interview and how the narratives would be used to contribute to the research project.

Ethical actions required for qualitative research, included confidentiality, ongoing informed consent, the relationship between participant and researcher (building rapport through respect and consideration), managing distress in the interview and ownership of the story (Twohig and Kalitzkus, 2004). All ethical guidelines were followed within my research undertakings. This included ensuring that individuals participated voluntarily, that all information such as comments and behaviours were treated confidentially, that participants were protected from any harm (psychological and emotional) with regard to the research, and by building and maintaining mutual trust between the participant and myself (Silverman, 2011: 97). Informed consent can be defined that “[individuals] have the right to know that they are being researched, the right to be informed about the nature of the research and the right to withdraw at any time” (Ryen, 2004: 231). It is the opinion of Silverman (2011: 98) that informed consent is a “process of negotiation”.

I tried to conduct the research with integrity and without causing any harm, but as Marvasti (2004: 136-137) argues:

“In theory, researchers should take every reasonable measure to protect their subjects from harm, but in reality, it is impossible to anticipate every risk. One reason for this is that your study might affect respondents in different ways ... even if your respondents voluntarily take part in your study, they may not be in a position to fully appreciate the potential harm they could suffer from their participation”.

Within a sensitive research topic, such as the personal testimonies of women diagnosed with breast cancer, I was aware that participants may have become emotional or upset during the interviews. In order to manage the interviews, I tried to reassure the individual by either letting her work through her emotion or by letting her change the topic or issue that might have upset her. After an interview (the following day), I contacted the research participant to ensure that she was alright and to ask her if there was anything more she would like to talk about concerning the interview. During this discussion I again confirmed – through verbal consent – their agreement that I could use the interview material before beginning with my transcriptions and analysis.

## **Chapter 5 – Identity and Femininity**

### **5.1. Strategy for Analysing “Identity”**

In the analysis I will implement the analytical framework presented by Brubaker and Cooper (2000) to replace the commonly used terms of “social identity”, “personal identity” and “role identity”. I will refashion these terms into specific and exact sections titled “identification and categorisation” “self-understanding” and “commonality, connectedness, and groupness”. For this research undertaking, the use of “identity” is too broad a term with many various interpretations and understandings attached to it. My rephrasing of “identity” can be seen as replacing it with words like “characteristics”, “self-image”, “self-perception”, and “personal experiences”. My aim with this approach is to use specific and concrete words or phrases to put forth what each of the participants felt, saw and heard within her breast cancer journey.

By reworking and redefining the broad concept of “identity” I aim to produce specific and more accurate themes within my analysis. This framework will also give structure and coherence to the presentation of my analytical findings.

#### **5.1.1. Relevant Themes and their Relation to Breast Cancer**

The relevant themes for this chapter are seen to comprise of “religion”, “gender and femininity”, “surviving and support” and “maintaining normality”. Each one of these themes will be discussed in detail with the incorporation of the theoretical framework of Brubaker and Cooper (2000). I will also link relating issues to each theme.

Before I present my findings, I will briefly highlight “identity” and how the participants viewed this concept. Even though I will find and implement alternative words or phrases into my analysis, I am of the opinion that it is important to see how each individual perceived, understood and integrated this notion into her everyday functioning.



### 5.1.2. “Identity”

My initial questions focused on the nature of the individual’s diagnosis. For each of the participants, her cancer diagnosis was a first-time experience. None of the participants experienced a secondary diagnosis or metastasis. My initial questions centred around the participants’ definition or explanation of self-perception. In the following sections I will relate the narrative of the eight research participants. I renamed the eight women who told me their stories, by giving them new names (pseudonyms). Therefore in the following sections the narrators will be Ana, Bella, Carla, Donna, Ella, Fiona, Gina, and Hala.

It became clear that questions around perceptions of the self required the individuals to apply a deeper cognitive process and all the participants needed guidance in first understanding the concept of the self. Self-perception is more commonly referred to as ‘personal identity’. Hala, is a 57-year-old widow with three adult children, makes this point by stating that her self-perception and her characteristics are closely interwoven, if not, the same. “Your identity is what you are made up of [and] your characteristics are what you are made up of”. Some of the participants equated who they were, and are, with physical appearance and at different points in this research a strong reference was made to hair. Gina, a 54-year-old mother of four and in a stable and happy marriage, is a qualified and experienced teacher. For Gina, self conception was closely linked to her hair: “I was afraid of the hair story. I am losing my identity [when I am losing my hair]”.

From trying to get an understanding of how each individual comprehended her view of herself, I tried to get an idea of whether this view had changed after her diagnosis. Each individual has a particular frame of reference and this reflects how she accepts her diagnosis and what her overall outlook on life would be. My questions yielded many different responses, but the underlying response was that in most cases one’s self-image did not change.

Donna is a 47-year-old divorcee who does not have much contact with her two daughters. She was in a relationship with Tom which had ended days before her diagnosis. During the interviews, it was highlighted that Tom is still her primary source for strength and stability. After her diagnosis, Tom resumed his contact with

Donna on a friendship basis, whereby taking care of her and helping her in tasks, such as taking her to doctors' appointments, treatment sessions and by preparing her meals.

From the interview and my background knowledge, it appears as if Donna has a pessimistic outlook on life and on her illness. When I asked her about her self-image and if it has changed since her diagnosis, she proceeded to tell me:

“I am trying to find myself again. I am trying to restore myself to normal again. [Tom] visits me and he is trying to stand with me as a friend, but he [has] got a whole life with his offices and his sons and his house and his things where I ... I can't go. So, he is creating a new life there and this dying person this side [is] hang[ing] on for what?”

It appeared that Donna has little contact with her family (immediate and extended). She also appeared to have a limited number of friends in which she could find support and comfort. Each question that I posed resulted in her finding a brief answer, but then simply reverted back to the topic of Tom. Donna apparently finds it difficult to separate who she is and how she sees herself, from her previous relationship with Tom. This has an effect on her attitude towards her illness and the perception she has of herself.

In contrast, Ana is adamant that she has not changed as a result of her illness and thus she regards her perception of herself as not having been influenced. This view is strengthened by the fact that her family accepts her just the way she is. Her support structure appears to be one of the main reasons for her positive outlook. “He [Ana's husband] assured me that nothing has changed. My children have accepted me the way I am [and therefore] I have not changed”.

With the exception of Donna's view, the other participants believed that their self-concepts had not changed. I expected more of a personal shift in self-understanding, perception and frame of reference. After inquiring further, each participant did acknowledge that the breast cancer experience has an impact on who they were, but this impact did not result in a dramatic change. This can be seen in 49-year-old Ella's response:

“I have a different outlook on life and on the little things. But I am still me and I am just moving on. [This change is] not [personally on] myself but things in life are different for me. Things I see in the future and in everyday life are different”.

Ella is a self-employed entrepreneur who is married with two children. Cancer is a highly sensitive subject to Ella, as her first husband was diagnosed with pancreatic cancer, which resulted in his death when he was in his mid-twenties. I had expected Ella to have presented with a more pessimistic outlook due to her previous experience with cancer. However, she appears to be in control of her emotions and future aspirations. To her it is important not to fall apart or give in. For the most part, Ella not only understands her illness, but has made a conscious effort to overcome it.

Each individual is made up of multiple characteristics where each characteristic contributes to the unique aspects and to the thoughts that the individual has of herself. My interest not only lay in understanding who these women were, but also in how their diagnosis and illness experience has changed them. Each participant linked her perception of herself to either internal or external characteristics. Internal characteristics can be seen to include qualities of “control” and “composure”, among others, whereas external characteristics can include qualities imposed by outside influences, such as within the support structure. The diagnosis of breast cancer and the medical procedures to cure the patient of the illness cannot be separated from personal experiences and alterations the individual underwent. The loss of breasts and hair, the burning of veins and skin, and whatever other side-effects, all have an impact on the individual and how she sees and understands herself.

Bella underwent a double mastectomy and debates with herself about her new appearance. She now appears physically disproportionate with a flat chest and a protruding stomach. She states that she is fine with who she is, but that the physical changes did indeed bother her:

“I had cancer and have been operated on there [pointing to her breasts]. [But there] is nothing that is going to change in me. I will still remain a mother, a nurse and a wife. Even outside [her appearance] because even if I put a dress on without a bra it doesn't look nice, I have something protruding here [pointing to her stomach] and nothing here [pointing to her breasts]”.

Bella did obtain prosthetic bra ziers so that when she would go out in public, she did not look different. In her acceptance and personal evolution, she has not only come to accept her illness, but also her new physical appearance: “I said [to my husband] you must get used to me being like this when I am not having a bra[zier] on. Let them [the community] get used to me when I am not wearing a bra[zier]. I am fine ... I am just going to town like this”.

Carla underwent a mastectomy to remove a lump and cyst of her left breast and made a clear point in stating that she will not allow her illness to dictate who she is and change her in any way. By staying positive, she is adamant to continue her life as before: “I [will not] be depressed and nothing is going to change. Nothing is going to change ... I am not going to sit here and cry and do nothing”. Carla has a clear understanding of who she is and where her future lies. “Nothing is going to stop me from what I want. [Because] I am not sick”. This way of thinking and approaching life is not simply escaping reality or stating words or phrases that she thinks I wanted to hear. Carla’s positive and proactive approach to life can be seen in the continuation of her studies, her active role in the community and the organising of a breast cancer seminar (which I was invited to and attended). “I am working at the hospital (as a nurse), I am [also] studying [critical care] and I am a HIV counsellor [for the community]”. Her acceptance of her illness and of herself allows her to view herself as being free. “That is why I am talking to you ... I am free”.

Bella and Carla shared an optimistic outlook of themselves, their family, their work and life in general. Donna, on the other hand, felt lost in herself and her future prospects. “I am just trying to keep myself together and it feels like I am going to go into shock. I am trying to find myself again. I don’t really think of the future [because I am] just trying to cope with the cancer”.

Each one of the research participants held strong opinions on religion, in particular the Christian faith. The religious aspect clearly plays a prominent role in the individual’s view of herself and her daily functioning. The trauma of an illness diagnosis opens the way for faith to become an integral part in understanding the question of “why me”, as well as in obtaining strength in overcoming negative emotions and thoughts.

## 5.2. Religion

Religion turns out to be an important issue in my research. Participants were seen to explore their faith to find a form of understanding as to why they were subjected to this illness. Breast cancer was not seen as a form of punishment, but rather that most of the participants explained that their faith in God and their religious conviction had grown stronger.

I will begin by highlighting Donna's experience. It is apparent that notwithstanding a general lack of emotional and physical support, Donna also found support and comfort through her faith. She maintains a daily routine to help her overcome negative thoughts and feelings:

“I am still feeling very negative about [breast cancer, but] I am reading a lot [of Christian literature] and watching TBN [Christian television]. I am looking to hold onto something in life [and that is why] it is so important that [I] feel the love of God”.

Each of the participants found, in some way or another, an approach to rationalise her diagnosis within a religious context. Their general frame of reference – be it an optimistic or a pessimistic inclination – played no significant role when inquiring and understanding their faith. They all proclaimed that this illness broadened their faith and trust in God. Each participant reflected uniquely on her religiosity, which resulted in various ways of reasoning.

Hala believes that God has a divine purpose for her and that her illness is, in part, preparing her for what He has planned.

“I am in God's hands [and] He knows why He allowed this to happen to me. There must be something that He wants to show me through this. There must be a reason why I must go through this. Perhaps He wants to use me in this area to help other people. I never felt that God was punishing me”.

Ana believes that God is guiding her back onto His path. She did not believe that her illness was a form of punishment, but rather a way of encouraging her to broaden her understanding. “God has means and ways to win you back to his path. I never

thought I am being punished. Yes, maybe to get me to understand some life issues better, but not as a punishment”.

With Ella’s previous encounter with cancer (the death of her first husband) she has not only immersed herself in her business, but also into expanding her religious understanding. “I [started] the business to keep me busy and not to think about what happened to me, [but] I need my faith. I use my faith to [get] through all this trauma”. In the case of Gina it is clear that she initially felt that God was “picking on her”, but over time she began to understand that this was not a form of punishment.

“I must say I did feel angry towards God. That did cross my mind to say: ‘Why me? Because I am not a bad person, so why me? Why are you picking on me now!’ I did feel that way. But I didn’t feel I was being punished because I did something [wrong]. [Then when] you rationalise things then you realise that bad things don’t come from God”.

Gina thus rationalised the occurrence of this illness and having had no family history of cancer. She was relieved that she was the one who got the illness and not one of her three daughters. “I thought to myself: ‘Rather let it be me and not one of my daughters’”.

Fiona saw her diagnosis with breast cancer as a positive event in her life. This must also be seen within the religious context of a test of one’s faith. “[It is important to me to be] faithful. My faith in God has deepened. I think it is a very positive thing that [breast cancer] happened to me”. She then also interprets her illness as a manner in which God is winning her back to His path.

Each of the participants used her faith to rationalise why she was diagnosed with breast cancer. Some of the participants were still in the process of understanding or rationalising the purpose or reason for their illness, but at the time of the interviews, each participant had accepted her diagnosis as a positive experience related to a higher power or from within a faith perspective.

### 5.2.1. “Self-understanding”

When applying Brubaker and Cooper’s (2000: 17) concept of “self-understanding”, the concept of self reflection and trying to make sense of the illness diagnosis occupies quite a prominent role. I am certain that this role is not unique to the research participants, but rather a common theme in all who have been diagnosed with a life-threatening illness. By understanding the self, one is able to not only rationalise the self as a whole, but also the integration and transformation of the self with breast cancer. Self-understanding is a subjective form of coming to terms – in this research project – with one’s diagnosis.

In my findings it is evident that faith assists the individual in the overall rationalisation of the breast cancer experience. A highlighting question that surfaced was “Why me?”, According to Pierret (2003: 5), the posing of this question is ultimately the “quest for meaning – Why me? Why now?”, which can be seen as the central theme to the overall illness experience. It is my opinion that posing this question can be seen as the catalyst to starting the journey of self-exploration. Self-exploration thus prompts the individual to re-negotiate and transform her personal understanding, self-image and self-concept. By re-negotiating and transforming the self, the individual aims to find a balance or equilibrious state within her present and future life.

Self-understanding is most commonly linked to the thought of “personal identity”, whereby encompassing the simplistic understanding of ‘who am I?’. This thought can be broken down into greater depth thus focusing on specific aspects of self-image, self-perception and self-concept. Religion and self-understanding can be seen as either a beneficial or detrimental aspect to overcoming this illness. When viewing religion and self-understanding as an optimistic theme, one may see that faith encourages the individual to fight and overcome her diagnosis. However, looking at this theme from a pessimistic stance, one may assign blame for this illness or even believe that this illness was sent as a form of punishment.

Within this research, each participant displayed an optimistic stance with regards to their religious context. As seen above, one can come to the conclusion that even though questions of ‘why me?’ were posed, none of the participants believed (for a

prolonged period of time) that this illness was a punishment from God. They rationalised this illness along the lines of: there is a higher purpose for them, to bring one closer to God and/or beliefs give the individual the strength (emotionally, psychologically and – perhaps – physically) to continue with the treatment trajectory and life.

