A THERAPEUTIC UNDERSTANDING OF WOMEN SUFFERING THROUGH THEIR BODIES

by

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DECLARATION

"I declare that ***A Therapeutic Understanding of Women Suffering through their Bodies*** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references."

SUMMARY

This study is concerned with the nature of suffering as experienced by women struggling with problems related to the body. Since the body is viewed to be integral in the formation of a woman's identity and self-concept, any illness, ailment or deficiency associated with it may lead the woman to experience pain and suffering. To explore meanings of personal suffering related to the body three contexts have been chosen. These are familial breast cancer, eating disorders and infertility. Common themes of suffering that were co-constructed in the interviews between six women participants and myself form the basis of this study. These themes emerged through the process of social constructionism and dialogue. Through the process of language, personal realities and meanings were discussed and shared to elicit a greater understanding of the nature of suffering. A qualitative approach, using the case study method, was also adopted to provide rich descriptions of the different experiences with suffering. The case study presentations illustrate the linguistic domain between the participants and myself. It is hoped that the information presented in this study will contribute to a therapeutic understanding of personal suffering as experienced by women.

Key Terms**:** Suffering**,** the body, familial breast cancer, eating disorders, infertility, social constructionism, qualitative research, case study, co-constructed realities, meaning in suffering.

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CHAPTER 1

INTRODUCTION

About suffering they were never wrong,
The old Masters: how well they understood
Its human position; how it takes place
While someone else is eating or opening a window
or just walking dully along.

(W.H. Auden)

Understanding and exploring the nature of personal suffering as experienced by women is the cornerstone of this thesis. It focuses primarily on the suffering women endure with regards to their bodies. Since the body is integral to the formation of a woman's identity and self-concept, any illness, ailment or deficiency related to it may result in the woman experiencing pain, misery, distress and suffering. To explore meanings of personal suffering, this study will consider three contexts grounded within socially constructed and culturally defined beliefs. These are familial breast cancer, eating disorders and infertility. It is hoped that the information presented in this study will contribute to a therapeutic understanding of personal suffering as experienced by women.

Suffering

For many individuals suffering is considered to be an essential ingredient of life (Israel, 1982; Kreeft, 1986; Longford, 1990). Just like love and hate, suffering and happiness are basic elements of human life affecting each and every individual. The nature and extent to which it occurs also varies amongst individuals. For some, it is part of a growth process – a means of gaining a deeper sense of existence and meaning (Israel, 1982; Kreeft, 1986). For others it is considered to be punishment for a sin committed – a "fierce, bestial thing, commonplace, uncalled for, natural as air" (Cesare Parese, in Soelle, 1975, pg. 84; Israel, 1982; Kreeft, 1986). It is viewed as an

incomprehensible mystery holding no understanding or explanation – "random and pointless, distributed according to no rhyme or reason but mere chance, and working no good, no end" (Kreeft, 1986, pg. 10). It is an experience which right from the beginning begs the question "Why me?" and then proceeds to leave the individual broken and shattered, empty and lost (Connelly, 1999; Greenberg & Bolger, 2001).

Suffering can be defined as a "syndrome of some duration, unique to the individual, involving a perceived relentless threat to one or more essential human values creating certain initially ominous beliefs and a range of related feelings" (Reed, 2003, p. 10). It is the matrix in which "fears, altered beliefs, and related emotions develop and in which they are embedded" (Reed, 2003, p. 11). It is also an experience from which distress, misery, anguish and agony emerge and which leads to an array of feelings such as agitation, unhappiness, torment, anger, frustration, hopelessness, destruction, fear and worry. Suffering also embodies a person's inner experience and varies in source and intensity depending on time, person and place (Reed, 2003). It is a unique personal experience and fate that only the sufferer is able to perceive and which he/she tries to understand by reflecting on its source and meaning (Gerstenberger & Schrage, 1977).

Suffering is mostly evident in existential problems affecting our lives on a daily basis (Israel, 1982; Longford, 1990). Problems include physical pain, torture, mental health problems, death, ageing and natural disasters. Other problems involve disease, illness, past experiences, human accidents, past and present relationships. For Morse (2001), the nature of suffering involves loss: "the loss of pain-free existence, the loss of health, the loss of dignity, the loss of movement, the loss of an anticipated future, the loss of another, the loss of self" (p. 49). It involves "discomfort, anguish, distress, torment, pain, heartache, misery, anxiety, and affliction" (p. 49). We realise how little control we have over our destiny and how much we need to fight for survival in order to conquer the affliction (Israel, 1990). It is a universal occurrence affecting every individual irrespective of race, creed, culture or socio-economic class. It affects those who try to live good and honourable lives and those who resort to breaking laws and rules. Suffering knows no boundaries and affects one's physical, emotional and spiritual self.

Motivation for the Study

By understanding the nature of suffering in respect to women and bodily problems, health care professionals may be in a better position to provide appropriate assistance to women in terms of counselling and therapy. Hence, the purpose of this study is to explore, from a woman's perspective, the experience of personal suffering in relation to familial breast cancer, eating disorders and infertility. The specific objectives include understanding the meanings women hold regarding personal suffering, the nature of suffering, and ways of coping with personal suffering.

A process of dialogue will be used to allow women to discuss their experiences and feelings related to bodily suffering. Exploring meanings of personal suffering will be carried out through the case study method and the social constructionist perspective. Specific research questions include the following: What is the nature of suffering? What does personal suffering entail? In what form and through which experiences and emotions is suffering experienced? How do women see suffering in relation to their bodies? What are the effects of such suffering on women's lives? What can therapy do to alleviate suffering?

To answer these questions, I have chosen to focus on three women's issues – familial breast cancer, eating disorders and infertility. The connection between these three afflictions entails physical, bodily suffering and its subsequent emotional and social impact. The reasons for choosing these specific afflictions are the following. Firstly, they are problems that have been encountered most frequently in my private practice over the last four years. Secondly, they are issues that affect mostly women, although men may also suffer from familial breast cancer, eating disorders and infertility. Thirdly, all three issues affect women fairly early in their lives. Eating disorders usually originate during adolescence and early adulthood, while infertility and familial breast cancer affect pre-menopausal women. Fourthly, all these problems affect women on a physical, emotional and social level. In terms of the physical level the women's body is affected, as is their body image. On an emotional level, common emotional experiences are felt including feelings of anger, depression, fear, anxiety, denial and low self-esteem. On a social level, relationships with society, spouses, parents, friends, children and so forth are affected and possibly threatened.

Lastly, all three contexts have a certain degree of privacy, secrecy and shame attached to them. This is generally the case in infertility and eating disorders, and may affect women with familial breast cancer who choose to have prophylactic mastectomies as a precautionary means. Most women struggling with familial breast cancer, eating disorders and infertility may also choose to keep their experiences to themselves or share them only with close friends in fear of social stigmatizing. This often causes women to suffer alone.

To highlight these issues, this study will be divided into eight chapters. Firstly, Chapter 2 will commence with the methodology chapter. It will focus on different aspects of qualitative research as chosen for this particular study. It also describes the influence of social constructionist principles on qualitative research. The chapter will conclude with the research design for the study, including the research process, the focus of the study, the epistemological framework, information regarding the participants, inductive data analysis and the emergent design.

In Chapter 3 a brief literature review of the female body will be provided. A general introduction to the female body will focus on historical and present day perspectives. It also considers the feminist and social constructionist perspectives. The chapter concludes with brief descriptions of body issues related to familial breast cancer, eating disorders and infertility.

In Chapters 4, 5 and 6 the perceptions and meanings held by six participants regarding the research topic are presented in verbatim form. The chapters will not only consider the interviews, but will also focus on literature pertaining to the various emerging themes. This will allow the reader to infer personal distinctions and meanings.

Chapter 7 will present the researcher's meta-perspective of the meanings elicited in the conversations with the six women. In this chapter emerging themes will be discussed in relation to suffering based on my own perceptions and distinctions.

Chapter 8 concludes the study with a discussion of the main findings. Hypotheses that were created, confirmed and/or altered regarding suffering are presented. In this chapter a brief discussion of the study's objectives, recommendations and limitations is also given.

CHAPTER 2

METHOD

In research the horizon recedes as we advance,
and is no nearer at sixty than it was at twenty.
As the power of endurance weakens with age,
the urgency of the pursuit grows more intense…
And research is always incomplete.

(Mark Pattison – English Educationist)

The objective of this study is to provide a therapeutic understanding of personal suffering as experienced by women. The study aims to describe and explain the social constructs influencing women today regarding what is acceptable, beautiful and efficient in terms of the female body, and then to consider these socially accepted beliefs in relation to three contexts. The contexts that have been chosen for this study are familial breast cancer, eating disorders and infertility. The aim will be to understand and explore the beliefs held by women regarding their bodies and the personal suffering they experience with regards to the three contexts. The focus is not on the particular problem, i.e. familial breast cancer, eating disorders and infertility, but rather on the women's experiences of suffering. Due to the exploratory nature of this study, a qualitative research design based on social constructionist theory has been chosen. It is important to gather data that considers the lived experiences of women in the familial breast cancer, eating disorder and infertility contexts without defining preconceived and biased notions of the topic.

Qualitative versus Quantitative Research

The methodological approach chosen for this study is based on qualitative research methods. This approach is preferred because of its congruence with my personal epistemological and theoretical assumptions. It is my aim to bring to the fore

a therapeutic description of meanings surrounding the female body and the physical, emotional and social suffering that is experienced with regards to familial breast cancer, eating disorders and infertility. The research method and the manner in which data are analysed are determined by the epistemology according to which the research problem is defined (Keeney, 1979). In terms of my personal epistemology, meanings surrounding personal suffering will be explored and described within the qualitative approach and social constructionist perspective. A discussion of qualitative research will form the groundwork for the ensuing inquiry.

A new way of viewing individuals, systems and problems has evolved out of the traditional approaches to research. It is a shift that differs fundamentally from previous quantitative methodology and assumptions regarding 'reality' and 'objectivity' (Atkinson & Heath, 1987; Hoffman, 1990; Lincoln & Guba, 1985; Shapiro, 1986). One such difference entails the researcher being "fully but not exclusively involved in the research thinking" (Heron, 1996, p. 26). This means that the researcher invites the participant to be partially involved in the research process while he or she is just as partially involved. In essence, the qualitative approach studies people *in situ,* i.e. in their own social setting, and tries to understand the participants in terms of their own categories, constructs, perspectives and epistemologies (Heron, 1996). Also, "qualitative research is concerned not just to understand, but also to empower, informants" (Heron, 1996, p. 28). This means that research may be carried out for various reasons. It may be carried out either because it is interesting, or because such knowledge will be useful or empowering to other people including the reader and the participants (Heron, 1996).

Firstly, quantitative or positivistic research is based on the idea that there is an external or 'out there' single and tangible reality. It is an approach that fragments independent variables, captures sensory data and processes it so that it is controllable and predictable (Lincoln & Guba, 1985; Reason & Rowan, 1981). Secondly, there is no subjectivity since researcher bias may influence and contaminate data (Atkinson & Heath, 1987; Lincoln & Guba, 1985; Shapiro, 1986). The researcher is seen to have the ability to predict and control representational knowledge and to reduce such knowledge of patterns and experience into quantities that can be measured. The researcher also "designs the project unilaterally, manages it directively without

consulting the subjects, and does not in any way engage in the behaviour that is being researched" (Heron, 1996, p. 25). Conclusions about the subjects' behaviour are then drawn exclusively by the researcher in terms of his or her own categories and theoretical constructs (Heron, 1996). These categories and constructs lead the research, define it and remain constant throughout (Heron, 1996). In terms of measuring data, generalisations of descriptions are ultimately seen as statements of truth that do not take into account aspects of time nor the complexities of social relationships and contextual factors (Bogdan & Biklen, 1992; Harré, 1981; Keeney, 1979; Lincoln & Guba, 1985). The researcher also avoids the depth that would occur in internal processes and activities, and thereby overlooks metaphysical assumptions, sensation and direct experience (Lincoln & Guba, 1985).

Quantitative methods include experiments in which "matched subjects are randomly assigned to experimental and control groups; quasi experiments that use nonrandomized designs such as non-equivalent control group designs and time series designs; single case experimental designs; surveys, including cross-sectional and longitudinal studies using questionnaires or structured interviews" (Heron, 1996, p. 25). The researcher will do all of the research thinking and decision-making and will not allow the research to be influenced by assumptions, theories, social or cultural norms, hypotheses, personal or individual perspectives and values of the researcher him/herself (Heron, 1996; Moon, Dillon, Sprenkle, 1990). Social intricacies and experiences that occurred between the participants and the researcher are not discussed or considered, but are rather reduced to theoretical terms that do not truly represent the actual experience (Bogdan & Biklen, 1992; Harré, 1981; Lincoln & Guba, 1985).

Quantitative research tends to ignore the human right of individuals to participate in decisions that aim to gather knowledge and information about themselves, especially since everything they do is under the 'exclusive control' of the researcher. Knowledge is therefore not grounded in the experience of the participants. They have not been consulted or involved in the selection of the constructs which are used to make sense of their experience (Heron, 1996).

By contrast, qualitative or naturalistic research refers to a process of inquiry that takes into account the mutual collaboration between the researcher and the observer. It is a suitable paradigm for investigating social relationships and contextual situations. Since it focuses on contextual and descriptive research, complex interrelationships between events and their natural environment are observed (Lincoln & Guba, 1985; Moon et al., 1990). As Lincoln and Guba (1985) write, "the outcome of naturalistic inquiry is a reconstruction of the multiple constructions that various respondents have made" (p. 212). One of these relationships involves the interaction between researcher and subject/s (Heron, 1981a; Moon et al., 1990; Reason & Rowan, 1981). Although the researcher organises and manages the research, he or she is constantly involved in a process of negotiation with the participants in their natural setting. By trying to understand the participants' world of experience, knowledge and meaning emerge from the project as the participants enter into a process of interaction with one another. In this recursive process, the researcher's account of the participants' experiences and perspectives is validated by the participants themselves such that credibility is established within the research process (Heron, 1996; Lincoln & Guba, 1985). Recursion is essential in the interviewing process as it follows the view that all parts within a system simultaneously act on each other (Boscolo, Cecchin, Hoffman & Penn, 1987; Keeney, 1979). Such recursion or circularity refers to individuals who are connected to each other in particular patterns through time (Boscolo et al., 1987). For example, "person *A* does not only effect person *B* without taking equally into account that whatever *B* does influences *A*'s next move and that they are both largely influenced by, and in turn influence, the context in which their interaction takes place" (Watzlawick, Beavin & Jackson, 1967, pp. 35-36). The researcher becomes a part of the participant's world and acts as a participant observer and data gatherer of the participant's experiences, perspectives and behaviours.

This implies that the researcher and the participant's relationship is examined within a specific time and context in terms of the "simultaneous interactions of all parts" (Keeney, 1979, p. 124). Neither the researcher nor the participant is seen as a separate or discrete entity but rather as inseparable and working together in a recursive and mutually influential world (Bogdan & Biklen, 1992; Heron, 1981a; Keeney, 1983; Lincoln & Guba, 1985). These interactions contribute directly to

hypothesis-creation, to formulations of conclusions and to processes in the interactions. Since naturalistic inquiry is value-bound, the research is influenced by the values of the inquirer, by his/her underlying epistemology, and by the values inherent in the context (Lincoln & Guba, 1985). The inquirer and the 'subject' of inquiry are seen in interaction with one another such that mutual influencing takes place (Reason & Rowan, 1981). Qualitative research further demonstrates that 'reality' and 'truths' continuously change with the passing of time and that they are based on social interpretation and intersubjective influences of language, past experiences, contexts and cultures (Bopp & Weeks, 1984). Since qualitative research purports to a lack of 'objectivity' or 'real world' (Maturana, 1988; Osbeck, 1993), social and historical phenomena are constructed through individual and societal interactions, which ultimately only remain partial and subjective viewpoints (Gergen, 1985; Lincoln & Guba, 1985).

Finally, qualitative research as compared to quantitative research is concerned with social processes. It is common for interviewers doing quantitative research to avoid probing beyond the 'yes' or 'no' responses (Jones, 1991). The interviewer acts as a detached 'outsider' or 'objective observer', while the qualitative researcher becomes an 'insider' in the research relationship. The researcher begins to interact with the participant, instead of just establishing a 'rapport' with the people to whom he/she is speaking and observing (Jones, 1991, p. 203). As a result, the presence of the researcher, as well as his/her personal epistemology and experience, are variables that have to be taken into account since "all researchers operate from within a theoretical overview and … affect the data at all stages" (Scott, in Jones, 1991, p. 203). Whereas quantitative research does not take into consideration changes that affect participants over a period of time, qualitative research takes into consideration time and changes that influence participants in the collection of adequate data (Allan, 1991). Instead of assuming "interval or ordinal data which are amenable to statistical manipulation", qualitative approaches reflect data based on the "perspectives, culture and 'world-views' of the actors involved" (Allan, 1991, p. 178).

Aims of the Study

The aim of this study is to show the relevance between my own constructs as well as those of the participants such that one is able to make sense of their personal experiences. The study will focus on meanings that emerge from human interactions, particularly those between the research participants and myself, while data will include the behaviours, experiences and meanings of participants within the research setting (Hoffman, 1990; Moon et al., 1990). Their experiences, meanings and points of view regarding suffering will not be quantified nor explained in terms of measurable data, but instead will be understood in terms of a particular setting and in terms of the meanings that they bring into the interviewing context (Heron, 1996). They will not be seen as objects with behaviours that can be readily measured, but rather as active participants with their own epistemologies, frames of reference, and experiences.

In this study, six women will be interviewed regarding their experiences with familial breast cancer, eating disorders and infertility. The emphasis of these interviews will be on equality and closeness rather than formality (Bogdan & Biklen, 1992). The six women will be interviewed over a period of weeks and months and the sessions will not be fixed in terms of their duration. Subjectivity and researcher bias will form part of the research process and will be made explicit throughout the thesis. I hope that the emerging experiences and meanings from the interactions between the participants and myself will lead to personal understanding, growth and development within the context of personal suffering. I also hope that the research emanating from this study will be used by the participants and the readers to gain a greater awareness of personal suffering in relation to familial breast cancer, eating disorders and infertility.

Descriptive Research

In descriptive research, data are not gathered nor are hypotheses proved or disproved (Bogdan & Biklen, 1992). It is also not referred to as data 'making' or data 'generation'. Rather, interviewing is understood as an interaction domain between participant and researcher drawing upon their respective cultural knowledge (Baker,

1997). The interviews are more or less an accurate description of experience as well as representations of reality (Holstein & Gubrium, 1997). Questions posed by the researcher to the participant are thus important for the research in that they cannot be viewed as neutral, but rather as playing an instrumental role in shaping how and what a participant shares in the interview. When responses are given to such questions they will be treated as a true account of their realities or as the "generation of versions of social reality built around categories and activities" (Baker, 1997, p. 131).

In this study, the conversations with the women will be described as truthfully as possible to lay the groundwork for descriptive research. Since all participants in an interview are inevitably joined together to make meaning (Holstein & Gubrium, 1997), generalisations and simplifications will be avoided because of the multiple and varying realities that exist.

Natural Setting

Qualitative or naturalistic research is carried out in the "natural setting or context of the entity for which study is proposed" (Lincoln & Guba, 1985, p. 39). The term 'natural' means that the phenomenon which is being understood is seen within the "relationship to the time and context that spawned, harbored, and supported it" (Lincoln & Guba, 1985, p. 189). This implies that by carrying out research in a specific context, existing realities will be seen contextually and not in isolation (Lincoln & Guba, 1985; Orford, 1992). Research can not fragment the reality into different parts but needs to take into account the entire context of the women's suffering and their interaction with the researcher (Hoffman, 1990). To separate the words, feelings and behaviour of the women's conversations from their context will contribute to a loss of valuable and meaningful descriptions (Bogdan & Biklen, 1992; Lincoln & Guba, 1985). Another characteristic is that researchers doing qualitative or naturalistic research spend time with their participants in their natural settings (Bogdan and Biklen, 1992). By spending time with them, the relationship becomes less formal and the researcher is able to help the participant feel more at ease to talk. Building this trust and making it clear to the participants that the information gained will not demean or otherwise hurt them is essential.

When the researcher joins the subject's world, he or she remains concurrently detached. The researcher may learn how the participants feel and think, but will not feel and think like the participants. He or she may learn from the participants' experiences, but will not necessarily be like them. Finally, the researcher will be involved in the natural setting, but will still collect and keep various forms of descriptive data, written or taped records of what has taken place (Bogdan & Biklen, 1992). In this study, the choice of the natural setting will be flexible and negotiated by the participant and the researcher. If other individuals, such as spouses or children, enter the context then these will be seen as part of the natural setting since they are instrumental in shaping the participants' setting and behaviour just as much as the researcher. In terms of the natural setting it is also important to consider the women's thoughts, feelings and actions as related to their personal world and life.

Case Studies

A case study can be defined as a "detailed description and analysis of an individual case" (Becker in Jorgensen, 1989, p. 19), or a detailed examination of a setting, a single subject, or one particular event (Merriam in Bogdan & Biklen, 1992). Case studies "stress the holistic examination of a phenomenon, and they seek to avoid the separation of components from the larger context to which these matters may be related" (Jorgensen, 1989, p.19). The case study may also involve the study of a culture, a society, a community, a group, an individual, beliefs, practices or any human behaviour. Within this structure, the researcher attempts to describe in a comprehensive manner a specific research problem and look at its particular meanings.

A case study is like a funnel in which researchers begin by asking questions that are not too specific, and then end by making the study wider. Researchers "scout for possible places and people that might be the subject or the source of data, find the location they think they want to study, and then cast a wide net trying to judge the feasibility of the site or data source for their purposes" (Bogdan & Biklen, 1992, p. 62). They decide how to divide their time, whom to interview, what to explore in depth, and which ideas to hold onto or reject. The design is continually modified and only with time, are specific decisions made regarding which part of the setting,

participant or data source will be studied. Once this is achieved, a research focus is developed, data collections are carried out and data analysis is done.

The case study method has been chosen for this particular study as it deals with the uniqueness of specific social worlds. It also deals with the identification and reconstruction of perspectives, patterns of action and interaction that constitute different social worlds (Miller, 1997). It incorporates the following characteristics as suggested by Lincoln and Guba (1985). Firstly, an "explication of the problem, evaluand, or policy option that is the occasion for the study". Secondly, "a thorough description of the context or setting within which the inquiry took place". Thirdly, "a thorough description of the transactions or processes observed in that context that are relevant to the problem, evaluand, or policy option". The latter two items are vital for "thick descriptions" to emerge. A fourth aspect to the case study is that it provides the research process with a "discussion of the saliencies that are identified at the site; that is, those elements identified as important that are studied in depth". And finally, "a discussion of outcomes of the inquiry", which are referred to as the "lessons to be learned" from the study (Lincoln & Guba, 1985, p. 362).

Purposive Sampling

All sampling is usually done with some purpose in mind (Lincoln & Guba, 1985). Usually, the main goal is to include as much information as possible, especially as qualitative research and naturalistic investigations place so much emphasis on contextual factors. Detailing the "many specifics that give the context its unique flavor" is thus essential (Lincoln & Guba, 1985, p. 201). In choosing this approach, the presence of multiple realities, mutual shapings and local values will be observed, documented and explored, and in this way, sufficient information will be generated for the rise of an emergent design (Hoffman, 1990; Keeney, 1983, Lincoln & Guba, 1985). Through purposive sampling, the researcher will be able to "adjust his control of data collections to ensure the data's relevance to the impersonal criteria of his emerging theory" (Glaser & Strauss in Lincoln & Guba, 1985, p. 201). Finally, the researcher will choose specific subjects to include in the research study since they are "believed to facilitate the expansion of the developing theory" (Bogdan & Biklen, 1992, pp. 71-72).

Inductive Data Analysis and Emergent Design

Data analysis can be defined as the process of "systematically searching and arranging the interview transcripts, field notes, and other materials that you accumulate to increase your own understanding of them and to enable you to present what you have discovered to others" (Bogdan & Biklen, 1992, p. 153). It is also the process of "'making sense' of field data" (Lincoln & Guba, 1985, p. 202). In this study, data analysis will involve working with the transcribed data and organizing these into units. These will highlight patterns and meanings inherent in the study and make embedded information more explicit.

In qualitative research, data analysis aims to produce data that can be used to "apply, extend and elaborate" on issues that are important to any research topic (Miller, 1997, p. 26). Such data analysis becomes a way of producing data that depicts social reality or social constructs while constructed meanings are grouped together by the researcher to form the basis of the data gathered (Goolishian & Anderson, 1987). One way of grouping constructed meanings together is through the development of a coding category or system, which allows the researcher to organise data. This process is similar to *content analysis*, and involves the uncovering of 'embedded information' (Lincoln & Guba, 1985). The analysis seeks 'themes' revealed across the interviews, including information such as the participants' thoughts, beliefs, attitudes, knowledge, perspectives and so on. Since these are expressed through language, such content is categorized and rearranged into themes which are recursively influenced by the researchers' assumptions regarding social reality (Baker, 1997; Miller, 1997).

Since data gathering progresses inductively, it is impossible for the researcher to determine at the outset of the research what exactly will emerge in terms of meanings and knowledge (Baker, 1997). The validity of the research only concerns the interpretations of the observations as they emerge in the conversation between researcher and participant. Theory developed in this way emerges from the bottom up rather than from the top down and is termed 'emerging theory' (Bogdan & Biklen, 1992; Lincoln & Guba, 1985). The theory emanates from collected data generated out of the interactions and interviews between the researcher, the participant and the

natural setting, while emphasis is placed on the meanings and multiple realities as determined by the context, the participant and the researcher (Lincoln & Guba, 1985).

Legitimisation

A possible disadvantage of qualitative research is that findings may be too subjective and uncontrolled (Atkinson, Heath & Chenail, 1991; Bogdan & Biklen, 1992; Lincoln & Guba, 1985). Qualitative research methods have also been criticized as being impressionistic and non-verifiable (Allan, 1991). For Atkinson et al. (1991), the legitimisation of research findings is not always determined by the research but by the reader/observer who has access to the research design and who thus provides communal judgement. In qualitative research, the reader/observer needs to be aware that the researcher can develop themes with respondents as they emerge and thus not adhere to a previously set formula. He or she must be made aware of the possibility of the researcher influencing the 'findings', and of such a study being prone to replication (Allan, 1991). The researcher must then present his or her personal way of organising experience to gain access into the process of inquiry as well as information and knowledge about the research topic (Allan, 1991; Atkinson et al., 1991). Gaining access to the researcher's personal process of drawing distinctions will allow the reader/observer to infer his or her own distinctions and punctuations about the research topic.

Trustworthiness

Another aspect involved in qualitative research is trustworthiness. Gaining trust is important in that it influences the exploration of issues grounded in the experiences of individuals (Treleaven, 1991). Trustworthiness includes the following four criteria: credibility, applicability, consistency and neutrality. In terms of credibility, the researcher needs to "carry out the inquiry in such a way that the probability that the findings will be found to be credible is enhanced and, second, to demonstrate the credibility of the findings by having them approved by the constructors of the multiple realities being studied" (Lincoln & Guba, 1985, p. 296). In this respect, it is vital that the researcher and the participant collaborate with one another to avoid biases within the research (Heron, 1996).

Finally, the research process for this study will be based on qualitative research principles and will make subjectivity and researcher bias explicit (Lincoln & Guba, 1985; Moon et al., 1990). It is assumed that the researcher and participants of this study are not objects or instruments, but rather participants with personal assumptions, frames of reference and values. The researcher will also take the role of a participant observer who will interact with the women participants over a period of time. During this time we will share in the research process, and together will co-create notions of suffering through the use of language and conversation (Anderson & Goolishian, 1988; Boscolo et al., 1987). Through our conversations, new social discourses, themes and meanings will emerge, hopefully contributing towards a greater understanding of personal suffering. To understand how these meanings emerge in language, a brief description of social constructionist principles is provided.

The Influence of Social Constructionist Principles on Qualitative Research

A major contribution to the language that researchers use to make sense of action and experience has come in the form of social constructionist thinking. This perspective focuses on the meaning creation process that takes place amongst individuals. Social constructionism emphasises the social process of language which is central to everyday life and experience, and which permits the construction of meanings and beliefs about existing realities that are never fixed or finite, but rather in a constant process of evolution and co-construction (Anderson & Goolishian, 1988; Cecchin, 1992; Cromby & Nightingale, 1999; Hoffman, 1992; Gergen, 1985; Owen, 1992).

Description of Social Constructionist Thinking

The main focus of this study is to describe what suffering is and how it affects women in different social contexts. To elicit the meanings and experiences of personal suffering, the study will focus on the language process that occurs amongst individuals within the research process. Social constructionists draw attention to the role of language and to the meaning process surrounding specific structures (Willig,

1999). In terms of this study the meaning structures are familial breast cancer, eating disorders and infertility. Since an individual's existence and knowledge of the world is not created nor experienced in isolation, it is essential to view the participant as part of a social domain where meaning structures and language processes exist (Anderson, 1992; Hoffman, 1992). This notion is based on the principle that language is a valuable tool for "representing and communicating knowledge" (Pujol & Montenegro, 1999).

Social constructionism also forms part of post-positivist thinking (Anderson & Goolishian, 1988). Firstly, it claims that all knowledge is historically and culturally specific and does not adhere to 'fact' or 'truth' since knowledge is embedded in and produced by a system of values and power relationships. Secondly, it reframes phenomena (problems such as alcoholism, eating disorders, infertility, familial breast cancer, criminality and mental distress) as being constructed in the social realm of social structures and power relationships. Thirdly, language is seen within the field of psychology as center-stage and as highly constructive (Anderson & Goolishian, 1988). Language is not viewed as simply a tool with which to communicate or as passive and unproblematic (Burr, 1999). Rather it "allows people who share a common tongue to generate a common currency of concepts and meanings. It is through their dealings in this common currency that people fabricate their world" (Burr, 1999, p. 115). Social constructionism describes the generation and construction of knowledge and follows the view that human systems exist only in the "domain of meaning or intersubjective linguistic reality" (Anderson & Goolishian, 1988, p. 375). It places emphasis on "social interpretation and the intersubjective influence of language, family, and culture…" (Hoffman, 1990, p. 2).

Within this perspective, human systems are considered language systems in which people generate meaning with one another through a process of language and conversation (Anderson & Swim, 1993). When this occurs, learning is made possible through the generation of new knowledge. Social interactions give rise to a set of evolving meanings wherein individuals are able to develop their own identities, scripts and personal meanings in the world. The individual's unique meaning systems are what allow him/her to make sense of personal experiences which will allow for the creation of personal and livable realities (Atwood & Ruiz, 1993). Shared

ecologies of meanings are thus co-constructed amongst people so that an intersubjective, co-constructed and negotiated reality is created to give an individual personal meaning. Such generated meaning and understanding is essential for all human interaction, especially as people "come to describe, explain, or otherwise account for the world (including themselves) in which they live" (Gergen, 1985, p. 266).

For Lax (1992), discourse is a process of conversation that takes place amongst individuals, groups, communities and larger networks. It involves conversations with others in that specific meanings and beliefs inherent in our daily lives are created and maintained. These discourses do not, however, mirror reality but instead describe interactions between people within certain contexts and during specific periods. An objective and absolute reality 'out there', independent of the observer, does not exist as a single truth (Lincoln & Guba, 1985). Instead, such a reality is constructed within relationships and mediated through the process of language. As Anderson and Goolishian (1998) point out, the 'problem' has existence only in language and is a "form of co-evolved meaning that exists in ongoing dialogical communication" (p. 379).

In this study, the conversations of the women and the researcher will be viewed as part of a social domain where meaning structures and language processes exist (Anderson, 1992; Griffith, Griffith & Slovik, 1990; Hoffman, 1992). Since the work of the therapist is to foster dialogue, the process of talking about certain issues will lead to the development of "new themes, new narratives and new histories…" (Anderson & Goolishian, 1988, p. 381). Furthermore, the languaging process between the women and the researcher will enact a "dance of verbal and nonverbal behavior" (Griffith et al., 1990). Knowledge will emerge through generative conversation (a dialogue which involves 'talking with' as well as a "co-exploration that leads to the co-development of alternative views, new learning, and solutions") (Anderson & Swim, 1993, p. 146). As Berger & Luckman (1967) point out, conversations and dialogue co-create knowledge such that it may be considered as a social invention. These inventions may arise regarding the meaning of suffering on a physical, emotional and social level as pertaining to problems such as familial breast cancer, eating disorders and infertility. However, since epistemologies and socially

constructed meanings are never fixed or finite, the reader must bear in mind that meanings may evolve and shift over the course of the study as seen within the context of dialogue, historical and societal changes (Gergen, 1985).

Criticism of Social Constructionism

The social constructionist perspective has been chosen for this study mainly to highlight the domain of social interaction between the researcher and the participants. Despite the value that social constructionism can bring to the qualitative research process, a criticism leveled against social constructionism must be mentioned briefly. According to various authors, social constructionism does not take into account the body as an important medium for meaning generation (Burr, 1999; Merleau-Ponty in Burr, 1999; Merleau-Ponty in Moi, 1999; Moi, 1999; Radley in Burr, 1999). It does not see the body as being responsible for the creation of meaning and knowledge but seems to ignore the capacity of the body to create and express meaning just as language processes do within social structures. In the past, for example, the body was regarded as simply a physiological and neurological function that produced mental and behavioural functions. This meant that important aspects of personal experience were marginalized and ignored. For Burr (1999) and Moi (1999), however, experience *can* be achieved through the body. These authors wish to make individuals and social systems aware of the body as a central and important function in the creation of meaning. Because humans are embodied, they have direct access to the world and are the origins of experience. Meaning must then not be seen as exclusively subjugated to discourse but also achievable through the body (Burr, 1999). It should be recognised as having expressive powers (Radley in Burr, 1999).

In this study it is not my aim to ignore the importance of the body as a meaning-making tool. Rather, the aim is to consider both points of view - the importance of the body as a situation or meaning-making structure and the importance of language within the research process - so that new meanings regarding personal suffering are created. It is my belief that both concepts have an important role to play in the creation of meaning and knowledge. As Merleau-Ponty points out, the relationship between embodied experience and language should be seen as a

"dialectical process in which each depended on the other for its form of expression" (Burr, 1999, p. 25).

The Research Design for this Study

The previous sections have highlighted the basic characteristics of qualitative research and social constructionist principles. In this section, a discussion of qualitative research principles that have been used for this study is provided. These include the research process, the focus of the study, the epistemological framework, choosing, contacting and interviewing the participants, the data analysis and the limitations of the study.

Research Process

Issues of personal suffering in women struggling with familial breast cancer, eating disorders and infertility have become salient in my work as a therapist during the last two years. In discussing their suffering within the therapeutic context, clients have revealed intimate accounts of their multiple realities and epistemologies. According to Keeney (1983) an epistemology can be defined as a process that specifies how one thinks, acts, knows and decides. It refers to a belief system or personal framework in which an individual operates on a daily basis, and which is fundamental in providing him or her with a way of ordering life as constructed through personal and meaningful experience (Becvar & Becvar, 1988). For Auerswald (1985), epistemology is a way of 'thinking about thinking' in which a closer look is given to the rules that govern thought processes and the expression of knowledge (p. 1).

In the context of private practice, listening to these varying epistemologies has made me aware of a deeper suffering that many women experience on a daily basis. Themes of survival, happiness, self-esteem, loss and loneliness are usually discussed and questioned, together with a search for meaning into dealing with specific problems. A first step in the therapeutic process is thus to elicit meanings and experiences of personal suffering. Once this has been done, both the client and the researcher can then move onto another level of finding new meanings regarding the

suffering. The title *A Therapeutic Understanding of Women Suffering through their Bodies* has been selected to highlight personal physical, emotional and social pain that women experience with regards to bodily problems. It considers the nature and significance of personal suffering within three different contexts namely, familial breast cancer, eating disorders and infertility.

The contexts - eating disorders and infertility – have been selected due to the amount of clients that have been seen with such problems in my private practice. The familial breast cancer context was chosen because of my involvement in the Familial Breast Cancer clinic at the University of Pretoria. Participating in the clinic led to the initiation of this research process. The clinic required the assistance of a therapist to provide counselling to women at risk for breast cancer. Based on the limited amount of research into familial breast cancer and psychological factors, it was felt that an inquiry into emotional and psychological pain would benefit long-term treatment. This led me to consider the theme of personal suffering not only within this context but also within the two other contexts where bodily suffering is also experienced.

Focus of the Study

In this study, the research focus will consider the experiences of women who suffer with familial breast cancer, eating disorders and infertility. The study will focus on relevant questions regarding suffering such as: "What is suffering?" "What does it entail?" "How do women cope with suffering?" "Is there meaning in suffering?" Research that focuses on such experiences is defined as the "kind of research on persons in which the subjects of the research contribute not only to the content of the research, i.e. the activity that is being researched, but also to the creative thinking that generates, manages, and draws conclusion from the research" (Heron, 1981b, p. 153). The focus is thus not on solutions, cause and effect, end results, proof or generalisations, but rather on the personal and unique aspects of the participants, as well as their interactions with the researcher. The descriptions of their experiences will disclose the meaningfulness of the study.

Although much information can be obtained about suffering in religious and medical literature, an understanding of suffering in terms of psychological literature

has been limited. It is my aim therefore for this study to provide a suitable and valuable understanding of suffering in terms of emotional and psychological issues. To accomplish this I intend to make the reader aware of the meaning of suffering through the experiences of six women struggling with familial breast cancer, eating disorders and infertility. Since the focus is mainly on suffering experienced by women, further research into the suffering of men regarding similar issues is deemed beneficial and pertinent.

As mentioned before, the purpose of this study is not to discover truth and objectivity, but rather to co-evolve and co-construct a new understanding of suffering with the participants. Also critical to the study, are the participant's experiences and assumptions regarding personal suffering. It aims to provide a descriptive discussion of the meanings that women have regarding their personal suffering, not forgetting the personal meanings and epistemology of the researcher who will interact with the women recursively (Hoffman, 1990; Keeney & Morris, 1985).

Epistemological Framework

It is assumed that the researcher and the participants view the world and their suffering (familial breast cancer, eating disorders and infertility) in a unique and idiosyncratic way. Multiple realities and meanings are thus essential to the inquiry context and will provide answers to the research questions. All individuals have their own particular view of the flow of interaction with themselves and others, leading to a variety of multiple descriptions and realities. The creation of these multiple realities is inevitable in any context under observation (Bateson, 1979; Keeney & Ross, 1992). Multiple realities or personal epistemologies are created in language and are context-specific. The notion of one 'true' set reality or one 'true' set of meanings is rejected, while the emergence of multiple realities are encouraged in order to provide the research topic and the reader with a greater description of suffering.

The above assumptions are based on social contructionist constructs, which were discussed earlier in this chapter. The belief is that the researcher and the participants will co-create the reality of the problem through recursive and linguistic interactions such that new ideas co-evolve. According to Maturana (1975) this is

called the 'consensual domain' in which realities emerge through the means of language and co-construction. It is hoped that the discussion and the mutual interaction will "evolve in a direction where the consensual definition of the problem as a problem is no longer central" (Fourie, 1996, p. 15). It is hoped that women's epistemologies regarding familial breast cancer, eating disorders and infertility will take on different meanings which can provide the researcher, the participant, the reader and the psychotherapist with a new understanding of suffering.

Meanings and constructions will then be identified and distinguished by the researcher into specific patterns and themes (Keeney, 1982). Punctuating the co-evolved meanings into patterns and themes is based on the researcher's unique and personal frames of reference. It must be kept in mind, however, that these themes do not describe reality as it is, but rather as an 'approximation' of the client's world (Keeney, 1982, p. 162).

Choosing the Participants

Six women, two for each context, were chosen for the study. Women aged 25 and older and from different backgrounds were included in the study. Two were chosen from the familial breast cancer clinic, two from the researcher's private practice, and two were referrals from a physiotherapist and psychologist. Only six women were interviewed in order to afford me the opportunity to be involved with each woman for a longer period of time, thus rendering their experiences more significant and meaningful.

Purposive sampling was used in this study in that the six women were not selected randomly but rather purposively (Lincoln & Guba, 1985). All six women were chosen deliberately because they met the study's goals, i.e. two with familial breast cancer, two with eating disorders and two with infertility. In order to reduce cultural biases and complications inherent in misunderstandings and misinterpretations related to other languages, it was decided to only interview women who spoke English. Speaking any other language would have made it difficult for me to ask specific questions related to the research topic. It would also influence the questions asked and the answers given.

The women in this study were thus distinguished according to the following criteria. Firstly, they all had to be women over the age of 25. Secondly, they had to suffer from problems in one of the three contexts. For the first context, participants had to have a family history of breast or ovarian cancer, i.e. a genetic risk of developing breast and/or ovarian cancer irrespective of whether they had it before or not. In the second context, participants had to suffer from eating disorders, which could entail anorexia nervosa, bulimia nervosa, compulsive overeating or obesity. Finally, in the third context, participants had to suffer from infertility, irrespective of whether the problem involved the women or their partners.

Contacting the Participants

For Lincoln and Guba (1985) it does not matter where the inquirer begins in the sampling process. Usually, the entry route begins with gatekeepers and key persons (Jones, 1991; Lincoln & Guba, 1985; Rees, 1991). These are people in important organisations and/or socially defined roles who make known prospective informants to the researcher (Lincoln & Guba, 1985). The gatekeepers in my research study included the breast cancer clinic, my private practice, and two health care professionals (a physiotherapist and a psychologist).

All six participants were asked if they would be willing to be part of the research process. Once they agreed to be interviewed, they were contacted telephonically and an appropriate time and place was set up. They were informed about my aims and assumptions regarding the research project and were assured of confidentiality. They were informed about the interviews taking on an unstructured format as well as the need to record the interview for practical transcription purposes. They were informed that no certain number of interviews would be stipulated and that they could choose to continue or withdraw from the investigation at any time. Finally, they were told that the aim was to gather information about their experiences and that psychotherapy would not be carried out. No benefits in terms of therapy or solution-focused therapy would emerge from their participation in the study.

Interviewing the Participants

Interviewing can be considered as a social encounter in which knowledge is constructed. This suggests that the interview is not "merely a neutral conduit or source of distortion, but is instead a site of, and occasion for, producing reportable knowledge itself" (Holstein & Gubrium, 1997, p. 114). Furthermore, participants are not considered to be informers but rather "constructors of knowledge in collaboration with interviewers" (Holstein & Gubrium, 1997, p. 114). It was with this in mind that unstructured interviews were conducted between April 2002 and September 2004. The interviews varied from one or more sessions and were of varying duration. Sessions were concluded as being dependant on the nature of the problem, the amount of information still to be collected, and the appropriateness of leaving the situation. Sources of data were recorded interviews, brief descriptions of telephone conversations I had with the women, and observations about important events taking place over a set period of time.

The interviews were designed to resemble a conversation rather than a set number of questions and answers. They began with a brief discussion of research aims and assumptions, and took the form of unstructured interviews. For Lincoln & Guba (1985) "planning is less a matter of prediction and control than of detecting errors (twists, shifts, unexpected developments) and responding to them" (p. 60). Interviews are not planned beforehand but evolve through the process of conversation and discourse (Anderson & Goolishian, 1988).

Although my aim was merely to gather information about women suffering on a personal level, there were times when some form of 'intervention' was unavoidable. Types of 'intervention' included the researcher's personal point of view, a need for more information in the form of specific questioning, alternative interpretation or understanding of the women's stories, and/or directives. Such interventions usually perturb the women's existing view or belief system and are sometimes done intentionally, while at other times unintentionally. As Holstein and Gubrium (1997) state, "while the active respondent may selectively exploit a vast range of narrative resources, it is the active interviewer's job to direct and harness the respondent's constructive storytelling to the research task at hand" (p. 125). It is impossible for the

researcher not to be an integral part in the exchange of questions and answers, which inevitably shape and influence the shifting of positions in any interview. This, however, is done in order to "explore alternate perspectives and stocks of knowledge" (p. 125). The effects of such 'interventions' will be discussed in Chapter 7.

Inductive Data Analysis

A process of inductive analysis was used to 'make sense' of the data in order to uncover and make explicit the embedded information (Lincoln & Guba, 1985). With this in mind, the recorded conversations were listened to and transcribed, while key themes, patterns and shared meanings emerging from the transcriptions were highlighted. As an active researcher in this study, it was my aim to present the data as a 'meaning-making process' (Holstein & Gubrium, 1997). It is hoped that the reader will gain an understanding of the research topic through the discourse through which the participants were able to produce meaning. The goal was to show how meanings were formed in the interview and how they can enrich the research topic. As Holstein and Gubrium (1997) suggest, "the analyst's reports do not summarize and organize what interview participants have said, as much as they 'deconstruct' participants' talk to show the reader both the *hows* and the *whats* of the narrative dramas conveyed, which increasingly mirrors an interview society" (p. 127).

Thematic information and emerging patterns were thus extracted from the interview data and formed the basis for the emergent design. It was hoped that *a priori* generalisations would be avoided and that data analysis would be open-ended and not deductive as with quantitative research. This process of looking for key themes, patterns and shared meanings took on the same form as with the interviewing in that, through data analysis, new questions about these finding emerged (Sells, Smith & Sprenkle, 1995).

Emergent Design

My first intention for this study was to explore and research issues related to familial breast cancer. My aim was to consider the emotional and psychological impact of genetic risk on the women attending the Familial Breast Cancer clinic.

Becoming aware of their emotional pain made me want to explore issues of suffering in general. At this stage I decided that I would want to examine these issues within other contexts and for this reason chose the contexts of eating disorders and infertility. The aim for this present study thus evolved into an exploration of personal suffering as experienced by women struggling with specific body issues.

Conclusion

Based on social constructionist principles and the qualitative approach, I hope to create a conversational domain with the six women participants in order to explore meanings, assumptions and experiences regarding personal suffering within the contexts of familial breast cancer, eating disorders and infertility. The objective is to create a languaging domain with the women such that the meaning of suffering and its physical, emotional and social effects can be deconstructed. Individual discussions of perceptions and meanings regarding personal suffering are provided in chapters four, five and six. Transcriptions of the interviews are available on request. These three chapters include brief theoretical discussions of the three contexts, as well as personal distinctions and punctuations of the participants' experiences. A theoretical discussion of how the body is perceived by women, men and society will be presented in the following literature chapter.

CHAPTER 3

CONTEXTUALISING THE FEMALE BODY

Taught from infancy that beauty is woman's sceptre,
The mind shapes itself to the body,
And roaming round its gilt cage,
Only seeks to adorn its prison.

(Tom Wolfe)

Women's bodies continue, as in the past, to attract a considerable amount of attention in our culture. Notions of the ideal female body by Western culture have historically undergone a number of transformations according to two different perspectives – one held by men and the other by women. While for men the body has been seen generally in terms of its shape, size, reproductive ability, sex and appearance, for women the body has been much more integral to the formation of her identity (Macdonald, 1995; Yoder, 1999). In this chapter, a brief and general exposition of the female body in relation to a historical, phenomenological, feminist, and social constructionist perspective will be provided. A discussion of three body issues chosen for this particular study – familial breast cancer, eating disorders, and infertility will conclude the chapter.

Women and their Bodies

For centuries authors have attempted to describe women in ways which portray who they are and how they behave. Women differ significantly among themselves (as do men) "by age and generation, by ethnicity and culture, by socioeconomic status and family status, by intelligence and appearance, and by other social or personal characteristics" (Orlinsky & Howard, 1980, p. 4). They also differ in terms of their biological differences and nature, particularly in their ability to reproduce. In the past, for example, women were defined in terms of their bodies and conceptualized as "being ruled by their bodies" (Ussher, 1989, p. 1). This could have been true in so far as pregnancy, childbirth and motherhood were concerned. The

way in which pregnancy and childbirth were construed in our society contributed towards the assumption that women were carers and nurturers, rather than achievers or providers (Ussher, 1989). These dominant beliefs regarding the female body framed women in their societal context.

For Macdonald (1995) and Tseëlon (1995), the body is integral to the formation of a woman's identity – even more so than for men. Although the perceptions women have regarding their physical appearance are complex and usually determined by evolutionary pressures, genetics, societal depictions, and individual attributes such as personality, the centrality of the body to feminine identity is still predominant (Macdonald, 1995; Tseëlon, 1995). A variety of characteristics shape the feminine identity including "ideal bodily shape and size; appropriate forms of make-up and cosmetic care of skin and hair; and the adornment of the body through clothes and accessories" (Macdonald, 1995, p. 194). Other characteristics involve the body as a "site of birth, growth, ageing, and death, of pleasure, pain and many things…an object of desires…a bearer of features…a biological machine that provides the material preconditions for subjectivity, thought, emotion and language…" (Cromby & Nightingale, 1999, p. 10). The connection between identity and body is thus unique to women and becomes visible during important life crises such as the impact of menstruation, the growth of breasts, the effects of menopause, gynaecological disorders, distortions of shape and bodily functioning produced by childbirth or osteoporosis, or the sense of loss that arises when breasts or the womb are removed (Macdonald, 1995; Ussher, 1989; Washbourn, 1977). Any search for psychological and spiritual wholeness will emerge from these particular life crises. These turning points almost always raise fundamental questions about one self and are instrumental in redefining a woman's self-identity in relation to how she perceives her purpose and value in life.

A Historical Understanding of the Body

Plato and Descartes

One of the earliest conceptualisations of the body is seen in the philosophy of Plato (422-347 BC). He viewed man as a dual creature. The duality involved a *body*, bound to the world of the senses, and an immortal *soul*, the realm of reason (Gaarder, 1995). Plato believed that the souls of human beings were separate from their human bodies. Souls would shape human beings but longed to be freed and distinct from the physical body (Spelman, 1988). The body was considered imperfect and insignificant and the soul was seen as invisible and unable to generate or decay (Canto, 1986; Crowley & Himmelweit, 1992; Spelman, 1988). The body would essentially keep human beings from achieving real, invisible and eternal knowledge. Any understanding of knowledge, reality, goodness or beauty would not be possible unless one recognized the distinction between soul and body. Freeing the soul from the lazy, vulgar, beguiling body was thus essential (Canto, 1986; Crowley & Himmelweit, 1992; Spelman, 1988).

As far as women were concerned, Plato felt strongly about women as embodied beings whose lives were filled with disarray. He pointed our, for example, that women were the ones who got hysterical at the thought of death and that their emotions overpowered their reasoning abilities, thus making them lose control. He believed that although there was, in reality, no fixed referent, the male body remained the natural standard against which the female body was measured and valued. The female body was therefore devalued and seen as "inferior, as different, as unsubstantial, as absent" (Spelman, 1988, p. 44).

Descartes (1596-1650) modified Plato's dualistic philosophy of the time into a more modern form in the seventeenth century. Both philosophers were rationalists who were convinced that reason was the only path to knowledge. Descartes believed that motions of all material objects (body, animal, human) involved mechanical processes but that man's soul was not part of this 'body machinery' and thus remained separate to the body (Gaarder, 1995, p. 196). According to Descartes, man has both a mind and an extended body and while the body is a perfect machine, it operates quite

independently of the mind. Constant interaction between mind and body was not denied but seen in terms of its link in the pineal gland of the brain (Gaarder, 1995; Kruger, 1988). Descartes believed that human beings have the capacity to rise above bodily needs and behave rationally. In essence the soul is always superior to the body. As Gaarder (1995) explains, "our legs can age and become weak, the back can become bowed and our teeth can fall out – [but two and two will go on being four as long as there is reason left in us]" (p. 201).

Descartes' radical dualism regarding mind and body suggested that our senses in Cartesian terms had a twofold reality. These were the *res cogitans* and the *res extensa* (Kruger, 1988). *Res extensa* incorporated the quantitative element of science, technology and measurement. It involved the corporeal body which was simply seen as a machine susceptible to a "mathematical – causal analysis of functioning" (Shildrick, 1997, p. 16). The *res cogitans*, however, involved the mind and the soul as well as the powers of intelligence and animation, spirituality and selfhood (Kruger, 1988; Shildrick, 1997). The two terms were given different statuses – the mind constituted the individual's essential being, and the body constituted a more arbitrary physical form (Crowley & Himmelweit, 1992; Kruger, 1988; Spelman, 1988).

Freud, de Beauvoir and Merleau-Ponty

The division between mind and body continued throughout the eighteenth and nineteenth centuries. Women's bodies continued to be seen as pathological; menstruation was occasionally seen as a disease, physical frailty was associated with the female body, and any usefulness would simply be associated with reproduction and motherhood. The female body was entirely hidden by clothing and any reference to sex, pregnancy and birth was avoided in polite company and never discussed in mixed company or in front of the unmarried (Meyer, Moore & Viljoen, 1989; Shilling, 2003). During 1892 and onwards, however, psychoanalyst Sigmund Freud, began to observe the female body in more detail and in contrast to previously held beliefs. He saw the importance of the body in terms of the physical energy model that viewed the energy of the body as the basic origin of all behaviour, including bodily movement, thoughts, fantasies, guilt feelings and dreams. He believed that all behaviour and thoughts were determined by factors in the personality and that the

psyche was motivated by psychic energy in the form of drives which lead to action (Meyer et al., 1989). Freud also viewed the body in terms of ease or dis-ease in living in the world through one's bodiliness. He concerned himself with the mouth, anus and the sexual organs as containing much psychological importance. He believed that the reality of sexuality, particularly in women, was being denied by the Victorian era and that this was to blame for the dis-ease that was being felt at the time. Freud highlighted how man had become more and more alienated from his body and how the mouth, anus and sexual body were in fact instruments receptive to all sorts of pleasures (Brennan, 1992; Kruger, 1988; Meyer et al., 1989). He also viewed the female body as an unsolvable mystery, and it would be this view of femininity that would provide the basis for the feminist's politically 'optimistic' view on women and the body (Moi, 1999).

Merleau-Ponty also viewed humans as able of perceiving through their bodies. The body became the subject of perception and through it, one would be able to understand people and things (McNamara, 2002). Meanings associated with body appearance, gestures and manipulations were not seen as separate cultural ideas but rather as forming an integral part of the structures that exist in the world. In terms of phenomenology, the body was no longer seen as a body belonging to physiology but more central in determining one's point of view of the world. It was not seen as dead, dissected or "an entity closed in upon itself" (Kruger, 1988, p. 104), but rather as "our general medium for having a world" (Moi, 1999, p. 63).

According to Burr's readings of Merleau-Ponty, human beings inhabit the material world by living *in* it and not by being observers of it. Our physical relation to objects and our movements around such objects become part of our body image. The body is then able to extend out beyond "the boundaries of its own skin to incorporate the experienced, lived world" (Burr, 1999, p. 121). For Merleau-Ponty, perception or perceptual experience is spatial in that our bodies are situated in space. Perception is thus a bodily event as all human beings are able to perceive through their bodies (Kruger, 1988). Merleau-Ponty's theory regarding the etchings of cultural femininity was based on the notion that the "existential condition of living in a body mediates our perceptual experience of the world" (Blake, 2000, p. 431). The 'spatial underpinning' of our existence is only taken for granted when our body or a

part thereof becomes impaired, and one is then forced to reorganize the senses and one's perceptions of the body" (Blake, 2000, p. 431). McNamara (2002) writes that a distorted perception of the body occurs only within a context where bodies are seen as potentially healthy. Health, like illness, is culturally mediated and any form of sickness is associated with social disharmony and disintegration.

A further perspective on the body is seen in Simone de Beauvoir's writings of women and the female body in her well-known book *The Second Sex*. De Beauvoir believed that a woman is someone with a female body "from beginning to end, from the moment she is born until the moment she dies, but that body is her situation, not her destiny" (Land, 1997, p. 76). She aims to direct our view of the body as a lived being and not only as rooted in biological terms (Spelman, 1988). In essence, the body is not a thing, but a situation. As Sartre mentions in *Being and Nothingness*, a situation is a structural relationship between our projects (our freedom) and the world (which includes the body) (Moi, 1999). By claiming that the body is a situation simply means that one acknowledges the meaning of a woman's body as relating to the way she uses her freedom. Since freedom is not absolute, but rather situated, as believed by de Beauvoir, situations and the particular lived experience will influence one's projects, which in turn will shape one's experience of the body (Moi, 1999). De Beauvoir also viewed women not as fixed realities, but rather as always being in the process of making themselves what they are. By seeing the body as a situation, a woman's experience of herself and of the world is created and established.

The body thus becomes one's perspective on the world and is engaged in a dialectical interaction with the environment and its surroundings. It is a "historical sedimentation of our way of living in the world, and of the world's way of living with us" (Moi, 1999, p. 65). If, however, the body becomes sick or crippled then an individual's experience of him/herself and of the world will not be the same in comparison to a healthy or athletic body. As Moi (1999) writes,

> "Our subjectivity is constituted through such on-going, open-ended interaction between ourselves and the world. We constantly make something of what the world makes of us. This view considers the body – and not only the sexual

different body, but the sick body, the athletic body, the ageing body, the black body, the white body, and so on – to be of fundamental importance" (p. 391).

A Twentieth Century View of the Body

The importance placed on the body has been subject to transformations that have occurred over time and to various influential factors in today's society. According to Shilling (2003), an increased focus on the human body has come about both as a cause and consequence of the following four factors. The first factor relates to the rise of feminism, which has to a large extent, highlighted the importance of the female body. Based on feminist influences, individuals have had to focus more on the female body than ever before. A second factor that has led society to look at the body in more detail has been the growth in the number of aged, specifically in Western cultures. This has become a matter of international economic concern as seen in social policies, state expenditures, pensions and medical provisions. A third factor has been the current consumer culture which views the body as a machine, able to be tuned, cared for, reconstructed and submitted to strict measures such as regular physical exercise, personal health programs and diets. Consumer culture has promoted the notion that bodies can be transformed – a risky notion implying that people now need to identify themselves either negatively or positively in relation to an acceptable 'exterior'. Finally, a fourth factor in promoting greater awareness of the body is the greater ability individuals now have to control their bodies. This ability has come in the form of better technology and is seen in advances such as transplant surgery, breast reconstruction, augmentation and reduction, artificial insemination, *in vitro* fertilization, plastic surgery, stomach and duodenum stapling, etc. (Shilling, 2003).

With such changes taking place in society, emotional and cognitive changes have also occurred. For example, the idea and image of the perfect female body is one which has developed over time and which has had a powerful influence on women's consciousness and behaviour. Today women in Western and non-Western cultures are bombarded with images of what the 'ideal' woman should look like (Ussher, 1989). This is due to acculturation and social change theories which focus on increased Westernization and exposure to how one should consume and how one

should regulate the body (McNamara, 2002). Studies of health and fitness magazines aimed at women and discussions of the female body ideal are popular and numerous, making the thin, well-toned, and fat-free female body exemplified by models, universally admired (Duncan & Robinson, 2004). Few consider that the possibility of body shape might not be the same in every culture. Although it is inaccurate to assume that the experience of Western/white women's body ideals stand for women of other cultures, the research regarding this cultural group is the most dominant one available (Duncan & Robinson, 2004). Since little qualitative research has been conducted on the body ideals in other cultures (e.g. African and Asian cultures), the following discussion will include only the investigations and writings of the effects of the dominant body ideal as expressed by white women in Western cultures.

Historically, the body was seen as integral to the formation of identity. Many women equate self-concept to body image, body size and facial characteristics, which become measures of desirability and popularity (Duncan & Robinson, 2004; Tseëlon, 1995). This centrality of the body to feminine identity can be subdivided into various codes of appearance including body shape, body size and adornment of the body through clothes, accessories, make-up, cosmetic care of skin and hair (Macdonald, 1995). The relation between identity and the body is also important during a woman's experience of significant changes and events in her life (Macdonald, 1995).

Notions of the ideal female body and its functions have, however, shifted with the passing of time. During the Renaissance period, the ideal female body as depicted in oil paintings was full and well-rounded (Macdonald, 1995; Seid, 1989). During the Victorian era, however, maternal roundness was transformed into the shape of an hourglass figure with the advent of the corset (Ussher, 1989). This soon changed in the twentieth Century when the boyish 'flapper image' and the 'slinkier, bias-cut look' came into being in the 1920s and 1930s respectively (Macdonald, 1995, p. 197). Although curves remained fashionable and acceptable in the 1950s, the 'Twiggy' or 'starved' look soon overpowered the previous look in the 1960s with an increase in raised hemlines and the arrival of the mini-skirt (Freedman, 1986; Macdonald, 1995; Ussher, 1989). Since then the ideal has been to look slender and thin, while any signs of round hips, fuller breasts and chubby waistlines were and

continue to be considered unacceptable and distasteful (Duncan & Robinson, 2004; Freedman, 1986; Macdonald, 1995; Weitz, 2003).

The Feminist Perspective

According to the feminist perspective, women's positions in society have been "undermined repeatedly by attempts to define their 'unstable' bodies as both dominating and threatening their 'fragile' minds" (Shilling, 2003, p. 40). These beliefs emerged in the eighteenth and nineteenth centuries when men were seen as superior and women as subordinate. To be embodied as a women was to have a body and a mind which were unable to "withstand the rigours of physical and mental exertion" (Shilling, 2003, p. 40). Women were seen as either invisible or as reproducers; little more than baby machines and stereotypically constructed in terms of their biological and reproductive bodies. Very limited sense of personal presence was expressed or exhibited. Shildrick (1997) writes that "in being somehow more fully embodied than men, women have been characterised simply as less able to rise above uncontrollable natural processes and passions and therefore disqualified from mature personhood" (p. 26). Furthermore, "it is as though bodies could somehow interfere with moral thought, instructing the mind, rather than the other way round as is the case with men" (Shildrick, 1997, p. 26). As a result of such beliefs, women movements began to draw attention to dangers of biological determinism. Even though female biological endowment was, and always has been, different from a man's, the dispute feminists tried to resolve was the belief that to have a woman's body meant to be at a "practical disadvantage in the world" (Land, 1997, p. 57). The movement also held strongly to the belief that as women, "our being-in-the-world cannot be understood by reference to any fixed or essential bodily core" (Shildrick, 1997, p. 43). Rather, ways of seeing and ways of knowing are grounded in the construction of bodies and selves. Thus, feminist work of the 1970s centered on reclaiming the female body from the self-hating and woman-hating culture of the time.

One of the dominant physical stereotypes regarding women is their attractiveness (Yoder, 1999). Feminists believe that although women's bodies attract much attention, they have predominantly been regarded by society as just bodies,

necessary for procreation (Yoder, 1999). Feminist thought attempts to regard the body as a means of acknowledging a woman's position in the world separate from that of men and capable of autonomous rational thought (Shildrick, 1997). Women frequently had to live with an 'over-burdened' body present in problems of sexuality, male violence, pornography, prostitution, surrogacy, pregnancy, childbirth, physical and emotional stress and pressures, fertility, domination, subordination, inequality and oppression (Shilling, 2003). Having a female body thus became central to the feminist position (Canto, 1986; Land, 1997; Shilling, 2003).