### **5.2.2. “Commonality, Connectedness, and Groupness”**

When reviewing the theme of “commonality” within the religious context, each of the research participants placed a strong emphasis on her faith as a means of finding strength in light of her diagnosis. A breast cancer diagnosis and religious understanding can be seen to represent a prime link of “commonality” outside of the broad characteristics of general and feminine qualities. This link can be further aided when the diagnosed individual finds a fellow survivor or mentor who shares her religious convictions.

Depending on the individual and her previous experiences, a certain level of “connectedness” will begin to develop within her faith (understanding and adhering to specific scriptures) and fellow members (prayer chains or groups). This religious connection can thus be seen to encompass the physical, psychological, emotional and spiritual. It is my opinion that strengthening these four fundamental aspects of human understanding, especially within the face of an illness, can be highly beneficial to the individual. The underlying spiritual dimension, within this research, can be seen as a strong requirement in understanding, accepting and eventually overcoming a breast cancer diagnosis. Each participant has stated that her belief falls within the religious concept of Christianity.

“Groupness” only comes into effect when the previous two themes (faith and diagnosis) worked together. Most of the participants have implied that they are affiliated with a religious organisation and within this organisation there are key members who are viewed as closer than others. This then inadvertently proposes a membership of a specific group. “Groupness” can represent a variety of different dimensions, but for this research undertaking can be seen to include: spirituality, a shared illness, treatment trajectories, side-effects and disfigurement. It is important



to remember that most of the individuals that partook in this research made it clear that they do not want to and will not be defined by their illness. Instead, this illness is seen as a chapter within their lives and that their faith will give them the strength to overcome the diagnosis. Hala appears to bring the themes of “self-understanding” and “commonality, connectedness, and groupness” together in the following exert:

“Cancer was one of those things where you realise that [you] cannot control [a breast cancer diagnosis]. I can do nothing about it so I [put my] trust [in] God [so that He] will see me through this [period in my life]. I am content [because] I know I am in God’s hands. I got so much support [from my church] and they prayed for me constantly. They really lifted up my hands and they placed their hands on me. [By] lift[ing] me up [they gave me strength to continue because] I was so sick I just wanted to lie down. I didn’t want to talk to anyone and I just felt miserable, but God told me ‘no, you will go through with this [treatment]’ and yes ... that is why I went through [with] it. Otherwise I would have stopped after the third session. I [also] wanted to make sure that [family members, church members and friends do] not see me as a sick person. [It is important to understand that] life does not come to a standstill when you [get] cancer. Life continues and life must go on”.

Hala’s opinion will not reflect all breast cancer experiences, but within this research, religion was not just an aspect of daily routines, but also a means of finding strength, acceptance and understanding to life with an illness. Other participants had similar view points, but stated their thoughts in a slightly more reserved manner.

### **5.3. Gender and Femininity**

#### **5.3.1. Gender**

The notion of “gender” is understood to be influenced by one’s cultural, societal and parental up-bringing. As I have previously stated in chapter four, a “gender role” is defined as “the attitudes, behaviours, and activities that are socially defined as appropriate for each sex and that are learned and reinforced through the socialisation process” (Kendall, 2011: 317).

Within this research undertaking all the participants are heterosexual. Participants in this project contributed their “gender identity” as part of their self-image. In the face of this illness participants did not view their perception of gender (i.e. femininity) as having been influenced or changed by their diagnosis. Bella is aware that she has changed physically, but as a woman (including her self-image) she believes she is still the same. “Nothing changed and everything has carried on as normal”. Fiona thus adds to Bella’s thought that once you have been diagnosed with breast cancer, you must not let this illness dictate how you should see yourself and how you should live. Instead Fiona believes that one should enhance one’s gender and “live life like you know ... [by being] proud of being a woman”.

“Gender identity” was not seen as a big issue for any of the participants as the illness did not disrupt their personal outlook or make them re-evaluate who they are as women. Each individual understood that this illness would alter her physically and emotionally, but none of the participants felt that they underwent a disruption whereby resulting in having to re-negotiate her self-understanding and perception of gender. When asking Carla if she felt that her gender perception had changed and that she had to re-negotiate her self-image, she replied: “I never felt less of a woman and I didn’t feel like something was taken [from] me”.

Gina was diagnosed in the month of August, which, in South Africa, is celebrated as women’s month. This month is seen to promote women, whereby paying tribute to all women and their accomplishments. When Gina was diagnosed with breast cancer in that particular August, she really did feel the burden of her gender. “[I was diagnosed] in August and August is women's month and I am a woman and I must go through all this drama”. This diagnosis did highlight her vulnerability of her gender, but overall Gina did not allow the illness to disrupt her self-image. “[No] there is no drastic change [to my femininity]”.

Being a mother is linked to one’s self-concept and the normative perspective of one’s gender. Gina loves being a mother and grandmother and during her marriage, there were times when gender dictated how she was to act. In Gina’s case, she would stay at home with the children when her husband went out. This did not bother her because her children were always her priority:

“I must stay at home. My husband was there for the kids, but he always felt that I am in charge of the kids. So he went on with his life. He played golf and went to parties and things like that where I said, ‘no, my kids [are my priority]’. So [in a way] I was a married single mother. But it is fine. I could do it and I did it”.

Bella was seen to share a similar stance to Gina, where she declared that there were times when her husband would go out with his friends. Bella would stay at home with the children but thoughts of infidelity did go through her thoughts:

“He is going to drink and is with his friends [and I will look after the children]. I am preparing my mind and I am telling myself that ‘no, he is with his friends, drinking and socialising and that is all’. If I start thinking [further] it is going to disturb [me]”.

The participants did not perceive breast cancer as a disruption to their self-concept of gender. Donna did not state that she lost her gender, but did state that she had lost a sense of her self-concept and self-perception. However, through her religious beliefs she expressed hope for finding herself again. Each research participant expressed an understanding that one is made up of or defined by differing self-understandings and perceptions (identities), thus making one unique. However, as my analysis reflects, becoming and being a mother is the greatest defining aspect to self-identification, self-understanding and categorical membership (gender) among this small group of women.

#### **5.3.1.1. “Categorical and Relational Identification”**

When looking at gender from a straightforward and uncomplicated understanding – thus not looking into aspects of “gender identity disorder”<sup>6</sup> – it is conceivable that appearance, characteristics and feminine behaviour will bring a woman into the sphere of relating and comparing herself to another. Identifying an individual to a gender-specific illness can prompt others to categorise this individual into a group that is labelled, stereotyped and stigmatised. This form of categorisation results in

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<sup>6</sup> Gender identity disorder – “If a person’s physical gender is not consistent with the person’s sense of identity. People with this disorder feel trapped in a body of the wrong sex.” (Barlow and Durand, 2009: 350).

the diagnosed individual to feel shame and disgrace for her diagnosis. When reviewing breast cancer, little is known about the actual origins of the illness, but with the growth of knowledge, this illness has come out of the shadow of shame and guilt within the middle-to-upper class socio-economic societies.

It is my opinion that how one identifies and categorises gender and illness can have either a positive or negative effect. One must not be under the impression that just because breast cancer is out in the open and talked about freely, stereotypical notions are void of this illness. There are still common perceptions that this illness only affects women and therefore this illness is commonly linked to the female gender. The linking of gender and illness can be detrimental not only to the individual, but to society as a whole. When illness presents itself, infected individuals are placed in groups with others who present similar symptoms, which can result in a segregation of gender groups, a community or a society. The research participants can be seen as a privileged group, whereby they not only understand this illness (through personal research and awareness campaigns), but also get support from their families and friends, thus encouraging them to embrace their gender and future prospects.

#### **5.3.1.2. “Self-understanding”**

There is much debate about nature versus nurture, but gender can be seen as an anatomical, cultural and societal understanding of the self. This research undertaking focuses on the social constructivist perspective, and therefore gender identification is influenced by various aspects, most importantly socialisation and expectations. It can thus be said that how one understands and perceives one’s gender starts from the parental influences and continues to the acceptable norms and values of a cultural and societal setting.

Once the individual has acquired a stable understanding of her gender and what this concept is to encompass, gender self-understanding becomes consistent in daily roles. This consistency thus equips the individual to overcome certain outside influences such as a breast cancer diagnosis. Even though breast cancer can be viewed as a predominant female illness, none of the research participants viewed

this illness as a detrimental aspect of their gender. Instead, they found strength in their religious convictions and embraced their “self-understanding” of their perceived gender. None of the participants stated or even implied that they wanted to change their gender (in perception or physically) but rather that from within their religiosity they believed that this illness allowed them to become closer to God and – in some cases – fulfil His purpose.

### **5.3.1.3. “Commonality, Connectedness, and Groupness”**

Gender can be seen and understood as a common trait shared by both men and women. What makes gender unique, are the attributing characteristics, attitudes, behaviours and outlooks the individual displays. Naturally and normatively, women display softer and gentler physical and psychological characteristics. These mentioned aspects highlight “commonality”, but also the “connectedness” of gender groups. This connection can be seen in physical appearance to thoughts and characteristics, among others.

Once an individual identifies with and understands her gender, she can be seen to fall into the theme of “groupness”. The research participants can be seen to represent various forms of “groupness”. This can be seen through the representation of gender, likes (such as hobbies), responsibilities (being a mother and a wife), and illness, to name but a few.

In bringing together these three themes (commonality, connectedness and groupness), the research participants understood and embraced their gender while still understanding that they are not alone in this experience. Each individual knew of and even in some cases indirectly experienced breast cancer before her own diagnosis. So understanding that her gender is vulnerable to breast cancer, each participant felt a unique sense of “commonality, connectedness and groupness” with other such women who were diagnosed and who were undergoing (or who had undergone) the same tribulation. The bond that breast cancer places upon diagnosed individuals is no light connection, but instead allows for an unspoken understanding and acceptance to develop. It must be stated that though there is a bond between breast cancer survivors, the participants in this project indicated that

breast cancer will not be their defining feature. Instead, this chapter in their lives will be remembered and gratefully embraced as a memory of the past. It was implied that once the individual gets a clear medical record (i.e. when she would be in total remission), that she does not want to be associated as just the “breast cancer survivor”, but instead as her previous pre-diagnosed self.

### **5.3.2. Femininity**

Losing a part of one’s body, in this case one’s breasts, would be a challenging prospect to most women. The importance of certain physical attributes, disproportionately emphasised by our everyday exposure to the media, is a notion supported by Western societal ideals. In particular, popular women’s magazines (for example *Elle* and *Cosmopolitan*) overtly convey the message that the female form, which is enhanced by the appearance of breasts, is an important asset that will boost a woman’s overall attractiveness. The perception of attractiveness can be seen to incorporate one’s own self-image and the attention or gratification of others. From the literature which was predominantly written from an American or first-world perspective, it was clear that the female form was what makes a woman feminine.

Again, I began this topic by asking each participant to describe her understanding of femininity. This question did not need to be broken down for any of the participants. Once more this allowed me a perceptual framework to work from and the ability to understand how each participant viewed her femininity. I was aware that this question could make the participants uncomfortable, given that they had all undergone a partial or full mastectomy in the near past. Within this project the responses I obtained from my participants resulted in the finding of two broad themes. Firstly, femininity is seen as an internal characteristic reflected in actions such as mannerisms, the way one speaks, choice of words and motherhood. Secondly, femininity is viewed as an external characteristic which is seen in how one dresses, the wearing of cosmetic products and jewellery and hair maintenance such as regular shaping and dying.

What was interesting to me was that not one of my participants mentioned breasts as being the main defining feature of femininity. It is important to understand that

when I asked this question, a good and trusting rapport had already been built between the individual and me. The reason why this is interesting is that by this point in the relationship, both the participants and I were comfortable and had already worked through various sensitive issues. Therefore, not having mentioned breasts as being a defining feminine attribute must not be mistaken as a sign of insecurity or embarrassment, but rather as stated by Hala: “You know I am a person, I live out who I am and I don’t have to stand out for any man”. The loss of a breast as seen by Carla is not seen as a loss of femininity, but just a change in physical appearance. “I am like I am ... the old person I used to be. Nothing has changed. I am not feeling ashamed. I am not feeling sorry. I am just myself”. I can therefore conclude that within this research project, breasts are not the predominant feature that is seen to make a woman feminine, but instead internal and external characteristics define femininity and this is re-affirmed by Ella:

“I think that it is the whole package [internal and external characteristics]. You don’t have to be beautiful to be a woman but you still have to look after yourself. You have to look after yourself and it [is] the whole package. There are [women] who are not [exceptionally] beautiful but she is still feminine and [therefore] she is still beautiful”.

The defining, understanding and applying of femininity were strongly linked to the participant’s chosen occupation. Participants who had physically challenging or more “masculine” jobs did not place much value on presenting the stereotyped feminine image. Ana, the emergency care practitioner understands femininity as an internal characteristic:

“I am always in boots and combat pants, a shirt that is hanging here [past her waist]. I never look feminine. I never even wear make-up. So for me it is the way you act, the way you talk and your inner characteristics. I am not that kind of feminine person, I am not the one who goes for facials and stuff like that”.

When looking at femininity from an external point of view, Carla, a professional nurse, explains that how you represent yourself and the clothing you wear not only makes you feminine, but also enhances one’s feminine qualities. “I know how to dress. I like [to] dress [up] so I know how to make myself beautiful. I am dressing up to fit myself [and my femininity]”.

Ana's view on femininity represents the strong point that femininity is an internal characteristic, where on the other hand Carla perceives femininity as more of an external characteristic. Gina, who works for the department of education and devises and implements educational programmes in public and rural schools and who travels, meets and interacts with many people, believes that femininity is based on both internal and external characteristics.

"I always say it [is] how you look, how you dress, and how you react. To me that is important. That is why I always go on with my hair because ... I just feel as a woman must look after yourself".

What has become evident from all three of these views is that Ana, Carla, and Gina – as with the rest of the participants – mentioned that how you view your illness reflects on how you overcome the physical changes. These changes can include the loss of a breast/s, weight gain, hair loss, blackening of nails, and discolouration of veins (going darker or turning black), but depending on the frame of reference, optimistic participants still believed they were beautiful throughout their illness experience and made a point of accentuating their internal and external femininity.

There is a third perception about femininity and this can be seen as femininity not being a priority and that during the treatment trajectory, all feminine aspects cease to exist. This can be seen as a coping mechanism, whereby protecting the self from further hurt. In contact sessions Donna made a concerted effort to explain how breast cancer disrupted her life and outlook. What I found interesting is that in the following insert Donna vividly explains her experience, while keeping in mind that she continuously described her experiences and her life as being hopeless. By asking her to define her femininity, she revealed that she was still fighting – not just to overcome the illness, but also to regain her health and indirectly her life.

"[I] was just fighting against cancer. You forget about your femininity and everything. You just fight to get through the cancer [and] you don't even worry [about] what you [are] wearing. When you [are] sick you get into the first thing that you get in your cupboard. You are in such a zombie shock mood thing, you don't know and you don't care. You don't worry [about] the feminine thing inside or whatever [because] you just try to survive. So I just accepted it. There is nothing of femininity, it is just survival".



In general, each woman has a broad understanding of femininity, but ultimately it is the unique individualistic perception of femininity that makes a woman feel beautiful. This perception is also influenced by the individual's mood. Women have good days and bad days, and with this in mind experiencing a bad day can result in feeling ugly and unfeminine, whereas experiencing a good day may allow the individual to feel beautiful and elegant. This fluctuation in mood can influence not only an experience, but also her outlook on life.

When trying to understand femininity in women diagnosed with breast cancer, one must keep in mind that mood, perception and understanding can also be altered by certain medication or the side-effects of the treatments, which can lead to drowsiness and weight gain. This can be seen to include a woman's physical, psychological and emotional understanding. This thought is confirmed by Dr Jackson who states that:

“99% of the patients are women in their 50s to 70s and occasionally younger. So you deal with female patients ... and emotional female patients with cancer. So sometimes you treat the emotions more than you treat the cancer”.

#### **5.3.2.1. Femininity and Hair Loss**

Within the emotional turmoil of femininity, the participants placed a strong emphasis on their hair. Due to the standardised treatment of chemotherapy, all the research participants lost their hair. From what I perceived, outside of the shock of the actual breast cancer diagnosis, hair loss was the most traumatic experience of the illness experience. What made this experience so traumatic was that hair loss was not immediate, but began gradually after the first chemotherapy session. The loss of hair was experienced to varying degrees. Some participants explained that they woke up one morning and their pillow was full of hair, while others noticed balding patches on their scalp. All the participants conveyed a similar thought which was that the hair loss solidified the diagnosis of “I have cancer”. This can be seen in Ana's rendition. “I got hysterical [and] not because of my hair, [but] because it was now final – [I have breast cancer]. You know that thing of denial, if you don't see something, you don't believe it”.

Some participants like Gina wanted to feel more in control of their hair loss, especially when the inevitable signs emerged that the chemotherapy was having its effect. The participants proceeded to cut and shave their heads before having to experience the loss of handfuls of hair or balding patches. Gina recalls the traumatic experience of her hair loss:

“Like yesterday I was feeling my hair was falling out. So I decided that I [do] not want to sit by the school and all my hair suddenly falls out. I need to be in control. [I] decide [to] just cut it off now than [have] somebody come in and see I have a piece of bald at the back [of my head]. So yesterday I said to my son and my daughter ‘I think it is time to cut my hair’. I was crying because I knew it was coming, but now it is time”.

Each of the participants decided to buy and wear a wig and all the participants designed their wig to resemble their original hair colour and style. Due to the uniqueness of the individual, some women were not ashamed of being seen walking around in their homes without their wigs whereas others were more reserved and would cover their heads with a bandana or a hat.

Family relations and humour helped lighten the mood within the tragic consequences of this illness. Yet even with support, the individual may find different ways to cope with the temporary situation of hair loss. The loss of hair is a tragic event in any woman's life, but depending on one's frame of reference, this event can be experienced differently.

Within an optimistic outlook, Gina conveyed a strong support system with her immediate family, which included her husband, three daughters and son. She explained that by including her family in the breast cancer milestones such as her hair loss, it allowed her family and herself to focus on the humour of the situation:

“To me it is important when my daughter was cutting my hair, my son was there and my husband was there supporting me. I was sitting there crying of course and if I look[ed] at my son I could see his eyes as well [filling with tears]. I didn't look at my daughter but she was like ‘no, ma, let me cut just a little bit off with the scissors and then I will take, you know [the shaver]’. I also said to my husband that if I need a hand, I want to have [yours] first and

shame, he said he would also shave his hair. I said: 'no ... you are going to look like a bandit ... Don't shave your head. I thank you very much but don't'. I always tell them let's rather laugh about it, make jokes [about] it and not sit and cry about it".

For Gina, family support was crucial to her experience of breast cancer, but Ella who also has strong family support, preferred to be independent and strong and not to allow her husband and daughters to see her without her wig. She felt that this was a personal issue whereby never allowing her family to see her without her wig. Even at night in the privacy of her own home she found comfort by wearing a bandana. Ella reflects this view by stating:

"For me, I don't even show my family, not my children and my husband. They must understand that this is personal for me and I don't want them to see that. They are very positive people and especially my husband is [a] very positive person. So he put on my wig and made a joke of it. I [just] don't want them to see me like that. [So] I always put something on my head so they don't see me without [my] hair".

When looking at this scenario of hair loss from a more pessimistic view, Donna declared that her appearance with hair was a vital part in defining herself through her self-image and in particular her femininity. She was aware that the chemotherapy's side-effects would result in hair loss, but when her hair began to fall out, she viewed this as part of her image and her feminine qualities being lost. Through the lack of family support and understanding, she took the sign of hair loss as being more of a shameful sign than just one of the side-effects of the treatment.

"I am used to my long hair ... I mean I have always had long hair and now ... I mean when I lost my hair it was quite traumatic. I did not want to look anyone in the eye and I didn't want anyone to know that I have lost my hair. That is why the wig was so important so that it looks like my hair".

Hair can be seen as a defining characteristic of being a woman and outside of the initial diagnosis, therefore losing hair can be attributed as one of the most challenging experience of the breast cancer diagnosis. Ana states "[For] me losing my hair was the second [worst] experience through this whole thing [of breast

cancer]”. For Gina, her hair and her appearance were important aspects of who she is. According to her, outside of the initial diagnosis, her hair loss was one of the most traumatic points during her breast cancer experience. “This is one of the biggest features that I would say that is negative to me: is to lose my hair”.

This response was not something I had expected. I was under the impression that hair and the loss of it would be but a somewhat minor inconvenience against the broader backdrop of breast cancer. This thought rapidly changed after my interactions with the participants. Bella, a professional nurse who works at a state hospital, is by no means ignorant to the side-effects of cancer treatments. However, when her hair fell out, she felt more than just uncomfortable. “I didn’t have any hair on my head [because] it all went off. I was having a wig but I was not comfortable wearing it. I wanted to be myself”. Stigmatisation can come in many forms and Bella explains that she experienced this through unusual staring of locals in her community and the playful ridicule from children. “When I come to the till [at the local super market] they are looking [at my bald head and my partial mastectomy]. You know sometimes [the children] laugh at my hair [or lack of it]”.

Hair is seen as an invaluable physical extension of the body whereby illuminating a great part of a woman’s defining characteristics. This defining characteristic is, in part, linked to a woman’s self-image. This can be seen in Gina’s words “I was going to lose my identity. If I take my wig off then I think ‘who am I?’ It is still my eyes but who is this woman looking [back] at me”.

Hair is a visible signifier of health and beauty, as depicted by the mass media and internalised by both women and men. Without hair, especially in the case of women, the common reaction is to stare and think or even to ask ‘what is wrong?’ Ana recalls her hair loss as the final indicator and physical sign to having cancer. “Cancer is associated with baldness. I think that was the final [nail] in the coffin. It [is] now final: you losing your hair and I think it is that association”. She further emphasised how hair loss was the last or final stage in erasing any internal doubt that you might have subjectively hoped for with regard to a misdiagnosis. Ana emphasises this thought: “Chemo[therapy] is making you lose your hair and you are getting chemo[therapy] because of cancer. You can lose a breast because of trauma. But losing [your] hair equals chemo[therapy], equals cancer”.

What has become evident is that the loss of a breast through a partial or full mastectomy is not as traumatic as the (expected and actual) experiencing of clumps or bundles of hair falling out. Hala experienced this hair loss by stating that “every time I combed my hair it came out in bunches”. This thought of hair loss is a dreaded stage where most women enquire immediately after a breast cancer diagnosis, for either reduced chemotherapy sessions (to lessen its impact) or to spare no expense for a wig that resembles their original hair colour and shape.

Gina put a lot of emphasis on the fact that her hair was important to her. She and her daughter did in-depth research to find a realistic wig immediately after her diagnosis. “Before the time [the actual hair loss], we investigated this thing with the wigs”. Hala followed suit by also buying a wig before her initial chemotherapy session. “I went and bought the wig in time. I think it was before I went for my first chemo[therapy session]”.

Donna on the other hand drove about 450km (from Bloemfontein to Pretoria) to view and buy her wig. “[Tom] actually stopped his office and everything and we went through to Pretoria and we got a wig there”. A woman’s perceived appearance is important and Gina is no stranger to this thought. She went and spoke to her friend and hair dresser who ended up designing and selling her the wig. “My hair-dresser said to me that I have a wig for you with natural hair and your colour but it is going to cost you R2000,00”.

When inquiring about hair loss and wigs, each participant, despite her frame of reference (optimistic or pessimistic), made a clear effort (distance travelled and expense) to buy a wig that resembled her original hair colour and shape. Depending on the individual and how she sees herself, hair loss can be lightened with a sense of humour within the family settings or seen as personally shameful. For Ella, her loss of hair was accepted by her family and they did try and lighten the situation, but Ella felt embarrassed for sporting a bald head. Even though all the married participants stated that their husbands and immediate family were very supportive of the physical and emotional transformations, some participants felt embarrassed of these transformations and in particular, the physical transformation of the loss of hair.

### 5.3.2.2. Femininity and Reconstructive Surgery

Even though the topic of reconstructive surgery was not a main focal point within this research project, I could not ignore the topic as the loss of breasts can alter the way a woman views her self-image. It is vital to remember that how a woman views herself influences and affects her self-concept and ultimately how she perceives her femininity. Therefore a loss of (a) breast/s can result in a woman feeling disfigured or even missing a part of who she is. According to Dr Jackson:

“If you take away a breast or both a woman will feel less feminine and unfortunately when you block a female’s oestrogen you take away her femininity. What gives you your secondary female characteristics? It is oestrogen and now we [oncologists] take it away for five years [as this is part of the hormonal treatment that follows the radiation]. You get hot flushes, dry hair, dry skin, you get painful joints, you get osteoporosis, you get vaginal dryness, you get bladder irritation and reduced bladder activity, and the list goes on. They [breast cancer patients] get fat and yes they are fat because they pick up 10% of their body weight. So yes these things all have a very bad effect on a woman feeling feminine ... they are one breast less and no hair”.

When inquiring about the research participants’ perception of reconstructive surgery, none of them, during the research period, received any form of reconstructive surgery. Most of the participants stated that they had no ambition to obtain any form of reconstruction as they viewed themselves as perfect just the way they are. Bella states “I am beautiful just the way I am now”. After Carla had the mastectomy of her left breast, her surgeon introduced the subject of reconstructive surgery whereby Carla replied “no [reconstructive surgery doctor], I am fine like this. I am beautiful [like this]”.

They did however have no problem in buying and using prosthetic braziers. A point of interest in the research was that both the African participant and some White participants viewed breasts not in the light of beauty or a sign of femininity, but rather the part of the female body that assists in feeding their infants. Thereby the loss of a breast or breasts did not pose a personal and physical disruption to many of the participants, as they were all of the age where they had had their children and did

not want to have more. Bella is a mother of three and a grandmother of one. She declared that she had had her children and that any form of reconstructive surgery would not make a difference in how she felt or perceived herself. “At this age it is not so bad because my children are grown-up”.

There were individuals in the research project who were open to the option of receiving reconstructive surgery. These individuals were under no illusion that reconstructive surgery would bring them back to their original form, but believed that the surgery would bring back their original physical shape. The down-side of receiving a mastectomy, either partial or full, is that nerve endings, tissue, skin, and the nipple can be lost. This results in the individual receiving multiple scars and diminished sensations. Even with reconstructive surgery the breast/s will never be the same and this is confirmed by Dr Jackson:

“It is never your own breast again. It don’t look like a breast in my personal opinion, through your clothes it looks like a breast, but by no means more than a silicon prosthesis does. [Also the reconstructed breast is] cosmetically inferior to just a prosthesis in the bra. They can either take the latissimus dorsi muscle [mid-back muscle] and then they have a big cut running from here to here [from the back around the torso to under the armpit]. Then that flap [is] swung around and sutured in the shape of a breast but it is your back’s skin sutured on your chest wall. Usually the colour is off and you have scarring where the skin was sutured [surgically stitched]. You haven’t got a nipple [so] they just tattoo a nipple on. There is no sensation in the breast ever, so they cannot feel it. So if they touch it, it is like touching someone else’s. Like I said it never looks like the other breast again”.

### **5.3.2.3. “Categorical and Relational Identification”**

The aspects of gender and femininity (with the inclusion of hair loss and reconstructive surgery among others) are all aspects that work together to bring forth how a woman identifies and experiences her feminine attributes.

Categorising women through their defining features (gender, hair and body shape) can have an adverse effect on one’s self-concept and self-image, by stereotyping

women who do not display the ideal body shape. According to Clark (2011: 4) “we are subjected to this ideal body type through fashion editorials, magazines ad[vertisement]s, and pictures taken from the runways ... However, these standards of beauty are not what are normal in our society; every girl is not a perfect size zero with long legs, perfect skin, [big breasts], and long hair”. This categorisation can segregate women who present differently from the perceived norm. One’s environment can determine how an illness and the diagnosed individual are perceived. It is thus up to society to aid individuals diagnosed with breast cancer with a positive identification and by avoiding the placement of labels which ultimately result in varying forms of stigmatisation.

Each of the participants was subjected to the full spectrum of the medical encounter which included: surgery, chemotherapy, radiation and hormone treatments. The subjective experiences that were brought on by this illness can be seen as a challenging burden. Each of the research participants felt that their environmental and spiritual support (family, friends and religion) gave them varying degrees of strength and empowered them to continue with the treatment trajectory. Outside of the occasional stare, none of the participants were subjected to any form of labelling or stereotyping.

#### **5.3.2.4. “Self-understanding”**

Within the notion of self-understanding, gender and femininity are firstly seen as subjective features and secondly, influenced by past experiences within certain social environments. The uniqueness surrounding an individual’s views and understandings of femininity can be linked to her overall self-understanding, her characteristics, her attitudes and her beliefs. Self-understanding may be influenced by certain environmental cues, but the overall representation of the feminine self is a personal effort by the individual.

It is my opinion that when focusing on self-understanding in relation to gender and femininity, these aspects are the most challenging part related to the overall diagnosis. How the individual re-negotiates her self-understanding of the physical and psychological changes that this illness brings about, must be seen against the



backdrop of the unique thoughts and experiences the individual has encountered. Only the diagnosed individual can come to terms with her new body shape, hair loss, and scarring – permanent or temporary – side-effects. Therefore, the individual's subjective self-understanding can be aided by supportive associations, but ultimately how the individual transforms and re-negotiates herself can only be achieved when she accepts her diagnosis and its side-effects. The feminine issue of hair loss was understood to represent the second greatest shock apart from the actual breast cancer diagnosis. Hair loss also held the signifier of firstly: "I really do have breast cancer" and no mistake was made in the diagnostic period; and secondly that: the outside world will see that I am battling with a form of cancer.

#### **5.3.2.5. "Commonality, Connectedness, and Groupness"**

Side-effects bring forth the notion of "commonality". This can be clearly seen in having to undergo a full or partial mastectomy, hair loss, darkening of veins and figure nails, scarring and burn marks and weight gain or loss. This uniquely places the individual in an exclusive category commonly known as "cancer survivors".

People who share similar attributes (such as when diagnosed with cancer and undergoing treatment) thus hold an indirect connection to one another. This can be prominently seen in the treatment areas of chemotherapy. The "connectedness" thus allows bonds to form which mostly link all cancer patients. Once a connection is made, a form of "groupness" is established which can be seen as either temporary or permanent. This "groupness" can be placed upon the individual while undergoing the treatment trajectory or even beyond, as seen in people becoming mentors and founding outreach programs.

The research participants were aware that they shared commonalities with other breast cancer patients. They were also aware that this brought about a sense of connectedness. But none of the participants wanted to be solely categorised into the "groupness" of "breast cancer patient or survivor". Instead they accepted the different levels of "commonality" and "connectedness", while still promoting their fighting spirit, but the notion of "groupness" can be seen as questionable within this study.