Human experiences of embodiment are vital for a healthy functioning of the self and one's quality of life (Castle & Phillips, 2002). For feminists, embodiment is seen as a process and not a split between body and mind (Shildrick, 1997). Such embodiment has been made difficult by the fact that women are now being marginalised and positioned in terms of an inaccessible body ideal. According to Shildrick (1997) "the micro-politics of power which are worked upon the bodies of women, and which are a focus of much recent feminist research, take the forms of such commonplace occurrences as dieting and weight control, elective cosmetic surgery, aerobics and body-building regimes" (p. 55). There seems to be an idealised notion of femininity that creates a desire on women's part to enter into the relentless struggle of attaining perfection.

Feminism attempts to refocus on and reclaim the body instead of viewing it as disembodied (Moore, 1994). It also aims to see it as one's primary location in the world and not as just anatomical, sexual, reproductive and/or maternal (Moore, 1994; Shildrick, 1997). Greer (1999), for example, believes that a woman's body is the battlefield where women fight for liberation. "It is through her body that oppression works, reifying her, sexualizing her, victimizing her, disabling her" (Greer, 1999, p. 114). A woman's physicality is thus a "medium for others to work on; her job is to act as the viceroy, presenting her body for their ministrations, and applying to her body the treatments that have been ordained" (Greer, 1999, p. 114).

De Beauvoir believes that the responsibility of acknowledging embodiment is essentially a woman's task. More than men, women are associated and virtually identified with the body while men are usually identified by their mental and physical

abilities (Spelman, 1988). In de Beauvoir's view, the body becomes a medium for having, perceiving and reacting to a world. A person's subjectivity is thus made up through the ongoing and open-ended interaction that occurs between the female body and such a world (Kvinge & Kirkevold, 2002; Moi, 1999).

The Social Constructionist Perspective

During the last few years there has been an increasing interest in the body. This has been seen in media, newspapers, magazines, television and in publications and broadcastings of ideal body images which are beautiful, young, sexy and in good functioning order (Bissell & Peiquin, 2004; Rubin, Nemeroff & Russo, 2004; Schooler, Monique Ward, Merriwether & Caruthers, 2004; Shilling, 2003; Ussher, 1989). Societal interest regarding the body has meant that cultural practices have to a large extent determined "normative social practices in relation to the human body" (McNamara, 2002, p. 25). Culturally defined notions of normal and disordered body image are then seen in the connection between individual embodiment and the social world (McNamara, 1995).

According to Foucault our body is always 'in the grip' of cultural practices (Bordo, 1992, p. 92). These are inscribed on our bodies such that they are constituted by culture. Disorders found in the body usually reflect and emphasize some of the central problems found in our culture. These may include "historical heritage or disdain for the body, to our modern fear of loss of control over our futures, to the disquieting meaning of contemporary beauty ideals in an era of female presence and power" (Bordo, 1992, p. 90).

For Seid (1989), we are all victims of our own times and this means that standards are in fact transitory and external. The ideal body in today's society is merely a complex mix of social and psychological behaviours as well as attitudes towards beauty, health, body and food. In Western culture, for example, the ideal shape transformed substantially from plumpness to thinness and to more acceptable parts of the body. For Duncan and Robinson (2004), this trend is now taking place in cultures which previously had their own unique histories, family and cultural

networks, social roles, values and expectations. They are now being shaped and programmed to reflect the ideal female shape of the white Western female body.

In terms of social constructionism, the body is viewed according to how society has shaped, classified and made it meaningful (Shilling, 2003). It emerges from 'discourse' and cultural constructions that transform the body into an object of knowledge as well as a discursive construction (Martin, 1992). Various truths are given to and derived from the female body within a social context and, since perceptions and knowledge about the body are discursive, women's lives are determined by and have direct bearing on such truths (Shildrick, 1997). Shilling (2003) believes that an individual's experience of life is mediated through the body. This means then that one's very ability to live, act and function in society is dependent on the management of the body through time and space. The body is no longer subjected to constraints and limitations but rather controlled and altered in ways that were not previously possible (Shilling, 2003). For example, due to developments in biological reproduction, genetic engineering, plastic surgery, sports science, artificial insemination, *in vitro* fertilization, weight loss programs and plastic surgery, many people have been able to change their bodies. Such changes have placed the body in a process of 'becoming'. The body is referred to as a "*project* which should be worked at and accomplished as part of an *individual's* self-identity" (Shilling, 2003, p. 4). Recognizing that the body has become a project entails accepting that its appearance, size, shape and contents are implicitly open to reconstruction in line with the designs of the owner (Shilling, 2003).

The belief that the body is a project and that it is culturally influenced by society through discourse is usually created during the onset of adolescence. According to research, an individual's obsession with the ideal body emerges with body transformations during the pubertal stage (Greer, 1999; Ussher, 1989; Wells, 1983). In some cases, this signals the possible onset of a lifetime of bodily concerns as young adolescents are shown what is acceptable in terms of what they should or should not look like. The idea and image of the perfect female body is central in creating conflict during puberty. During this stage, the body transforms itself from a thin look to one which is heavier and rounder, but one which is perceived as less attractive and unacceptable in today's 'perfect' body society (Ussher, 1989; Wells,

1983). Children, adolescents and young adults learn that some parts of the body are more admired than others and are thus lovely or shameful to look at. When acceptance, rejection, satisfaction and dissatisfaction become attached to body parts, so then are internal self-images transformed (Wells, 1983). The attitude of keeping the body acceptable in the eyes of society results in constant worry over weight and bodily appearance. The young woman begins to evaluate her self-worth in terms of shape and weight (Motz, 2001). If women are positioned in relation to and measured against an inaccessible body ideal, such 'disablement' may indeed be a threat to their self-identity. As a result, women who see themselves as 'disabled' may then find their bodily experience even more invalidated and 'doubly dis-abled' (Shildrick, 1997, p. 50).

It is the body image's positive or negative value that ultimately determines how women see and experience themselves and others. Body image then becomes central to a woman's self-identity and self-concept (Freedman, 1986). For Oktay and Walter (1991) body image is defined as the way in which one views oneself physically. It is divided into three areas namely, body reality (the body as it really is), body ideal (the mental picture of how one's body should be) and body presentation (how the body is presented to the outside environment) (Price in Kraus, 1999). If there is a discrepancy between the ideal and the real then women may feel pressured to remodel themselves to fit into the popular mould (Freedman, 1986).

In terms of social constructionism, body image is related to negotiated cultural messages about women's appearance and ideal body shape. Research shows, for example, that there is a connection between frequent media use and greater body dissatisfaction as etched in cultural ideals of femininity. Exposure to thinness depiction and media promotion usually leads to distorted body-image perceptions in school-age females and tertiary education women (Bissell & Peiqin, 2004; Rubin et al., 2004; Schooler et al., 2004). The existence and operation of appearance-based stereotypes in both adults and children have also been well established. The hourglass figure of the Barbie doll became a huge success for young girls who now wanted to live up to the 'unreal' proportions of the body. The practice of foot binding in China was also another example of cultural ideals being forced onto young women who would only be considered worthy with respect to their feet size (Blake, 2000).

Cultural representations of what women should look like either through medical practice, fashion and cosmetic industries, as well as the discipline of exercise, has contributed greatly to women letting go of the rights to their own bodies (Freedman, 1986; Macdonald, 1995; Tseëlon, 1995).

Although idealized models of female beauty have been fashioned and worshipped, twentieth-century technology and visual media have had more of an impact on self-image than during the Renaissance Venus figure era (Freedman, 1986). During the Renaissance, bodily figures were romanticized and glorified as unattainable. Today, however, modern technology has blurred "the boundaries between romanticism and realism", while television has injected "a potent dose of beauty imagery into the mainstream of life" (Freedman, 1986, p. 43). It also seems that women are turning unconsciously to the stereotypes surrounding them to confirm current beauty norms and to be reminded of their own flaws. Freedman (1986) writes that "in search of self-acceptance, a woman becomes prey to the subtle web spun by clever ad makers, whose message is loud and clear. No matter how hard she tries to attain acceptability she remains unfinished or imperfect. No matter how good she looks or smells, something is always missing" (p. 44). Today's media culture constantly reminds women of their more inferior features. For example, 'white beauty' continues to influence the 'black ideal' despite attempts to enhance it through 'Black is beautiful' campaigns (Bissell & Peiquin, 2004; Freedman, 1986; Rubin et al., 2004; Schooler et al., 2004).

The influence of body image on self-identity is also greater for females than for males, and studies have shown that women tend to equate themselves to what they look like, what they think they look like or what they believe others think they look like (Bissell & Peiquin, 2004; Freedman, 1986; Rubin et al., 2004; Schooler et al., 2004). Women with a negative body image may be more likely to struggle with low self-esteem, sexual problems, psychosomatic symptoms, stress, feelings of shame and guilt, anorexia, obesity, agoraphobia and depression (Freedman, 1986). This may occur as women try to live up to rigid cultural expectations where impossible standards to attain perfection are present.

In the next section, three cultural standards advocating an ideal body will be examined. These include the standard for thinness and the standard for having a perfect and well functioning body. These cultural constructs have been seen predominantly in problems of familial breast cancer, eating disorders and infertility. Social beliefs that permeate today's cultural body ideals are discussed.

Body Issues in Familial Breast Cancer

For the purposes of this study one of the contexts that has been chosen to highlight the suffering that women experience in relation to their bodies is familial breast cancer. In general, breast cancer is associated with suffering, pain and the potential for death. The risk of developing breast cancer at some stage based on a genetic mutation will likely create as much anxiety and suffering as someone without the mutation (Baker, 1991; Landmark, Strandmark, Wahl, 2001). For many women breasts symbolise motherhood, nurturing, femininity and sexuality. They are revered and glorified by many cultures and are important outward signs of sexuality for the developing woman throughout adolescence and adulthood (Baker, 1991; Ussher, 1989; Wells, 1983). According to Young (2003) the breast symbolises bodily change as seen in the transition process of changing from girl to woman. It also shows the possibility of pregnancy, the beginning of menstruation, and changes during lactation. Young (2003) writes that "breasts are an important component of body self-image; a woman may love them or dislike them, but she is rarely neutral" (p. 152). Women's feelings about their breasts may thus be positive or negative, and are usually dependant on what is reinforced by culture and society (Paludi, 1992).

According to Greer (1999) women deal with their breasts in different and unique ways. A healthy breast may not be a sexy breast but can be considered healthy if it has lactated before the age of thirty or so. A reconstructed breast, however, is not considered a 'happy' breast since mammoplasties, implants and mastectomies do not always heal properly, can become infected and may result in scarring and disfigurement. Implants can also shift, move around and cause painful experiences. In terms of being aware of breast cancer and its dangers through awareness campaigns, stress and turmoil may also be experienced. Greer (1999) points out that

if women examine their own breasts for signs of cancer, they are never sure that they have done it correctly. On the other hand, if they put themselves through the screening process they worry about the time lapse before the next examination. They also have to undergo the unpleasantness of mammograms which are "systematically and deliberately underplayed by the proponents of mass screening" (Greer, 1999, p. 56).

In some cases, however, women can be tested for a genetic risk of developing breast cancer by looking at their family histories. Familial breast cancer implies that the individual has a certain percentage of risk for developing breast cancer but that for the moment, does not have breast cancer. If test results show that they carry the breast cancer mutation - BRCA1 or BRCA2, choices regarding their futures need to be made. Choices are few and include medication, constant surveillance or prophylactic mastectomies (Baker, 1991; Keitel & Kopala, 2000). If the last option is chosen, it is assumed that the loss of one's breasts will undoubtedly be a traumatic experience for the women, and its symbolism with reproduction, nourishment, warmth, life, motherhood, female pride and sexuality will be severely threatened (Kraus, 1999; Young, 2003). Since breast cancer attacks the most visible symbol of women's femininity and sexuality, any attempt to remove the breast will lead to distress amongst women who identify their breasts as essentially themselves. However, choosing to remove the breasts without actually having developed breast cancer can be even more emotional and problematic (Baker, 1991; Keitel & Kopala, 2000; Kraus, 1999). In families, where breast cancer has affected significant family members such as mothers, aunts and grandmothers, women who choose to be tested are acutely aware of the pain, trauma and suffering related to breast cancer. They may, for example, see their breasts as a threat or an enemy to their well-being and survival. They will also have to weigh the intense sadness of having to lose their breasts with the relief of having been given a second chance in life. Choosing prophylactic treatment may also depend on the women's body image and their belief regarding their sexual desirability within intimate relationships. The wish to have more children and the consequences of prophylactic treatment also needs to be considered.

Within the counselling process, counsellors need to assess the importance of women's breasts in relation to their self-image, identity and sexuality. Decisions regarding mastectomy and reconstruction may hinge on these feelings, values, and attitudes (Keitel & Kopala, 2000). Furthermore, "if the woman has a partner, it is imperative to assess his or her reactions to the breast cancer experience and the woman's changed body" (Keitel & Kopala, 2000, p. 68). Based on the limited research, it seems that women who feel good about their appearance and their femininity, who have strong identities and self-concepts and who are less concerned with physical presentation of breast size and shape, may experience less distress after a prophylactic mastectomy (Keitel & Kopala, 2000; Kraus, 1999).

A positive option involved in prophylactic treatment entails the reconstruction of the woman's breasts. Since breast surgery usually includes changes in self-concept, self-worth, differences in expectations and life-style, alteration in sexual interactions with the partner, and fear of death and dying, breast reconstruction options should be considered if prophylactic mastectomy is chosen (Schain, 1978). It may make the experience less traumatic and decrease the risk of morbidity, especially if women feel that it is more devastating to develop breast cancer than to lose a breast (Alagaratnam & Kung in Oktay & Walter, 1991; Sandelin, Billgren & Wickman, 1998). Women may also be more accepting of the prophylactic treatment if they regard it as a potential improvement for personal survival. Understanding intellectually the rationale for such treatment may help the patient come to terms with the decision (Houlihan & Goldwyn, 1995). The impact of familial breast cancer, or the possibility thereof will be further explored in Chapter 4.

Body Issues in Eating Disorders

A second context chosen for this study is eating disorders. The ideal female body, in particular, the white female body, has been subjected to various changes over time. From roundness to thinness, women have tried to live up to the accepted ideal norm as socially constructed by society. For Bartky, "the body by which a woman feels herself judged and which by rigorous discipline she must try to assume is the body of early adolescence, slight and unformed, a body lacking flesh or substance, a body in whose very contours the image of immaturity has been inscribed" (in Weitz,

2003, p. 35). Women feel that by working the body or controlling the mind in terms of ideal weight and food restriction, positive rewards may be achieved. These rewards include enhanced self-esteem, a better appearance, the ability to wear fashionable clothes, mastery over the body, a positive identity, willpower and self-discipline (Macdonald, 1995). When, however, women are unable to change their bodies out of self-willpower and self-control, other options are sought. These options may not always be the most beneficial but do offer women, who are obsessed with their weight and physical appearance, a solution. The solution is usually in the form of controlling one's food consumption and body weight, which may lead to anorexia nervosa, bulimia nervosa, obesity and emotional eating. It is through eating disorders that women are able to carve their bodies into "objects of desire and trophies testifying to their self-control and self-sacrifice (Motz, 2001, p. 194). In the case of anorexic woman, "the weapon of this act of destructive self-control is the body. Her control over her appetites offers the anorexic woman a sense of power and mastery within the private sphere of her own body" (Motz, 2001, pp. 194-195).

Anorexics, bulimics and overeaters are also subject to a distorted body image. It is common for many women not to like their bodies since most believe that their thighs are too big, their busts to small, their hair too thin, or their stomachs too fat (Zerbe, 1993). Those who are a size 12 wish to be a size 10, and those who weigh 60 kg wish to weigh 50 kg. Each day becomes a battle to reach the ideal weight. Because they have distorted beliefs and opinions about themselves, some believe they are not good enough, pretty enough, intelligent enough or successful enough. These thoughts can be so rigid that the individual will place primacy on her body image and neglect aspects of her life such as work, home and society (Zerbe, 1993). When such a preoccupation with the body takes over the woman's life, she may suffer from body dysmorphic disorder (Kaye, Strober & Rodes, 2002; McNamara, 2002; Phillips & Heining, 2002; Rosen & Ramirez, 1998; Zerbe, 1993). According to the DSM-IV, body dysmorphic disorder involves a serious preoccupation with some imagined defect in one's appearance. It can also involve an excessive concern with a slight physical defect such as with the nose, the hair, ears, etc (Sue, Sue & Sue, 1994). Such a preoccupation creates a considerable amount of physical distress, especially as these thoughts are believed to be true. Many anorexics, bulimics and binge-eaters begin to

worry unrealistically about their perceived 'abnormal' appearances and use starvation, purging and excessive dieting as a means of coping.

Part of the physical suffering experienced by many women with eating disorders is the dissatisfaction and 'self-disparagement' they feel on a daily basis regarding their bodies (Bullerwell-Ravar, 1994, p. 33). Such suffering involves being in a "dreaded state of being with their own bodies" (Zerbe, 1993, p. 167). Women's fears of becoming fat, obese or unacceptable in the eyes of society, including their desperate attempts to lose weight renders their suffering great and their treatment much more difficult (Arenson, 1989; Zerbe, 1993). The fear of becoming obese and losing one's control over weight issues is likened to a paradox or a 'catch 22' situation. By dieting and restricting food, binge eating takes on uncontrolled proportions and leads to the very effects the patient fears –weight gain. A vicious cycle ensues, leading to specific consequences and outcomes on all levels of being - physical, social and emotional (Bullerwell-Ravar, 1994).

Since our present culture has placed emphasis on the idea of physical perfection, many women strive to achieve a high degree of physical perfection with their own bodies. Many believe in this notion of perfection and magnify or highlight their flaws into failings that 'merit self-hate' (Seid, 1989, p. 271). Unrealistic expectations are created and beliefs that the idealised body is the norm are entrenched. Women compare themselves to beauty professionals whose 'perfect' bodies are prominently and frequently displayed by the evermore "persuasive and influential media" (Seid, 1989, p. 271). For women on the street, the assumption that there is no gulf between them and celebrities is created and held. Unrealistic expectations and self-deception disallow women to understand that women in the limelight have been chosen precisely because of their unique beauty, for their approximation to the ideal, and that any blemishes are merely covered up and minimized by cameras, lights, angles and touch-ups (Freedman, 1986; Seid, 1989; Stanten & Foley, 2004). A hate relationship emerges towards the body and women begin to distance themselves from food, hunger and consequently from their bodies. They fail to look at their genetic make-up and hereditary factors and instead develop an almost 'schizophrenic separation' from their bodies, 'one endorsed by the whole culture' (Seid, 1989, p. 273). Finally, women come to regard their bodies "not as vessels through which we

live and try to realize happiness and meaning in life, but as objects whose perfection will give us that happiness and meaning" (Seid, 1989, p. 273).

Eating disorders are thus considered complex conditions, which involve psychological, developmental, cultural and biological factors (Gold, 1999). In this section we discussed the nature of eating disorders and in particular its effects on the body of the woman struggling with anorexia nervosa, bulimia nervosa or compulsive eating. These women may in fact be risking their physical well-being and, although the physical suffering may not always be overt and visible (except in cases such as obesity and anorexia), the physical aspect is usually denied and hidden (Zraly & Swift, 1990). It also seems that the meaning attached to eating disorders is one of secrecy and shame. Many individuals struggling with eating disorders will not openly demonstrate such suffering but will battle on a daily basis to fight the destructive relationship they have with their bodies and with food. A discussion of eating disorders will be elaborated on in Chapter 5.

Body Issues in Infertility

A third context chosen for this study, which is a major cause of suffering to women, is infertility. Previously, as demonstrated in feminist thought, women were seen at a most basic and reductive level as 'baby machines' (Shildrick, 1997, p. 22). The assumption was based on the belief that the reproductive role was more that of the woman than of the man. Providing sperm was represented as hardly bearing comparison with the long process of conception and gestation. For Crawshaw (1995), not being able to bear children because of infertility problems was and could still be considered to be a source of shame and spoiled identity. Many women who are unable to bear children may feel a physical void within themselves believing that their bodies do not meet the standards of a perfectly functioning body.

Becoming a parent is for many women the realisation of a life-long dream. It is viewed as a celebration of the union between a man and a woman and the fulfillment of a deep yearning to be a parent. Being a woman is synonymous with being a mother, because of the "central importance of 'mother' within female identity" which results in an "ideological symmetry between 'woman' and 'mother'"

(Nicolson in Ussher, 1989, p. 80). It is also seen as providing status for women, not only in terms of a positive identity but also as a sense of achievement or adult status. It is a woman's "crowning glory, the pinnacle of her achievement: what we are all destined for, and ultimately the only means of true fulfillment" (Ussher, 1989, p. 80). Since motherhood is an integral part of our identity as women, pregnancy becomes a significant life event which is the precursor of significant changes in an individual's life circumstances and life style, including relationships with spouse, partner, significant others, and the work context (Ussher, 1989). For many women, motherhood is seen as a way of bringing joy and fulfillment to their personal lives, and from a very early age, many believe that having a child is a biological right and a natural occurrence which can take place at any planned moment.

Some women choose pregnancy and motherhood only after certain goals have been met - completion of studies, marriage or long-term relationships, careers, the buying of a home, buying of a car, and travelling. Those who are unable to fall pregnant may feel an emptiness, which career, financial independence and social relationships cannot fill. When these dreams and hopes are shattered because of infertility, women may engage in negative and disheartening discourses of being "barren, unfruitful, addle, arid" (Ussher, 1989, p. 100). The diagnosis of infertility marks the beginning of a shocking and painful journey.

According to most physicians and fertility specialists, the diagnosis of infertility should commence only after one year of unsuccessful conception, although some couples seek help six months into the process (Dunkel-Schetter & Stanton, 1991; Mazor, 1984; Salzer, 1991). With the first visit to a physician, a general physical exam is done on each partner, as well as further tests to aid in the clarification of problem areas. The majority of infertility tests and treatments, however, focus mostly on the woman's body, irrespective of her being infertile or not. She is the one who needs to be aware of her ovulation for sexual relations to take place at the correct time. She is also the one who "receives direct evidence every month of failure with the onset of menstruation", and who makes most of the decisions regarding the appropriate treatment to be pursued (Abbey, 2000, p. 333). Infertility becomes a process whereby the woman charts her daily temperature (usually done in the mornings), determines which day is optimal for sexual

intercourse and endures being poked and prodded during gynaecological exams. Such processes of medical interventions serve to further stigmatize women and devalue them for any accomplishments outside of reproduction (Whiteford & Gonzalez, 1995).

Finally, infertile couples must also reexamine their sexual feelings as three kinds of sex now confront them regularly: sex for love, sex for the physician and sex for reproduction" (Taymor, 1990, p. 107). What used to be just sex for love and pleasure is now tainted by various other obligations and needs. For some, sex becomes routine and mechanical – a means to attain a specific purpose. The special quality attached to sexual life between a woman and a man who are committed to one another is lost in the midst of all the invasive but necessary examinations. A discussion of the physical, emotional and social impact of infertility will be provided in Chapter 6.

Conclusion

The body, in particular, the female body has undergone numerous transformations over time. The view of the body has largely been influenced by social constructs that have been dominant in society at different times. Since 350 BC, humans have tried to explain the body in terms of its position in the world through various theories. A few of these theories - historical, phenomenological, feminist and social constructionist – have been discussed in this study to highlight varying notions related to the body. The chapter has also focused on one social construct that continues to determine how the body should look in today's society. This construct is based on the idealised notion of a perfect-looking and perfect-functioning body. Any deviation to the norm will create anxiety, discomfort, disease and dissatisfaction for the individual. For this reason, eating disorders, infertility and familial breast cancer are contexts that have been chosen to highlight the suffering women experience when their bodies do not meet the standards of the ideal body image. These bodily issues have been discussed briefly in terms of socially constructed norms. Detailed discussions of these issues are provided in subsequent chapters.

CHAPTER 4

FAMILIAL BREAST CANCER

My faultless breast the furnace is,…

(Robert Southwell)

The purpose of this chapter is to illustrate the perceptions and assumptions held by two women struggling with familial breast cancer. The case illustrations are in verbatim form and names have been changed for purposes of confidentiality. A detailed presentation of these women's assumptions regarding familial breast cancer will be provided in four sections. These are the women's biographical information, their experiences of suffering, the emerging themes from the conversations and psychotherapeutic implications. The reader will be able to draw his or her own distinctions about the women's personal distinctions and assumptions. Before presenting the case illustrations, however, a brief understanding of familial breast cancer is required.

Background to Familial Breast Cancer

Breast cancer is considered a life-threatening illness, which impacts on the lives of women of all ages, races and backgrounds. It is also the most prevalent form of cancer amongst women creating considerable stress on the physical, emotional and social well-being of the individual (Borovanová & Soucek, 2002; Holmberg, Scott, Alexy & Fife, 2001; Keitel & Kopala, 2000; Landmark et al., 2001; Rees & Bath, 2000; Stoll, 1995). Cancer is caused by defects or mutations in genes that are responsible for controlling the normal growth and death of cells. It is these deviations which are responsible for the overgrowth of cells into tumors which then enter into the blood stream and the rest of the body (Love, 1995). Some individuals may inherit these mutations during their lifetime but exactly what they are and what causes them

is still largely hypothetical (Love, 1995). This study is concerned with two such inherited gene mutations - BRCA1 and BRCA2 genes.

The cloning of the BRCA1 and BRCA2 genes has made it possible to identify mutation carriers within some families of breast cancer. Testing for mutations in both genes has become the basis for estimating disease risks for women who present with a strong family history of breast cancer. These mutations account for an estimated eighty percent of hereditary breast cancer which are responsible for five to ten percent of all breast cancer cases (Antoniou, Pharoah, McMullan, Day, Stratton, Peto, Ponder & Easton, 2002; Armes & Venter, 2002; Bishop, 1999; Chart & Franssen, 1997; Coupier & Soppa-Lyonnet, 2002; Hoffmann & Schlag, 2000; Hoh, Heitjan, Mérette & Ott, 2001; Goodwin, 2000; Greene, 1997; Kuhl, 2002; Lalloo & Evans, 1999; Phillips, 2001). Bilaterality is also a recognized feature of hereditary breast cancer, and usually presents itself at an early age with a contralateral risk of 10 years (Lalloo & Evans, 1999).

Inherited susceptibility of developing breast cancer has been extensively researched during the last ten years and active surveillance of women at increased risk has become beneficial in the early detection of breast cancer. The demand for genetic services for women with a family history of breast cancer has increased to such an extent that specialised clinics have been established for the early diagnosis and treatment of women at risk (Moller, Borg, Evans, Haites, Reis, Vasen, Anderson, Steel, Apold, Goudie, Howell, Lalloo, Maehle, Gregory & Heimdal, 2002). Although the effects of such interventions have not yet been proven, it seems that screening young women with a significant family history of breast cancer may be effective in terms of survival (Macmillan, 2000; Moller et al, 2002).

One clinic which offers genetic counselling and predictive testing is the Breast Cancer Family Clinic, based in Pretoria, South Africa. The clinic has been offering genetic counselling since the mid-nineties and sees women referred by health professionals. The clinic consists of a nurse, a geneticist, a gynaecologist and a psychologist. The services provided are those of genetic counselling which help individuals become aware of their risk for breast cancer. Members of the clinic try to encourage women to educate themselves about their family history, aid them in

making specific choices and help them cope with the physical, emotional and social effects.

Each individual is assessed by a registered nurse according to the extended family medical history in the form of a pedigree format (Middleton & Peters, 2001). The pedigree includes information about the patient, his/her children, siblings, parents, aunts, uncles, grandparents and their siblings. Important information such as names, dates of birth, cancer history and/or other medical problems is noted (Middleton & Peters, 2001). Other information which is necessary for genetic counselling includes knowing the age of the family member at the time of diagnosis (pre- or post- menopausal), the patient's age and the number of first or second degree relatives that were affected by the disease (Chalmers, Thomson & Degner, 1996; Coupier & Stoppa-Lyonnet, 2002; Keitel & Kopala, 2000; Lalloo & Evans, 1999; Lynch, Watson, Conway & Lynch, 1991; Muhonen, Eerola, Behmanen, Nevanlinna, Aktan, Blomqvist, Kääriäinen & Pyrhönen, 1997; Stoll, 1995).

If a strong family history is shown on the pedigree, the geneticist will suggest that predictive testing be done by means of a blood test. During the predictive testing session, women are informed about their options should a mutation be found. Since the majority of options (screening, chemoprevention, anti-estrogens, lifestyle modifications and preventive/prophylactic surgery) are still limited and unproven in the long term, more clinical research needs to be done regarding the available options (Evans, Lalloo, Shenton, Boggis & Howell, 2001; Evans & Lalloo, 2002; Goodwin, 2000). Once predictive testing is done, the women are then asked to come back to the clinic to receive the results of their blood tests. Depending on the results, specific information about management risk and options is given to the women.

Genetic counselling also involves psychological and emotional counselling although information about psychological impact is limited (Di Prospero, Seminsky, Honeyford, Doan, Franssen, Meschino, Chart & Warner, 2001; Mann & Borgen, 1998; Moller et al., 2002). For Lynch, Lynch and Conway (1995) "there are undoubtedly many similarities between the emotional responses and behaviour of breast cancer patients belonging to hereditary breast cancer families and those without such family histories" (p. 130). Issues such as cancer risk perception, anxiety about

cancer, communication of test results to other family members, attitudes towards surveillance, attitudes towards prevention options, satisfaction with clinical and medical services, and the need for support are then discussed (Di Prospero et al., 2001).

Case Illustrations

Laura's Story: The Generational Curse

Biographical Information

Laura is a 41 year-old mother of three who first came to the Breast Cancer Clinic in Pretoria at the age of 39 for genetic counselling. She is married to Derek and they have a 13 year-old son. Laura was previously married to Mark whom she divorced at the age of 27 and with whom she had two children, a daughter and a son. Two years later, Mark was killed in a car accident. Laura lives in Pretoria and is a sales representative for a building construction company. She is the eldest child in a family of three and has a younger brother and sister. Her mother died of breast cancer when Laura was 28 years old. She currently looks after her father, who until recently was living on his own, but now requires medical care and attention.

I came into contact with Laura in August 2002. Her sister had previously been for genetic counselling and had referred her to the clinic based on the strong family history of breast cancer. Laura felt it necessary to test for the genetic mutation since both her great grandmother and grandmother had died of breast cancer at the age of 42 and 72 respectively. Laura's maternal aunt also died of breast cancer at the age of 50, while her mother was diagnosed with bilateral breast cancer at the age of 40 and 51. She died two years after the second diagnosis. Based on the pedigree information and predictive counselling done in the first session, Laura felt ready to be tested for the mutation. A few weeks later she returned to the clinic to receive the results.

Facing the Suffering

Laura experienced shock and denial at the positive test results. Although she said she had tried to prepare herself beforehand, she never expected to feel so overwhelmed and upset. She had come to the clinic on her own and felt vulnerable at not having a family member or friend present to support her. She expressed disappointment at her sister who had been tested negative for the mutation but had chosen not to tell her. She found out about the results through her father. Laura felt very alone and desolate throughout the report back session. She expressed concern at the life choices she would have to make to protect herself and her children.

Brief counselling was done with Laura but the team suggested that she see me on a professional basis. She told us that she was already seeing a psychologist. At this point, I mentioned to her that I needed a participant for my study and that she could help me with my research. In turn, I would try to help her with her experiences and future choices regarding the risk of developing breast cancer. She agreed to see me believing that she could only benefit from talking to someone who was more aware of the situation. She made an appointment with me for the following week. We saw each other for five, one hour sessions during August 2002 and February 2003 at the Breast Cancer clinic.