Naturally all the women understood that they had commonalities with one another when looking at the concept of gender. This connection is seen as a permanent connection whereby sharing certain experiences and therefore a feeling of groupness exists. Femininity, within this project, was not reflected on during particular stages of treatment, but once the treatment trajectory was completed, each participant was under the impression that her femininity would continue as before her diagnosis.

I can therefore state that breast cancer is seen within this study as an illness that temporarily disrupts femininity, but not the notion of gender. While some of the participants still made a point to enhance their feminine attributes throughout the treatment trajectory, others felt that this facet was not of immediate priority. Also, some research participants relied more heavily on the internal features that define them as feminine and mentioned that the physical changes had little effect on their notions of femininity.

#### **5.4. Surviving and Support**

Both the topics of “surviving” and “support” are interrelated and interdependent. This can be seen in the lives of individuals who had strong support systems reflecting the perception that they would overcome the illness, whereas individuals with minimal support felt the strenuous effects of breast cancer, which influenced their survival outlook.

I will begin by reviewing the participants’ understanding of “surviving”. In the current literature, this is commonly referred to as “survivor’s identity”. In my representation of this concept, I highlight the individual’s perception and understanding of this notion, while still showing what prompts the individual to survive. I will then proceed by highlighting the perception of “support” and if this support was or was not present in the participants’ lives. I will look at three variations of support which can be seen in the perception of the self and social support, social interaction and age, and the shared perception of breast cancer.

### 5.4.1. Perception of Surviving

This research revealed that the participants did initially view this illness as a potential death sentence, but with time and support came to understand that their diagnosis was not necessarily going to end their lives. None of the participants felt silenced or alienated by their diagnosis. Donna can be viewed as pessimistic and fluctuating in her description of herself and her support system, but my underlying conclusion is that she may or may not consciously know that she is still fighting to live. In her own words, she remarked: “Like I said, if [I] don’t put up a fight against it [breast cancer] to live then I [will not] make it”.

Each participant was put at ease that once she was diagnosed with breast cancer, the surgeon was able to remove the lump or breast. Each participant can be seen to link survival to her religious beliefs. Carla refers to the Bible by stating “I am happy that the thing that was a danger to me is out. I will always refer myself to the Bible where it says ‘where an organ is giving you some trouble you must remove it’ so that’s that. I have removed the breast and now I am okay”. This is a re-interpretation of the Holy Bible (2007: 580), book of Matthew 5, verse 29-30, which states:

“So if your eye – even your good eye – causes you to lust, gouge it out and throw it away. It is better for you to lose one part of your body than for your whole body to be thrown into hell. And if your hand – even your stronger hand – causes you to sin, cut it off and throw it away. It is better for you to lose one part of your body than for your whole body to be thrown into hell”.

Though none of the other participants quoted any specific scriptures from the Bible, all of them believed that God was the reason for their survival. Just after Hala’s diagnosis, she believed and stated that “God has already healed me”. Ana confirms this thought by adapting her religious understanding to God guiding and teaching his believers. “God has means and ways to win you back and yes maybe to get me [to do] more or to understand some life issues better”. Each participant had a different and unique view and understanding of why God would allow her to get sick. Each individual also believed that there was a purpose with her diagnosis and thus with her survival.

The perception around the theme of “survivor’s identity” has also promoted some of the participants to consider helping other women with their breast cancer experience. For Gina, mentorship is a life experience that she would consider doing. She has already enquired about the process, revealing that:

“You must be recovering for two years from your breast cancer. Then they train you to visit people in hospital and things”.

Carla on the other hand, had not officially become a mentor, but through her church work she helps individuals with life issues. “I am a mentor and if you can see [me] at [volunteer] work you [would not] say I am sick”.

Most participants conveyed the opinion that in today’s current understanding, breast cancer is an illness that has a high survival rate. This is confirmed by Dr Jackson: “breast cancer is one of the easiest cancers to treat oncologically but one of the most difficult cancers to treat emotionally”. This survival rate is seen in accordance to undertaking the prescribed treatment trajectory. Most research participants showed that they were not ashamed or embarrassed by their illness and thus revealed a positive outlook for their future endeavours.

It is my opinion that within this project, the perception of ‘survivor’s identity’ is seen from an optimistic frame of reference. Each individual rationalised her illness by linking it to a religious purpose. Most of the participants were open to the thought of becoming a breast cancer mentor and even becoming more involved in partaking in breast cancer awareness campaigns. These campaigns can include the annual breast cancer walk in October and the annual CANSA “Shavathon” in March.

#### **5.4.2. The Self and Social Support**

Most of the participants agreed that support aided them in keeping an optimistic outlook and maintaining a stable understanding of themselves. Participants who lacked emotional and physical support from a husband or partner, children, family members and friends regularly brought up the question “what-if?” and revealed a more pronounced fear of metastasis or secondary diagnosis. It is important to note that metastasis or secondary diagnosis is a concern to all the research participants,

but that due to their faith they believe that they will overcome this illness and focus mainly on their future endeavours. Donna lacked enough emotional and physical support in her illness experience and shared her thoughts by stating:

“There was n[o] emotional support. I feel now, what about if they test me [and I have a recurrence of breast cancer] and I have to go through all of this again [the breast cancer treatment trajectory]. I don’t think I am going to do that. I [will] rather shoot myself, you know. Stuff like that goes through my brain. You are fighting with yourself”.

Both emotional and physical support is vital to dealing with the illness. Positive support provided a positive platform to acquire mental strength and to keep negative thoughts at bay. When Carla is alone at home, negative thoughts do tend to creep in. “Sometimes when I am sitting alone, then those questions which you don’t have answers [for come up]”. These thoughts apparently dissolved when her support network, which includes her family and friends, are around. “You become strong. You become really strong, because they [friends and family] are close to me. All of them my friends and my sisters”.

By allowing the individual to explain her given and chosen roles, a clearer understanding as to how the illness impacted on her daily routines and relationships developed. This also highlighted the point that the illness did not only disrupt her life, but that it had a wider effect and affected her relationship with those around her.

Gina’s main support comes from her family. She highlighted the point that the illness did not only affect her, but also her immediate family:

“I think your main support is your family that lives with you in the house. It [has] an impact on them as well and they are part of this. Even though they don’t feel it on their body, they do encounter the emotions and trauma”.

Among the participants, cancer support groups and organisations were not seen as an important requirement of comfort and support. They found emotional and physical support from family members, friends and religious organisations. These support networks were not sought out after the individual’s diagnosis, but have been existent and regular social gatherings subsequently started to play a more prominent role in providing comfort during the illness trajectory.

Hala did not look for or attend any specific social support groups, but instead found support through her belief in God, her family, friends and her community. “I had a very strong support system from my local church, my family, my friends [and the] community”. Ana’s support is similar to Hala’s support network, which is seen to comprise of her family, friends and work colleagues. Her main concern throughout her illness experience is not to be labelled, and more importantly, not to be put into the “sick-role”. “My husband, my aunt, my daughter, my colleagues and staff members [are my support system]. They give me support and they are not putting me into the sick-role”.

Gina was the only participant who felt inclined to draw upon a local breast cancer support group. When she attended her first meeting, she went with an open mind. When I went to see her the following day she was unimpressed with her experiences.

“I went last night [to the support group] and I went with an open mind. [I was] like a parachute. Your mind must be open like the parachute, but I was disappointed. I was not fitting in there. I didn’t feel like I belonged there [and] I just couldn’t relate to these people. I didn’t like it that the men were there. I personally felt that this wasn’t a place for a man. You couldn’t talk about breasts and sex with [strange] men [in the room]”. ‘I felt [that] I don’t need you people’. I might be arrogant, but I don’t need these people to support me. [The] things that they are talking about ... [for example] – one woman [was saying that she] lost her husband 30 years ago but she must clean her house because her son was coming and that she has got a mother who is in an old age home. The mother wants a Chocolate Log and a Sprite and a little carpet. What is the reason behind this? I don’t know, it was just not giving me anything. I would rather [talk to] my friends and I suppose I am more selective [in who I want] supporting me in this [experience]. [My friends] mean more to me than this group”.

### **5.4.3. Social Interaction and Age**

The participants' age influenced how they viewed their diagnosis and prognosis. Participants in this research project who had a strong support network or younger children revealed, a more optimistic outlook towards their illness and life in general. When an individual is diagnosed with breast cancer, social interaction can either be strengthened or fade away. Within this study, optimistic participants revealed that certain relationships became stronger. Initially, Ana's closest childhood friend did not know how to handle her illness, but once the two women sat down and worked out the sensitive issues, they are now closer than before. "[She is] like a sister. I don't think [the breast cancer] will impact [us] negatively. I think officially after last week's talk, we are [a lot] closer [than before]".

Within Ana's outlook on social interaction and age, she explains how her attitude and her children help her maintain a daily routine. "If I was very negative, I think I would have been sick longer. I have these things that I must have ready for Monday mornings because I have to take the children to school".

After Bella's double mastectomy her social network improvised as she attended meetings and hosted social gatherings at her home:

"They even came to me because I could not attend church with the tubes [in] my body. They used to come here and sit with me and pray. And then [we] can talk about anything. I found it helpful because they came to me".

Gina follows suit with Ana and Bella in that since her diagnosis, her social interaction with her friends have become stronger. "Socially I would say I [have] got a bit more contact with my people than before [my diagnosis]".

### **5.4.4. Knowledge and Shared Perception**

After being diagnosed with breast cancer, those with an optimistic frame of reference perceived their concept of self as having been strengthened, whereby conveying the understanding that self-knowledge had improved. Ella responded with "I am what I am. But my outlook on life [has] changed ... for the better". I proceeded to inquire

further on what had changed and if the perception of herself had been influenced or altered through the illness experience:

“No, not my identity, I am still me. It is difficult to explain, I have a different outlook on life and on the little things. But I am still me and I am just moving on. Not myself, but things in life [are] different for me. Things I see in the future and in everyday life [are] different [and more positive]”.

When reviewing the same questions and responses from a pessimistic frame of reference, concept of self seemed to have been lost. By the term “lost” I refer to the “biographical disruption”, where the illness has promoted doubt and uncertainty and a greater sense of negotiating the self. In the following insert, Donna highlights her self-perception and how it has changed since her diagnosis:

“[Tom] has been through the whole system [of cancer personally]. His mom and ex-wife also died from cancer. [That is why he is so] rough on me. [But for me is this illness different to just] putting a gun in your mouth? [Right now I am] fighting to resist from pulling the trigger because the doctor cannot tell me that I am not going to get cancer again”.

This uncertainty was followed by not wanting to gain further knowledge about her illness. “I didn’t want to know. I depended on what [the doctor] is saying. I am listening to [Tom]. It was just too much for me and I just didn’t want to know”.

Due to the high incidence rates of breast cancer, each of the participants knew of, or was in contact with a friend, a family member or an acquaintance who had been diagnosed with breast cancer. Some of the participants had experienced the death of a friend or acquaintance also diagnosed with this illness. This contact added a beneficial aspect to the participants’ own diagnoses. In Hala’s case, her sister was diagnosed with breast cancer three years prior to her own diagnosis:

“My sister went through this whole thing of breast cancer. She had a lumpectomy but she also got chemotherapy and the radiation about three years ago. And when she went through this I was there for [her] and that really helped me a tremendous lot [with my diagnosis]”.



Even with Ella's connections to the medical field, she still felt that she needed advice from a friend who had been through this experience:

"I was talking to one of my friends who also got breast cancer and she said the moment that you get diagnosed with breast cancer you need somebody to tell you exactly what is going on. I [thought] that I was dying and she told me: 'listen it's not that bad'. She showed me [her reconstruction and scars] and said look at how I am looking. It is better to hear it from somebody who has been through the whole process [of breast cancer]".

This first-hand interaction with a fellow survivor not only aided Ella in her understanding of what lay ahead, but also showed her that breast cancer is not a death sentence.

Friends and former survivors can have a profoundly positive impact on newly diagnosed individuals. Any advice and interaction helps the participants to orientate themselves within their diagnoses. This orientation can be seen to include the removing of the illusive stigma that is linked to this illness. After Fiona was diagnosed, her friend gave her three rules or tips to overcome breast cancer:

"A friend of mine said there are three things that you must do: live a healthy lifestyle, keep your mind healthy and have faith. I think those three things are the most important things that I [do] in my life [now]".

Even though Gina has many friends who have been diagnosed with this illness, she never thought that one day she would be fighting the same battle. "To me [I thought] it was them [my friends that would get the illness] and then I mean it just came up [in one of my check-ups]". Once it was confirmed that Gina had breast cancer, she found herself in the same position as her friends. By personally knowing breast cancer survivors, Gina not only found support, but the added advantage of being given various helpful ideas and techniques to aid her recovery:

"I have a lot of friends that had breast cancer. I think [knowing friends who have this illness] plays a big role. [A close] friend also got [breast cancer the same time I was diagnosed]. [Even] my GP [general physician] had breast cancer last year, and she lost both her breasts, so I went to her [for advice]".

When a woman is diagnosed with breast cancer and seeks advice or support from a fellow survivor, a unique and special bond can be created. This bond can be seen in Carla's rendition. The bond that Carla has with her friend and mentor can only be described as a one of admiration and love. Carla's friend is a breast cancer survivor and has been at Carla's side helping her with her breast cancer experience:

"She is a mentor really. I think because she knows better than me [from her personal experience with this illness]. [I trust her] and maybe if I was alone, it would be [more] difficult. She is my mentor, because she is there for me. I love her because she [has] made me strong [again]"

Within this project I found that when a participant seeks more information about her illness she not only understands her illness better, but also can prepare for the emotional, psychological and physical challenges this illness inflicts. What the participant deems important is again unique to the individual.

### **5.5. Maintaining Normality**

How the individual reflects on life after breast cancer must be seen in light of future planning and projecting as none of the participants have entered this stage of their life, i.e. being breast cancer free. The thought of maintaining normality can be linked to the thought of support and survival. The striving to maintain normality is seen in part as a way of overcoming the physical and emotional trauma surrounding the illness. By being treated by family members and friends as 'exceptional' made some participants uncomfortable and endorsed a sense of irritation and insecurity. These participants expected to be treated by their support system in the same way as before their diagnosis. This is the case with Ana, who at one family gathering had to announce that she was not disabled – physiologically or physically – and expected everyone to treat her like before:

"When I was released out of hospital, my mother made my lunch; she made this and brought this. I [was] not allowed to do [anything] and I got so frustrated that I told her: 'don't treat me as an invalid'. After I had that outburst ... and luckily I only had to have it once. Most of the family was together when I had the outburst and since then everybody is treating me like nothing has

happened and that is how I want to be treated. There is nothing special and I don't like being treated otherwise".

Fiona did not have to display an outburst, but she simply does not want pity or sympathy. "Don't feel sorry for me. I don't want people to think I am dying because I am not. I don't want [any] sympathy". Hala adds the dimension of labelling and not wanting to be seen as just the 'sick person'. "I wanted to make sure that [family and friends] will not see me as a sick person. It was important that [my family and friends know] I can be weak but I will get better".