At the clinic, both the gynaecologist and pathologist advised Laura to consider having a hysterectomy. It was also suggested that she consider either continual surveillance or prophylactic mastectomy. Specific counselling factors were addressed during this session. These included beliefs and meanings regarding Laura's femininity, her decision-making skills, the reality of surgery, recovery, loss, grief, anxiety and the psychological impact of the family medical history (Lloyd, Watson, Oaker, Sacks, Wuerci della Rovere & Gui, 2000; van Dijk, Otten, Zoetewij, Timmermans, van Asperen, Breuning, Tollenaar & Kievit, 2003). Issues of breast reconstruction were also discussed. When she came to see me a week later, she decided that she would have the hysterectomy a month later and a prophylactic mastectomy thereafter. Since prophylactic mastectomies decrease a woman's risk of developing familial breast cancer by about eighty five percent (Keitel & Kopala, 2000; Lloyd et al., 2000; van Dijk et al., 2003), Laura felt this to be the only way of

protecting herself from breast cancer. Although this seemed to be a radical choice, Laura felt confident that this would be her only means of survival. She decided to prepare herself in advance and visit as many doctors as possible. She would embark on getting the best possible medical information by talking to women who had already had prophylactic mastectomies. She phoned me the week after our first session to inform me that she had chosen the doctor and the most appropriate surgical procedure. Laura had also contacted someone who had undergone the operation and based on her positive reaction, Laura decided to book the prophylactic mastectomy for January 2003. She would also continue to see her psychologist for other personal reasons but wanted to continue seeing me until the operation.

Nature of the Interaction

The nature of the interaction between Laura and myself was initially one of participant and researcher. My goal was to gain as much information about her family history with breast cancer and the emotional, physical and social pain associated with it. In our first three sessions I started off by asking all the necessary questions, while Laura provided me with personal feelings, thoughts and meanings regarding her suffering. In our last two sessions, however, the nature of the interaction changed to one of client and therapist when I introduced a few psychotherapeutic techniques into the conversation. I tried to be aware of social constructionist principles and kept these flowing throughout the sessions.

Although I did all of the questioning, Laura did direct the nature of the conversation. She needed to discuss in detail her relationship with her sister and the implications of her being positive and her sister negative. Laura also needed to talk about how the diagnosis was changing her perspective on life and her views regarding specific relationships. The conversation also centered around the physical changes she would have to endure with the prophylactic mastectomy. When discussing these physical issues, I tried to bring in emotions regarding her fear and worries. Questions were asked such as “Do you worry about losing your breasts?” “What do your breasts mean to you?” “What are you most upset about?” “What emotions do you experience in response to the various thoughts you have?” These questions made Laura think more deeply about her situation. In return, she openly and honestly discussed how

she felt. After the operation, Laura manifested that it was really important for her to talk to me about her feelings since she was unable to do so with her family and her husband.

Our relationship was an open one and Laura felt comfortable talking to me about personal issues. She also felt comfortable in expressing anger towards her family's lack of understanding and was able to cry when she wanted to. During these times, I would allow her to talk and then either ask her to elaborate on her feelings or to look at the situation from a different perspective. She came across as a strong-willed and determined individual. She expressed what she felt at the time and would only move forward with a specific problem when she felt ready to do so. She preferred to work on her emotional issues slowly, vent her frustrations in the sessions, take what she needed from our interaction and work out her issues on her own. However, with each new session, I noticed a change in Laura's perspective. These changes would either take place in her actions towards a family member or in a life decision that had to be made. I highlighted these changes within the sessions using positive reframing. I noticed that Laura enjoyed me complimenting her on the shifts that were taking place in her life.

I became aware that Laura experienced a different emotion or experience in each session. I understood later that this was a means of Laura preparing herself emotionally before the operation. It was her way of dealing with the imminent suffering.

Emerging Themes

An in depth inquiry of the interviews brought to light various perceptions and meanings held by Laura regarding her personal suffering with familial breast cancer. A few of these were related to physical, emotional and social suffering.

Loss of identity

Many women see their breasts as a symbol of motherhood, femininity and sexuality. They form an important component of a woman's body and self-image and any attack or damage to such a visible symbol may lead to distress in women who identify themselves with their breasts (Baker, 1991; Kraus, 1999; Ussher, 1989; Wells, 1983; Young, 2003). For Laura, having to remove her breasts without having the breast cancer was a radical option to consider. At first she was reluctant to remove her breasts since she felt that they were a part of her character and personality and that to remove them would be to remove something within herself. The new breasts would merely be 'dead lumps' that could never match up to her natural breasts. She expressed how so many women, including herself, took breasts for granted and that very little appreciation was given to them.

She was aware that the operation would be a daunting experience as she would have to endure much pain, including the loss of her back muscles. Her biggest concern was, however, the pain and the drastic physical changes. She could not picture what she would look like after the operation and this caused her much distress:

I'm not only going to lose my breasts. I'm going to lose my back as well. I'm not going to have any sensation anywhere. I think of myself just lying there. What are they going to do first? Open up everything and close everything? At some stage they'll have to turn me around to get to my back. Do you know how much I'm going to hurt when I wake up?

Fear and Anxiety

Women with a family history of breast cancer may experience feelings of anxiety, fear, anger and helplessness as they face the possible risk of developing breast cancer. It is hypothesised that reactions towards familial breast cancer are similar to those of women without the genetic mutation (Butow, Lobb, Meiser, Baratt & Tucker, 2003; Cull, Anderson, Campbell, Mackay, Smyth & Steel, 1999). On an emotional level, Laura felt fear right from the beginning in that she did not want to be

another cancer statistic like her grandmother, mother and aunt. She was also afraid of her children having to be raised without a mother:

I'm scared that my chest will look ugly – full of scars. I know it will not look like a model's chest but the bottom line is that I don't want my kids to be left without a mother. They don't have anybody. What's going to be of them? Their father is dead. Their grandmother won't help. My sister neither. My brother can't either. I have to do it for them.

It must be noted that prophylactic mastectomies work as a preventive measure and are a new and controversial treatment option for women with familial breast cancer. Choosing this option instead of breast conservancy and regular medical examination is fraught with psychosocial implications which can lead to further emotional distress (Houlihan & Goldwyn, 1995; Keitel & Kopala, 2000; Kraus, 1999; Lloyd et al., 2000). In Laura's case, it would have been more distressing for her to conserve her breasts since she would be constantly preoccupied about the breast cancer developing. It was more important for her not to die, to see her children grow and to live a full life. She openly expressed that she did not want to die like her mother who was never able to see the good times. The anxiety she experienced was triggered by the realistic dangers which could threaten her life as well as the experiences of close family members who had previously died of breast cancer (Gyllensköld, 1982). She expressed anxiety and fear of losing herself:

You know, I see myself like these cheap plastic dolls – empty inside. That's how I see myself – an empty person because they'll be taking away everything. I thought of what I'm going to look like directly after the op. I know it's not going to look good. I'm actually imagining what I'm going to look like, how my back is going to feel and I begin to feel sorry for myself. I think it's going to be painful. I've been telling myself that it is only physical and I've decided that I won't let the physical destroy my self-esteem. Yet, I'm very nervous. I'm really nervous. I'm fearing that it won't be a success. I'm fearing that I will only have scars.

Anger

Losing a family member to breast cancer and then being identified with the same genetic risk may trigger feelings of anger (Baker, 1991; Lynch et al., 1995). Women, who are at an increased risk, may show unique emotional needs such as unresolved grief and anger (Entrekin & Summerlot, 1995). For young, pre-menopausal women a pervasive sense of anger may be experienced as they face issues regarding their own death, unwanted surgical operations, physical pain, side effects of surgical operations and a possibility of their own children inheriting the mutation (Baker, 1991). The question "Why me?" is often asked. Anger may also be felt towards the individual herself, the medical fraternity, the family for passing on the mutation, healthy people without the mutation and even God (Kuuppelomäki & Lauri, 1998). The feeling of being out of control over a genetic mutation creates a sense of rage and anger within the woman and is heightened when she realises that she is unable to predict the development of breast cancer.

Laura expressed anger throughout the first three sessions. The anger was mostly directed towards her family's lack of support and understanding of the situation. She also felt anger towards her mother who had passed on the genetic mutation; anger towards the genetic mutation; anger that she had been tested positive; anger at friends who never bothered to call her to give her support; and, anger towards her husband for not giving her time and space to deal with the confusion. At a later stage she confessed that the anger she had felt in the first three sessions was a means of protecting herself against the hurt she was experiencing at the time.

Sadness

Mood disorders are commonly experienced by women who are at risk for breast cancer (Vogel, 1995). Feelings of sadness and depression may also be expressed as in the case of Laura. She shared how she felt sadness at having to lose a part of her self-esteem and personality through her breasts. She would cry when sharing painful feelings of loss and change as well as the feeling of being alone in her struggle with decision-making. She wanted people to understand that she was mourning the loss of her breasts and of herself:

Sometimes I just feel that they are going to take me apart and put me together in another way.

She also felt a strong sense of hopelessness:

It's horrible. I don't actually know how I deal with this. I just live day to day. Sometimes I get so 'hopeless'. I feel hopeless knowing that I cannot get away from it. If I do the op I'll be without breasts. If I don't do the op I'll probably die from cancer. That's the worst of it. That I had to make that choice. What a choice to make.

Laura also expressed that the hopelessness had to do with feeling as if she were going nowhere. She felt stuck and wished for a return of normality and happiness in her life. She felt consumed by the upcoming operation and the continual thoughts of its effects.

Loneliness and Lack of Support

A contributing factor towards feelings of fear, distress and anxiety are situations where social support and understanding are missing. Just as a breast cancer diagnosis is experienced as a traumatic crisis in which relationships disintegrate, so too can this apply to women who learn of their familial risk with breast cancer (Landmark et al., 2001). The issue is not that family members and friends are not helpful but rather that they lack the necessary knowledge regarding familial breast cancer and genetic mutations (Chalmers et al., 1996). Women who are aware of their risk may exhibit stress-related problems and these are likely to have an effect on the women's social system. An individual's social context and social support system (partner, husband, family, friends, relatives and medical professionals) is therefore vital for an individual's survival of breast cancer (Baker, 1991; Landmark et al., 2001).

In order to meet the needs of dealing with a personal risk of breast cancer, communication patterns within the family system are essential. Social support will help validate the feelings, experiences and perceptions of women who live with or

who have lived with a relative's illness. Any lack of support may "leave the woman feeling overwhelmed with her sense of risk" (Chalmers et al., 1996, p. 208). Laura felt that she did not always get the support she needed from her family. At times she felt that they were minimising the extent of her fears and concerns:

I called my sister when I got home and I told her about the positive results but she got angry at me for me being so emotional and upset. She said I should at least be happy about knowing. I am glad but I'm not laughing about it. She just doesn't want to speak to me about it.

During a later session, Laura continued to feel the frustration of no one truly understanding what she was experiencing:

It's hard to speak to someone about it because if they aren't in the situation they won't understand what I'm going through. That's the worst – the emotional suffering. People not knowing how I feel and me not getting that understanding from family and friends.

She also felt a lack of support and understanding from her husband. For Laura, support meant space, time, a listening ear and a sense of understanding. She wanted close family members to allow her time to deal with her pain and to support her in her decisions. She also wanted them to acknowledge and respect her feelings of anger, sadness and fear. She expressed the following in relation to her husband:

He mustn't reject me. He mustn't leave me because of the way I look (crying). He says it doesn't matter but I know it matters. I just want him to understand that I need him to be with me.

For women who choose prophylactic treatment, support from the spouse or partner is vitally important. Because many women experience decreases in sexual desire in the months following a mastectomy, as well as anxiety, fear, depression, fatigue and a negative body image, support from the partner is essential. Women may require the partner's assuredness that they are loved and beautiful together with a sense of closeness in order to cope with their situation (Kuuppelomäki & Lauri,

1998). For Thoits, "the simplest and most powerful measure of social support appears to be whether a person has an intimate, confiding relationship…Having a confidant significantly reduces the effects of stress experiences on both physical and psychological outcomes" (in Wylie, Smith & Botkin, 2003, p. 35).

Psychotherapeutic Implications

Psychotherapy that occurs in a genetic counselling context should take into consideration all the relevant factors pertaining to the woman's situation. These factors include a family history of breast cancer, the age of the patient and age of the relatives who were diagnosed with breast cancer. On a psychological level, patients presenting for risk evaluation should also be evaluated in terms of their attitudes and feelings. By spending more time with patients and encouraging them to ask questions or express fears and concerns, women may find that they are better able to handle their emotional turmoil (Vogel, 1995). Such communication is not only necessary between the patient and the members of the clinic (geneticist, oncologist, gynaecologist and therapist), but also with the spouse, partner and family members (Kuuppelomäki & Lauri, 1998). Communicating about, recognizing and overcoming fears, anxieties and distress may help women put these into perspective and deal with the stressors of a positive or negative outcome.

In my therapeutic sessions with Laura, the aim was to elicit as many emotions, thoughts and meanings about her personal experiences with familial breast cancer. In gaining the required information I also hoped to help her find meaning in her suffering through the languaging process and to see whether there were any shifts in her perspective as flowing from the interaction.

Finding Meaning in the Suffering

According to the existential point of view man is not content to live a meaningless life. One's quest is to live a worthwhile life, mean something to someone and achieve something in life. Without these experiences, one may feel spiritually unfulfilled and deprived in one's purpose (Frankl, 1986; Meyer et al., 1991; Shantall, 2003). During the last two sessions with Laura, I felt it necessary to help her

find meaning in her suffering. Although the experience of pain and suffering she had experienced since the report back session was devastating and full of turmoil, she admitted that she had gained something valuable from the situation. The most important experience she gained was a renewed belief in herself as a women and also in her ability to survive:

I've realised that I am special enough for God to have given this to me because he knows that I'm strong enough to handle this.

Laura also felt that the crisis had provided her with an opportunity to look closer at herself and by doing so, was able to gain self-respect and greater self confidence. She was able to stop criticising herself for who she was and start accepting her choices and her situation. Meaning was also gained in terms of her social relationships. She stopped seeing herself as a victim and more of an active participant. She could now ask people for what she wanted and have more of her personal needs met by significant others in her life:

Do you know what I did the last two months? I was at home for a few weeks and I took stock of myself and I decided that I don't like the person that I am. I hate being the victim. I've been the victim for so many years. It's going to stop now and it stopped.

I'm trying to protect myself and if that means that I'm not important for other people to consider my feelings then they must go. I always consider other people's feelings. If they can't do that then they must go.

Significant Shifts

Laura had started the journey as a victim who looked for acceptance, support and acknowledgement from others including her father, sister, brother and husband. When she was unable to receive these she became angry, frustrated and rejected. In our conversations throughout the seven months, Laura was able to move away from the anger, frustration and rejection and overcome these negative emotions through self-examination. Through the languaging process, Laura began to feel stronger about

asking people for what she needed and to rely more on her strengths. There was a significant change from being submissive and silent to being more outspoken and determined. For example, Laura's father had planned a holiday with her sister during the hysterectomy. Laura was distressed knowing that she would not have their support during that time. However, after our third session, Laura confirmed that she had had the courage to speak to her father and ask him to postpone his holiday. In our last session I asked her why it had been so important for her to speak to both her father and sister. She replied:

Because I needed him to be there. Because there is nobody else from my family. I needed him. In my eyes, the doctors are taking me apart and putting me back together in another way and that is big. This is not something someone does every single day. I've also told my sister that she must stop making everything seem nothing. That she must try to listen to me and try to feel what I'm feeling. It did feel strange talking to my dad. But I did it, and I'm glad I did it. I also told my brother that I wanted him to see how I'm struggling. It was really difficult to do all of that but I did.

A major shift also took place in Laura's perspective regarding the loss of her breasts. Although in the beginning she toiled with the notion of her breasts being connected to her identity, later she would tell me differently:

I'm starting to look past it. I know it's not a permanent thing. It's just to get past it.

When I asked her, "Are you still afraid of losing yourself through the removal of your breasts", she answered as follows:

No. I won't lose myself. I'm concentrating on not losing myself. It's only physical.

Reality Check

Although it was important for me to find out if Laura had gained meaning in her suffering, the physical and emotional pain of the operation would still take months to heal. For this reason, I felt it necessary to discuss with her the reality of her

situation. This meant dealing with future pain and suffering that should not be avoided or ignored. It was emphasised that emotional ups and downs would occur and that she could face further struggles. She was aware of this reality.

I think I still have a long way to go. At least a year. I still have a lot of sore places. Even though I'm doing much better I still get a few down days. I know it's going to take time. But I'm just going slowly.

Into the Future

Laura had the operation in January 2003. We kept telephonic contact on a monthly basis. Sometimes Laura would phone to update me on her progress or to discuss specific feelings and experiences with me. For example, she encountered a few complications with the muscle surrounding her right breast and had to be operated on twice during 2003 and 2004 to rectify the problem. She is doing well at present and still has not been for the nipple attachment. She feels she needs time to get back to normality and to settle down. She now sees herself as important and worthy in her relationships with others and continues to see herself as a survivor. She holds no regrets regarding the prophylactic mastectomy. She talks openly about her experiences and emotions and looks forward to spending time on holidays, having a successful job, feeling part of a family and looking forward to a healthy future. She believes that she can offer other women support and encouragement in terms of a family history with breast cancer and the choice for prophylactic mastectomy.

Christel's Story: The Unexpected Twist

Biographical Information

Christel is 32 years old and is married without children. She first came to the clinic in 2000 with her elder sister who wanted to be tested for the breast cancer mutation. At the time Christel did not want to be tested even though the BRCA1 gene had been identified in her family. In January 2003, Christel came back to the clinic after she had been diagnosed with breast cancer 8 months earlier. In May 2003 the results of a positive mutation were disclosed to Christel.

Christel is the youngest daughter in a family of three daughters and one son. Christel's mother died of ovarian cancer at the age of 44 when Christel was 4 years old. Her mother's sister also died of ovarian cancer at the age of 43. After her eldest sister was diagnosed with ovarian cancer at the age of 38, genetic tests were carried out three years later to determine if there was a genetic mutation. This was confirmed in 2000 when the family attended the clinic. Six months later, Christel's eldest sister died of ovarian cancer.

When Christel's mother died, her father remarried one year later. She lived with them until her first year of university but then decided to move to Johannesburg to live with her eldest sister. She was able to complete her Bachelor of Commerce degree at the University of Witwatersrand 3 years later. Six years later she married Simon and has been working as an accountant for a well-known business firm for two years.

I came into contact with Christel during her fist visit to the clinic in January 2003. When the positive test results were given to her in May 2003, the team suggested that she see me on a private basis. She was not interested in entering into long term therapy but when I explained to her that I could perhaps interview her for my research project, Christel agreed. She felt speaking to me would not do her any harm and that it could be beneficial. She was willing to come see me in Pretoria and our first appointment was scheduled for a Saturday morning. We had two one-hour sessions where Christel shared with me feelings of sadness, fear and anger.

Facing the Suffering

I was surprised at first at Christel's reaction to the positive test result. She did not demonstrate any shock, denial, sadness or anger during the report back session. The team saw this as unusual and suggested that she speak to a psychologist about the outcome. At the time I felt that Christel had not shown any emotions because of shock and denial. Throughout the session she came across as independent and strong, while never displaying any vulnerability.

When we met I asked Christel why she had been so emotionless during the report back session, she explained that she had already been through so much emotional turmoil in the last year with the breast cancer that this was no worse than the experience she had had. She also said that she had expected the results to be positive, based on her diagnosis, and that she had prepared herself for such confirmation. She admitted that she had never expected to get breast cancer considering that none of her family members had been diagnosed with it before. Her family only had a history of ovarian cancer and so Christel never really paid much attention to her breasts. However, at the age of 29, while working in her garden, Christel felt a hard lump on her right breast. She assumed that because it was so big and so hard that it could only be a muscle. She made an appointment with her gynaecologist the next day. He did a sonar on her breast and said that it looked like a cyst. He further added that she was too young to have breast cancer and that she should come back in a month's time should it last. Two months later she went back and this time the doctor did a fine needle aspiration on the lump. He confirmed the presence of a tumor and not a cyst. She was sent for a mammogram and was booked for immediate surgery. A few days later Christel and her husband received the news that the lump was indeed an aggressive tumour, which had spread into her lymph glands. Christel was given the option to either have one or both breasts removed. After discussing the diagnosis with her oncologist, Christel decided to have a bilateral mastectomy with the aim of undergoing reconstructive surgery at a later stage. Christel also received a series of high doses of chemotherapy and radiation during May 2002 and December 2002.

Christel still hasn't been for reconstructive surgery. Her oncologist advised her to wait two years after the surgery to prevent reoccurrence of the breast cancer. Allowing the skin to settle down after radiation was advised.

Nature of the Interaction

At first it was difficult for me to ask Christel to participate in my study since she had come across as distant and unemotional during the predictive testing and report back session. I felt as if I was intruding into her personal life and crossing boundaries by asking her to share with me personal and painful experiences. When

the gynaecologist and geneticist suggested that she speak to me, Christel was not too adverse to the idea. However, when I suggested that she participate in my study, she became open to the possibility of sharing her pain and suffering. She agreed to see me at my home in Pretoria. The fact that she offered to see me in Pretoria made me feel that she wanted to share her experiences with me. Later she would tell me that she wanted to see whether or not she was coping with her situation.

The mood and atmosphere in the first session was a relaxed and comfortable one. We started by discussing her family history with ovarian cancer and her diagnosis with breast cancer. My impression of Christel during this session was completely different to my initial impression of her at the clinic. Although she was controlled, independent and capable of handling her emotions, she did allow herself to express feelings of fear, anxiety and anger. She cried a few times and seemed comfortable doing this in front of me. I allowed her to express her feelings by giving her space and time to share them with me. I did not sympathise with Christel nor did I attempt to change the topic during the more emotional moments. Silence between the two of us was not threatening and I felt that she really needed to open and express herself. I was pleased that after one year of struggle she was able to share her pain instead of trying to bottle it up.

During the session I asked a few questions while Christel did most of the talking. I refrained from being the therapist and entered the role of the observer and information seeker. The interaction consisted mainly of me trying to gather as much information as possible regarding her experiences with familial breast and ovarian cancer.

Emerging Themes

Although the main emphasis of this chapter has been on familial breast cancer, it must be noted that germ-line mutations within the BRCA1 mutation are not only responsible for different proportions of inherited susceptibility to breast cancer but also to ovarian cancer (Reeves, Yawitch, van der Merwe, van den Berg, Dreyer & Van Rensburg, 2004). In Christel's family, the BRCA1 mutation led to inherited susceptibility of ovarian cancer as seen with Christel's mother, aunt and sister. She

believed that she had to protect herself from developing ovarian cancer and did not consider the possibility of breast cancer. When diagnosed with breast cancer, feelings of shock, denial and fear were experienced.

Shock

When Christel felt the lump in her right breast she never expected it to be a malignant tumour. At first she thought it was a strained muscle, and secondly, because of her young age, she doubted the presence of breast cancer. When she consulted a physician for the lump he, too, confirmed that she was too young and that it looked more like a cyst. When the lump was examined in more detail two months later, by means of a fine needle aspiration and surgery, the unexpected was confirmed. Christel did indeed have an aggressive form of breast cancer, which had already spread to the glands under her right arm. For Christel, the diagnosis was a shock:

The day I had the mammogram I didn't think there was anything wrong. I just thought this can't happen to me. I have enough in my life. But I was suprisingly calm. I only had a disappointed feeling. There weren't many emotions attached. It was that disappointed but scared feeling that there is a possibility that something's not right but never thinking that I had cancer. Never. Never at all. The day he told me it was cancer, I shed a few tears but I didn't cry. I haven't cried till this year. I think last year I was just coping. There wasn't time to feel emotions. Last year there were too many things I had to cope with – so many different things.

I asked Christel if she had been shocked at the news that she carried the BRCA1 mutation. She said she suspected that she had inherited the gene when she was diagnosed with breast cancer. Finding out through the blood test was not a surprise since all suspicions had been confirmed. She expressed that she is an unemotional person by nature and that early on in her childhood she stopped expressing her emotions. Christel explained how she lived in an unemotional and verbally abusive family. Although she had a loving father, he remained distant and was unable to express any emotions towards Christel. Her stepmother, on the other hand, disallowed Christel from expressing emotions such as anger, hurt, sadness, fear, happiness and excitement. She learnt to keep her emotions to herself and sometimes

found it difficult to allow herself to feel. According to Christel, she married someone who also expressed very little emotions. In our session, Christel admitted to feeling vulnerable when emotional. Sharing her feelings with me was unfamiliar and at times difficult. She found it extremely difficult to place herself in a position of vulnerability and saw it as allowing other people to gain an upper hand and to take advantage of her emotional weakness. In being emotional with me, the feelings of vulnerability were present. She admitted that it was frightening for her to open up to me, to share personal feelings and experiences with someone whom she did not know very well and to discuss personal details of her childhood and adolescence. I asked her if she was afraid of people taking advantage of her vulnerability and was surprised to hear her answer:

Absolutely…In a way I am afraid of people walking over that vulnerability. I would have liked to be taken care of but people also keep their distance. They just leave you alone yet you want them to take care of you. People leave you alone because they think you can stand on your own two feet. There are times when I can't.

Fear

Women feel very uncertain about their futures regarding how the disease will develop and what they can do to avoid it (Kuuppelomäki & Lauri, 1998). Results in one study showed that women with a first-degree relative with breast cancer showed more negative attitudes and anxiety about breast cancer, were more likely to engage in appropriate screening behaviour and viewed their risk for getting breast cancer as greater (Hailey, Carter & Burnett, 2000). These women recall close family members who suffered from the disease and bring these thoughts into their present experience. Some of these flashbacks may bring forth fears of intense pain and possible death (Chalmers et al., 1996; Kuuppelomäki & Lauri, 1998; McAllister, Evans, Ormiston & Daly, 1998; Meiser, Butow, Schieden, Gattas, Gaff, Harrop, Bankier, Young & Tucker, 2000).

In Christel's life story, seeing her sister die of ovarian cancer was a traumatic experience. She relived the trauma when she, too, was diagnosed with cancer. The pain and suffering of losing a close member of the family was brought to the fore

when she had to have chemotherapy and radiation. She recalled with sadness and tears how she had been constantly worried and fearful after her sister's diagnosis. She had spent three years of her life waiting for her sister's death and even though she tried to remain positive, Christel knew that her sister would not survive:

We were all realistic. She was a qualified nursing sister and she knew. So I lived three years in anticipation of the day she would die. The doom of not knowing when it was going to happen was tough.

I wanted to know more about Christel's current experiences with fear since the breast cancer diagnosis. She confirmed that she did fear a new diagnosis of cancer and the resultant chemotherapy and radiation treatments. The fear of the cancer reoccurring or developing in a different place did come to the fore, but for the moment, she would focus primarily on her mental strength instead of the physical concerns. She would try to remain positive and keep herself busy at work and at home:

I am fine. Look, there are things that are bigger than me but without me cancer can't survive. There is always the concern of life expectancy, but nine out of ten people survive breast cancer and I'm going to be one of those nine. People survive cancer. Everybody that I know with cancer has died but I will be the exception.

Sadness and Depression

Three areas in Christel's life where she expressed a sense of sadness were the following. Firstly, she felt a physical sadness at the loss of her breasts, secondly, sadness at how people viewed her, and thirdly, sadness when alone. In terms of the physical sadness, it has been mentioned that women feel a great sense of loss when they lose their breasts. Breasts are a symbol of sexuality, femininity, and motherhood. Any threat to a woman's breasts is usually considered unacceptable, frightening or devastating. Although Christel did not equate her identity to her breasts, emotions of sadness were nevertheless expressed:

Christel: *Yes, from my side, where I found that breasts were a very feminine, sexual expression. My husband says it's not a problem so maybe he wasn't a breast person, but it is. It made me feel like a sexual being. Yes, I can have reconstruction but it's not going to be the same.*

Paula: *When you lost your breasts, did you grieve for them?*

Christel: *I think so.*

Paula: *How do you see the loss of your breasts?*

Christel: *I'm sad that I didn't appreciate them. Regret for not appreciating them. Other than that they are non-essential organs almost. I often think about breast-feeding. I'll never have that opportunity.*

Paula: *And I suppose there are a lot of situations where you cannot really be open and natural.*

Christel: *No, you have to dress appropriately to wear a prosthesis. I'm a vain person, so the external changes are hard to deal with. Say I want to go out to the beach in my bikini, I can't, so there I feel sorry for myself. And you know, physically, the scars aren't pretty. Yet I know that they are a reminder of the fact that I am a breast cancer survivor.*

Christel also experienced sadness when surrounded by people who showed pity and empathy towards her. She did not want people to look at her as if she were suffering and felt that in them doing so, they would see her as different or as someone who would eventually die. This belief created much discomfort and sadness, specifically because she had previously felt this way towards other people who had had cancer. This discomfort amongst people has made Christel separate herself from the world, which in turn has created much loneliness. She expressed her loneliness in the following way:

Christel: *I don't know what it is but if I'm on my own now I get sad, depressed and I cry.*

Paula: *What thoughts and feelings do you experience when you are alone?*

Christel: *Why me? I've seen the hard side of life so can I have a break now? It's a constant worry of the cancer coming back and a constant concern of the aches and pain. I just want normality in my life.*

As Vogel (1995) mentions, notifying a woman of her increased risk may negatively impact on her mood. This may then be expressed in persistent worry, confusion, sadness and depression. Christel's isolation was creating the exact situation. Failure to discuss or express these negative emotions would lead to more depression, helplessness and hopelessness (Leedham & Meyerowitz, 1995).

Psychotherapeutic Implications

The agreement I had with Christel was that she would be seeing me for the following two reasons. Firstly, to assist me with my research topic by discussing and sharing experiences regarding her personal struggle with familial breast cancer. Secondly, as a means of letting go of some of the emotions she was experiencing in order to make sure that she was not suppressing or avoiding them.

Christel: *What I've learnt is that my past experience has made me bottle up a lot of anger and then years later you have to deal with it as opposed to dealing with it at the time. I would think it's better to deal with it and get it out of the way.*

Paula: *So there have been issues in your life that you have repressed, bottled up and they have come to the fore?*

Christel: *Yes.*

Paula: *Do you prefer to deal with the emotions of the familial breast cancer now, with me?*

Christel: *Yes, I feel less angry with time but I'll always have that anger. But I've brought it to the surface and I've dealt with it better now. It's the same with the emotions I feel now. Let me rather deal with them now. I want to make sure that I'm not suppressing the emotions.*

The need to talk about the emotions defined the nature of my interaction with Christel and her interaction with me, as well as the direction of the conversation. My aim became one in which I would try to elicit as many feelings and thoughts possible regarding Christel's personal suffering with the breast cancer. Having expressed her aim for the session, Christel was then able to open up to me and to discuss anger towards her upbringing, sadness and pain at the loss of her mother and sister, fear of the breast cancer reoccurring, regret for not appreciating her breasts, loneliness in terms of social support, and peace at having survived the cancer.

Empathy (transmitting to Christel a sense of being understood), reassurance and recognition of these feelings were shown throughout the session. Only towards the end of the session did I find it appropriate to ask Christel to be more specific about any meaning she had gained in her battle with breast cancer.

Finding Meaning in the Suffering

Christel was asked whether she had found meaning in her ordeal with the breast cancer, the surgery and mastectomy, and the chemotherapy and radiation.

Paula: *What do you think you got from all this pain and suffering?*

Christel: *Tenacity.*

Paula: *What do you mean by tenacity?*

Christel: *I know I can do anything I want if I want to do it. The fact that I survived the adversity in my childhood and with the breast cancer means that I can survive anything. I just have to be brave enough. It taught me to be brave.*

Paula: *How?*

Christel: *To walk into situations where I'm scared and just take control, have the confidence to do it. Like I came to Joburg with no self-esteem and no self-confidence.*

Paula: *So you gained tenacity, self-confidence and a feeling of being brave.*

Christel: *Yes, I can be anybody I want to. I can portray myself in any way.*

She also expressed how she was able to find out who she was, who her real friends were and what strengths she had. Coming to this realisation felt like a breakthrough for Christel since she had never considered her struggle from this perspective. She ended the session by saying that she had found 'a better person'. Even though the old Christel was not a bad person, she was nevertheless expected to perform in front of others and be what others wanted her to be. She did what made other people happy and never what made her happy. At the end of our session, Christel expressed how she was able to walk out of her situation with a renewed liking of herself, greater self-esteem and a sense of survival.

I handled the whole thing with dignity. I'm an example to other people. They all say that I'm so strong but my words to them are, "You don't know how you're going to handle this." We all say that. None of us really know how others feel.

Significant Changes

The most significant change Christel experienced one year after the breast cancer was the sense that she had found out who she really was. Through this process she was able to change into someone more authentic. She shared that due to her

emotionally abusive childhood, she never really defined a personal identity for herself. She always felt inferior amongst friends, never received any praise for achievements at school, and always felt left out and alone. In the last year, however, things had changed:

Christel: *I think my identity has changed over the last year.*

Paula: *How?*

Christel: *I used to be a person who needed a lot of control over minor things and I would worry. Now, its like there are bigger things in life to worry about. I'm more relaxed, laid back.*

Paula: *Do you like the person you are now?*

Christel: *Oh, yes. It's so much better. I feel like there's a big burden lifted off me. When you put little worry A against big worry B – cancer, chemotherapy, the future – you realise that that stuff doesn't really matter.*

Christel experienced a sense of a new person emerging and a new opportunity to get to know herself all over again. I likened it to the shedding of skin and the creation of a new identity. She agreed that she had become a calmer and more accepting person. I asked her if the breast cancer had allowed her to become this new person and she answered as follows:

Christel: *Absolutely, definitely. (Crying). I am no longer searching and searching for me, for who I was at the end of the day.*

Paula: *And your experience with breast cancer allowed for that to happen?*

Christel: *I think so. I think it brought me down to a point where I had no strength to be anybody else. I couldn't use clothes or make-up or hair to be somebody else. So I just had to be who I was.*

Paula: *So your experience with breast cancer gave you something?*

Christel: *Yes. I once said to my sister that it's the worst and the best thing that happened. It wasn't pleasant and I have to deal with it for a long time to come, but the fact of the matter is that I gained something. If I didn't gain something from this then I might as well be dead because everything happens for a reason. And I think the reason behind this was for me to find who I was.*

Paula: *Do you sometimes feel that you have lost a lot?*

Christel: *Yes, but I also found. I definitely found. I found who I was. I found out who my real friends are, I found what my strengths are and I found what I enjoy. (Laughs). So, yes, breakthrough. I found. The new me is a better person. And I've come out of it with being me and actually liking me.*

Into the Future

I contacted Christel one year after the interview and was unable to speak to her personally. Her husband told me that she had been doing well in the last year but had recently gone back to hospital. A malignant lump had been detected in her right breast. She was undergoing radiotherapy at the time and did not want to speak to anyone. She had temporarily stopped working.

Conclusion

A family history of breast cancer can impact significantly on a woman's life. Not only does the knowledge of familial breast cancer impact on the choices she makes on a physical level, but also on an emotional and social level. In fact, such knowledge may provoke intense emotional reactions – fear, anger, anxiety, guilt, grief, helplessness, lack of self-esteem and depression. As a researcher, it was a privilege to enter into Laura and Christel's world and to experience with them the

personal suffering they face. Both women witnessed the early onset of cancer in two or more close relatives, which resulted in a greater sense of personal risk and psychological turmoil. Both women were open and honest in their conversations with me and through our conversations we were able to elicit as many emotions, thoughts and experiences as possible with regards to the suffering. In all our sessions, I felt that I needed to give them something back, and found it necessary to make them aware of any meaning or shifts that had been gained through their suffering. I believe that a certain amount of meaning and closure was achieved. It is important to note that genetic counselling is advised so that women can be better prepared to make informed decisions regarding their susceptibility to familial breast and ovarian cancer. It is also important that they deal with the emotional, physical and social suffering in a constructive and meaningful way.

CHAPTER 5

EATING DISORDERS

Dis-moi ce que tu manges, je te dirai ce que tu es.
Tell me what you eat and I will tell you what you are.

(Anthelme Brillat-Savarin)

The purpose of this chapter is to illustrate the perceptions and assumptions held by two women struggling with eating disorders. The case illustrations will be presented in verbatim form and the names changed for purposes of confidentiality. The chapter will consist of four sections namely the women's biographical information, their experiences of suffering, emerging themes from the conversations and psychotherapeutic implications. These will include a detailed presentation of the women's assumptions regarding eating disorders. It is hoped that the reader will draw his or her own distinctions about the women's personal distinctions and assumptions. A brief overview of eating disorders will be presented before the presentation of the case illustrations.

Background to Eating disorders

An eating disorder is a physical and psychological disorder in which an individual uses food to resolve emotional problems (Maloney & Kranz, 1991). Three different eating disorders have been defined by the *Diagnostic and Statistical Manual for Mental Disorders* (DSM-IV) (Robert-McComb, 2001). These are anorexia nervosa, bulimia nervosa and eating disorder not otherwise specified. Eating problems are characterised by symptoms of binge eating, compulsive and addictive eating and attempts to lose weight through dieting, self-induced vomiting, laxatives, diuretics, or excessive exercise (Evans & Wertheim, 1998). These behaviours influence all aspects of the individual's life including the physical, emotional and social contexts (Garvin, Striegel-Moore & Wells, 1998; Orzolek-Kronner, 2002).

Eating disorders are considered complex compulsive eating behaviours carried out by different people (male and female) and in different contexts (Mickley, 2001). Since the focus of this thesis is on women's suffering through their bodies, eating disorders will only be discussed in terms of the female perspective.

Anorexia Nervosa

Women suffering from anorexia usually restrict food and literally starve themselves to death (Maloney & Kranz, 1991). They choose different ways of losing weight through dieting, fasting, consumption of food in small quantities, self-induced vomiting, misuse of laxatives, diuretics, enemas and excessive exercising (Robert-McComb, 2001). Although the result is a considerable amount of weight loss, anorexic women continue to see themselves and their weight loss as never thin or sufficient enough (George Hsu, 1999; Maloney & Kranz, 1991; Mickley, 2001). Many weigh only ¾of the weight that is normal for their height while others look as thin as 'prison-camp victims' (Maloney & Kranz, 1991, p. 48). The biggest problem with anorexia is the consumption of insufficient calories. This leads to the slowing down and destruction of the body's metabolism and vital body functions (Mickley, 2001).

According to the DSM-IV the diagnostic criteria for Anorexia Nervosa are the following (Kashubeck-West & Mintz, 2001; Robert-McComb, 2001; Zerbe, 1993; Zraly & Swift, 1990):

A. Refusal to maintain body weight over a minimally normal weight for age and height.
B. Intense fear of gaining weight or becoming fat, even though underweight.
C. Disturbance in the way in which body weight, size or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the current low body weight.
D. In females, absence of at least three consecutive menstrual cycles when otherwise expected to occur. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g. estrogen administration).

About 95% of anorexics are female and mostly between the ages of 12 and 24. Most girls come from upper or middle-class families, families with older parents and/or small families. Families with anorexic children generally appear to be perfect on the surface, but troubled relationships between parents and their 'model' children usually exist (Clopton, Haas & Kent, 2001; Maloney & Kranz, 1991; Orzolek-Kronner, 2001; Robert-McComb, 2001; Thode, 2001).

Physical problems related to anorexia include the loss of menstrual periods and destruction of crucial stages in puberty, impaired bone formation and osteoporosis, heart failure and irregular heart beat, loss of brain tissue, problems with stomach functioning, low blood pressure, anemia, bruises, a layer of fine body hair (lanugo) which protects the body from the cold due to loss in natural padding, dizziness, insomnia, feelings of numbness in hands and feet, dehydration, kidney failure, lowered body temperature, low tolerance for cold weather, grey or yellow-like skin, dry, patchy hair, fatigue, sunken eyes, loss of concentration and/or irritability (Maloney & Kranz, 1991; Mickley, 2001; Robert-McComb, 2001; Zerbe, 1993).

Anorexics also suffer from a distorted body image. Despite the physically unattractive qualities, weight loss is still considered beautiful, acceptable and necessary. Anorexics are so proud of their new bodies that they are able to ignore the hunger pains and substitute normal food with low-calorie options (Robert-McComb, 2001). These behaviours are usually successfully managed as the anorexic strives for the perfect body.

Bulimia Nervosa

Bulimia nervosa is more common than anorexia nervosa and consists of the same obsessions with body image and appearance. The slight difference is that the anorexic gives the impression of a perfect, fragile individual, while the bulimic presents herself as elusive, perfect and successful (Maloney & Kranz, 1991). Bulimic women will feel terrible hunger pains, eat large quantities of food, experience guilt feelings for having eaten so much and then try to regain control through purging. The initial stage is termed a binge when huge amounts of food are ingested – up to ten

times the usual amount at one time. A purge is when the food is expelled either through the misuse of laxatives, vomiting or excessive exercise (Arenson, 1989; Kahm, 2001; Maloney & Kranz, 1991; Robert-McComb, 2001). Binge foods tend to be high in fat and high in starch - sweets, ice-cream, puddings, bread, chocolate, pastries, cakes, chips, peanuts, cheese, cookies and pastas (Robert-McComb, 2001; Romano, 1999).

The following criteria in the DSM-IV define bulimia nervosa as an eating disorder (Maloney & Kranz, 1991; Mickley, 2001; Robert-McComb, 2001; Romano, 1999; Zerbe, 1993; Zraly & Swift, 1990):

A. Recurrent episodes of binge eating. An episode of binge-eating is characterized by both of the following:
    1. Eating in a discrete period of time (e.g. within any two-hour period) an amount of food that is definitely larger than most people would eat in a similar period of time and under similar circumstances.
    2. A sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating).
B. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, enemas, or other medications; fasting; or excessive exercise.
C. A minimum average of two binge-eating episodes a week for at least three months.
D. Self-evaluation is unduly influenced by body shape and weight.
E. The disturbance does not occur during episodes of anorexia nervosa.

Bulimics come from all socio-economic levels and present themselves as having no apparent weight problems. Bulimia may begin between the ages of 15 and 24 years of age and develops mostly at transition times e.g. adolescence, starting a new job, marriage and loss (Maloney & Kranz, 1991). Bulimics come from families where a large amount of emphasis has been given to outward appearances or where insufficient emotional care and time has been spent with the individual or child. Bulimia nervosa also arises from the socio-cultural values, norms and expectations regarding femininity, thinness, physical attractiveness and beauty (Robert-McComb,

2001). The bulimic is aware of the ideal female stereotype as reflected in the media and in magazines, and by fashion models or Hollywood stars (Jambor, 2001). These internalized societal values regarding thinness continue to influence the adolescent into adulthood (Maloney & Kranz, 1991; Mickley, 2001).

Eating large amounts of food serves various functions. One function is the ability to be in control of food consumption as a compensatory behaviour for loss of control in other areas of life. Another function is to provide calmness in the face of anxiety. These feelings of control and calmness are, however, only temporary and soon a vicious cycle ensues as seen in the following description: the individual binges in order to escape negative feelings and dissenting experiences, but feels shame, guilt and disgust for her loss of control. She then tries to take control through purging, laxatives or excessive exercise. Doing this makes her feel out of control and incapable of handling her problems. She turns to food once again in order to escape the negative feelings (Arenson, 1989; Maloney & Kranz, 1991). The cycle continues for months and years until help is sought.

Physical symptoms experienced by the bulimic include pressure on the liver due to purging, fatigue, sore throat, sores and tears in the oesophagus due to vomiting, dental problems and tooth decay, heart problems due to nutritional imbalances, infected salivary glands, dry skin from loss of fluids due to diuretics and laxatives, rash or skin eruptions, dehydration, edema or water retention, abdominal cramps, irregular or even absent menstrual periods, bloating, loss of potassium and electrolytes, muscle weakness, inability to have normal bowel movement due to laxatives, gyneacological and obstetrical problems (Maloney & Kranz, 1991; Mickley, 2001; Robert-McComb, 2001; Zerbe, 1993).

Eating Disorder Not Otherwise Specified

This category involves eating disorders that meet some but not all of the specific criteria for anorexia nervosa or bulimia nervosa. The diagnostic criteria are:

A. For females, all of the criteria for anorexia nervosa are met, except that the individual has regular menses.

B. All of the criteria for anorexia nervosa are met except that, despite significant weight loss, the individual's current weight is in the normal range.
C. All of the criteria for bulimia nervosa are met, except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for a duration of less than three months.
D. The regular use of inappropriate compensatory behaviour by an individual of normal body weight after eating small amounts of food.
E. Repeatedly chewing and spitting out, but not swallowing, large amount of food.
F. Recurrent episodes of binge-eating in the absence of regular use of inappropriate compensatory behaviours characteristic of bulimia nervosa (Maloney & Kranz, 1991; Mickley, 2001; Robert-McComb, 2001; Zerbe, 1993; Zraly & Swift, 1990).

Women identified under this category struggle emotionally with food and although they may eat large amounts of food they may do so when not feeling hungry (Romano, 1999). Their behaviour is characterised by the following: eating until feeling uncomfortably full, eating much more quickly than normal, eating alone because of the possible embarrassment of the quantity of food, and feeling depressed, guilty and disgusted with oneself once the bingeing has ended (Katz, 1991; Robert-McComb, 2001). A compulsive eater may also diet compulsively for a while and then binge uncontrollably. Such behaviours may have developed as learned responses to emotional issues and emotional distress during childhood, adolescence or young adulthood (Zraly & Swift, 1990).

Physical effects of compulsive eating include obesity that may develop after prolonged eating. If the person is 25% or more over normal body weight then this can be considered risky to one's health. Other effects include diabetes, cardiovascular disease, blood circulation difficulties, high blood pressure, problems in mobility, anorexia, bulimia, depression and anxiety, bone and joint problems (Maloney & Kranz, 1991; Mannix, Dempsey & Engel, 1999; Robert-McComb, 2001; Zraly & Swift, 1990).

Case Illustrations

Lisa's Story: Facing the Truth

Biographical Information

Lisa is 28 years old and is currently completing her degree in physiotherapy. She left South Africa for America after completing Grade 12 to work as an au pair. After the first year as an au pair, Lisa decided to continue living and working in America. She began working as a receptionist for a small company and remained there until December 2000. She returned to South Africa at the age of 24 to begin her studies at the University of Pretoria. Lisa currently lives with her parents in Pretoria and is the eldest child in a family of two. She has a younger sister who is also completing her studies in Accounting. Lisa hopes to get a place of her own once she is able to find a job to support herself.

Lisa came to see me in May 2001 for therapy because of an eating disorder. She always had a problem with her weight and with food, particularly during high school, but while in America it had become an obsession and she had started a pattern of bingeing. Lisa was referred to me during her first year of studies and sought help for exam pressures and binge eating episodes. We saw each other for three sessions until Lisa decided to stop therapy due to her busy schedule and unavailability during the day. She then decided to join Overeater's Anonymous on a weekly basis every Tuesday evening. We remained in telephonic contact during her attendance of Overeater's Anonymous. I was aware of the organisation's services and believed that Lisa would benefit from being with people who shared the same problem. In June 2002 Lisa went to America on holiday. We did not maintain contact with one another until June 2004 when I met Lisa at a shopping mall. She said she was still struggling with the eating disorder and pressures at university. She had also been to see another psychologist for help with stress, anxiety and depression. Her eating disorder had, however, not been resolved.

I mentioned to Lisa that I was busy researching eating disorders for my doctoral thesis and asked if she would be willing to talk to me about her experiences

with food and weight. She agreed. She felt that she would benefit from opening up to someone whom she already knew and with whom she had always felt comfortable. I said I would contact her telephonically and set up an appropriate time. We saw each other at the end of July 2004 for our first interview session (one-hour long) and two weeks later for the second session (one-hour long).

Facing the Suffering

From the process notes I had gathered on Lisa in 2001 it was clear that she was struggling significantly with her weight and with overeating. When I met Lisa, she was thirty kilograms overweight and since then had only lost five kilograms. The biggest problem for Lisa at the time was the bingeing that took place on a daily basis. Lisa would stop at convenience stores almost every day and purchase large quantities of junk food – chocolates, chips, sweets and fizzy cool drinks. She would consume them before reaching home. Once at home she would search for food in the cupboards or fridge and continue to eat as much as possible. She would only do this if the house was empty. With family and friends, Lisa would be on her best behaviour and eat small, healthy meals. She mentioned how this was ruining her emotions and her body. She struggled to socialise with friends who often ate lunch and dinner at fast food places. Although she wanted to be part of the group she felt silly taking healthy food along. Often she would land up eating the fatty food but feel guilty for having done so. Her conversations with me were wrought with guilt for eating and choosing the wrong foods most of the time.

Lisa also mentioned feeling as if she were on a roller coaster. On some days she would be really 'good' and on other days she would be very 'bad'. She was unable to maintain a balance in terms of eating, and either ate excessively or moderately. She was frustrated, upset and irritated at herself for not being able to control her eating habits. During that time I tried to help her make the food-emotion connection and realised that the biggest reason for her 'bad' eating days was directly linked to feelings of loneliness and anxiety. In fact, it came to light that the only reason why her eating disorder had intensified in America was because she had felt so lonely and anxious. She did not have a social life and remained in her apartment during most evenings and weekends. She had started a pattern of bingeing when

alone. During her last year in America, Lisa met someone with whom she became seriously involved. They dated for eleven months. The relationship, however, did not last and Lisa decided to come back home. Back in South Africa, Lisa continued to feel lonely and out of place. She was unable to continue with past friendships from school and also felt older in comparison with her fellow students.

Three years later, speaking to Lisa for my doctoral research, I realised that she was still struggling with her weight and food. Her eating disorder remained problematic, if not worse. She had now started to purge after heavy binge episodes and use laxatives to get rid of excess food. She still felt completely out of control in terms of eating appropriately. I did notice, however, that Lisa had matured considerably. She was able to speak to me more openly and tell me in more detail how she felt. She was also more aware of how her emotional state contributed to her eating patterns.

Lisa's pain and suffering had obviously not subsided in the last three years and was noticeable in the two sessions I had with her. She was still keeping many secrets in the dark and felt very ashamed admitting to some of the binge episodes. Lisa expressed frustration at not having found a solution, and depression at not being able to control her eating and her weight. She also felt anxiety and fear in terms of relationships with men, her future and her studies.

Nature of the Interaction

My first interaction with Lisa three years ago was difficult in that Lisa came across as a very shy and introverted young adult. She struggled to open up to me and to share personal experiences. During our sessions, I did most of the questioning and talking and felt that I was not getting much from Lisa. She would often answer 'Yes', 'No' or 'I don't know'. I recall feeling frustrated at not being able to get more from Lisa in terms of her feelings and thoughts. Most of the time I would discuss with her what I knew about eating disorders and how I saw the connection between food and feelings. I noticed that Lisa was looking for answers to her eating behaviour and was happy when I was doing most of the talking. At the time it seemed that all Lisa wanted from me was advice and insight. Our roles seemed to be those of teacher and

student and I felt uncomfortable continuing in this manner. I was unable to deal with these issues any further when Lisa informed me that she would be ending therapy to join Overeater's Anonymous in the evenings. Her busy schedule made it difficult for her to attend therapy sessions during the day.

Three years later, I noticed a very different person. It seemed that previous therapy sessions with her psychologist had helped Lisa to speak and open up more. Also, the fact that I would be speaking to Lisa as part of research and not therapy, seemed to be less threatening. Our interaction with one another this time was on an equal basis and I did not feel as if she were seeking advice. This time she also showed a greater awareness regarding her emotions and her eating behaviour. There was also more sharing from her side and less advice giving from mine. My role was that of the researcher and hers of the participant, while the goal was to gain as much information about Lisa's eating disorder as possible.

Emerging Themes

Loss of Control

Young women suffering from eating disorders such as bulimia nervosa usually believe that they are able to control their environments (Robert-McComb, 2001). In general, they may experience feelings of ineffectiveness and lack of control over basic issues in life. These issues may be related to relationships with parents, boyfriends, peers or school in which relationships are wrought with overly restrained emotional reactions or conflicting feelings regarding what is expected of them within societal norms and values. Their inability to resolve these feelings and issues perpetuates itself into an eating disorder, which although obsessive in terms of food, weight and body, still provides them with a sense of control. It was clear from the session with Lisa that she was struggling with issues regarding her studies, her looks and relationships with members of the opposite sex.

I feel like I don't have control over anything – my future, my studies, my body. For example, with my studies I'm supposed to decide how much I must study and how well I must do but I fail to do that. I have no control even with the food. I should be able

to eat differently but I can't and I don't. I don't even feel control in my relationships, especially with my previous boyfriend or other guy friends I've met since I've been here.

Throughout the two sessions the biggest sense of loss of control was regarding her food intake and her weight. I asked her if she felt out of control when it came to eating. She answered:

Definitely. There are times when I just lose control.

I asked her to describe those times in more detail.

Well, I'll feel a negative emotion and when I'm driving home I decide I feel like eating. I'll stop somewhere and I will buy a lot – like a big packet of chips, chocolates, sweets, fizzy cool drinks. I just eat them in the car and then throw everything away. If I get home then I'll just eat everything there is – whether there is bread or anything else. Anything that I can find, I will put my hands on it.

People will be shocked to know how much I eat. I mean I can stop and eat a big packet of chips and eat the whole thing. I can buy myself three chocolates at a time. You'll think any normal person can't eat this much!

I asked her how much control she had over food, considering that she was the one who decided what, when and where she ate.

Well, I feel I control the food first, but then when I overeat I feel out of control. Maybe for that moment I feel good but afterwards I feel guilt and I'm mad at myself. But, yes, I suppose I am in control because I decide what I want to eat, when and where I want to eat it. The problem is afterwards. I feel like I've lost control and I feel sick.

Unfortunately, the feeling of being in control is only temporary as soon as Lisa realises what she has done. Whereas before she was convinced that she was in control of what she ate, she is now confronted with a sense of guilt and a lack of self-control.

Her desire or obsession to control her eating has failed. Feelings of anger at the binge and the lack of rationality now begin to weigh in and she realises that she is, in reality, not only unable to control her life but also her behaviour with eating. She now believes that weight and food issues are actually running her life. "The control that is so hoped for to gain attractiveness, acceptance and ultimate success leads only to failure – failure to lose weight, failure to stay healthy, failure in interpersonal relationships and very often, failure to stay out of the hospital as well" (Rothenberg in Haas & Clopton, 2001, p. 45). The belief that she is incapable of achieving independence and control is confirmed in her actions regarding food.

I want to be perfect in all areas but I just can't get it right. I feel like I don't even have control over things that I should have control over – like what I eat.

Feeling of Emptiness

Women who experience problems with their weight and with food, as in the case of bulimics and compulsive eaters, do not know what physical hunger is. For them, physical hunger has been replaced by an emotional hunger that works very differently to normal physical hunger pains. Physical hunger means that one's body is sending the signal that every single calorie that was taken in through food has been used up by the body for the maintenance of certain bodily functions such as, metabolism, growth, body temperature regulation and so forth (Kahm, 2001). Its primary function is therefore, to refuel and maintain the human body in it's everyday survival.

With bulimics and overeaters, however, food does not fulfil these functions. Instead, it is used to fill empty spaces and cover up emotions that are too unbearable to solve (Ritchie, 1994). "When a woman is obsessed with food, she makes it the focus of her existence. It is as though she cannot think about anything else. Her whole life appears to revolve around the object of the obsession" (Meadow & Weiss, 1992, p. 17). Such an obsession provides women with a safe place where they can place all their feelings of disappointment, rage and sorrow. As long as they are obsessed with food, women with eating disorders will feel that there is a concrete and substantial reason for their pain (Roth, 1991). Since they are obsessed with food, it is

common for them to indulge on particular foods for a period of time and eventually lose control over such behaviour. They may feel as if their emotional pain is being soothed and tranquilized but will later find that this is merely a façade.

Lisa, for example, mentioned that although she felt out of control and guilty after a binge, it still helped her ease the pain inside. She described it as follows:

It's like taking medication. When I'm bingeing I can't stop eating, or even if I buy something I usually tell myself that it won't be enough food. So I just buy. Sometimes I decide I'm going to buy or eat the food and that's it! There's nothing that's going to change my mind. I gobble my food down and I eat really fast. Sometimes I am unable to stop and I just go on and on and on. You just go on. You know that you're way past being full, but you just eat.

Depression

According to Lisa, depression was and continues to be a major reason for her eating disorder. Evans and Wertheim (1998) show that eating problems have been linked with negative mood states and high levels of depression. Many depressed compulsive eaters feel like victims before and after. They not only see life in helpless and hopeless ways but also see their situation as impossible and unchangeable. "Almost everyone suffering from an eating disorder feels depressed" (Arenson, 1989, p. 187). Whether it precipitates or follows the beginning of the eating disorder, depends on the individual's personality and life circumstances.

Lisa mentioned that she was prone to feeling depressed and that this had been ongoing even before leaving for America. She was still taking medication on a daily basis to handle the depression. I asked her if there was a link between her depression and her eating disorder.

Yes, because when I'm depressed I want to eat. It makes me feel better. The food doesn't make me feel so down.

In our first sessions together we had concluded that her depression was linked to feelings of loneliness and anxiety. The connection between food and loneliness/anxiety is not uncommon as food has been found to aid the lonely individual. Since food is always readily accessible and easy to get hold of, it remains the perfect companion (Abramson, 1993; Arenson, 1989; Romano, 1999). It must be noted that relief is only temporary and that feelings of loneliness and anxiety soon reappear. Lisa had the following to say:

It becomes really bad when I'm alone and I feel depressed quite often. Weekends and at night are the worst times for me. I just feel down in the dumps. I get the Sunday blues a lot. Maybe that's why I overeat on the weekend all the time because I know what's coming.

I asked her to explain these feelings in more detail.

I feel fear and anxiety but I can't explain what. Especially when I'm alone. Also if there is something wrong in my house, for example, someone is stressed, sad or angry then I feel it. I can cry with my sister when she cries. I hate it when my family is upset or sad. I have a lot, a lot of anxiety about everything. That's why I can't be mad at someone or, if someone is mad at me, then I need to sort it out immediately. I hate fighting.

I also can't distract myself by going to the computer or TV. I have to eat. It makes it better. I can't sit still with the anxiety but the food definitely calms me. I even get these anxiety attacks when I'm on my own. I really struggle being at home alone. I cry, I don't know what to do, sometimes I feel like I just can't breathe.

Low Self-Esteem

The theme of depression, which surrounds Lisa's life also brought to light feelings of low self-esteem and self-worth. These had existed when I first met Lisa three years ago and wanted to know if she still felt the same way. She discussed how she still did not think much of herself and that America had not really help her develop confidence or self-worth. This experience of low self-esteem in women

struggling with eating disorders is not uncommon and seems to be a determining factor (Arenson, 1989; Button, Sonuga-Barke, Davies & Thompson, 1996; Marcus, 1999). Adult women struggling with eating disorders and low self-esteem will behave in ways that demonstrate self-sacrificing and people-pleasing behaviour. They feel that they need to buy approval by being dependable and subservient to other's needs and wishes (Arenson, 1989; Marcus, 1999). They believe that if they act kindly, creatively, confidently and sincerely then others will keep from seeing their actual feelings of low self-esteem. Such a façade keeps them from having to show who they really are by being what others expect them to be (Kahm, 2001; Thode, 2001). Women with low self-esteem will usually neglect their own needs, interests and desires and choose to put others first (Arenson, 1989; Pettus , 2001).

When asked about her self-esteem and self-confidence, Lisa mentioned that she had very little of it, in particular, with her studies, boyfriends, people she did not know very well and her weight. Although she felt good about herself in her family and friendship environments, she still believed that she was incapable of being successful and of making something worthwhile of her life. She expressed how she would only be content and fulfilled once she had lost weight.

I feel life would be so much better if I was thin – so much easier. I'd be happy. I know it doesn't matter but the age I am now – trying to find a husband – it does matter. That's how life works. Men want to marry attractive women.

I asked her what would give her peace in terms of her eating disorder. She answered:

To be thin. And that's the only way to be happy. My whole struggle is to get there. Once I'm there everything will be ok, and then I'll be able to eat all the stuff I want so bad because I am going to be thin and I will have control.

Perfectionism

Another common problem related to adult eating disorders entails perfectionism (Kahm, 2001; Rohwer & Massey-Stokes, 2001). The need to bridge the gap between societal ideals and the individual's expectations is often very difficult to

attain such that feelings of 'inadequacy' and 'failure' are quickly relieved through the use of food – the soothing comforter (Meadow & Weiss, 1992). When good feelings do not flow from certain activities or daily life, the individual turns to food for the provision of pleasant feelings (Abramson, 1993). People feel comforted and nurtured through food mainly because "it is easy; it is almost always readily available; it doesn't require the approval or help of anyone else; and especially with snack food, no special equipment or involved preparation is required. In other words, you can have what you want when you want it!" (Abramson, 1993, p.61). For the perfectionist, eating is probably the most effective and least expensive method for self-nurture. Escaping life's pressures by choosing an option where weight gain is the only side-effect, is more acceptable (Steinhardt, Bezner & Adams, 1999).

As a perfectionist who sets exceedingly high standards for herself, any form of a minor fault is monumental (Arenson, 1989; Rohwer & Massey-Stokes, 2001; Steinhardt et al., 1999). This can be seen in the following process. Firstly, the woman's aim is to have the perfect life, the perfect career, the perfect family and the perfect body. This is not always realistic and so any attempt to deal with unattainable goals and negative feelings is to turn to food for comfort. When she is unable to avoid an extra helping of food or an 'illegal' snack, the perfectionist begins to feel like a complete failure. Instead of just deviating from her diet for a brief moment, the perfectionist's sense of failure heightens and greater feelings of inadequacy are encountered (Fairburn, 1995; Haas & Clopton, 2001). The destructive cycle continues as she turns to food once again.

This lack of inflexibility and the all-or-nothing style of thinking exhibited by the perfectionist emotional eater only creates more guilt, frustration, anxiety and self-punishing thoughts and behaviour (Haas & Clopton, 2001). There is no middle path between perfection and failure, and therefore no room for error (Arenson, 1989). They continuously tell themselves "I should have done that better", "Why can I not even control what I eat?" or "Why did I let myself eat like that?" Their symptoms (emotional eating and emotional disorders) become their main problem.

I asked Lisa if she considered herself to be a perfectionist.

Lisa: *Yes, that's just the way I am. I either do everything or I do nothing. I need to do well in every aspect of my life. For example, with the studying I have to do really well. With my looks too. I can't believe that I'm not a perfectionist there. I just can't get it right. How will I ever be fine with what I eat because I will need to do it perfect. Either I eat healthy or not. I can't eat healthy and then eat something I'm not allowed to eat. I can't do it.*

Paula: *So if you were to have a chocolate once in a while, would you have ruined everything?*

Lisa: *Yes. I know people who eat really well during the week and then get to have one cheat day when they can eat whatever they want. I just feel I can't do it. I have the habit of weighing myself very often. If I were to do that, by the Friday I would have lost weight but after the cheat day I would just go back to where I started.*

I asked her where the perfection had come from.