Each of the participants forwarded the thought that they did not want to be seen as disabled in any way, which included not wanting any form of sympathy and labelling. Donna was the only exception; she was inconsistent in her thoughts surrounding the illness and what she perceived as her normality. "[I am] sick so [I] can't do [my] nails. I don't even know what to wear. You get into pyjamas and that [is] the only thing that you [wear]. Now you must get out of the pyjamas and get a life". In this extract one can see she is in a state of depression, but on the other hand Donna wants to find herself, her health and her independence. "I go to church, I go to groups, or I go out to [visit] people. I am still searching for something... [Christian scripture or] words ... I don't know ... to get me up again and [to] go on with life".

By maintaining normality indirectly highlights the move towards regaining health. It is a priority to the participants to maintain their routines and future aspirations. Maintaining the everyday practices also helps keeping negative thoughts at bay whilst promoting mental strength.

### **5.5.1. "Commonality, Connectedness, and Groupness"**

When doing a general overview of support I first need to distinguish the two prominent themes within this research project. Firstly, I can highlight the theme of strong support systems and secondly, the lack of support systems. When reflecting on the first system of support I can state that this is seen to share a common link with optimistic thoughts towards surviving. On the other hand, individuals who lacked support systems could not be linked to having many optimistic thoughts or having an overly ambitious outlook towards their survival. Due to the scope of this study, I am

not comfortable in stating if there is a strong theme of commonality, connectedness, or groupness in individuals who display negative thought patterns and weak support structures. I am of the opinion that certain experiences, attitudes, characteristics and life prospects will influence an individual's outlook in different ways. Therefore, support structures can be seen to aid an individual, but not determine if that individual survives or not.

## Chapter 6 – The Medical Encounter

### 6.1. Dual Health Care in South Africa

Before I can highlight the participants' experiences surrounding their medical encounters, it is important that I give a brief context of how a private South African medical institution differs from a public or state hospital. In reality, most South African private hospitals are seen as rendering better care over state hospitals. Ana, who is a paramedic and an employee of a state hospital, expands on her personal experience with the state hospital, and how she perceived her cancer treatment to go:

“I thought [my treatment] would be like [that in the] state hospitals. Where you sit on a straight chair, get irritated the whole time, and the personnel is stiff [and unfriendly]. I did not expect this [private hospital experience]. You must understand that state hospitals and private hospitals [are] two different things. The experiences that I have [being] a worker [and employed] in the state hospital is completely different than in the private hospital [setting] – especially with the personnel [because] in state hospitals they don't care. They don't even talk to you, they [just] put the drip up and that's that. In [the local state hospital] where we take cancer patients to, there is no compassion, nothing. So I had this perception that this [private hospital would be] like [that]”.

South Africa currently has a dual health care system whereby either you have the financial means to obtain private medical care or you do not. Most of the middle-to-upper class population has the economic means that allows for private health care. In light of breast cancer, middle-to-upper class women view this illness as a curable illness, but lower class women perceive this illness as a death sentence. According to Inga, from the Cancer Association of South Africa (CANSA), the socio-economically burdened women who seek Western medical assistance for breast cancer often do not complete their prescribed treatment trajectory. This is due to the financial burden, common beliefs and stigma attached to the illness, as well as the inability to understand how the treatment trajectory and medication works.

According to Inga, from within the South African context, the socio-economically burdened women who seek Western medical assistance for breast cancer often do not complete their prescribed treatment trajectory. This is due to the financial burden, common beliefs and stigma attached to the illness, and their limited understanding in how the treatment trajectory and medication work.

“[With their beliefs] they don’t believe in mastectomies [because] they want to die whole. [Even] if the doctor tells them that it will spread to the other breast, then they say, okay then let it spread! [When they start their first chemotherapy session], they think: ‘I was better before I went to the doctor and before I went for the chemotherapy. Now I come back [home] and I am sick and vomiting and nauseous’”.

In light of this research, only focusing on women who receive private medical care, it is important to keep in mind that these renditions are formed with the aid of previous knowledge (media and awareness campaigns which are aimed at the middle-to-upper class), financial security and a very different treatment trajectory.

## **6.2. The Medical Experience**

My main area of interest within the medical encounter was to understand how the participant negotiated her knowledge and understanding with the physicians and staff. I will discuss two aspects with regard to the medical experience. I will firstly discuss the individual’s experiences and secondly, my personal experience within the medical environment.

Within this research project, I was afforded the privilege of being present at chemotherapy sessions with some of the research participants. These experiences have become invaluable to this research project. Not only am I able to understand the treatment trajectories at a deeper level, but also relate my experiences with what my participants reveal within their own experiences. It must be noted that relating my experiences does not include understanding the full physical and emotional extent of a breast cancer diagnosis or the felt side-effects, but rather intricate details of what the treatment environment encompasses.

### 6.2.1. Participants' Experiences from Diagnosis to Radiation

The level of comfort, trust and openness between doctor and patient is a fragile and important aspect in the overall treatment trajectory. The relationship that is formed should optimally allow for honesty, confidence and respect. Creating an open, trusting and respectful relationship, a more positive and humanising experience with the doctors, nurses and technicians can be achieved. This positive experience can be seen to help in removing the perceived anxiety a hospital environment can bring. How the primary physician interacts and speaks to her patients can influence not just the relationship, but also how the individual views herself as a person. There are two views to this thought which are seen by Charon (2006: 47), that the patient either becomes “like a number assembly line ... singularity is not valued and ... [the patients are] reduced to that level at which they repeat other human bodies”, or on the other hand, (Charon 2012, in Rasminsky, 2012: 1) that the patient’s “habits, fears, beliefs, and family circumstances” are taken into consideration. “[This technique] enhances a [doctor’s] ability to interpret [experiences and renditions, whereby taking] the imaginative leap into a world other than [his/her] own”. When doctors listen to their patients’ narratives on life and illness, “[they] become better doctors” (ibid.: 1).

These two views are closely defined by how a doctor speaks to his/her patients. It is therefore important that the language and terminology used is somewhat simplified. According to Hala, when her doctors were explaining all the medical procedures and treatments, they promoted an atmosphere of openness and removing the chance of facilitating a “narrative surrender”. When Hala did not understand a certain term or issue within their communication, she felt comfortable enough to ask for a more simplistic explanation:

“I am not ashamed to ask [the doctors] if they are talking their [medical] language. [I would say] ‘please, help me understand better and explain what that means’”.

62-year-old Fiona wanted to know what she may experience with her diagnosis and treatment of breast cancer. The following extract is her recollection of the conversation between the oncologist and herself:

“I had a lot of questions to ask and [he] answered everything I wanted to know. From how it started, to what is going to happen, to how it will affect me physically and emotionally. I think [this] comforted me in a huge way”.

In my analysis of the medical encounter, I will begin by defining what the private medical encounter entailed to the individual and how she perceived and experienced her interactions with the medical personnel. My aim is to give the reader a clear understanding of not just what the medical encounter encompasses, but also how each interaction affected the individual psychologically, emotionally, and physically.

Each individual experienced the medical interaction differently, but the underlying conclusion was that each participant was comfortable with her primary physician and the staff. Fiona recalled the hospital personnel as being very optimistic. “They were very friendly people [who exuded] high spirits. [They] never [make you] feel like [you are] a sick person when you enter[ed] the [hospital]. Carla found that the medical support was what defined the staff. “They were very supportive, all of them, the staff and the doctors. They were not rude, [instead] they [talked] to me nicely”.

Due to Ana’s work as a paramedic, she had anticipated a somewhat different form of interaction to what she actually received. “I really did not anticipate the friendliness I got. It was completely different to what I [thought] it would be [like]”. Even Donna highlighted the positive interactions she had with the medical staff. “They really do go out of their way [for you]. They treated [me] so nice[ly]”. Gina sums up her experience as “[The medical personnel were] comforting [with] a lot of empathy and sympathy. I really cannot say anything negative about the medical encounter and the staff that I encountered”.

The only criticising comment was the one by Ella who felt that not enough information was given straight after her initial diagnosis. Ella states that:

“If I could change something for people that will be diagnosed in the future is to give [them] more information the moment they tell you something is wrong. You know after two weeks I came to the doctor and he told me this is the type of cancer you [have]. I went to hospital [and] they did the lumpectomy. The next thing they put me on the machine and they [took] a sonar of [my] skeleton. They don’t tell you they will do that and why they will do that. I would



[have] liked more information before I [went] through this. They [should have said] ‘we will take out the lump and then we will do this and [that] to see what is happening’. [I would have liked to have had statistics like] 80% [of women get] this [cancer] and 20% [get that cancer]. So you can just understand more before you go through everything. [This is me though] I would like to know [but perhaps] another [person] doesn’t want to know”.

On the other hand Bella had a very different experience, whereby her doctors explained and even elaborated by drawing her pictures to fully depict what they would be doing and how they planned to do her surgery. The following extract is from Bella during the interim period from after her diagnosis until the surgery where she would receive a double mastectomy:

“The doctor at X-ray explained [that] now the cancer is operable. ‘I will refer you to somebody who can operate on you and is very good’. Then I met that doctor and she was a very funny lady and she explained [everything]. She even put up some pictures to explain and show[ed] me how she is going to work and what [she is going to do]”.

Carla also experienced an interactive and guided treatment interaction with her medical personnel “[The doctor] explained everything. What type of cancer [to the surgery]. She even drew a sketch for me on what is happening and what she is going to do. So I understood [everything]”.

Due to personal characteristics, each participant expected a somewhat different approach to how the doctor and the staff should handle her and the illness. Within the phase of diagnosis and surgery, each participant not only wanted, but needed to be the leading physician’s primary focus, but as much as the doctor wants to focus his undivided attention on one patient, in reality, this is a nearly impossible act to achieve. Medical practitioners see multiple patients on a daily basis and this is true for all the staff at this private institute.

Regarding my personal experience as researcher, each time I made an appointment to see Dr Jackson, I would arrive 15 minutes early. There was not once that the oncology’s waiting room was empty, and at times all the seating would be occupied, thus prompting me to offer my seat to a newly arriving patient. Due to the fact that I

was not a patient, I did not mind and it became quite the norm that I would wait an hour past my appointed time to meet with the oncologist. I am of course aware that Dr Jackson made his patients his priority by attending to them within our scheduled time. The way in which medical matters were conducted in Dr Jackson's practice was exemplary. There were even occasions where I would receive a telephone call after 8:00pm from Dr Jackson offering information about my research. This work ethic was confirmed by the participants who made the following comments:

“At 9 o'clock [at night] or something like [that Dr Jackson would] phone me. [Dr Jackson is] still in his office and is trying to help people. He is supposed to go home. It is after hours and he is trying to phone back patients and get them sorted out” [Donna].

On the other hand, Hala felt that due to her doctor's busy schedule, not enough attention was given to her when she required it. She made the following comment surrounding Dr Klein, the physician who diagnosed and operated on her:

“He did return calls when I left a message, because he was never available [when I called]. I know one night it was at 9:30pm [when he got back to me]. I know that he is very busy, but at that point in time I was actually feeling that he could do more. [Do] you know what it is like when [breast cancer] is diagnosed in you? You want feedback now and you want them to move as fast as possible”.

Even though personal attention is perceived on a subjective level, none of the participants felt side-lined or rejected by any member of the medical personnel. Each participant built and, within the research time frame, had an open relationship with the medical personnel, including face-to-face and telephonic interaction and the negotiation of the treatment trajectory.

Within any form of communication: (be it a face-to-face consultation or telephonically), the research participants felt that they were a priority to the doctor and were comfortable to query issues surrounding their illness and certain side-effects. This can be seen in the statement made by Gina who not only felt, but elaborated on how open and helpful the medical staff were:

“[Dr Jackson] even said to me any time I need to speak to him I must phone him and let him know if I feel something is worrying me. I must phone him [or] even the three [chemotherapy] nurses. The [one chemotherapy] nurse said to me that if [I] feel sick, nauseous or [my] stomach isn’t working ‘you phone us’. [Then] you come in and we will give you an injection and if [it] is still not working, then we will take you up into hospital again and settle everything”.

When the illness was diagnosed, all the participants wanted varying degrees (some more than others) of information on breast cancer and how the illness would affect them personally. Each individual was given a verbal explanation by her doctor (surgeon or oncologist) about breast cancer, which included: how the illness begins, how it affects the body, the different stages and prognosis, the best treatment techniques for their form of diagnosis and common treatment side-effects.

Gina was quite eager to acquire any and all information surrounding her form of breast cancer. This interest was encouraged and supported by the oncologist. Therefore Gina’s explains:

“I felt to myself that I am studying medical science now with [Dr Jackson]. He even took my email address and he said to me ‘I will send you articles on this’. He said the HER2 positive [cancer] is very aggressive cancer and [then] he sent me two articles that I read”.

The language that was used by the physician was adjusted to the patient’s level of understanding; this included the terminology used and depth of medical terminology. The research participants were not shy when it came to asking questions or inquiring about their breast cancer. On the whole, depending on the individual and her interest surrounding breast cancer, her knowledge would vary.

While understanding the uniqueness of each participant, it is my conclusion that they all felt comfortable during their contact sessions with the medical staff. The main focus was on the breast cancer and its stage, the treatment and the common side-effects. Donna viewed her illness from a more pessimistic stance and she had the following to say when asked about her interaction with Dr Jackson surrounding her diagnosis and the treatment:

“He has a very peaceful way of talking to you. He keeps you stable when he talks to you. [He] seems very in control. [He] makes you feel like you are in good hands. That is my feeling about him, [because he] talks to you [and tells you], okay this is now going to happen and you are going to have [or feel] this”.

Fiona experienced her interaction with Dr Jackson as comforting and informative. She reveals this experience by stating:

“Well, [he] explained everything to me very clearly. I had a lot of questions and [he] answered everything I wanted to know. I think that comforted me in a huge way. That [he] never hesitated in any way. He took his time with me [and sometimes for as long as an] hour he [would] explain everything to me and my husband”.

Even if an individual had a history of medical knowledge, the doctors would still forward the relevant information surrounding her specific diagnosis which can be seen in Ana’s account. “I told him I know what you are saying but he [explain everything anyway]. [He was] with me for a whole half an hour in the ward explain[ing] to me [what he is] going to do”.

This can also be seen in Bella’s rendition: she is a professional nurse working at a local state hospital. In her account she wanted the surgical doctor to phone and confirm with her husband the devised surgery plan. Bella’s husband is also a professional nurse:

“I even said [to] the surgeon that you can phone my husband, he [is] also a nurse. He will understand and just explain to him everything you have just said to me. She [then] said ‘I [have] talked to your husband and everything is fine and I can go on with the operation’”.

When Bella had completed her surgery, Dr Jackson came to see her to discuss the next phase of her treatment whereby she recollects the experience as:

“He came to me when I was still admitted and he told [me] that after the surgeon is through with everything and once I have healed – [because] I was not [yet] totally healed – I had to attend chemotherapy and then attend

radiation because my cancer was more advanced. I was a 60% risk and therefore I must get chemotherapy and the radiation. [Dr Jackson] even used to phone me and say don't forget that on the 14<sup>th</sup> you must start with your chemotherapy. I said 'no, doctor I haven't forgotten, I will be there on the 14<sup>th</sup>'. He used to follow up [with me] as well. I was very comfortable [with him] and [he was] very open and honest [with me]".

Carla, also a professional nurse, was diagnosed by a fellow physician who she worked with at a state hospital, and she disclosed that:

"Dr Long told me I had breast cancer. I know him and I wanted his advice, so he volunteered [and said] that, 'sister, I am going to remove that cyst' and he was the one [that did the] biopsy. He is [also] the one who told me [the cyst was cancerous]. He was supportive because he always called himself my colleague. We are close at work [and] he is one of the doctors who is nice to [the] staff and everything. [When I started my chemotherapy], I phoned him and I said to him 'thank you doctor you saved my life because if it wasn't for you I would have not found out it was cancer'. So he is my hero, he saved me".

I am able to conclude that from these responses, each of the participants seemed comfortable and well informed by their diagnosing physician and oncologist. This information included their form of breast cancer, their stage, and the prescribed treatment trajectory. All the participants understood what was said by their doctors and depending on the terminology and level of understanding, each individual felt comfortable enough to ask for further information or an explanation in simpler terminology. I am also able to conclude that this private institute acted very efficiently, by not only doing the surgery or following the prescribed treatment trajectory, but also phoning their patients to find out how they are doing, reminding them of appointments and ensuring that problems, issues, or side-effects are reported as they happen. These actions thus reassure the patient that she is valued and respected.

### 6.2.1.1. The Medical Encounter and “Identification and Categorisation”

Within the theme of the medical encounter, one is able to identify and categorise patients to varying points. These points can also be seen in a breast cancer diagnosis, the treatment trajectory, shared side-effects and emotional upheaval. It is important to note that a breast cancer diagnosis is not the only illness that displays similar experiences among those diagnosed with this particular illness but in the case of other illnesses there will also be shared experiences among those diagnosed with the particular illness.

A diagnosis of breast cancer can be seen as a form of “identification”, in the sense that women diagnosed with breast cancer are grouped together with others with similar treatment trajectories. This can be seen to include surgery, chemotherapy, radiation and hormone therapy. This identification then leads to treatments and their shared side-effects. Breast cancer patients will experience unique aspects of their diagnosis and treatment, but within this research the common side-effects are seen as: hair loss, nausea, vomiting, burning of veins and skin, weight loss and fatigue. These side-effects are the physical aspects of the treatment trajectory but there are other dimensions – emotional, psychological and spiritual – that each individual has to deal with, which are also the result of the treatment trajectory.

In Bella’s account, she reveals that the staff at the private hospital not only accepted her, but also made sure that everything from the paper-work to understanding her surgery and outreach programmes were taken care of on her behalf. This ethic-of-care approach<sup>7</sup> made an impact on Bella’s illness experience and her overall outlook:

“The staff accepted me and said I looked pretty. Even with my admission, they organised everything for me. [When] I was discharged, they organised that I go to [a local organisation] with [these specialised] bra[ziers]. [They said that the lady with the bra[ziers]] will measure [me] and do all these things for the bra[ziers] so that [I] look the way [I] looked before [I was] operated on. [The

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<sup>7</sup> An ethic-of-care approach – “stresses that the caring response is determined in a concrete way for each unique patient within that patient’s particular network of relationships and given that patient’s unique needs and desires” (Cates and Lauritzen 2001: 58).

hospital has] so many channels they can send you to after your operation. There were [even] some sessions where you were visited by these beauticians and they pamper[ed] you. There were about ten or twelve of us for the sessions that they [gave and it] is free of charge. They give you the cleansing material, the moisturisers, the lipsticks and the blushes. They give [you] all [this] stuff that makes you look beautiful”.

The treatment that Bella received appeared to be client-centred, whereby Bella as the patient was seen as a priority to the hospital and not just a body with an illness. Her emotional well-being seemed to matter to this institute and to the staff. By making the patient the priority, the medical facility not only aided the individual to a better recovery, but also improved her outlook on her illness experience. Gina recalls her experience with the chemotherapy nurses as guiding and helpful:

“I went for my first chemo[therapy and] they said to me just cut your hair a bit shorter. So that the day you lose your hair it is like shorter ... shorter ... gone. That [was] the only advice that they gave me about my hair. I didn't have anybody giving me anything else except those books that I read [from] those ladies [from the support group that visited me after my surgery]”.

Gina was of the opinion that the hospital was helpful, but could do more. She did not hold strong criticism of the institute, but further emphasised that it is also up to the individual to ask for more assistance or help in a particular area:

“I suppose [the hospital] can improve, but I always say if you need [something], you must also from your side reach out. It is not always [the hospital who must] reach out, you must reach out [for more help]. Sometimes you get people who get irritated by [other] people barging in and saying ‘do this and do that’”.

When working around the experiences of the participants, it is clear that within the medical encounter one can identify cancer patients (physically), but cannot identify their specific form of cancer, without consulting the oncologist or speaking directly to the patient. Within the hospital where the research participants were treated, it was possible to identify their illness by connecting it to the oncology section where they found themselves. Cancer is linked to oncology and therefore all treatment areas are

in close vicinity to the oncology department. When one enters this section of the hospital, one needs to be prepared to see and meet sick individuals who display common side-effects of cancer like baldness and scars. Within this research project, after several encounters, I could identify and classify the participants as women who have lost a part or whole breast/s, who suffered from weight loss due to the nausea, seemed fatigued, displayed physical changes such as scarring, blackening of veins, and burn marks on the chest or neck.

The framework of “identification and categorisation” within this research should be seen as highlighting points within a breast cancer diagnosis and its treatment and not be misinterpreted as a means of segregating, classifying, labelling, or stereotyping women according to their diagnosis and visual side-effects from the treatments. It must be noted that “identification and categorisation” within a medical environment can lead to labelling and stereotyping, which inevitably spreads to the broader public awareness. Therefore, before one considers the theme of “identification and categorisation”, I feel that one should first know relevant personal information on the individual before assuming anything. In this research project, I interviewed eight women from a middle-to-upper class socio-economic status. The research participants shared similar backgrounds in terms of professions (teachers, nurses, a paramedic and an entrepreneur), family systems (all were married) and support structures, religious convictions (Christian-based beliefs) and financial security which allowed them access to private medical care. These similarities could be seen as contributing to why their breast cancer outlooks and experiences were rather similar.

#### **6.2.1.2. The Medical Encounter and “Self-understanding”**

How an individual understands and perceives the medical environment and herself will strongly influence how she views her illness. Hospitals are commonly perceived as terrifying or menacing places that are avoided when possible. Within this research, none of the participants displayed chronic or disabling symptoms of fear, but did reveal that going to the hospital was anxiety-provoking and daunting. Gina states that the medical environment would naturally be avoided, but because of her illness she works with and abides by the treatment regimen. By being actively



involved in overcoming this illness and regaining her health, she has transformed her understanding of the medical encounter and the medical staff. “I don’t like being in a hospital and I don’t like being sick. So the [medical staff] are not my favourite people. But [now] I am forced to deal with them and to me it [is] positive”.

This “self-understanding” of the medical environment can have various origins, but it is my opinion that when one goes to hospital for oncology treatment, one might be inclined to expect the worst. The participants explained that even just going for their prescribed treatment was a traumatising experience. Donna explains her feelings and anxieties towards the institute by using the analogy of a cat: “If I drive past the hospital now, all my hair [stands up] and I feel like a cat. I hate that place and I don’t want to go there”.

Due to Ella’s understanding and knowledge of the medical environment, her actual medical encounter was different from other breast cancer patients. This can be attributed to the experience of her first husband. Even though he had passed away in his twenties from pancreatic cancer, Ella still had contact with many of his colleagues. This therefore allowed her the ability to request particular physicians to tend to her at short notice. What becomes clear is that by having this personal contact with the medical world, Ella had a better self-understanding that took away common anxieties and stresses that other individual’s would normally go through.

“I knew everybody in [the medical environment] so I could select the best for myself. I [also] knew more about cancer [from the previous knowledge of being married to a doctor, experiencing his death of cancer and being a trained microbiologist]. For me to wait four days [was] terrible, so luckily I phoned [a] doctor [that I knew] and I got an appointment for the next day. When I got to the surgeon, he said ‘listen, I know your history, you will be okay. It is fine and don’t think it is the end of the road. Many people live with breast cancer for many years”.

“Self-understanding” is vital to how the individual acknowledges her illness and her interaction with the medical encounter. The common stigma attached to doctors and hospitals can be detrimental to how the individual sees and thus enters into the medical environment. This will also determine how she goes into and negotiates her relationship with her primary physicians, nurses and technicians. Professionals in the

area of medical sciences can benefit the individual not only by sharing knowledge, but also by promoting an empathetic and humanistic approach by medical personnel.

In this research one can see that Ella, Carla, Ana and Bella have a somewhat different outlook on their illness and their medical encounter. I attribute this to their medical background. Even though the other participants did not have the same privileged encounter that Ella and the others had, they did not feel that they were given any partial or inadequate treatment. Instead, these participants took it upon themselves to broaden their knowledge through books, journal articles, the internet and their primary physician's advice. It should be noted that – within this research undertaking – the medical encounter was seen by all the participants experiencing high quality treatment and that none of the participants felt that any part of her treatment trajectory lacked in expertise, compassion, empathy or knowledge.

#### **6.2.1.3. The Medical Encounter and “Commonality, Connectedness, and Groupness”**

When I integrate Brubaker and Cooper's (2000) framework into this section of my analysis, I can only highlight the broad similarities that each of the participants displayed towards one another. This can be seen to include: being women and sharing stereotypical, gender associations, coming from a rather similar socio-economic status, each participant is/was a wife and mother, was diagnosed with breast cancer, sought treatment at the same private institute and experienced similar side-effects (varying degrees) from the treatment trajectory.

When identifying and categorising women diagnosed with breast cancer, it seems to be a common notion to place them in a “sick-role”. For Ericksen (2008: 257), “individuals who are chronically sick may look fine but may have an illness that is a silent killer” and thus are seen and defined as “sick”. Being placed into this form of a “sick-role” often makes the individual feel vulnerable and disempowered. According to Ana, she was placed in this role by her mother, family members and friends. She had to make a purposeful point in rectifying this thought:

“I took it onto myself to say wherever I go [and to whoever I meet] “don't treat me as an invalid” I am not an invalid. I am still a human being, it is just the

breasts that have been cut off and I can still use my right hand and my left hand”.

Ella is well known in the community and was very reserved in revealing her breast cancer diagnosis. For her it was important that daily activities continued as usual. By not revealing her diagnosis to extended family and friends was to avoid the chance of being assigned to the “sick-role” or even labelled:

“I tried to keep [my diagnosis] quiet. A lot of people know me and it is easy to gossip. [Like] you know her and you know what happened to her. I don’t want them to do that. When [I was] at the ‘look better, feel better’ workshop for cancer patients yesterday, I asked them not to take pictures of me. [Because] if they put the pictures in the gazette [local newspaper], people will see me and I don’t want them to know”.

Carla took a proactive approach to avoid the possibility of being assigned the “sick-role”. She is very proud to announce that she has no secrets and because of this she made her diagnosis known to any and all people in her life. By taking this approach she believes that she took away people’s power to label or stigmatise her.

“I don’t give them the chance [to label me]. Because I don’t have [any] secrets. They know me as talkative and when they see me I am just laughing and making a joke, like you know what? ‘I have bought a new breast’ and they all laugh. So no one is label[ing] me and no one has treated me differently. Even at work no one is gossiping [about me]”.

It is important to note that none of the research participants are ashamed of their illness or the side-effects of the treatment trajectory. Instead they are afraid that people will treat them differently because of how the illness has altered them physically. This differential treatment can be perceived as a form of groupness, whereby resulting in labels and even stigmatisation.

### **6.2.2. The Researcher's Perception and Experience of Chemotherapy**

By having had the opportunity to not only interact, but also to accompany some of the participants to their treatment sessions, I have gained a better understanding of a breast cancer experience and the illness narrative. I am aware that I cannot truly comprehend the emotional, psychological and physical experience of this illness, but by having shared and experienced areas of the treatment trajectory, I can perceive and understand certain aspects of the illness narrative on a more in-depth level.

Within the private hospital settings each participant remarked on the exceptional medical care that she received. This included how the doctors spoke, worked with and tended to the patient. All the medical personnel were sensitive and compassionate towards the participants. This is especially true of the three chemotherapy nurses that worked at this specific private hospital. I can personally confirm this, as I was allowed to attend multiple chemotherapy sessions.

During these sessions, I not only spoke to the attending nurses, but also to other patients receiving chemotherapy. My aim was not to intrude on these medical sessions to confirm perceived perceptions and notions, but instead I entered the chemotherapy lounge with an open mind and with utmost respect. At first I was sitting quietly in a corner and observed the interactions between the nurses and patients, the administration of medication, the immediate side-effects that medication had on some of the patients and how the patients interacted with one another. Each session varied, but usually lasted about four hours. I was truly honoured to personally experience this part of the research, as this not only allowed me a clearer understanding of what the cancer treatments are like, but how cancer patients interact and understand their diagnosis. I would like to recreate what I saw, how I felt, and what I learnt, thus giving a more comprehensive and complete understanding of what a chemotherapy session is like.

When talking about a hospital setting, it is commonly perceived that hospitals have clean long corridors with sombre coloured walls and a scenic painting every now and then. When entering the short corridor to the chemotherapy lounge, my immediate thought was: "am I in the right place?" This particular entrance smelt like a hospital, but what I saw was not something I had thought would be part of the hospital decor.

There were three vivid paintings, bright orange and red chairs, and a table with a big bouquet of flowers on it. My first thought was that I had entered the hospital café as there was a happy mood with people chatting and the odd laugh gliding through the air.

As I walked around the corner I realised that I was in the correct place as there was a room filled with people of all ages and races. This room consisted of ten dark brown La-Z-Boy chairs, a Nestle coffee machine, a little kitchenette with a sink and two microwaves on the counter. On the ceiling were metal bars that had thin moveable chains attached to it and each chair seating had one or two chains dangling above it. From these chains hung the IV (intravenous) bags and depending on the different treatment the individual was receiving, the bags contained either a red-orange coloured fluid or clear fluid. There are various forms of medication that are used to treat breast cancer and according to the New York Presbyterian Hospital (2008: 1), these are seen to include: Doxorubicin (Adriamycin), Cyclophosphamide (Cytoan), Tethotrexate (Folex, Mexate, Amethopterin), Fluorouracil (5FU), Epirubicin (Ellence), Paclitaxel (Taxol), Docetaxel (Taxotere), Paclitaxel (Abrazane), Capecitabine (Xeloda), Gemcitabine (Gemzar), Vinnorelbine (Navelbine) and Ixabepilone (Ixempra). These IV bags also range in sizes according to the prescribed dosage that the patient required. As I entered this room, I was greeted by all the patients with a “hello” or a smile before they carried on with their conversations.

This atmosphere is not something that I had previously perceived within a normal hospital environment, in particular in the treatment areas. Hospitals usually emit a more melancholic vibe. This thought is shared by Ana who recalls her pre-conceived idea of what the chemotherapy lounge would encompass:

“I was scared of coming here [for chemotherapy]. I was like it is old people and what am I going to say to old people, but [here] everybody takes everybody [in]. [You are] a family member here, especially in this room because I am not different from you and you are not different from me, we are all here for the same thing. It [is] just the variation [of the medicine] that differs. You know what my daughter said to me? ‘Mommy, it is old people, what are you going to do for two hours?’ I said: ‘I have no idea!’ Then I came here and everyone accepts everyone just the way they are”.