I think from when I was a kid. My mom says that whenever I ate I would not dirty myself. I always wanted to be neat and clean. Since I can remember I've always wanted to be perfect. Even in the colouring in of pictures. I had to be perfect. I couldn't go over the lines. So today, I believe I should be perfect even in the way I look.

Psychotherapeutic Implications

Eating disorders involve an intense relationship between an individual and food. It is a relationship where intense love, hate, comfort, confusion and obsession exist. For Ryan (2001), the relationship with food can be viewed as a metaphor for how one connects to the world. It therefore seems sensible that in order for recovery to take place, the individual's relationship with him/herself, with others and with the

world should first be considered. I asked Lisa to speak to me about her eating disorder mainly because of my previous encounter with her and also because of the need for a research participant. The intention was not to do therapy but merely to elicit as many meanings possible about her struggle with food and weight. Even though I did not introduce any therapeutic elements into the conversation, two important issues were discussed with Lisa in terms of understanding and dealing with her eating problem.

Emotional Awareness

When I first saw Lisa for therapy three years ago I was aware of the lack of emotional awareness she had regarding negative emotions and the desire to binge. She was not in touch with her feelings and was unable to see the connection between difficult situations or relationships and eating. In general, I found that there was an overall confusion regarding emotional anxiety and physical discomfort, and an inability to tell the difference between physical and emotional hunger. Speaking to Lisa three years later I realised that she was now able to recognise and share feelings and thoughts which lead her to binge. She could see that her eating disorder persisted as a way of coping with personal issues of anxiety, fear, lack of control, low self-esteem, depression and perfectionism.

Paula: *When did you learn to use food as a source of comfort?*

Lisa: *At first in high school, then in America I started to pick up weight because I was bingeing and overeating. Only later did I realise what I was doing. Only now do I realise that I was eating over the emotions.*

Paula: *Did the bingeing make you feel good?*

Lisa: *Yes, but just for that time. I didn't know then why I was doing it.*

I was also surprised to see that Lisa was able to name the emotions that were causing her to overeat. Three years ago she had been unable to even mention them.

Lisa: *I still do it all the time. I satisfy an emptiness within me. When I feel down or depressed or I feel like I've failed, I try to make myself feel better by eating.*

Paula: *What is the emptiness all about?*

Lisa: *Issues in my life. Things from the past, fear of the future. Anxiety about my studies, getting older and not being in a relationship, looking the way I look.*

Paula: *When do you feel that emotional hunger and the need to fill the empty hole?*

Lisa: *When I feel I have failed, when I feel like a failure, stressed. When I have the emotions inside and when they become unbearable.*

I also wanted to know if she had gained anything from previous therapy sessions and, if what she had gained, was helping her cope with her present problems. She answered:

Well, the first psychologist, years ago, was doing hypnosis on me and I didn't feel good about that. I decided it was stupid and I just wasted my time and his. It was silly. It wasn't working and I didn't like that treatment. Then I saw you for a short while and that helped a lot in that I understood that my eating is connected to my emotions. I learned a lot from you. I always thought I had these genes from my family and that I could eat the same as my sister but I would be the one to get fat. Anyway, at that time I learned that it wasn't just genes. I did actually eat a lot. I binge a lot and I do so over the emotions. The third therapist helped me deal with specific issues in my life such as depression and anxiety. With her I began to take the medication which has really helped a lot. I also got to deal with issues that I had at the time like the relationship with my ex but never really with the food.

I was surprised to hear what she thought of herself as the client:

You know, Paula, I think I get all this advice from therapists and therapy but I choose to go home and not do it or carry on with it. I'm starting to think that I do that with all areas of my life. I give up. I don't follow through.

I asked her if she was looking for a quick solution to losing weight, finding a boyfriend and doing well in her studies. Lisa answered:

For sure. It's too much physical and emotional effort and work otherwise.

Facing the Truth

Treatment of an eating disorder is enhanced when the woman discovers the reasons why she is eating. Finding the connection between feelings and food will hopefully make the individual aware of the triggers and the situations that lead her to turn to food as a way of managing life. Over the last few years, with the help of therapy, Lisa had been able to find this connection although she still continued to binge, purge and eat secretively. During our conversation, the biggest threat I foresaw with regards to Lisa's recovery was the secretiveness she held regarding her eating patterns. She was still eating in silence and was not opening up to anyone regarding the details of her eating behaviour. In fact, she mentioned that she found it awkward to be sharing with me particular details of her eating. I was concerned about her keeping her problem in the dark and decided to highlight this in the session as a psychotherapeutic implication.

Paula: *Does your family know about your eating patterns?*

Lisa: *No. Maybe my mom sometimes knows but I'll be very mad if she asks me. It's something I've learned. It's so weird. You become clever. If my mom buys bread and there are just a few slices left, and I know my mom will see a difference then I won't touch it. But if it's a lot of bread then it's easy to take it without anyone noticing. When I eat in front of people I eat perfectly normal and I know people are wondering*

how come I'm overweight. Like my mom, she sees me eating a small breakfast, small lunch and dinner but nobody knows about the other stuff. It's only me who knows about it and I find it scary telling you this.

Paula: *But you have opened up to me in the past and you've done a bit of that in these sessions.*

Lisa: *Not in so much detail. I never told you exactly what I eat.*

Paula: *Do you feel like you're living in darkness, in a secret? Isn't it better to share that burden with someone, to bring the pain into the light with someone you can trust and be open with?*

Lisa: *Sure, but you don't always want to think about it or say how much you've eaten. Sometimes the guilt is too much and too embarrassing. I lie all the time. I just can't tell the whole truth.*

Paula: *Don't you feel that as long as you're being dishonest to yourself about what you're eating you can't really deal with the issues?*

Lisa: *Yes, I think so. And I have also noticed that I do feel better when I talk about it. I feel even better if I tell the whole truth. What makes me feel better is the fact that you listen to me, analyse it, give your opinion. I want to hear something back from the person I'm opening up to immediately. I need to talk and get feedback immediately.*

I got the sense that Lisa was burdened by her eating disorder and wished to talk about it, although the fear and the pain of opening up completely were still too threatening. I was reminded of recovery plans set out by different therapists, who believe that in order to help the client, he or she should aim for a *decrease in isolation, an increase in support, and an improvement in self-awareness and self-esteem* (Garvin et al., 1998). I felt that if Lisa were to resolve her eating disorder, she

would have to start by sharing personal details of her behavioural patterns with food and her more personal emotions.

Into the Future

Lisa will be writing her final exams at the end of the year and aims to graduate next year. She is keen on doing one year's community service and prefers to move away from home. She remains concerned about finding a boyfriend because of her age. She would like to settle down, get married and have children. In terms of the eating disorder, Lisa has mentioned that she would like to resume therapy with me again. For the meantime, however, she wants to focus on her studies and complete her final year successfully.

Anita's Story: Masking the Pain

Biographical Information

I met Anita in January 2003. She had recently been employed by a Portuguese medical aid company, which had in the past been referring Portuguese-speaking patients to my private practice. She was employed as the account's executive at the company and was thus aware of my services. We had previously spoken on two occasions about my private practice's accounts. On these two occasions, Anita felt comfortable enough to also discuss personal issues in her life, namely her weight and her marital problems. She mentioned that she used to weigh 60/65 kilograms before the birth of her daughter and that since then her weight had doubled. She had tried every diet on the market but was unable to lose any considerable amount of weight. If she did lose weight, she would regain it immediately. I mentioned to her that physical problems are usually related to unmet emotional needs and that it would be wise to speak to someone about her pain. She decided that she wanted to open up to me about unresolved hurts and feelings and asked if she could see me after hours for therapy. At that point I had already decided to include eating disorders in my research and asked her if she would be willing to be one of my participants. This would not only benefit me in terms of having a participant for my research, but it would also benefit

Anita financially. We agreed to see each other the following week at her home.

Anita is 38 years old and is married to Sam. They have a son and a daughter aged twelve and seven respectively. They live in Pretoria and have been married for thirteen years. Anita openly admitted that she has been having marital problems for over five years. She is the eldest in a family of four and has two younger sisters and brother. She said she has always had difficult relationships with her mother and siblings and that past issues have never been resolved.

Facing the Suffering

In our first meeting Anita openly discussed problems with her food and weight. She said she was unhappy with the way she looked and was concerned that other people in the office were judging her for her body weight. She was extremely conscious of being the topic of many tea-room conversations. Despite her relationships with other colleagues, she felt content with the nature of her job and felt that she was being productive for the company. Concerning relationships at home and in her social environment, Anita mentioned that she sometimes found it difficult to be herself behind the weight and that this caused her much sadness and regret. She also mentioned that her husband did not see the real Anita and that the success of their marriage depended on her losing weight.

Nature of the Interaction

Since our first meeting before the therapeutic sessions, the connection between Anita and myself was an open and trustworthy one. Anita felt comfortable enough to discuss a few personal issues with me without feeling a sense of betrayal or judgment. My impression was one of Anita being able to communicate freely about emotional and personal problems - even with people she did not know very well. I tried to understand the ease with which she opened up to me by putting it down to my being a psychologist dealing with individuals on a private and confidential basis. In fact, when introducing myself to Anita, I had mentioned that my work with the company's patients was confidential and that I maintained that ethic when speaking to other employees in the company. From what Anita shared with me I suspected that she

was struggling with an eating disorder not otherwise specified. I had seen a few anorexia and bulimia cases but very few related to eating disorder not specified. I wanted to be of some help to Anita. I could also see how anxious and concerned she was about her weight and her relationship with her husband.

During the sessions, the same ease I had experienced at the office with Anita was once again encountered. She was able to open up to me and felt comfortable enough to cry when she wanted to. I never felt as if I was intruding when asking challenging or personal questions. I felt very comfortable in the sessions and found it easy to connect with Anita within the therapeutic context. Although my main focus was on the eating disorder, it was inevitable that we also discussed the main reason for her current problems, namely her marital relationship. My aim was to keep the eating disorder issue alive in the research context by relating it to issues between Anita, her husband and her mother, instead of isolating the specific relationship from the weight problem.

I saw Anita for six, one hour long sessions. We met at her home before work when her husband and children had left for work and school. We saw each other every second week, and although I still had to interact with Anita at work on a monthly basis, personal issues were kept to a minimum and only discussed in the sessions. After our sixth session, Anita felt that she had gained a lot from the sessions and wanted to try an alternative solution to her weight problem. She decided to undergo surgery in order to lose weight quickly and felt strong enough to cope on her own. She wanted to know whether I would resume the sessions should she need to speak to me about personal issues. Up to now (one year later), Anita has not asked to see me on a private basis. We maintain an open relationship when we see each other at work and often end up discussing how she is feeling. The feelings of openness and comfort have not diminished since our sessions together.

Emerging Themes

An in depth inquiry of the interviews brought to light various perceptions and meanings held by Anita regarding her personal suffering with her weight and her

relationship with food. These meanings were related mostly to physical, emotional and social problems.

Struggle for Independence and Control

Many reasons exist for the possible onset of an eating disorder. In Anita's life, learned behaviour and loss of control were the contributing factors. Anita was taught from an early age to eat all the food on her plate. She mentions how she was told by her mother to eat even when she was full. It is common, for example, for parents to tell their children to eat because of 'children starving all over the world', to eat before they are allowed dessert or simply to clean their plates without protesting (Abramson, 1993; Katz, 1991). Messages such as these become ingrained in the memories of children, which eventually influence them as they grow and develop. For some women struggling with eating disorders, such learned behaviour makes it difficult for them to leave or waste food on their plates despite the feeling of fullness.

Through therapy, however, Anita was able to see that the main reason for her eating disorder was the lack of control she had in her life and the amount of control her mother had exerted over her in the past.

I was told to eat my plate of food. I was told to have my breakfast, lunch and supper. I was told not to argue the point. If I wanted to go on a diet I was not allowed to. I had no control over what I ate as a child. And at high school I had to sit at home to look after my youngest brother while my sisters did whatever extramural activities they wanted to. Obviously when my mom got home she expected supper on the table, dishes done, laundry and ironing finished. She was a complete control freak. In fact, she still is.

It is common for many women struggling with food and weight to experience a lack of control and independent thinking in their lives. Such women feel as **f** control lies outside them and that they are unable to own and direct their own lives effectively (Katz, 1991; Zerbe, 1993). Women, struggling with independence and control issues usually believe that they are not capable, powerful or smart enough to make their own decisions. As a result, they believe that what they have achieved in

life is not because of their own efforts but only because of luck or external influences (Zerbe, 1993).

Feelings of lack of control and independence may start during childhood, adolescence or early adulthood. They are usually the result of various situations experienced by the individual, either in the family or social context, and may continue throughout adulthood. Women who are anorexic, bulimic or compulsive eaters may have felt dependent on, or emotionally enmeshed with parents, family members or significant others. According to Zraly and Swift (1990), such relationships could have been "characterized by immature patterns of thinking, feeling, and behaviour that would be considered appropriate at a younger age but, given the patient's age, are inappropriate" (p. 54). A sense of separateness, autonomy and individuality was not achieved and many are unable to form an identity (Louw, 1991; Zraly & Swift, 1990).

Anita found it extremely hard during her adolescence to gain control from her mother because of fear of conflict. Being unable to separate emotionally from a family member or even a spouse (during adulthood), and not being able to express feelings, thoughts and behaviours in an open manner leads women to fight for this control in alternative ways. With food women are able to have control over what, when, where, how and how much they eat. The powerful message being communicated is "I am a separate person from you, and I can do what I like with my body" (Maloney & Kranz, 1991, p.63). Furthermore it is believed that "the issues of control – over our actions, our feelings, other people's behaviour – is central to any compulsion" (Roth, 1991, p. 37). Women are able to find an outlet for expressing emotions which otherwise would not be dealt with and expressed. The result is behaviour that leads to bingeing on 'prohibited' or 'fattening' foods. They feel automatically better, independent and in control.

Although Anita did not feel a loss of control in her work environment she said this was not the case within her home, marriage or social environment.

I've never been able to have or show power and control to either Sam, friends, family or even my children. When they were smaller I could still control but now they do

whatever they please. And if I get angry with anyone, they all throw their toys and say that I am acting like a fish-wife or a wicked mother.

She mentioned how afraid she was to stand up to anyone. If she stood up to her husband she would be afraid of him walking out the door and never coming back. If she stood up to her mother she would receive a '*whack*' from her. If she stood up to her kids she would face them going straight to her husband or mother-in-law to complain, and then she '*would be in trouble*'. I asked how all these patterns of interaction with others made her feel. She answered that it made her feel useless, teary, rejected, worthless and ready to go straight to the fridge. Unfortunately, this is a common reaction when the woman feels out of control (Katz, 1991; Zerbe, 1993). Her first and foremost reaction is usually to eat food in order to suppress emotions.

I hate arguments and maybe that's why now it is so easy to grab anything from the fridge. (Crying). It doesn't matter if it's a carrot. I can go for weeks without eating and starving myself but then get the day when the fridge is not full enough and I want to eat. It pains me to know that I have no self-control. I can't stop this cycle of starving and then bingeing. If I were bulimic it would be easier but I just can't vomit. I cannot throw up.

A significant pressure on Anita in terms of her weight gain was the ultimatum her husband had given her.

My husband says he won't have sex with me until I've lost weight. (Crying). I always thought love was unconditional. And that's not what I get from him. Instead I can't fight with him. I can't express myself and how I feel. Every time I fight he tells me "You know what the consequences are." "You know what must happen." And what must happen is I must lose weight. I must get thin. I must be 60. I must be the wife that I was when he married me. For him the biggest problem is the weight. So sex is a turnoff and therefore he won't come near me. Our fights might start off with him being moody but then it spirals down to "You know what I want." He won't even let me buy new clothes until I've lost all the weight.

I asked her if she was punishing him for the pressure he placed on her and whether she was showing anger towards him by controlling her food intake. She agreed that it was one area in her life where she did have control, but wasn't sure whether she was actually punishing him. I also asked whether she desired to lose weight for herself or for others. She admitted that she was losing weight for her husband and for the sake of their marriage.

Emotional Hunger

Anita also mentioned that the moment she feels unhappy, anxious, angry or confused, her first action is to eat. This relationship with food displays a common pattern in women struggling with eating disorders. At times food is seen as the person's best friend, a comforter and a nurturer. It is to food they turn to when they need to be comforted, supported or made to feel happy. In this case, food has nothing to do with physical nourishment and is used to fill empty spaces within the woman's existence. When emotions become unbearable, the compulsive eater is able to "hide or pack down her own feelings with food" (Ritchie, 1994, p. 93). Only through our therapeutic interaction was Anita able to see the connection between her emotional and physical hunger. When this was revealed to and understood by Anita, she cried uncontrollably.

That's why I have battled for years to lose weight on a diet. Sometimes I'll have two bars of chocolates instead of one. I won't stop until I've had a full packet of chips. Food has given me strength to cope. I never know what's coming through the door. (Crying). "Is he upset, is he angry?" Eating allows me to cope. The other night Sam went out to a bar and only came home after midnight. I didn't know where he was, nothing. When he came in I did not shout. I didn't say a word. But the next evening I was still angry at him. He bought pizza for the kids so instead of having one slice I had four. I knew what I was doing but I couldn't stop myself. I was so angry with him that I just ate over it. Then I realised what I had actually done and then what I did do was eat some sweets. I know it's not right but it was sort of dealing with the fact that I hadn't vented my anger.

The most common feelings associated with emotional eating are anger, loneliness, fatigue, depression, sadness, low self-esteem and perfectionism (Abramson, 1993; Arenson, 1989; Hume, 1998; Maloney & Kranz, 1991; Zerbe, 1993; Zraly & Swift, 1990). Emotional eating is triggered only by these emotions or signals in the mind and not by a physical sensation arising in the stomach (Katz, 1991). People use food as a means of forgetting pain, dealing with or avoiding negative experiences, or gaining a sense of peace and relaxation (Zraly & Swift, 1990). It seems that most overeaters want to overcome their problems with food and their bodies but are afraid to do so because of having to change situations in their lives that lead to personal turmoil (Arenson, 1989). These situations may include "having to learn to ask for what they want, or having to go to work and support themselves, or moving away from the dependence on parents or spouse" (Arenson, 1989, p. 10). Such changes can be threatening and fearful, and avoiding them seems easier and less complicated.

It is so difficult to change what you have been doing for years on end. I find it easier telling outsiders what I think of them. Like at work, I do tell people how I feel and when I'm not happy with the work. But not to those close to me.

Lack of social support

The social suffering that many women encounter may also be related to the interpersonal relationships they have with significant others (Evans & Wertheim, 1998). Examples of intimate relationships include the father-child, mother-child or woman-spouse/partner relationships (Arenson, 1989; Gold, 1999; Hudson, Ritchie, Brennan & Sutton-Smith, 1999; Orzolek-Kronner, 2002; Zerbe, 1993). Since people do not exist in a vacuum and are all interconnected to others, looking at the eating disorder in isolation will not contribute towards a greater understanding. It is important to not only focus on the physiological and emotional systems from which the individual functions but also to see his/her interrelatedness with the world in terms of the larger socio-cultural and family system (Becvar & Becvar, 1988; Thode, 2001). This view is vital especially if one considers that eating disorders usually develop within the family system during adolescence and young adulthood. Many families do not always know how to deal with issues of independence and, as a result, unhealthy

ways of dealing with the child or the parents set in. When the dynamics of the family system change, emotional discomfort, tension and anger emerge (Abramson, 1993; Maloney & Kranz, 1991; Thode, 2001).

From the case history it seems that for Anita, the troublesome relationship she had with her mother may have been the precursor for her problems with food and weight. Currently, however, the biggest influence on her weight is the relationship between Anita and her husband. She expressed how lonely and sad she feels knowing that he does not support her.

Everything revolves around what he wants. I've asked him to help me lose weight but he says that he did it in the past and it didn't work. He says I must show him I want to lose weight. I said I wanted to go to gym and he said he wouldn't get me a gym contract. I would like to lose weight and sometimes I can see a difference in my clothing. They seem loose. But I also want him to see the difference. If he saw the difference it would ease the stress. He drives me mad because he keeps throwing it at my face. (Crying). I'm on my own and I just wish I could get some help, some support. Not have to do it on my own.

Low Self-Esteem

Self-esteem has been defined as "the difference between the real self and the ideal self. The real self reflects the person as he or she truly is, while the ideal self is who the person wishes to be. The greater the difference between the two, the more a person's self-esteem is lowered" (Pettus, 2001, p. 283). People with low self-esteem usually ask the questions, "Who am I?" "What worth do I have as a human being?" "Am I special and worthy enough?" "What do I want for my life?". For those struggling with low self-esteem, the answers are usually self destructive and negative. Many will answer by saying that they are "unacceptable, clumsy, no-talent, stupid, ugly…" (Arenson, 1989, p.117).

It was clear throughout the sessions that Anita not only struggled with her external body image but also with her inner self-concept. On several occasions she mentioned how unhappy she was with her weight, how self-conscious she felt

amongst friends and strangers and how her weight kept her from being who she really was. In our fourth session issues of self-esteem were discussed and the following feelings and thoughts were described:

I just want to sort out the way I feel. (Crying). I want to get thin. I have to become independent and dependant on myself. I want to build within myself confidence because there is none. I'm getting desperate enough to look for alternative methods of getting there. I want to get thin. I'm tired of looking this way. It isn't the way I looked and it's causing so many other problems in my relationships. I'm sure people at work chat about it. People saying how fat I am, people not offering me food because they're looking out for me. I just get my coffee and head off to my office. I feel like an outsider. (Crying). If this is the only stumbling block then I must overcome it. I can't stand the dejection anymore. I can't stand being shunned anymore.

Women who experience feelings of low self-esteem and self-worth believe that they can gain these through the way they look. Since society places much worth on outward appearances, their obvious choice is that of 'fixing' their bodies. Trying to lose weight and keeping the kilograms at a desired level becomes their primary objective. The problem arises when many of them are unable to find their identity, try to become what others want them to be and struggle to gain control over their lives. Many choose to deal with emotions of anger and dissatisfaction through food and weight loss, and fail to deal with the rudimentary problem of low self-esteem and self-worth. The lack of foresight to understand that they are not dealing with the root problem but rather with the symptoms, leads them into a world of eating disorders, yo-yo dieting, bingeing, purging and starvation. For Katz (1991), "a diet of living and loving makes a diet of overeating impossible. If you do not love yourself, no one else will; you will feel rejected and you will make up for it with food" (p. 53).

In our last session Anita shared with me that she wanted to postpone the sessions for another time. She had consulted with a specialist to have a duodenum operation. According to Anita the reversible operation involves changing seven metres of the small intestine into 35 centimetres. The rest of the seven metres are tied up and not cut off. This prevents the individual from absorbing too much fat in the

small intestine because food is discharged immediately. She said that radical weight loss is assured. The operation would cost about R 10 000 and she was waiting for her husband to help her out financially. I asked her about any side effects. She replied:

The disadvantage is that you can't take any paracetomal because it harms the liver. The other disadvantage is that if you don't eat then it's a problem. You need to eat all the time otherwise the big intestine will swallow the little one. It thinks it's food and if does do that then it is very serious. I told him that at times I tend to starve and he said I would be fine as long as I drink water or cold drink – anything. Now I have to go into the mind shift of eat, eat, eat.

I asked her how she felt about this.

I'm very positive. I want to do this. I just need to discuss the money issue with Sam. He basically wants me to make the decision. He's not convinced that I'm serious about it and I'm quite adamant to show him that it's not just talk.

Psychotherapeutic Implications

When doing therapy with an individual struggling with an eating disorder, it is important that the therapist be aware of the dilemma and understand the food/emotion connection that existed and continues to exist in the individual's life. The therapist needs to grasp the meaning of the client's relationship with food and weight as well as his/her personal beliefs regarding social approval, self-esteem, self-worth and personal happiness (Ryan, 2001). It is of no benefit to directly attack a patient's eating symptoms or to focus on the particular facts surrounding his/her behaviour with food. Rather, using the eating metaphor as a way of staying close to the patient and then helping him/her see and understand the underlying feelings, thoughts and behaviours which keeps the individual's life 'so tortured' will be more advantageous (Ryan, 2001, p. 79). The individual should be encouraged to tell his/her story with food over and over again so that specific meanings, underlying fears and entrenched beliefs and thoughts can emerge. This will help the individual own such feelings, face them directly within the safe context of therapy, and disallow food and weight issues to act as cover-ups for the 'real' experience.

Understanding the Connection

For the limited amount of sessions, my only aim with Anita was to show her the difference between emotional and physical hunger. I also aimed to show her how she uses starvation and bingeing as a solution for low self-esteem and low self-worth. My approach was to help Anita work towards positive restructuring of negative thoughts and beliefs in the form of small changes. These would include the assertion of personal rights (with her husband, mother and work colleagues), the development of independent thinking and acting, praising and complimenting herself, expressing feelings and accepting her limitations. I hoped to show her that the eating disorder is merely a symptom of the actual problem, and choosing food to deal with the problem will only land up perpetuating and confirming the low self-worth that she already experiences.

Paula: *Do you think your weight is serving a function or a purpose especially in your relationship with Sam?*

Anita: *(Silence). Yes, he's hurt me so much that it's a distance barrier?*

Paula: *What do you mean by 'distance barrier'?*

Anita: *I stay fat because when he hurts me I have that as my comfort blanket.*

Paula: *What do you do to comfort yourself when you feel hurt by him?*

Anita: *Put more food into my face.*

Paula: *What message are you giving him by not losing the weight?*

Anita: *The message that I'm giving him is that I don't want to. When I get more and more deflated the desire gets less and less because every time he fights with me I just lose the motivation.*

Paula: *Do you get angry with him?*

Anita: *Yes, I do. He expects X, Y, and Z. But he must have a bit more patience. If I can't do it then I want him to be patient, more compassionate and more understanding.*

In our last session I was concerned about her radical decision to have the duodenum operation. I tried to find out what her real motivation was for this decision.

Paula: *Do you think you are doing this for the right reason?*

Anita: *Do you know what I realised the other night? I'm doing this for me. If he doesn't want me, that's fine. I've done everything I could. I've done everything physically possible to be thin.*

Paula: *But are you still doing it for him?*

Anita: *Yes, it is still for him. It is still to try and save my marriage and it is still to make him happy but yes, it's also for me.*

Although my aim for the sessions was to highlight the use of food in her life, particularly in terms of emotional emptiness, the task to do so in all six sessions was not as easy as I had anticipated. Before our sessions, Anita was not aware that she was using food and weight to deal with personal problems and emotions of anger, sadness and loneliness. It seemed that her understanding of this connection was overshadowed by her desire to lose weight quickly. Other more tangible and faster measures were sought instead of the lengthy process of long-term therapy or the pain of dealing with unexpressed emotions. Since Anita had decided to refrain from dealing with the emotional issues and resort to an operation, my main focus was to highlight the underlying reasons for her wanting to do so. I still suspected that she was doing it for her husband and felt that she placed everyone else's needs and desires above her own. I hoped that she would realise that the only one who should benefit from whatever choices she made would be Anita herself.

Into the Future

Anita has not, up to this point (one year later), been able to financially afford the operation. She still hopes to go through with it one day and is waiting for such an opportunity. She has not continued with the eating plan her dietician drew up for her since she finds it difficult to eat five small meals a day. She continues to have relationship problems with her husband and feels that it will end up in separation or divorce. She continues to speak to me openly about her problems when we see each other. She says she is grateful for our sessions since they allowed her to see that she does have some worth and that what she feels determines how and what she eats. In the last year I have found that Anita is thinking more about herself and her needs. She seems stronger in this respect as compared to when I first met her. She has up to now lost two kilograms.

Conclusion

Eating is a basic human function necessary for the survival of all species. In the human species it involves patterns of what, when, how much and where one eats. When such normal patterns become problematic, excessive or limited, the individual may be facing an eating disorder. The primary types of eating disorders are anorexia nervosa, bulimia nervosa and eating disorders not otherwise specified. The last one encompasses emotional eating, obesity and overeating (Robert-McComb, 2001). Behaviours related to these disorders entail the ingestion of large amounts of food, the letting go of food already ingested or the restriction of food to its minimal intake. These behaviours and eating choices demonstrate an expression of personal turmoil and emotional difficulties that the person has with the world and with others.

For the purposes of this thesis, both Lisa and Anita allowed me to enter into their lives to experience some of the suffering they feel on a physical, emotional and social level. Both struggle with emotional issues and use food as a means of comfort and consolation. Although their eating patterns are different and their turmoil encompasses different problems, they both hope for a sense of control in their lives, self-worth and happiness. This desire to gain happiness has been a hard and long quest for both women and both have found the process difficult and tiresome. My

intervention in their lives did not bring about any concrete changes but I do believe that the sessions provided them with an awareness into the connection between their emotions and their weight. Although meaning and closure was not possible in the limited amount of sessions, being aware of the reasons for the eating might lead both Anita and Lisa to search for solutions and retain the hope.

CHAPTER 6

INFERTILITY

So for the mother's sake the child was dear,
And dearer was the mother for the child.

(Samuel Taylor Coleridge)

In this chapter I will illustrate the perceptions and assumptions held by two women struggling with infertility. As in the preceding chapters, the case illustrations will be presented in verbatim form and names will be changed for purposes of confidentiality. I will provide a detailed presentation of the women's assumptions and meanings regarding infertility. The chapter will once again be divided into the four sections, namely the women's biographical information, their experiences with suffering, emerging themes from the conversations and psychotherapeutic implications. I hope that the reader will be able to draw his or her own distinctions about the women's personal distinctions and assumptions. Before presenting the case illustrations, however, I will provide the reader with a brief understanding of infertility.

Background to Infertility

Infertility can be defined as the inability to conceive a child. A couple is considered infertile when it is unable to conceive after a year of regular sexual intercourse without the use of contraceptives (Abbey, 2000; Abbey, Andrews & Halman, 1991; Dunkel-Schetter & Lobel, 1991; Dunkel-Schetter & Stanton, 1991; Gibson & Myers, 2002; Glazer & Cooper, 1998; Kikendall, 1994). Secondary infertility, on the other hand, involves the inability to conceive after at least one previous documented conception (Dunkel-Schetter & Stanton, 1991). This inability to conceive can cause disruption and anguish to individuals and couples, and often

physical, financial, emotional and social stressors become a part of the couple's life (Greenfeld, 1997).

Infertility has existed ever since the beginning of mankind. The Bible refers to many situations where women were unable to conceive, as seen in the stories of Abraham and Sarah, Jacob, Leah and Rachel, Hannah, and Samson's mother. The ancient civilizations of Babylonia, Persia, Greece and many others worshipped and prayed to the goddesses of fertility through fertility rites and practices to ensure the natural continuation of generations (Mazor, 1984; Taymor, 1990). Even with the onset and use of female contraceptive measures in the 1970s, infertility was still an issue for women who actively desired and pursued parenthood (Kikendall, 1994). Due to medical and technological advances, however, dramatic developments took place in identifying the causes of infertility and in applying successful medical counter measures (Abbey, 2000; Kikendall 1994). These, however, have not always been successful, and many measures still remain out of reach for some women because of high costs, timing and low rates of conception.

There are several reasons for infertility which affect all races, all economic classes and all geographic areas (Salzer, 1991). Firstly, the act of fertilization is in itself an intricate and complex occurrence. Normally, 40 to 150 million sperm are released during a single ejaculation. Only 10% survive the journey through the cervix, uterus and fallopian tubes while usually only one sperm gets to fertilize the egg (Darajan & Israel, 1991; Gunn, 1988; Salzer, 1986; Yovich & Grudzinskas, 1990). The production and release of only one egg also complicates the process at a particular time of the month. This is termed ovulation and is part of the woman's menstrual cycle (Salzer, 1986).