During my visits, I had ample opportunity to observe the environment, given all the standard procedures the participants had to go through before actually starting the treatment. Because of all the different departments and the number of patients they need to attend to, I waited about half an hour before the participant had completed her blood testing, because before the progression of the chemotherapy session the patient is required to give blood to establish her cell count. While I waited, I had another look around the room, noticing that there was a platter of sandwiches and sliced fruit on a table and a door at the other end of the room which I later found out was the bathroom.

While I was taking in my surroundings, one of the chemotherapy nurses came to me and asked if I was alright. I then told her about my research and that I was waiting for one of the participants to begin with her treatment. The nurse then smiled and offered that I make myself comfortable and that I was welcome to help myself to food and coffee. I later learnt that the three chemotherapy nurses were commonly referred to as the “three angels”. Gina recalls these nurses as the “three angles working for God on earth, [who] are kind and compassionate”. Hala elaborates on Gina’s thought by including the radiation staff and the other patients:

“[The three chemotherapy nurses] were so gorgeous [and] so friendly. You felt so at home there. Also the people at the radiation department are really sweet. It is like we became kind of a family”.

These nurses portrayed everything that you would ideally want in such a situation. They were happy, positive and empathetic without being over-bearing or superficial. Being an observer, I could see that these nurses were well trained and knew exactly what they were doing, while still managing to remember a patient’s name and a few personal details that were revealed in previous conversations.

This kind of compassion and attention seemed truly genuine and it is my opinion that each of these nurses found her dedicated calling. This was reflected in one of my later sessions with a participant who had completed her four red-orange IV chemotherapy treatments and was to begin with her first of four clear IV treatments. The nurse came and began the treatment: within 10 minutes of the commencement of the IV, the participant became dizzy, stopped breathing and passed out. Even though one would think that this process would take some time, I immediately ran to

get a nurse when the participant began to complain that she was not feeling well. By the time I came back with a nurse the participant was unconscious. The nurse kept calm and knew straight away what medication to administer and how to cope with the situation. Within five minutes, the participant regained consciousness. When my participant was stable, I asked the nurse what had happened and she explained to me that the new phase of treatment was rejected by the participant's body and that she had had an allergic reaction. This was interesting to me and I wanted to know if this was a common side-effect in chemotherapy, and was told by the nurse that it is a rare occurrence, but with the help of steroids the participant would be fine.

Even though the above section was what I experienced, this research project was on what the participants perceived and experienced within their treatment trajectory. By having been given this opportunity to experience the treatment trajectory of chemotherapy, I can declare that I build stronger trust relationships with each of the research participants and was also able to relate to their experiences on a deeper and more comprehensive level.

#### **6.2.2.1. The Concept of “Family in the Chemotherapy Lounge”**

What I saw and partook in could be viewed as a glimpse behind the veil of what cancer treatment entails. Within my description of the chemotherapy lounge, I can say that the chemotherapy patients in this research project displayed a perception and understanding of their treatment trajectory. These patients are proactive in overcoming their illness. The action of overcoming a cancer diagnosis is challenging as the treatment makes you sicker before you become better.

The cancer patients that I met and conversed with can in all respects be identified and categorised as optimistic. While I was in the treatment area, I saw people and not patients, interacting with each other. Trivial boundaries such as status and race were dissolved because of a shared illness. If you were in this particular room, you were there for a regimented dose for cancer treatment. The broad label of cancer thus indirectly placed the individuals in a unique understanding of not just themselves, but also of other individuals in the chemotherapy lounge.

The chemotherapy lounge reflected a form of unconditional understanding and acceptance. This could be seen as a quiet ice breaker between strangers. What I thought was remarkable was that some of the participants felt and regarded other members of the chemotherapy lounge as family. This can be seen in Ana's words:

“Everybody takes everybody in as a family member here in this [chemotherapy] room. Because I am not different from you and you are not different from me. We are all here for the same thing – CANCER”.

Hala also viewed her chemotherapy experiences as being part of an exclusive family. “The nurses remember me and they are friendly and chatty. They make you feel like [you are part of the] family”.

By reading these testimonies, one can hypothetically relate to what Ana and Hala are trying to say. By having experienced a part of this, I can confirm that when cancer patients started their treatment trajectory, they viewed each other as complete strangers, but unintentionally become a family because of their shared illness.

#### **6.2.2.2. Personal Notions of the Treatment Trajectory**

When entering the chemotherapy lounge, one does not enter without any preconceived notions. When I entered the treatment area, I had envisioned patients sitting quietly in their chairs waiting for the time to pass. I perceived these patients to display a stereotyped picture of being pale, bald and sickly. Needless to say my perception was incorrect. Instead I entered a room with people chatting and, outside of the indicator of baldness and the administration of medicine, they displayed a picture of optimism in regaining their health.

Many of the individuals were originally of the thought that I was a new patient to the cancer ward. In fact, this was true, but not in the sense that they had thought. I was a little sceptical about stating that I am just a researcher whereby influencing the atmosphere of “shared experience”.

Once I had made it known that I was there to interview a research participant, the other patients became somewhat curious. I explained what my research was about



and this prompted other patients to open up about their cancer experience. It should be noted that once the participant arrived – from her blood tests – to begin her session, the other patients respectfully withdrew to allow us (the research participant and me) to begin our session. However, once the interview was over, the other patients began to include us into the broader conversation of the room.

Within this conversation, I realised that by sharing personal experiences, each person in the room re-negotiated and broadened her/his self-understanding. This interaction within the medical encounter could be seen as a form of group therapy. This therapy is not led by a counsellor or therapist, but instead guided by the group members themselves. It is my opinion that being a first time patient to this treatment, one can learn some of the most invaluable aspects and perceptions of cancer. Each individual undergoing this treatment not only wants to share her journey with a willing participant, but also comfort and guide a new cancer patient to this reality. This can be seen as a form of patient mentorship within the treatment trajectory.

Self-understanding is personal knowledge and comprehension of the self, but within this treatment area self-understanding, re-negotiations and transformations are shared. The saying by Donne (1624: 1) “no man is an island, entire of itself” comes to mind when deconstructing what I experienced during these chemotherapy sessions. As much as self-understanding is a solely personal aspect, cancer patients seem to have made sharing their self-understanding, perceptions and experiences a way of coping and overcoming their illness.

### **6.3. Re-negotiation of “Identity” and Femininity within the Medical Encounter**

When inquiring if this private institute promoted or aided in the re-negotiation of identity and femininity, I obtained two varying, but distinct answers. These answers could be seen as either affirmative that the hospital and its staff helped in this transformation process – or negating that the hospital had an impact in this area of the individual’s life. One of the participants was of the opinion that throughout the breast cancer journey, there was no prominent aspect of maintaining femininity. She stated that it was more about fighting to survive.

This can be seen in the extract by Donna:

“I think as a patient I just tried to get through it. It is a thing of survival and you don’t feel anything about femininity and stuff like that. It is just you are so sick, you just trying to get the chemo[therapy] out of your body and fight against depression and what the chemo[therapy] actually does to you”.

Most of the participants held the opinion that breast cancer had not impacted on their identity or femininity, and therefore any assistance from the medical encounter regarding this matter would not hold sway with these individuals. The individuals who were of this thought – that their identity and femininity had not changed – did state, however, that their outlook on life had changed. This outlook was understood within a more appreciative and positive view of current experiences and future prospects.

Hala highlighted that her experience with the institute was positive and helpful in her journey to overcoming breast cancer. With her personal understanding of who she is, the medical encounter had had no influence on her identity or femininity. “The information [the hospital] gave [me] didn’t change my identity. Yes, of course they gave me information and I am very happy for that, but it did not change my identity or my femininity”. Gina shared a similar thought whereby she was given pamphlets and articles informing her of breast cancer, but when I inquired if the institute aided her in any way with regards to her re-negotiation of her identity and femininity, she simply stated “no, I didn’t get any [assistance] in that matter”.

The reserved and self-controlled Fiona gave this question some thought, but ended up replying with the opinion that the medical encounter did not aid her in her re-negotiation of identity and femininity. “That is a difficult question [to answer, but] I don’t think they had a role to play [in that area of my life]”. Throughout Ella’s interview, she held the opinion that her self-concept and understanding had not changed. What she did state as having changed is her outlook on life and that material things did not hold as much value to her anymore. Instead, family and friends were seen to be placed above material objects. “[There is no change] on my identity. I am what I am, but my outlook on life changed [for the better]”.

For the individuals who felt that the medical encounter did influence their re-negotiation of their identity and femininity, I will start by highlighting the views of

Bella. The support that the medical encounter provided Bella was described by her as remarkable. Throughout the entire interview session Bella did not have one negative remark to make about her illness experience. This included areas where she could have added positive criticism to the improvement of certain areas of the hospital. Bella recalls one of her medical encounters as stating:

“[The hospital brings in beauticians] especially for breast cancer [patients]. They tell you even if you don’t attend [this] session you [must] come for another session. [They come and help] the people to clean their face[s] and have a cup of tea with us and talk. [These beauticians gave us] very expensive products [like] moisturiser and blush. [This hospital provided me with] very strong and good support that [was] free of charge”.

Carla perceived identity and femininity somewhat differently. She did state that the hospital had a role in helping her re-negotiate her self-image and concept through respect:

“[Yes they did help me re-negotiate my identity and femininity] because they were able to give [me] respect. The way they talked to [me and] the way they treat[ed] [me resulted in] feel[ings] of love and respect”.

Each of these answers fit the individual and her perception, self-image and overall understanding of her illness experience. In conceptualising how the participant perceives and understands her identity and femininity, these thoughts will filter through to how she re-negotiates and transforms her self-image, self-concept and self-perception.

### **6.3.1. “Self-understanding”**

Due to this research project being undertaken while all the research participants are still in different stages of their treatment trajectories, it is important to state that these renditions may be altered due to new experiences or reinterpreted over time. Each participant will re-negotiate aspects of the self. This might lead the individual to accept and overcome her illness experience. I am of the thought that if the individual denies certain (physical, psychological and emotional) transformations, she may fall

into a stagnant state whereby never truly accepting her diagnosis and her overall experience with breast cancer.

When looking at the participants' self-understanding in relation to their re-negotiation of identity and femininity within the medical encounter, the majority of the research participants believed that their identity and femininity had not been influenced by their illness. In a reflexive view, it becomes evident that the individual's self-understanding of herself, her image, and her social environment has encouraged a strength that has been unwavering in her illness experience. These individuals have the ability to accept their illness and the physical changes it produces. They are aware and partake in the re-negotiation of their self-image, self-concept and self-perception, whereby viewing the illness experience as a chapter within their lives.

On the other hand, some of the research participants felt that the medical encounter had influenced a re-negotiation of identity and femininity during their illness experience. It should be seen in light of the strong support that the medical environment gave to these individuals, which aided them in accepting their breast cancer diagnosis. This support thus aided the individual in her self-understanding, re-negotiation and transformation of her self-image and self-perception.

## CONCLUSION

The common notion that breast cancer is a death sentence is, in this research project, found to be inaccurate. This study brings forth the notion that breast cancer is not perceived as final. With regular medical check-ups and increasingly sophisticated treatments, it is perceived more along the lines of a chapter or period in one's life-journey and that it is an illness that can be overcome. When looking at the overall survival rates for breast cancer in South Africa, Albrecht (2006: 7) is of the opinion that women have a "64% chance of survival" after completing their treatment regimen.

When beginning this project, I was under the assumption that I can enter this research in an objective and unbiased manner, but I have come to realise that I did indeed hold certain biases and preconceived notions on what the life-world of a person diagnosed with cancer and undergoing treatment would be like. These notions were shattered through the in-depth interview sessions. I realised that even though the common theme of a breast cancer diagnosis is what brought each individual to this study, it was their unique outlooks, characteristics, knowledge, beliefs and understandings that added substance to this project.

How the individual viewed her illness and her life-world brought forth how she would understand and react to her illness. This was my main area of interest, to obtain the subjective views of each of the participants and to review my findings to determine if this illness experience produced aspects of commonalities or differences among the research participants. Due to each of the research participants having rather similar socio-economic characteristics in terms of class and education, most of the participants – indirectly – shared similar thoughts towards the illness. For example, most of these women were interested in, broadening their knowledge surrounding the diagnosis and the treatment trajectory and they all experienced this chapter in their lives by accessing treatment at a private hospital, which inevitably influences subjective experiences greatly (in terms of quality care, but also in terms of a caring and pleasant environment where the treatment takes place). When looking at the above-mentioned points from a social constructivist and existentialist worldview, one could say that the reaction to the illness and its surrounding aspects could be linked

to cultural and societal normalisation. The socialisation of individuals synchronises norms, values and beliefs, and therefore how breast cancer is understood and experienced can be attributed to the broad conceptualisation that society (and those who form part of the society) deems acceptable.

As this study focuses on the re-negotiation and transformation of identity and femininity in women diagnosed with breast cancer, I can conclude that following the initial shock of a breast cancer diagnosis, each of the research participants has to re-negotiate various aspects of her self-understanding. This self-understanding varies because each individual is unique in terms of attitudes, perceptions, experiences and knowledge. Once the individual has accepted her diagnosis and integrated a proactive stance to her treatment regimen, she begins to refashion her personal understanding towards her illness, her gender, her self-image, her femininity and towards her overall self-concept. This transformation is often aided strongly by her religious belief systems which also assists the individual in responding to the question “Why me?”

The perception of the self and of femininity was strongly associated with the seemingly inevitable loss of hair after the onset of chemotherapy. In fact, it was found that the reality of breast cancer diagnosis only manifested once the research participants started losing their hair, which is obviously a very visible sign of undergoing cancer treatment. Through the prescribed treatment chemotherapy, where hair loss is one of the main side-effects, each of the participants experienced a form of identity crisis. This included a re-negotiation of personal understanding (psychological re-evaluation of “Who am I?”), self-image (it is still my eyes, but who is this person in the mirror looking back at me?), and the overall self-concept (physical and emotional changes highlighting one’s gender vulnerability). Each of the research participants mitigated these visible and psychological changes by investing in wigs (resembling her previous hair colour and shape) and continuing with beauty regimens (particularly the use of cosmetic products). This implementation of normality gave the individual a sense of stability within this challenging period of her life. Despite this superficial aspect that touches on issues of femininity, donning a wig was an important mechanism to maintain a level of normality during the trying period of treatment. However, some participants indicated that all aspects related to

femininity were on hold during the difficult phase of fighting breast cancer, as the fight for survival was stronger than the urge to flaunt feminine attributes commonly associated with women and their stereotypical notions of “beauty” (especially physical beauty).

Strong personal support systems such as family, friends, and religious memberships prompted the diagnosed individual to adopt a much more optimistically inclined outlook of herself, her illness and her future prospects. This seemingly invaluable support also created an atmosphere of acceptance of the illness and of the diagnosed individual where physical and temporary changes did not negatively affect the support structure but instead, day-to-day routines were negotiated to accommodate the diagnosed individual undergoing treatment. Within this project, a more pessimistic stance was predominantly linked to the lack of support structures which included family, friends, and support groups. In cases where an individual presented with a pessimistic outlook much emphasis was placed on potential aspects of recurrence and metastasis thus prompting the individual to echo words of “what-if” and “suicide”. What was seen to aid both the optimistic and the pessimistic individuals was the emotional and, in some cases, the physical support of religious organisations. Here each of the participants was able to re-negotiate and transform herself by striving to regain her original health with the aid of the medical assistance and through her belief that “God will heal her”.

In understanding if the medical encounter helped the individual’s re-negotiate her self-perception and femininity, most participants were of the opinion that the medical encounter did not play a role in this aspect of her illness trajectory. Other participants did state that their specific medical encounter helped them in re-negotiating issues around their perception of self and even their femininity. This was mainly conveyed in relating how the medical staff showed a tremendous amount of empathy, respect and acceptance towards the diagnosed women. This was further enhanced by additional medical services which included the relaying of information about support groups and organisations that produced prosthetic braiers and wigs, as well as beauty sessions that were held on the hospital premise and a friendly and homely environment in which the treatment sessions took place. This additional medical assistance did seem to play an important role in prompting the individuals to come to

terms with and accept their diagnosis and by going the extra mile in facilitating the treatment process and rendering it a positive experience. Ultimately, the re-negotiation of self-perception and femininity is done on a personal level which is achieved solely by the diagnosed individual.

Due to the research participants viewing this illness as a chapter within their lives, most were of the opinion that breast cancer will not define who they are or who they will be. They saw this diagnosis as a chapter in their lives and therefore once they have completed the treatment trajectory (surgery, chemotherapy, radiation, and five years of hormone therapy) and obtain a clean bill of health, they will continue with their life as before their diagnosis. This thought also reflects the point that breast cancer has not prominently disrupted the individual's perception and concept of self. Rather this illness will be accepted as an experience and memory that is used to encourage the individual to pursue more passionately her future plans and prospects, given her close encounter with a profound existential dilemma.

In concluding this dissertation, it is important to remember that individuals diagnosed with breast cancer will share certain commonalities within their illness experience, but one must not forget that each woman is unique in her understanding, her knowledge and her perception especially around issues that pertain to questions of life and death. This uniqueness can thus be associated with how, or even if, the individual re-negotiates and transforms her self-perception and femininity. Cheng (2010: 209) is of the thought that "just as there are different interpretations on a piece of artwork or a music score, there are mosaic interpretations and meanings that women attribute to their breast cancer experience". The description of the illness experiences of these women, especially related to their treatment, could possibly be closely read to those of women from first-world countries. Their privileged access to private health care and their exposure to messages of hope and healing are similar to those of women in affluent parts of the world such as America and the United Kingdom.



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## SUMMARY

It is commonly thought that breast cancer, like many other cancers, is an illness equivalent to a death sentence. Though this may be true in some cases, the majority of women diagnosed with breast cancer do survive this illness. Breast cancer is a growing illness and consequently is continuing to affect women worldwide, including in developing countries like South Africa. In this dissertation, I look at how eight middle-class South African women experience their breast cancer diagnosis and the subsequent treatment. I aim to understand how each participant re-negotiates and transforms her self-perception, her “identity” and issues around femininity. I am also interested in seeing how the prolonged and intense medical encounter is experienced, as well as how this encounter influences the individual in her re-negotiation and transformation of “identity” and femininity.

Social constructivist, social existentialist, and phenomenological approaches are combined to highlight the rich experiences of the collected narratives. These narratives are aimed at gaining a deeper insight into what a breast cancer diagnosis and its concomitant treatment entail. The main method for collecting the experiences of the research participants is in-depth interviews. The interview schedules were designed to prompt the individual to expand on relevant topics for the study. When working through a topic, most participants broadened their narratives by going deeper into their personal experiences and unique understanding by revealing more personal thoughts of their breast cancer journey. This in turn, led the narrative analysis to produce themes such as the role of religion, femininity and gender, surviving and support, maintaining normality and the medical experience. It is also evident that these eight women have access to state-of-the-art medical treatment, given their adherence to private medical insurance schemes. This reflects a very specific experience, very similar to accounts in existing literature of women in first-world countries who undergo a similar diagnosis and treatment.

Each research participant elaborates on the self-understanding of her illness which reflects either an optimistic or pessimistic attitude in as far as her self-concept and self-image is concerned. The participants’ self-understanding and attitude (optimistic or pessimistic) are found to be closely linked to the level of support that they have access to, as well as to their religious beliefs, outlooks and understandings. This is



reflected in how the illness is accepted and also in their current outlook towards future prospects.

This study aims at humanising the illness of breast cancer through listening to the personal accounts of individuals who have had to experience the diagnosis and treatment of breast cancer. Within these personal illness narratives, I aim to expand our understanding of this illness and the experience of those who were diagnosed and treated for it.

## OPSOMMING

Dit word oor die algemeen aanvaar dat borskanker, soos baie ander vorme van kanker soortgelyk is aan 'n doodsvonnis. Alhoewel dit in sommige gevalle waar mag wees, oorleef die meerderheid van vrouens wat met borskanker gediagnoseer is. Die omvang van borskanker neem toe en gevolglik beïnvloed dit vrouens wêreldwyd, insluitend in ontwikkelende lande soos Suid-Afrika. In hierdie verhandeling kyk ek na hoe agt middelklas Suid-Afrikaanse vroue hul borskanker diagnose en die daaropvolgende behandeling ervaar. Ek poog om te verstaan hoe elke deelnemer haar self-persepsie, 'identiteit' en kwessies rondom vroulikheid heronderhandel en transformeer as gevolg van die diagnose en behandeling van borskanker. Ek is ook geïnteresseerd om te bepaal hoe die langdurige en intense mediese interaksie ervaar word, asook hoe hierdie interaksie die individu beïnvloed in haar heronderhandeling en transformasie van kwessies rondom 'identiteit' en vroulikheid.

Sosiale konstruktivisme, sosiale eksistensialisme en 'n fenomenologiese benadering word gekombineer om die ryk ervaring van die versamelde vertellings na vore te bring. Hierdie verhale is gemik op die verkryging van 'n dieper insig in wat 'n borskanker diagnose en die gepaardgaande behandeling behels. Die vernaamste metode vir die insameling van die ervarings van die deelnemers is in-diepte onderhoud. Die onderhoudskedule is ontwerp om die individu toe te laat om uit te brei oor relevante onderwerpe vir die doeleindes van die studie. Gedurende die onderhoud, het meeste deelnemers hul vertelling verbreed deur dieper in hul persoonlike ervarings te gaan en hul unieke begrip bloot gestel deur die onthulling van meer persoonlike gedagtes oor hul borskanker ervarings. Dit het dus daartoe gelei dat die narratiewe analise met die volgende temas voorendag gekom het: die rol van godsdiens; vroulikheid en geslag; oorlewing en ondersteuning; die handhawing van normaliteit; en die mediese ervaring. Dit is ook duidelik dat hierdie agt vroue toegang het tot top gehalte mediese behandeling gegewe dat hulle almal behoort aan private mediese versekeringskemas. Dit weerspieël 'n baie spesifieke ervaring, soortgelyk aan voorbeelde in bestaande literatuur van vroue in eerste-wêreld lande wat soortgelyke diagnose en behandelings ondergaan.

Elke deelnemer brei uit op haar unieke begrip van haar siekte wat of 'n optimistiese of 'n pessimistiese houding weerspieël met betrekking tot haar self-konsep en

selfbeeld. Die deelnemers se self-begrip en houding (optimisties of pessimisties) word nou verbind aan die vlak van ondersteuning waartoe hulle toegang het, sowel as hul godsdienstige oortuigings, visie en begrip. Dit word weerspieël in hoe die siekte ervaar en aanvaar word en hoe hul huidige vooruitsigte daaruit sien teenoor toekomstige vooruitsigte.

Hierdie studie het ten doel om borskanker uit 'n humanistiese oogpunt te beskryf deur te luister na die persoonlike stories van individue wat reeds die diagnose en behandeling van borskanker ervaar het. Binne hierdie persoonlike vertellings streef ek daarna om die alledaagse begrip en persepsie van die siekte en die ervarings daarvan uit te brei.

## **KEY TERMS**

Social constructivism

Phenomenology

Breast cancer

Experiences

Self-understanding

Self-perception

Self-image

Femininity

Treatment trajectory

Support

Religion

## APPENDIX A: ETHICAL APPROVAL



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Ms H Strauss

2012-09-21

REC Reference nr 230408-011  
IRB nr 00006240

MS AK HEGGENSTALLER  
DEPT OF SOCIOLOGY  
FACULTY OF HEALTH SCIENCES  
UFS

Dear Ms Heggenstaller

**ECUFS NR 150/2012**

**PROJECT TITLE: BREAST CANCER AND THE MEDICAL ENCOUNTER: EXPERIENCES, PERCEPTIONS, NEGOTIATIONS AND TRANSFORMATIONS OF IDENTITY AND FEMININITY.**

- You are hereby kindly informed that the Ethics Committee approved the above project at the meeting held on 18 September 2012.
- Committee guidance documents: Declaration of Helsinki, ICH, GCP and MRC Guidelines on Bio Medical Research. Clinical Trial Guidelines 2000 Department of Health RSA; Ethics in Health Research: Principles Structure and Processes Department of Health RSA 2004; Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa, Second Edition (2006); the Constitution of the Ethics Committee of the Faculty of Health Sciences and the Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines.
- Any amendment, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.
- The Committee must be informed of any serious adverse event and/or termination of the study.
- A progress report should be submitted within one year of approval of long term studies and a final report at completion of both short term and long term studies.
- Kindly refer to the ECUFS reference number in correspondence to the Ethics Committee secretariat.

Yours faithfully

  
.....  
**PROF WH KRUGER**  
**CHAIR: ETHICS COMMITTEE**

Cc Dr K de Wet



## APPENDIX B: CONSENT FORM

**Research Title:** Breast cancer and the medical encounter: experiences, perceptions, negotiations and transformations of identity and femininity.

Thank you for considering participating in this study. The purpose of this study is to understand the personal testimonies of women diagnosed with breast cancer. This will be done by firstly looking at identity in terms of three aspects: the relationship between the self and illness; the sick-role; and femininity and secondly by recounting the participants' perspectives, reconstruction, and narration of the medical encounter (interaction with medical practitioners, language use, and negotiation/decision making).

Participation in this study is strictly voluntary and any possible identifying data will be held in the utmost confidence. The results of the data collected will be treated with the highest level of confidentiality. However, due to the small sample, certain characteristics will enable a level of identification. All participants will be provided with access to transcriptions, as well as final analyses as part of building in extra layers of trustworthiness and triangulation.

Your participation in this study will serve to provide a better understanding of what it is like to undergo a breast cancer diagnosis and how each individual re/negotiates their identity and their femininity. The study also aims at understanding how the medical encounter and the treatment trajectory affect participants' sense of identity (the relationship between themselves and the illness, the sick-role, and femininity). This study has the support and backing of the University of the Free State under the Department of Sociology.

As previously stated, participation is entirely voluntary and should you feel the need, you may withdraw from this study at any time.

Please complete the following section if you are willing to participate in this study.

Signature of participant: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of the researcher: \_\_\_\_\_

For any further inquiries regarding the research, please feel free to contact:

The Researcher, Alessandra Kim Heggenstaller: 082 563 8243

The Research Supervisor, Dr Katinka de Wet: 051 401 2918

## APPENDIX C: INTERVIEW SCHEDULE

### **Basic information:**

1. Name and surname
2. Age of participant
3. Marital status
4. Children
5. Religious affiliation
6. Occupation
7. Family history of breast cancer
8. Form of breast cancer diagnosis
9. The treatment trajectory (agreed upon and undertaken between the patient and physician)

### **The diagnosis**

1. Is this your first time being diagnosed with breast cancer?
  - a. If yes, can you give the exact date of diagnosis?
  - b. If no and breast cancer is recurrent, when was the first time you were diagnosed?
    - i. The latest diagnosed was made when?
2. How did you perceive breast cancer before your diagnosis?
3. How did you perceive breast cancer after your diagnosis?
4. Did you feel any form of responsible towards your breast cancer diagnosis?
  - a. If yes, why do you feel responsible?
  - b. If no, how do you rationalize this understanding or thought pattern?
5. What were your feelings and thoughts towards the diagnoses with regards to your future aspirations?

### **Identity and femininity**

1. What do you perceive identity to be?
2. What do you perceive your identity to be before the breast cancer diagnosis?
3. How did you perceive your identity after the breast cancer diagnosis?
4. What are your dominant roles on a day to day basis? (mother, wife, provider, etc)
  - a. How do these roles define who you are as an individual?
5. Within the different societal roles that you adapt to, how do you deal with being labelled as being sick and therefore classified into the sick-role?
  - a. How does the sick-role impact on your day to day functioning?

6. What is your perception of femininity?
7. What do you perceive your femininity to be before the breast cancer diagnosis?
8. How do you perceive your femininity after the breast cancer diagnosis?
9. How did you/ are you negotiating your femininity during your treatment trajectory?

### **The medical encounter**

1. Who was your attending physician?
2. Were you comfortable with your doctor and other health providers?
  - a. If yes, what were the characteristics and manners that promoted this relationship?
  - b. If no, what made you feel uncomfortable?
3. How did you perceive the medical encounter?
  - a. Did the doctor explain the diagnosis in lay terminology, thus making it easier for you to understand?
  - b. Did your Oncologist speak to you and try to comfort you after revealing you diagnosis?
  - c. Did the doctor include your values and views in devising a treatment regime, such as negotiating different treatment paths?
4. Did the medical encounter encourage you to broaden your knowledge on your form of breast cancer?
  - a. Did the media play a role in how you perceived and understood you breast cancer diagnosis?
5. Does the medical encounter play a role in how you re/negotiate your identity and femininity?
  - a. If yes, how did they aid you re/negotiating your identity and femininity?
  - b. If no, how did you re/negotiating your identity and femininity?
    - i. Would you explain how the medical encounter could improve their techniques to help you through this traumatic life event?

### **Support**

1. What do you perceive a support structure to encompass?
2. What are your views on breast cancer support groups?
3. Are you affiliated with any support groups?
  - a. If yes, what support group are you associated with?
    - i. How often do you attend these groups?
    - ii. Do you find these interventions supportive and helpful?
    - iii. Why do you find these groups supportive and helpful?



- iv. Do you find comfort in sharing your experiences and hearing other women's experiences and thoughts?
- v. How do you help each other deal with the challenging times?
- b. If no, where does your support come from?
  - i. Do you confide in family or friends?
  - ii. How does your family or friends help you deal with the challenging times?
- 4. Do you have any influences in your life that aid or support your transformation in re-discovering and/or re-negotiating your identity and femininity after the diagnosis?

### **Social interactions**

1. Since your diagnosis of breast cancer, has your social encounters and interactions changed?
  - a. If yes, how have they changed?
  - b. If no, how do you interact with others now that you have been diagnosed and are viewed as a sick individual?
2. Do you think age plays a role in how you view your diagnosis and its consequences?
  - a. If yes, what is your unique age related social needs?
  - b. If no, do you perceive your age to be a non-relevant factor in relation to your diagnosis?
3. Has your age related diagnosis changed your future aspirations?
  - a. If yes, how have your future plans changed?
  - b. What personal aspects have changed?
  - c. What aspects (spouse, children, reaching a desired old age) will be affected in your current future outlook?
  - d. If no, how do you continue with your perceived future goals without letting the diagnosis affect your day to day functioning's and personal understanding?
  - e. Do you not think that the diagnosis will change certain aspects of who you are and thus reflect in how you want to continue into your future?