A second reason for an increase in infertility is the current trend for both women and men to delay marriage and childbearing into their thirties and forties. Since both men and women are maximally fertile in their mid-twenties, postponing childbearing due to personal, social and economic reasons, may contribute to many couples experiencing difficulties with conception at an older age (Corson Appleton, 1983; Mazor, 1984; Yovich & Grudzinskas, 1990). A third cause of infertility affecting the female physiology is *endometriosis.* This is a condition in which part of

the endometrium, or the lining of the uterus is outside the uterine cavity (Gunn, 1988; Jennings & Lee, 1995; Mazor, 1984; Salzer, 1991; Taymor, 1990). With endometriosis, the "extrauterine tissue bleeds and sheds, and may cause pain, scarring, and cyst formation, depending on its location. This condition affects approximately one quarter to one third of infertile women and becomes more disabling with each menstrual cycle" (Mazor, 1984, p. xvii). Other reasons for infertility are: *blockage in or damage of the fallopian tubes*, o*vulation problems*, which may interfere in the normal process of egg production, *pelvic infections, structural abnormalities, cervical problems, smoking, diet or alcohol excess* (Salzer, 1991; Taymor, 1990; Van Horn & Reed, 2001).

In terms of male infertility the following factors may exist for infertility: *varicoceles* (varicose veins in the scrotum which prevent the normal production of sperm due to excess in heat), *impaired spermatogenesis, testicular problems, adult mumps, injury of reproductive organs, retrograde ejaculation and hormonal imbalances, obstruction in the vas deferens, chromosomal defects and infections, diet, alcohol, smoking, stress and environmental factors* (Gunn, 1988; Mazor, 1984; Rowe & Vikhlyaeva, 1988; Salzer, 1991; Taymor, 1990; Van Horn & Reed, 2001; Yovich & Grudzinskas, 1990).

Whereas in the past, admitting to infertility was 'taboo' the current openness about sexual matters has made it less shameful and embarrassing. Advances in the treatment of infertility have also contributed to a more open acknowledgement of infertility (Abbey, 2000; Salzer, 1991; Taymor, 1990). Despite the many advances in infertility treatment, there are those who still face infertility and who, when choosing treatment, enter into a process of physical and emotional suffering (Gibson & Myers, 2002). The treatment process is not only taxing on the woman, but also on her partner and her social environment due to the amount of time and effort involved (Schwan, 1988). Being aware of infertility problems, especially during the first year of conception, then entering into endless and unsuccessful medical treatments, and finally coming to terms with the possible setback, places great stress and pressure on the woman and her partner. It is a setback which may alter the woman's perspective of her world, her relationship with herself and others, as well as her attitudes towards children. The infertility process involves finding the best doctors, undergoing the

correct tests, getting the most effective treatment and utilizing the best options. Such a crisis not only poses a threat to previously held beliefs and dreams, but also threatens an individual's personal sense of control, self-esteem, self-confidence and self-respect (Abbey, 2000; Glazer & Cooper, 1988; Kikendall, 1994; Salzer, 1991; Schwan, 1988).

Case Illustrations

Denise's Story: The Bitter-Sweet Struggle

Biographical Information

Denise was referred to me by a physiotherapist in September 2003. Denise had been to the physiotherapist for treatment and both had formed an open and trustworthy friendship. They had discussed Denise's struggle with infertility in detail. The physiotherapist was aware of my research project and suggested that I call Denise, who was keen on discussing her struggles with me. I spoke to Denise telephonically and explained to her that her experiences would form part of my research project and that the sessions would have to be recorded. Denise was aware of the implications and agreed to see me. We saw each other for two, one-hour sessions.

At the time of the interview, Denise had just turned 39 years old. She is married to David for twelve years and they have an adopted two-year old son, named Robert. David was previously married and has two children in their teen years. They live in another city and seldom see their father. David has his own company and Denise used to work as a sales executive for a pharmaceutical company. Since the adoption of her son, Denise has chosen to stay at home to care for him on a full-time basis. She is the eldest daughter of a family of two and has a sister who lives with her parents abroad. She is able to see her family every year.

Denise married at the age of 27 and one year later tried to conceive. Denise was unable to fall pregnant and both she and David decided to see a gynaecologist. The gynaecologist did not detect any major problems and asked Denise to come back

six months later should she not conceive. Six months later Denise returned to her doctor. This time a scan was done and a cyst was found in her left ovary. At the age of 29, Denise went in to hospital to have the cyst removed by means of a laparoscopy. The doctor later told her that the cyst had been removed but that they had detected a serious case of endometriosis. This would be the beginning of Denise's struggle with infertility.

Facing the Suffering

Denise's dream for her life was to be married and have children. When she was told of the endometriosis, Denise was unsure of what it entailed. She had not heard of it before and did not really think it was a serious problem. Only after her consultation did she decide to read up about it. Despite the diagnosis, she firmly believed that she would still be able to fall pregnant. She went back to her doctor and this time was told to start treatment as soon as possible. The treatment consisted of a course of Zolodex and Clomid. Clomid was prescribed in order to make sure that she was ovulating. Regular temperature checks also had to be charted to check for ovulation times. Denise found having to do this every month routine and mechanical. She expressed that she felt shy and embarrassed, not only in her relationship with her husband, but also when visiting the gynaecologist and the clinic. It was hard for Denise to undergo simple procedures such as internal scans. She also disliked being injected in her stomach with Zolodex. At a later stage, Denise and her husband chose to have artificial insemination. They had four cycles of artificial insemination. With the third cycle, Denise discovered that she had fallen pregnant and, during a normal scan she was able to see a heart beat. She was six weeks pregnant. Unfortunately, Denise started to bleed and lost the baby. She was never able to fall pregnant again.

Nature of the Interaction

Denise made me feel at ease right from the start of our interaction. She came across as mature and demure in her words and approach towards me. She made me feel comfortable by telling me in detail about her experiences and sharing with me personal pain in her struggle with infertility. She felt comfortable enough to cry in the first session and did not feel ashamed to do so in the second session too. She allowed

me to ask personal questions about her struggles, and answered the challenging and painful questions honestly. She tried to accommodate me as much as possible by giving me all the information I required. Although the empty pain of never bearing her own child was constantly present, she came across as realistic and positive in terms of what she had already accomplished. Her inner strength was visible throughout the sessions.

Both Denise and I were able to form a close relationship based on her personal pain. In our sessions with each other, joyful and sad emotions were shared and expressed at different moments. The sharing of these emotions helped Denise to express her pain, disappointment and longing for having a child of her own. I felt that she needed to talk without receiving advice as so many people in her life were already doing this. Her need was for someone to listen to her pain and to her struggle with infertility. I experienced this need right from the beginning and tried to not enter the role of rescuer or helper. My aim in the session was to reflect and to listen and because of this therapeutic stance, Denise was comfortable enough to share.

Emerging Themes

An in depth inquiry of the interviews brought to light various perceptions and meanings held by Denise regarding her personal suffering with infertility.

Shock and Unbelief

Being able to have a child of one's own is seen by most women as a natural objective of adult life. When this goal cannot be accomplished due to infertility, the woman's ability and sense of accomplishment is threatened (Salzer, 1991). According to Williams (1997) psychological effects of infertility are defined in reference to eleven themes namely, negative identity, worthlessness/inadequacy, lack of personal control, anger/resentment, grief/depression, anxiety/stress, lower life satisfaction, envy of other mothers, loss of the dream of co-creating, 'emotional roller coaster' and isolation. Loss of self-esteem, anger, depression, fear, shock, denial and stress may also be experienced. For Denise feelings of shock and unbelief were experienced when her struggle with infertility began at the age of 28.

My ideal was to get married at twenty-three/twenty-four. I probably thought a boy and a girl would be nice. I didn't want a lot of children because I come from a small family. I knew that I didn't only want to have one child because I have a younger sister with Down's syndrome. So it's almost like being an only child. So I wanted two. And then I got married when I was twenty-seven and, funny, my husband thought we should start trying for a family immediately. I thought "No, let's wait for a year". That's the done thing. So I went onto contraception -Triphasil and took it religiously because I wasn't going to fall pregnant. After one year my husband said "Come on, let's start a family!" People also asked, "Aren't you going to start a family?" People ask these questions and then when I think about it, they shouldn't really because it is a private thing. But we ask as if it is a natural thing. Then we started. I suppose consciously trying, I thought, "Well, it will be a couple of months. Let's give it three to six months." And then, after a year, I went to see the gynae for a general check-up and I told him that I wanted to have a baby. He said, "No, you're stressing about it too much. Wait a year. For a natural couple it takes about a year." He said, "You just go away." I said to him that I had a bit of discomfort in periods and intercourse and he said that I was worrying too much. "Go away and come and see me in six months time." And so after six months I went back to see him.

During her second visit, Denise was told that she had an ovarian cyst, which had to be removed. The laparoscopy also showed that Denise had endometriosis and that this was causing her problems with the conception of a child:

At that stage I still didn't worry. It wasn't something I had heard of. I suppose I read more and more about it and I remember my mom's doctor saying that it could be solved. So I still wasn't worried. In my mind I still thought I would have children. I don't know, you still think it will happen.

As in Denise's case, infertility entails the disappointment of a childhood dream – a fulfilled marriage with children. Some women believe that conceiving a child and becoming pregnant is a right that can be accomplished at any time (Glazer & Cooper, 1988; Salzer, 1991). When these dreams and rights are denied, an emotional crisis ensues in which loss and destruction for an ideal, which always seemed so perfect and attainable, is felt. To make matters worse, this life crisis is not

experienced only once or for short periods of time. Instead, it becomes an unfolding process in which doctor's appointments are made, treatment procedures are carried out and a 'series of crises' are encountered (Dunkel-Schetter & Stanton, 1991; Salzer, 1991). For Denise, exposing her body for medical checkups and revealing intimate details of her sexual life compounded her feelings of shock and denial (Abbey, 2000).

I'm a shy person and that's what I used to find really hard. I remember the first time when the doctor was going to scan me. I thought "Oh, my goodness!" He would have to do an internal scan and, not having had children before, I thought, "What's going on here?" Then I would say to him that needles were my worst fear. What happens? I get Zolodex in my stomach.

Feeling Isolated

Throughout the conversations, it was clear that Denise was consciously and continuously aware of her own pain and emptiness. According to Mazor (1984), when infertile women find themselves in the midst of pregnant women, mothers and children, feelings of sadness, envy and emptiness may be felt. Infertile women wish they could have the same opportunities as other women and constantly feel besieged with images of fertility. Some may have to attend social events with children, watch television and read novels that focus on motherhood, go on holidays or shopping malls where mothers, fathers and children are present. Such reminders keep the infertile women constantly aware of something they cannot have. No matter what they do to avoid or minimize the pain, the reality of the infertility is always there. The theme of deprivation is not only present throughout the infertility treatments but will, most likely, linger with them forever (Mazor, 1984). Denise had the following to say regarding feelings of isolation and deprivation:

What had a big effect on me was when we would make friends with people who did not have children. It was almost like I would be so happy because they didn't have children. I didn't feel so left out. We would go out especially with the one couple who always gave us the impression that they did not want to have children. So, on the one hand, it was a comfort for me but on the other hand I wanted to say to her, "Do you realise that if you can have children, have them!" Now she's actually got three

children…Later I just didn't want to go out with people anymore because you're always waiting for them to say "Oh, do you know what, we're pregnant!" Funny how I always had a sixth sense about someone being pregnant.

I asked Denise what the hardest moments were for her in her ten-year struggle with infertility. She replied:

I think when friends and cousins younger than me were all having children. "We're going to have a baby, have a baby, have a baby." That was hard for me because I love them and you want to share in their joy but there are so many times when I can't say "Congratulations! I'm so happy for you." I've never ever been able to say that to anyone. It's almost being selfish.

I asked her if she felt guilty. She answered:

No, I think they understand. I would always give them a gift and I didn't ignore them completely.

Anger

Although feeling isolated and deprived were painful themes in Denise's struggle with infertility, she also expressed feelings of anger towards well-meaning friends. The feeling of anger is a common reaction in the infertility experience and may occur when dreams of having a child are not fulfilled or when infertility tests and treatment procedures are numerous and unsuccessful. This anger is usually directed inwards and feelings of worthlessness and depression are experienced. Anger may also be directed at others in the fertile world such as, friends who are pregnant, partners who are infertile and partners who do not 'really' understand what they are going through. They may express anger at people who neglect and abuse children, and at women who choose to abort. They may also become angry with physicians and treatment specialists who make them undergo countless operations, medication, injections and frequent medical appointments (Glazer & Cooper, 1988; Salzer, 1991; Whiteford & Gonzalez, 1995).

It must be noted that feelings of anger are a normal response to infertility even though many women feel uncomfortable in terms of it being considered negative and unacceptable in societal terms (Salzer, 1991). It is important, therefore, that the women express these feelings constructively by talking to close friends, family members or professional counsellors. Sharing these feelings and venting the tension and rage may be of benefit to women experiencing anger.

Denise expressed anger towards medical procedures and treatment options:

I can't tell you how disappointed I was with those failed IVF's (in vitro fertilization). *You know, they actually write on you hand how many eggs you have. So the girl lying next to me, she's in tears because they only got four eggs. Anyway, I come out and I know I had seventeen eggs. I was ecstatic. I said to David that this was going to work, but it didn't. You see, it doesn't actually matter, it's the quality that counts and only one has to take. So, really it doesn't matter whether you've got seventeen or two. But, yes, there was anger. Every time we did the IVF's (in vitro* fertilization) *we were spending 17 to 20 thousand rands. You're thinking about that. Your body also puts on weight, there are side effects from the hormones. That was really hard.*

She also mentioned being angry with God and people who do not see the value of having a child:

You know, at times when you're feeling down, I hate to say it, but I was angry at God and I think you also think, "Well, what have I done to deserve this?" In my beliefs though I know that there are tests and trials that you have in life. This is one of them.

I do tell people that my son is adopted. But people usually say, "Why don't you have another one?" Some people think that you go to a shop and you buy a baby. Sometimes I'm shocked at people's reactions. So, I'll say to them, "Well, if we could we would or, if you know of anyone, please let us know." Then they realise that I'm being serious. Then sometimes you hear people saying, "Oh, I'm going to try for a boy now or a girl." And I think, "Just try for a healthy baby."

Personal and Social Stress

The experience of stress is another emotional reality faced by women who struggle with infertility (Hart, 2002). Not only can it affect their personal lives but also place significant pressure on the emotional and sexual relationship with their partners (Ponjaert-Kristoffersen & Baetens, 1999). Potential damage, disruption and hostility may arise within the marital relationship (Lee & Chu, 2001). Pengelly (1995) writes that the threat of losing one's fertility "goes right to the heart of a couple who are failing to conceive a baby. It can be felt as destroying their entire *raison d'être* as creative partners – as well as threatening each individual's profoundest sense of his or her personal destiny and purpose in adult life" (p. 80). The pressure placed on them can be so consuming that couples lose their ability to communicate and share their feelings with one another, thereby placing great distress on their abilities to support each other. The opposite may also occur when the pain that is shared between the couple actually helps to strengthen the marital relationship (Mazor, 1984).

This was the case with Denise and David. Although stressful moments were unavoidable, the infertility problem had not created significant distance or emotional separation, and despite the many medical procedures they had to endure, both were able to stand together and support each other.

You know, David was always there for me. The infertility problems brought us together. We could share the pain. Yes, there were times when it was stressful, when David would say that I was always the one who would get depressed. There would be days when I'd cry and tell him that it's unfair. Often I would say to him that he didn't know how I felt. Then he would say, "But, I'm also here. How do you think I feel?" And then I would say, "But you've got two children." And he would say, "Yes, but I want children with you." He says, "Don't you think I'd love to have a child with you?"

Another big challenge facing the infertile couple involves social and interpersonal relationships (Glazer & Cooper, 1988). Although some problems are easier to keep private, infertility may become a social issue as friends and relatives

question the couple about their decisions to become parents or not. Even strangers may ask couples, in a matter-of-fact way, if they have or plan on having children. Being asked such questions on a continual basis is a painful reminder for the woman facing infertility. Not only is she experiencing an array of feelings, but she also has to decide how much information she must divulge in public. A seemingly private matter ceases to be private and can easily turn into public knowledge. Choosing to share this problem with family, friends or strangers depends entirely on the woman and her partner (Abbey, 2000; Mazor, 1984; Glazer & Cooper, 1988; Salzer, 1991; Whiteford & Gonzalez, 1995). In some cases, painful remarks will be made and they will find it difficult to handle certain comments and questions.

A possible reason for social stress involves culturally constructed responses to infertility that are "embedded in a complicated web of personal, familial, social and medical expectations that are often damaging and stigmatizing" (Whiteford & Gonzalez, 1995, p. 28). The stigma of infertility may create feelings of failure, hopelessness, grief, isolation and alienation from family, friends and acquaintances, especially since most women feel as if "they have broken some accepted, if unspoken, cultural rule and they pay for it by being classified as 'other'" (p. 29). Inadequacy, failure, de-valuation, incompleteness and abnormality may also be experienced (Abbey et al., 1991; Kikendall, 1994; Salzer, 1991; Whiteford & Gonzalez, 1995; Zucker, 1999). If they are infertile, women feel like disappointments to themselves, to their partners and to the rest of the family. It is common for those closest to the infertile couple to also experience feelings of loss, sadness and helplessness (Glazer & Cooper, 1984). Denise commented on the social stress:

You do feel something is wrong with your body – that you are damaged and also that people are judging you. Some guys have said to David, "Come on, lend her to us. We'll see what we can do." Can you believe that? And those are people we know!

I'm careful of what I say to various people. I just think that people try to say things to me. But it is always easy for them to give me advice. Like this one girl said to me, "That's the right way to go – only one kid!" But then she's got two.

Another said to me, "Well, at least you didn't have to go through childbirth. I think adoption is the way to go." Then I have to tell myself to be rational like, "Ok, maybe she was taken aback when I told her Robert was adopted, so she's saying that it's ok and she's trying to make me feel good."

So many people say that when you adopt you fall pregnant – that doesn't happen. Not one person in our support group has fallen pregnant. Not one. Wherever the statement comes from…I don't know.

Denise also expressed feelings of sadness with regards to other women who are now having their second children.

My biggest battle today, I think, is people who are having their second children. I think about Robert and about how happy he would be to have a sister or a brother. But sometimes I get cross with myself because I'm never satisfied and I should be. I once said to David, "Wouldn't it be nice for Robert to have a brother or a sister?" At that time we had thought of going for a final treatment. We decided not to because we wouldn't want Robert to think that he was never enough.

(Crying.) I hope and pray that Robert will just know how much we love him, that we absolutely adore him. I just hope that he knows that we adopted him just because we love him and that we only want the best for him.

Depression

Another response to infertility is that of depression and grief (Berghuis & Stanton, 2002; Robinson & Stewart, 1996). Thoughts about death, meaninglessness, loss of self-identity and the failure to want to live are brought to the fore. These feelings can range from mild depression (feelings of sadness, despair, tearfulness, fatigue, pessimism and lack of interest in normal activities) to more severe depression (feelings of gloom, hopelessness, anxiety, weight loss, aches, somatic complaints, unworthiness) (Glazer & Cooper, 1988; Salzer, 1991; Sizer & Whitney, 1988). When depression is experienced, it is important for the woman to seek help in order to confront feelings of sadness either by talking to others, writing a journal, finding a

therapist or joining support groups (Salzer, 1991). The danger with depression and infertility is that there are no clear cut answers to when it may come to an end, especially because of the nature of the treatment process and its indefinite time period.

Denise recalls how she used to feel when she was undergoing the medical treatments:

Some days you feel … down. I think going through the treatment with all the needles, examinations, this and that, you just feel like a piece of flesh – being prodded and poked. Those days you feel really terrible and you just don't feel happy. I also think it affects your self-esteem in some ways.

Although Denise experienced some feelings of depression and grief, she was able to overcome these to a certain extent through the adoption.

What keeps me going is Robert. If we had had a baby then we wouldn't have had Robert. He is so special. (Crying). That's when I really feel bad because that's when I think that I wouldn't NOT want to have him. Thank goodness we had him. That's when I know he is the reason why I had to go through all of this.

I'm so happy with Robert. I just carry on and say, "Yes!"

Psychotherapeutic Implications

Counselling couples with infertility problems should focus on removing psychological barriers to fertility, and assisting them in their decision-making process or in the resolution of feelings (Robinson & Stewart, 1996). Although it seems likely that a psychological intervention would benefit the woman facing infertility, her way of handling the crisis may be different and unique in comparison to other women (Abbey, 2000). The different choices may also depend on the nature and severity of the problem, its duration and the existence of either a positive or negative outcome. If therapy is chosen, however, women are supported to regain their sense of self-esteem as well as some control over their lives by highlighting specific areas in which they are still able to make decisions. It is also recommended that patients gain strength

from previous difficult situations where personal coping skills were used. The aim is for them to make use of similar coping skills in dealing with infertility (Mazor, 1984).

Other psychological interventions, which may differ amongst women may include the strengthening of the woman's ability to cope with infertility, reducing the conflicts experienced by the couple through open communication; accepting the fact that the physical condition may not be receptive to medical treatments; and, providing support for the many changes which may result in the future (Stammer, Wischmann & Verres, 2002). Emphasis is also placed on social coping resources and growth-fostering relationships with partners and family members (Gibson & Myers, 2002). For example, a confidant who communicates, supports, avoids conflict and understands the pain, will help the infertile woman's emotional and social adjustment considerably (Abbey, 2000). In terms of the relationship between the couple, Stammer et al., (2002) describe various psychotherapeutic techniques which can help the couple deal with infertility. These include, amongst others, *normalizing crises and negative affects*, e*xternalizing infertility and thereby maintaining self-esteem*, *talking about the couple's present sexual relationship, allowing mourning and grieving, making couples aware of the resources they have*, and *facing the prospect of a future without children*. By being aware of these techniques, therapy may increase the individual or couple's capacity to have a wider and more realistic range of emotional communication. It helps those who feel powerless and desperate to express feelings and thoughts in a safe and open context.

Acceptance

For many women, having to accept infertility is a difficult time when personal decisions are made regarding what to do next. For example, in Denise's case an alternative to parenthood was found through the process of adoption. Decisions such as these may, however, involve other problems for the couple as new issues surface and place extra burden on the relationship (Mazor, 1984; Schwan, 1988; Taymor, 1990). After several failed attempts, Denise had to 'wean' herself off from the treatment process, which consumed her life for months and even years. According to Mazor (1984) many women may experience a void after the endless treatments,

doctor appointments, focus on ovulation cycles and sexual relations. Although these procedures caused pain and suffering, they nevertheless filled the woman and her partner's life with a purpose and a goal. When this is no longer present, many women may experience a loss of direction (Mazor, 1984).

For each individual the resolution of the problem is unique and is "often contingent on prior experiences in coping with disappointment and loss" (Mazor, 1984, p. 34). For some, the struggle will only really end once a child has been born, while for others adoption and childfree living will be satisfying enough. Salzer (1991) writes that "whatever your particular ending turns out to be, you can be assured there is life after infertility, and a very happy one at that!" (p. 307).

For Denise it was important that she continue to hope and believe that she could still fall pregnant. I asked Denise if she had found acceptance or if she still had some hope of falling pregnant. She answered as follows:

Every single day I hope. Every single month you wait for the news. Every single month you have that bit of anger.

I'll probably continue to hope until I get into menopause. They never ever said I couldn't have children. I don't know, even if I can't fall pregnant, once I get into menopause perhaps that's when the grieving will start. Until then I will continue to hope every single month.

I think I would just like to be pregnant for a time. Just to experience it because as a woman you're supposed to. And, sometimes, I think that David is such a hands-on-guy and I think he would like for me to be pregnant. But we're just grateful to have Robert and I must say I'd shudder to think if we didn't have Robert. I think getting older it would be worse.

Restoring Balance

One way of helping infertile women is to make them aware of the resources they have. This is important to bring about a restoration of balance in their lives and

to help them focus on current resources and successes. From the sessions, Denise spoke extensively about one such success – the adoption of her son and the joy in her life since his birth. I tried to focus on this meaningful relationship:

Paula: *How has the adoption helped you deal with your loss?*

Denise: *I know there will always be pain but we're just so blessed to have Robert. There are other couples who want to adopt but who just can't. I also think that through this experience I've had a totally different perspective of life. This experience has enabled me to have empathy and I can share with others.*

I asked her some more questions about Robert:

Paula: *How do you feel towards Robert?*

Denise: *He's the best thing ever. He really is the best thing ever.*

Paula: *What was the whole process of adoption like?*

Denise: *You're so ecstatic at the time and I don't think anything can prepare you for that moment when he was handed to us. We were there when he was born and I held him first. They can't prepare you for that and I never for once thought or think that I haven't given birth to him. We bonded from that second. David and I never thought, "Well, what is he going to look like?"*

Paula: *Isn't it amazing how he has red hair just like his dad?*

Denise: *Yes, I totally believe that it was God. I go so far as to believe that there are some children who say, "We want to go to those parents." I think Robert must have said to God, "You know, those two have had such a hard time, I'm going to them."*

For Denise, the greatest sense of balance came from her relationship with her son, Robert. It is this relationship which has kept her strong and which makes her life worth living.

I don't feel left out because I'm so happy with Robert. My parents are in America and sometimes I do feel lonely and my heart aches for them. Sometimes I think that we are there for my parents and if we didn't have Robert, who would be there for us? You see, I don't have nephews and nieces and if we didn't have Robert…It's the best thing that ever happened to us.

Finding Peace

For Salzer (1991), finding resolution is the ability of "making sense out of the confusion; building bridges where relationships have been severed; accepting a future that is perhaps different than expected; and most important, making peace with yourself". Because Denise had not made peace with her inability to have children, my aim in the second session was to focus on current coping skills. I wanted to know how she managed to face her suffering on a daily basis and deal with the pain. I wanted her to be aware of any coping skills she could utilise presently and future wise. She answered:

The big thing that helps is the praying. On a hard day I just pray a little harder and I know that Robert can be a wonderful husband and father one day. That's basically all that you can do – that is, give Robert a good life. The comfort is that God is in control. It's just during those dark days that you need to tell yourself that it's a plan and He knows what's happening. He is aware of the aches and pains and I believe that you won't go through pain that you can't handle.

Into the Future

Denise recently celebrated her fortieth birthday. Her son is three years old and has started a playgroup in the mornings. She has not considered adoption or artificial insemination again. She believes that Robert is a miracle from God and so continues

to stay at home to enjoy her life with her husband and son. She has not given up hope of falling pregnant.

Claire's Story: The Long Wait

Biographical Information

Claire is 47 years old and has been married to Gary for fourteen years. They adopted Keslyn when Claire was 43 and Gary 33. They live in Pretoria, where Gary works as an engineer and Claire runs her own business from home. Claire has struggled with infertility all her married life. She became infertile due to medication she was taking for childhood epilepsy. Both Claire and Gary struggled with infertility for ten years and finally decided to adopt when Claire was diagnosed with an ectopic pregnancy. They were able to adopt Keslyn three years later.

Claire was referred to me by a psychologist friend. The psychologist was aware of my doctoral thesis and the need to contact a woman struggling with infertility. The psychologist had come to know Claire through her business and asked if she would be willing to share her experiences with me. Claire agreed to the interview. She viewed the interview as a means of helping women deal with personal issues of infertility. Claire and her husband are usually contacted by adoption agencies to provide information to other couples regarding adoption. Claire felt that by participating in this study she would merely be contributing to society.

I interviewed Claire in the beginning of September. We saw each other for two, one hour long sessions. During the session, Claire openly discussed her experiences with infertility and adoption.

Facing the Suffering

As with most women, Claire had always dreamt of marrying and having a family. She left home at the age of 23 to study nursing and became involved in several relationships until she met Gary at the age of 32. She got married at 33 and immediately tried to fall pregnant. Three months into her marriage she found out that

she was pregnant but miscarried a few days later. She consulted with doctors who told her that she was unable to have children because of medication she had taken for childhood epilepsy. At the age of six, while playing cricket, she took a severe blow to the head and immediately had an epileptic fit. After that incident, the number of epileptic fits increased and she was prescribed chronic medication. The doctors failed to mention to the family that one of the side effects of the medication could cause infertility. Claire only found out about the link between epilepsy and infertility after her first miscarriage. She immediately stopped taking the medication but feared the return of the epilepsy. Nine months later, Claire fell pregnant for the second time. After three months into her pregnancy, Claire miscarried once again. She was 34 at the time.

Claire was unable to conceive after the second miscarriage. Five years later she fell pregnant for a third time. She was three months pregnant when she started to experience distressing pains in the middle of the night. Because her husband was away on business at the time, Claire called two of her friends to take her to hospital. From her background in nursing, Claire suspected that she was having an ectopic pregnancy. Her friends did not think it too serious until she fainted on the bathroom floor, bleeding. She was rushed to hospital where she had to be operated on twice. The first operation involved the removal of her fallopian tube and half of her uterus. She had to have a second operation because of internal bleeding. During the emergency, Claire had to be resuscitated twice but eventually pulled through. Her doctor advised her not to fall pregnant again because of her age (39) and the fact that she only had half a uterus and one fallopian tube. The doctor referred her to an adoption agency and suggested that Claire and Gary consider this option.

Claire decided to take a few months to recover from her ordeal. During that time, Gary was transferred to Botswana for work purposes for two years. Before their departure to Botswana, Claire and Gary contacted an adoption agency in Johannesburg and attended an intensive family life course. This made them eligible to adopt a child. Claire was concerned about her age at the time. She knew that it was the birth mother's choice to choose the appropriate adoptive mother and that her age could be a deciding factor. When they returned from Botswana, Claire was

contacted by the agency and told that a baby girl had been born. Claire had been chosen to be the adoptive mother. She was 43 years old.

Nature of the Interaction

I interviewed Claire at her home and was able to meet Gary and Keslyn. I had contacted Claire by telephone the week before to set up an appropriate time and place and explained to her what the interview would entail. Gary was aware of the interview and offered to baby sit Keslyn while I interviewed Claire. Both Claire and Gary made me feel at home and relaxed. I noticed that this was not the first time they were talking to a stranger about their experiences. It was clear that they were used to sharing their pain with couples who were struggling with infertility, and the fact that I was there to interview them was just another opportunity for them to help others.

The atmosphere between Claire and myself became very relaxed once I asked her to describe her experiences with infertility. She was open to discussing personal feelings and thoughts with me. She was also detailed in her descriptions of the last ten years with infertility. I could see that she had come to terms with the infertility and that discussing it was not as difficult as it might had been in the past. Although she still cried a few times during the interview, she mentioned that the pain she had been through had been overwhelming, but that so many things had changed in her life for the better. She felt she had made peace with her circumstances and that she was now in a place where she felt satisfied and happy with life.

My primary role during the interviews was that of inquirer and information seeker. I asked the questions and Claire answered them openly and honestly. She was capable of discussing emotions in an open manner. When the meaning of pain was discussed, however, I shifted my role from inquirer to that of therapist. This took place at the end of the session when we both looked back at the ten years of infertility and tried to make sense of the suffering. I felt the shift was needed primarily because Claire had never really spoken to a psychologist or counsellor regarding her pain. She had never been in the role of the client to receive comfort or guidance. For the last four years she has been the one who gave information, comfort and guidance to

couples experiencing infertility. I wanted to give her something back and so decided to concentrate on the meanings and significance she had achieved in her suffering.

Emerging Themes

The following themes and meanings regarding infertility emanated from the interview between Claire and myself.

Shock and Unbelief

As mentioned in the previous case illustration, many women experience shock and unbelief when they are told that they cannot conceive. Mazor (1984) writes that women who learn that they are infertile are usually "surprised, even shocked, to learn that they were unable to conceive once the decision to have a baby was made" (p. 26). Many women who thought they were in control of their lives in terms of marriage, relationships, careers, building homes and being financially independent become distressed, shocked and angry at the lack of control they now face. What originally starts as denial (the refusal to admit that something unpleasant or painful has occurred, especially if sudden and unexpected), turns into anger with exclamations of "No, not me!" or questions such as "Why me?" "What did I do to deserve this?" "What have I done wrong?" (Corson Appleton, 1983; Mazor, 1984; Sizer & Whitney, 1988). During Claire's ten year struggle with infertility, feelings of shock and unbelief were also experienced:

When I found out I could not have children, it was heartbreaking. This was really what I had wanted out of life – marriage and children. That's just what I think most people want and it was heartbreaking. This is my body and this is what it has done to me! You feel a lot of conflict in your life because you intend to do something and then you don't get it right. You feel like a failure. Before you have control and now you can't even get falling pregnant right.

Claire also discussed feelings of shock when discussing the ectopic pregnancy:

I was in deep shock with the ectopic pregnancy. I couldn't believe it. I knew it was ectopic when I had the pain in my shoulders. Blood pushes up to the diaphragm and you feel pain up here (pointing to her shoulders). That was a lot of shock. And after that you feel empty because you know now that there is no way you can fall pregnant. I went through a major crisis.

Salzer (1991) defines a crisis as occurring "whenever you face a difficulty that you are unable to solve with you customary coping skills. You become disorganized and confused, often making many unsuccessful efforts at solving the problem. Being confronted by failure and helplessness, you feel increasingly anxious and immobilized. This is what happens when you are faced with infertility" (p. 8). For Claire, the crisis entailed the disappointment of a life long dream – a fulfilled marriage with children. During her emotional crisis, Claire decided to consult a psychiatrist.

I saw a psychiatrist who said to me I was not coping. She put me on Prozac. At that time, I was angry with other women, I was angry with myself mostly, I was angry that life had dealt me these cards. I was angry with God. I went away from Him for a long time. I kind of didn't want to talk to Him because I didn't think He would listen to me. I think it got so bad that I actually started getting panic attacks and that's when I went to look for help. Anyway, the psychiatrist said "You're not coping. You've had epilepsy, you've been on medication all your life. It has probably destroyed a couple of neurons as well as the fertility." So she said "If you're going to do yourself a favour and live life as you should, then take something for it." So I did. I've been taking it ever since. I've never actually gone off it. That's how I think I coped through most of that crisis.

Anger

Rational or irrational anger related to infertility is commonly directed towards the medical world, physicians, specialists, friends with children, pregnant women, women who neglect and abuse their children, God, partners and so forth (Glazer & Cooper, 1988; Salzer, 1991; Whiteford & Gonzalez, 1994). Claire discussed how angry she felt during her struggle with infertility with various people:

I was angry at the doctors who had prescribed the epilepsy medication. I felt that nobody had informed me about the side effects. I was angry at the doctors. Very angry. I thought all my life I've worked as a nurse and you don't really go into the area of infertility and epilepsy. You would never put the two together and you don't really meet epileptics who are infertile anyway.

She also mentioned anger towards her fellow nursing colleagues:

At the time I was working with other nurses who had children and they used to work twelve-hour shifts. I used to get angry with them. "How can you leave your baby with a nanny or a daycare or a crèche and work here during these hours? Why is money so important to you? I mean why can't you take a half day job?" I know a lot of women have to work. It's not a possibility for them to stay at home. I truly understand that. But there were women who would want children, fall pregnant, have the child and then come back after three months. It was like, "Agh, it's just another baby!" "How can you do that? What gives you the right to have children and then ignore them when I don't have one myself and would love to have one?" We gave up everything financially when Keslyn came and I didn't carry on working. I don't believe it's right to do that. So, I used to get very angry with them and not be able to say anything.

I asked her to elaborate some more on the anger. She replied:

I think the anger was not only because they were working such long hours and not being there for their children but also because they had children and I didn't. It wasn't just because they didn't look after them. Now I see that. But at the time, I didn't have that pity for myself and I didn't feel sorry for myself. I just felt anger towards them and guilt towards myself. Guilt that I had let myself down and let my husband down.

Guilt

Feelings of guilt are also common expressions in the struggle with infertility. For some women guilt and shame are experienced because they have internalized the social norms expressed in dominant gender roles that they should bear children (Whiteford & Gonzalez, 1995). Reasons for wanting children are mostly based on the beliefs that motherhood is a 'natural instinct', a 'stage in the development of a relationship' and a 'social expectation' (Ulrich & Weatherall, 2000). Not only does motherhood provide physical, psychological and social completeness for the women but also personal fulfillment. Consequently, if women are faced with infertility, the emotional upheaval experienced will not only place great burden on the woman but also on her partner. If the infertility problem resides within her, then a possible reaction is the internalisation of guilt feelings, inadequacy and failure (Ulrich & Weatherall, 2000). Women may feel damaged, defective, physically unfit and guilty for not being able to provide their partners with a child (Abbey et al., 1991). Some even believe that they are being punished for imaginary sins they have committed (Salzer, 1994). Mazor (1984) writes that "the infertile spouse may fear actual or emotional abandonment by the other; some will continually test and provoke the partner with comments like "If you had married someone else you'd have a family by now". The fertile partner may feel an obligation to maintain a "front of unswerving loyalty, to disavow any disappointment or anger" (p. 28). Salzer (1991) points out that some partners make direct offers of divorce as they believe that they are of no benefit to the other partner. Such individuals fail to see that marriage is based on far more than the 'ability to procreate' and feel that they can no longer remain in the marriage (p. 25). Some women also feel the need to continue with medical treatment especially 'for the sake' of the fertile partner. The guilt to continue may place severe emotional and physical burden on the infertile woman. Denise shared a few of these guilt feelings:

I think I've blamed a lot of the infertility on myself. I had a few relationships before I got married and I did get the occasional infection. Perhaps that contributed towards the ectopic pregnancy that I eventually had. It is a possibility, you know.

I also had a lot of guilt in terms of Gary. (Crying). He never stressed that that was his ultimate goal – to have a child. He always said, "If we have children then we have children, if we don't, then we don't." But he is so in love with his nephews and nieces and plays with them so much. That made me think "Whew! What have you done to your body and what have you done to you life?"

I felt a lot of personal guilt for having had other relationships. At the time I was only looking for love. That's all I wanted. But you only realise that afterwards. Gary has never said to me that he has forgiven me but he's also never made a fuss of it. It's never been a big deal. He just accepted the fact that I was looking for love. He's a great guy.

I asked her to describe her relationship with Gary. I wanted to know if they had experienced stress and conflict in their marriage because of the guilt.

Well, there was a lot of stress but from my side only. Gary just said, "If we're meant to have a child, then we will, if not, we won't." I always knew that he wanted me and loved me but sometimes I would wish that he hadn't had me. I sometimes felt that he should have married someone else who could have given him a child. That was the stress I put myself through. And Gary just went on with life. The whole thing brought us together when I had the miscarriages. He would take me away on holidays. So it did bring us together. But he still didn't really understand how I blamed myself. He thought that was so stupid. "How can you blame yourself? That's your body. That's what God's done and that's the way life is." But I still blamed myself. (Crying).

At this point we discussed if the guilt was connected to feelings of depression. She agreed:

I felt depressed often. That's when I thought that Gary should maybe go and find somebody else. I cried a lot. I didn't feel like getting up in the morning. I lacked meaning in life because I knew that I was letting us down. It wasn't like I was a single woman having a baby. It was us. (Crying).

Fear

While discussing issues of blame, guilt and depression, I asked Claire if she had also experienced feelings of fear. Based on literature, part of the feeling of anger and blame is the experience of fear (Mazor, 1984). Fear is usually experienced in the question "What now?" What choices do the woman and her partner need to make? What will happen to them in the future? What will their lives be like without the children they so hoped for? These questions, and so many others, undoubtedly create fear and questioning for women who are unsuccessful in having children. Claire described her feelings of fear:

The fear I experienced during those ten years manifested itself in my panic attacks. I felt fear in my surroundings. Because my emotional state was so low I feared everything. I feared Gary leaving me, I feared never having a child. My relationship with my husband was very important to me. To know that he loved me and accepted me without a child was important, and that if we did have a child it would be a bonus. His unconditional love was wonderful. I also feared being ostracized by the community. My husband has younger friends, all ten years younger than me. All their wives are having children. You would go to braais or go out with them at night and all they talked about was babies.

Loss of Self-Esteem

The final theme to be discussed in Claire's experience with infertility is that of loss of self-esteem. When the woman and her partner are faced with the inability to conceive, feelings associated with a positive sense of identity, self-esteem and self-image are threatened. As Glazer & Cooper (1988) write, "one's self-esteem is determined not only by external or societal reinforcements and cues, but also by internal cues that we perceive in our bodies. A healthy, well-functioning body enhances our self-image" (p. 33). People "take on beliefs and develop an internal representation of themselves based on the messages that they have received about themselves" (Crawshaw, 1995, p. 40). If the message involves not having children because of a physical defect, then one's self-esteem and self-worth may be threatened (Dunkel-Schetter & Lobel, 1991). Women may experience difficulties in "achieving

a congruity between their outer and inner worlds and a centered sense of self" (Crawshaw, 1995, p. 44).

As in the case with Claire, women who are devastated by the inability to conceive may experience a wide range of feelings detrimental to their self-esteem and self-image. These include feelings of being damaged, defective and inadequate (Abbey, 2000; Abbey et al., 1991; Dunkel-Schetter & Lobel, 1991; Greil, 1997; Kikendall, 1994; Zucker, 1999). The sense of failure causes them to place blame on their 'impaired body', thus continuing the destruction of their confidence, worth, image and esteem (Crawshaw, 1995, p. 55). Claire described how she had seen herself during her struggle with infertility:

Oh gosh! I didn't have much self-esteem at the time. I think that's where my panic attacks came from. I felt inferior to most people. I felt I wasn't as good as they were. It was just a whole cycle of not feeling good about myself. I had self-confidence at work. I had always done well. I worked hard. Otherwise, outside I had no confidence in myself.

When we went to braais, I found it difficult to chat to the women. It was difficult because I wished I would join in their conversations. I wished I could be part of the group but I wasn't. I could talk about nursing and they would talk about babies. I would often go and talk to the men. I would spend a lot of time with them. I would say, "I don't need this. This is not for me now. I don't really want to get depressed, so let's just leave this."

I asked her about her internal thoughts at the time.

I believed I was useless. I felt these thoughts all the time. I just couldn't shake it. I would read motivational books, I would see somebody who would say how great I was, but it just didn't click. I think it came from my background and me not feeling loved. I felt I wasn't. The growing point was Botswana where I was appreciated there as a person. People didn't know me, they didn't know my background. They didn't know anything else about me and they liked me. They appreciated what I did and there was only praise. In nursing you don't ever get that. You're constantly told

you're wrong, you're not doing things right by doctors, patients, etc. In Botswana, everyone was going on holiday and they were booking trips and flights through me. Everyone was happy. I was happy.

I also asked her how she felt about herself presently and if the feelings of self-esteem had changed. She answered:

My self-esteem is fine today. Based on those years in Botswana where I wasn't nursing and I wasn't reminded of my infertility. It's amazing to look back now and see the difference.

Psychotherapeutic Implications

A final phase of the infertility journey usually involves the acceptance and resolution of the life crisis. This is the time when personal decisions are made regarding what steps to take next including other alternatives to parenthood. These may include adoption, artificial insemination by a donor or childfree living (Mazor, 1984; Schwan, 1988; Taymor, 1990). Coming to this final stage of resolution is a significant and necessary milestone. It does not mean that feelings attached to infertility disappear (Salzer, 1991). They may resurface at specific times in the woman's life. However, such feelings will no longer rule the woman's life as it is hoped that she will have integrated the physical problem into a "subjectively meaningful scheme of things" (Stammer et al., 2002, p.114).

Acceptance through Mourning

Claire was finally able to accept her infertility through grieving her inability to have children and eventually through the adoption process. Experiencing grief and mourning occurred when Claire and Gary reached a point where they considered ending their efforts to fall pregnant. The grieving and mourning process usually takes place when the couple realises that they are unable to have biological children of their own (Mazor, 1984). This process usually entails painful episodes of crying, depression and despair (Salzer, 1991).

The time of grieving and mourning is a difficult one, especially since infertility is not a tangible and visible loss. Instead, it is a loss of a biological child, the loss of knowing what it is like to be pregnant and deliver a child, the loss of a dream, the loss of human potential, the loss of self-esteem and self-identity, the loss of control, and the loss of feeling like a woman (Abbey, 2000; Dunkel-Schetter & Lobel, 1991; Salzer, 1991; Schwan, 1988; Stammer et al., 2002; Whiteford & Gonzalez, 1994). Women will mourn a part of themselves that will never be realized.

For Claire, accepting this reality was a painful and difficult process. She had to re-identify herself in relation to herself and to others. Her acceptance of the grief and loss would include the assessment of support systems, focusing on her marital relationship, being aware of her personal coping skills, creating a positive self-image, working on her self-esteem and extending her areas of strength. Claire was able to do this when she did the family life course and when she moved to Botswana.

I think you grieve your babies when you lose them. It doesn't matter if they're two days old or three weeks in your uterus. It is a baby and you feel that you've lost. That baby has left your body and it is no longer living. I think I grieved for the loss of ever being able to have a child in Botswana the most. Even though I saw women having babies all the time and all over the place, and even though I got angry with them I quickly realised that I wasn't doing myself any good. You can't get angry. So slowly, with my self-esteem increasing I was able to come to terms with it and become my happiest in Botswana.

Social coping resources and growth-fostering relationships have been found to aid the stress arising from infertility (Gibson & Myers, 2002). In particular, partner and family support is probably one of the most important coping resources available (Abbey, 2000). Having the partner as a confidant can enhance the infertile woman's emotional and social adjustment. Communication, support, lack of conflict and understanding may also help the emotional state of the woman as long as the coping styles of each partner do not differ radically (Abbey, 2000).

When Claire and Gary began the adoption process, they had to enroll in a family life course to prepare them for possible adoption. Becoming involved in

something like this encourages the couple to build on its own relationship and also relationships with families, peers and the community. This connection to others through growth-fostering and social support is considered to be central to the psychological well being of women experiencing infertility (Gibson & Myers, 2002). Being aware of differences in the marriage and discussing them openly in therapy will allow the couple to voice personal anxieties and fears. Discussing intimate problems and expressing oneself in an honest manner can give the couple a new perspective. The focus Claire placed on her relationship with Gary helped her to come to terms with the infertility.

I also made peace with the infertility when I started going to the family life course. It improved my relationship with my husband. We could actually talk more about our marriage, our problems, the adoption process and about my body letting me down. We were able to walk out of the course feeling that everything was going to be okay.

She also mentioned that she felt optimistic and positive knowing that there were alternative methods for having children.

We knew we were in Botswana to get some capital together to pay off the house and then to eventually get a child. I also think that if I hadn't adopted, I would have gone for surrogacy. I had a few other options. Knowing that we could try for a child in some other way gave me a sense of hope. You're still a bit uncertain but there is a glimmer of hope at the end of the tunnel.

Learning from the Pain

For me it was important to ask Claire whether she had been able to make sense of the pain and suffering in her battle with infertility. I asked her if she was able to look back at her four years of motherhood and tell me what she had learnt from her ordeal.

Paula: *If I consider what you have said up to now, it seems that you are coping well with everyday life. You are a mother, a wife, you run your own business, you look after your home, you socialise with friends and*

so forth. With all of the 'busyness' that surrounds you, are you able to look back at those years of suffering and find any meaning?

Claire: *Oh yes, I changed from a very angry person to a person who can understand more. For example, I have friends who feel a great emptiness inside them and who are angry with the world. I can now sympathise with them and understand what they are going through – ok, not fully, but you do think, "Yes, you do get like that. You do feel that way." You realise that everyone feels something different. I have grown in that my eyes have been opened to the realities of life. It has been a growing experience. It's amazing to look back now and see the difference. I've often thought of working with infertile ladies on a one-to-one basis and showing them the light at the end of the tunnel.*

Paula: *How would you help them accept the reality of their physical problems?*

Claire: *When you're there you can't always see it and that's why one would have to let women go through that pain and work through it to the very end. This includes depression, feeling like a failure, guilt – everything. This is the only way of coming out of it. I think if you ignore it, it will never go away. I tried to ignore it but it didn't work. I had to face it head on. Only then can your attitude change. You can't be upset about your physical problems forever. You need to reach a point where you have to realise that there is a much bigger picture.*

Claire felt that the infertile woman needs to deal with issues of pain and suffering. I agreed with her that women struggling with infertility were entitled to personal feelings of pain and that denying or avoiding it would only hamper the resolution of the crisis in the long-term. At a later stage I asked Claire to discuss what she had gained from the adoption process.

Claire: *To be a mother is the most wonderful experience. It's a whole new lease on life. My life has become filled and I don't have any regrets*

anymore. All the nonsense I went through, the fears of never having a child, my desire to have one, letting my husband down, letting my body down and letting myself down all disappeared. They all disappear when you have a child. Keslyn is definitely from God. Nothing happens by accident. She was planned all along. It was a plan that we should have her. But you don't know that so you go through all this pain and suffering. You don't trust that God is going to give you a baby and you should, because everything works out in the end.

Paula: *I know you believe that God had a plan for your life. Do you think God gave you Keslyn because you wanted and needed a child, or do you think He gave you Keslyn because He knew she needed you and Gary?*

Claire: *Actually, I never thought about it in terms of helping Keslyn. I always thought of it as satisfying me. (Laughs). Keslyn would have been adopted by someone else but I do think she is a lucky little girl because we love her so much.*

I decided to focus on this point and show her that she had something good to contribute towards Keslyn's life. Just as Keslyn had been placed in Claire's life for the fulfillment of her dreams and needs, so too, had Claire been placed in Keslyn's life for some reason.

I never thought about how Keslyn was affected by me. I never thought of that. I've never really considered that. But doing so now definitely brings me a sense of happiness.

Debriefing

I believe that therapy is beneficial because it increases an individual's capacity to have a wider and more realistic range of emotional understanding. It helps an individual who feels powerless and desperate to express feelings and thoughts in a safe and open context. In my interview with Claire, I felt that I had delved into

personal emotions and experiences that had not been dealt with since the arrival of Keslyn. I was particularly concerned with the crying and at times doubted whether she had made peace with her struggle with infertility. I needed to know if I had perturbed her with the nature of my questions. She answered as follows:

Claire: *I think it has been good to open up and to work through past feelings. It's something you don't often talk about in its entirety. You only mention it to people. People ask questions about Keslyn and you say you were infertile, couldn't have children and eventually decided to adopt her. But you never really go into the feelings that you experienced then.*

Paula: *Those were ten years of your life where very strong feelings ruled your day to day experiences.*

Claire: *Yes, and you actually bring those emotions to the fore by talking about them. Your emotions come back to you.*

Paula: *Has this session been hard for you?*

Claire: *I don't actually mind crying and experiencing emotions. You have to. A good cry now and then is actually good for you. You release things inside and you work through it more and more. It becomes easier and easier.*

Paula: *In a way, it is like a scar. It reminds you of the pain and doesn't completely disappear. Going into all of these emotions is bound to do something to you.*

Claire: *Yes, you do start to feel emotions that you haven't felt for years now. But Keslyn is almost four and I'm fulfilled and happy. I'm glad I was able to look back and see how far I've come. It's been a long process but I think I'mok.*

I left the session with a sense of uneasiness. I felt that I had dealt with painful and hidden underlying issues. Claire assured me that she would phone me should she need to speak to me again. For the meantime, however, she was coping and was gla d to have been of help to me and to the research.

Into the Future

I phoned Claire several weeks after our interview. She mentioned that she was doing well and that the interview had been a good experience. She was able to gain perspective on her struggle with infertility and realised that she was happy with her life at present. She sold her house and was planning on building her dream home in the ensuing months. She and Gary continue to enjoy their marriage and parenthood.

Conclusion

Infertility may be defined as the inability to conceive a child after one year of regular and unprotected sexual relations. Infertility, as a physical problem has no boundaries and may affect men or women of all races and economic classes. It is a condition that has increased in numbers due to, amongst other reasons, the tendency to delay childbearing in to the thirties and forties, the possibility of contracting venereal diseases, birth control methods, abortion and risks of infection (Glazer & Cooper; 1988; Gunn, 1988; Taymor, 1990). Infertility, as an emotional problem can also be taxing on the infertile couple. Most couples and in particular, women, believe that it is a God-given and biological right to have children. Assuming that they are in full control of their lives in terms of being parents, being diagnosed as infertile can be a severe shock and blow. When this occurs, a developmental crisis ensues, directly influencing the individual's self-esteem, self-control and self-confidence. Infertile individuals feel defective and damaged when they realise that they are unable to become parents. They are then faced with the emotional trauma of medical treatments, the pain of constant reminders, the stigma within their social environment and the guilt for failing to reproduce. Discovering a new perspective or a solution may be painful and take a long time. With the necessary support, understanding and counselling, however, the physical, emotional and social suffering attached to

infertility may lessen thus allowing infertile couples to live a more fulfilled and happy life.

In this chapter, I interviewed Denise and Claire who struggled with infertility for ten years. Both fell pregnant but lost their babies due to endometriosis and infertility problems. After several years of trying, both decided to adopt. Although Denise still hasn't lost hope of ever falling pregnant, Claire has reached a point in her life where she is unable to conceive because of her age. She has, however, found peace and acceptance through a process of grieving and mourning. Both believe that the support they have received from their husbands and family members has been vital in their coping with the struggle. I believe that my intervention in their lives simply allowed them to consider their pain and their strengths in dealing with their suffering. In the next chapter I will look at the meaning of suffering by referring to all three contexts and to the lives of all six women participants.

CHAPTER 7

MEANING AND SUFFERING

And this song is considered a perfect gem,
And as to the meaning, it's what you please.
(C. S. Calverley)

In this chapter the co-constructed and shared meanings and themes that emerged through the process of language between the six participants and myself will be considered. Central assumptions and themes that emerged during the interviews will be discussed within the context of social constructionism and in terms of meaning and suffering. The chapter will entail a meta-level commentary of such themes ensuring that the link between theory and practice remains present. The reader will also be provided with an opportunity to infer his or her own personal assumptions.

The Social Construction of Shared Meanings

As mentioned in Chapter 2, social constructionist thinking advocates that when language occurs in any particular context, the obvious outcome is the generation of and co-construction of shared meanings and beliefs (Anderson & Goolishian, 1988). Furthermore, in terms of the qualitative/naturalistic approach, all values, ideologies and social institutions are man-made (Gergen, 1985). Based on these two perspectives, meanings and belief systems thus emerge out of the interactions taking place between people in different contexts (Hoffman, 1990; Moon et al., 1990). Because language is never static or constant, but rather always changing and evolving through a process of dialogue, this chapter will look at the meanings and assumptions that emerged from the conversations between the six women participants regarding personal suffering. It was also through the sessions and conversations that our previously held constructs and beliefs were challenged and questioned.

In terms of social constructionism, a system that converges around a problem will be considered a linguistic system where beliefs, meanings and understanding are mutually co-constructed (Anderson & Goolishian, 1988). The linguistic system in

this study comprised the interviews that took place between the participants and myself. The interviews involved a discussion of suffering experienced by the six women in their day to day living. Their suffering pertained to physical bodily problems within the contexts of familial breast cancer, eating disorders and infertility. A 'consensual domain' was formed between the participants and myself as we reciprocally shared ideas, beliefs and meanings about suffering (Maturana, 1975).

The aim of social constructionism, and hence the aim for the interviews, was to give rise to a set of evolving meanings where the six participants were able to develop their own identities, scripts and personal meanings through a process of social interaction. Since an individual's unique meaning system allows him or her to make sense of personal experiences, my aim was for the women to use the context of the interviews to create a reality which would provide them with personal meaning (Atwood & Ruiz, 1993). It was hoped that knowledge, understanding and meaning would emerge within this social domain regarding their personal suffering.

Suffering

For the purposes of this study, no theory of suffering was discovered through a literature review. Limited information regarding the understanding and meaning of suffering could only be fully explored within the religious and medical contexts. I was also unable to find a comprehensive psychological description of suffering and thus made it my aim to explore notions of suffering through research and ultimately through the lives and meanings of six women struggling with bodily issues. The conclusions and findings of what I believe suffering entails will be discussed shortly. It is hoped that my personal punctuations of the meaning of suffering will assist the reader or the therapist to understand personal suffering in such a way that the individual may be helped to deal and find meaning with the specific problem. I also aim to show that there are various themes related to suffering and that new themes may constantly evolve and emerge depending on the individual's experience of pain. The themes that will be discussed in this chapter are only themes of suffering that emerged in my conversations with the six women participants. They are not final descriptions and definitions of suffering but merely a co-construction of personal meanings, values and experiences.

Suffering is Loss

Based on the co-constructions of the previous three chapters a common theme of suffering was described in the form of loss. In terms of familial breast cancer, eating disorders and infertility, loss of control and loss of identity formed the basis of personal suffering. For Reed (2003), an individual's perceived sense of loss may result in temporary distress. Losses that patients interpret as significant may lead them to question 'what is sustaining their lives' while wondering what is the meaning of life (p. 14). Loss may not only entail a specific loss such as the removal of breasts, the inability to conceive or the loss of controlling what one eats, but may also ramify into other personal losses. These may include, for example, altered roles in the family, workplace or community. The women participants in this study experienced loss in the following areas.

Loss of Identity

An individual's identity refers to the conscious perception he/she has about him/herself. It refers to an awareness of the individual as an independent, unique person who occupies a specific place in society (Louw, 1991). It involves the formation of a continuous, integrated total image of the self, a socio-cultural identity, a sex-role identity and an occupational identity (Louw, 1991). It includes one's personal drives, wishes, abilities, skills, beliefs and past experiences which ultimately help the individual be aware of his own uniqueness in the world. An individual's identity is a complex concept and can therefore be defined as the individual's image of him/herself, including the experience that his/her self-image and the view others have of him are fundamentally in agreement (Meyer et al., 1989). With an identity, an individual is able to know him/herself and determine his/her place in society as a free individual (Meyer et al., 1989). When the concept of identity is undeveloped or harmed by a specific circumstance or experience, a sense of confusion about distinguishing characteristics, roles, abilities, and value systems is experienced (Louw, 1991). An individual's sense of wholeness is threatened and he/she is unable to integrate developments into his/her self-image.

In terms of this study, the experiences women had regarding familial breast cancer, eating disorders and infertility all involved a loss of identity. This loss of identity created for them an experience of suffering and was directly related to the physical body. In all three contexts – familial breast cancer, eating disorders and infertility – the women experienced their bodies as having betrayed and let them down externally and internally. Since the body is a symbol of beauty, femininity and sexuality, and because it forms an important component of a woman's self-image, any defect or blemish directly lead to distress in the women who identified themselves with their bodies. In the conversations with the six women, personal suffering was directly related to their loss of identity and their bodily 'defects'.

For example, Laura expressed that she saw herself as a cheap plastic doll – empty inside. She saw herself as an empty person whose identity was going to change once her breasts had been removed. Christel also experienced a loss of identity with the removal of both her breasts due to cancer. She not only grieved the physical but also the emotional aspects of her breasts namely, her femininity and sexuality. For Christel, the external changes were hard for her to deal with since they symbolised her identity and her personality.

In the context of eating disorders, Lisa also expressed a loss of identity through her body. Her identity was directly related to the fact that she did not possess an ideal body shape as depicted by models in cover magazines. She would only be worthy and deserving if she could lose the excess weight and became thin. Her need for perfectionism would not allow her to maintain the identity of an overweight individual. Her identity as a human being could therefore only be validated when she lost the excess kilograms. In Anita's case, her loss of identity was not only related to her body size but also her incapability of being the 'good' wife. Her husband had placed pressure on her to lose weight and blatantly told her that he would only be intimate with her once the weight had been lost. Her suffering was due to this loss of identity. Anita, like her husband, was unable to see her true identity beneath the weight. Her identity was only that of an overweight women. Any abilities, characteristics, skills, values and beliefs were instantly overshadowed by the extra kilograms.

Within the infertility context, loss of identity was also a leading cause of suffering. Not only had the women's bodies failed them physically, but their identities within the context of motherhood were now endangered. For Denise, her identity as a woman was closely linked to her potential to be a mother. Any threat to that dream would automatically create in her a sense of identity confusion and loss, especially as her identity during the infertility struggle had been that of a damaged woman, unable to carry out a task which was rightly hers. Claire also experienced the same feeling of loss of identity with the miscarriages. The loss of identity she felt was due to her inability to bear children and her inability to give her husband a child of their own. Both Claire and Denise expressed how they had regained a sense of identity only after the adoption process. Having children in their lives had given them a purpose to live and a sense of identity – an experience they would not have achieved had they remained childless.

All six participants were unable to completely develop an integrated sense of identity during their suffering. They were unable to preserve their uniqueness and centeredness in spite of their physical inabilities.

Loss of Control

Feeling vulnerable and fearful of pain and suffering may create a sense of uneasiness and dread in the individual (Reed, 2003). Not knowing what the future holds for the individual usually leads to feelings of helplessness and powerlessness. The sufferer embraces the belief that he/she has no control over his/her life and that problems are uncontrollable and unsolvable. The person may feel ineffective, hopeless, confused and desperate.

All six participants felt that they were unable to create and shape their own destinies. In the familial breast context, the two women participants experienced suffering because they felt they had no control over their genetic make-up or their risk for breast or ovarian cancer. Not being able to predict whether they would ever have breast/ovarian cancer made them feel powerless and vulnerable. Their future was entirely in the hands of their genetic make-up. Being able to know whether they

carried the BRCA1 or BRCA2 genes through the blood results only provided them with a limited sense of control.

For Laura, knowledge that she carried the mutation only helped her to make the decision regarding total mastectomy. She felt more comfortable taking a pro-active role in minimising her risk for breast cancer. She was prepared to go to any measures to avoid getting breast cancer in the future. She had experienced her mother's struggle and loss with breast cancer at an early age and was determined to prevent her children from experiencing the same loss. In the beginning, her loss of control was a lead cause for her suffering and only after her journey with the mastectomy was Laura able to finally find a sense of peace. She had been able to change a seemingly uncontrollable situation into a more controllable one.

Christel, on the other hand, did not feel comforted or more in control knowing that she carried the mutation. She had already suffered with the breast cancer itself and the removal of both breasts. At the time she had felt an extreme sense of loss of control, especially because the expected ovarian cancer had been replaced with breast cancer. Knowing that she was powerless with regards to the breast cancer had shocked her in the beginning of her struggle with breast cancer, but had little effect after the blood test results had been given to her.

Loss of control was also a major cause of suffering in the lives of the two women struggling with eating disorders. For Lisa and Anita, control over their weight and food was non-existent. It was this loss of control that contributed mostly to their feelings of depression, sadness, pain and suffering. Both were powerless to resolve emotional problems that were perpetuating their eating disorders. The loss of control, which had now become an obsession with weight, food and the body, also represented a loss of control in other areas of their lives. In Lisa's case, her suffering was mainly due to the loss of control she felt in terms of her studies, her looks, her relationships with boyfriends and her future. For Anita, the loss of control was seen predominantly in her relationship with her husband and the inherent lack of communication, understanding, support and friendship. Both were unable to achieve any sense of control.

In terms of the infertility context, both Denise and Claire felt helpless and powerless at not being able to conceive due to physical problems out of their control. All their lives they had expected to fall pregnant and have children. It was never questioned whether they would have endometriosis or any other physical defect. They felt in control and capable of eventually having a child. Facing the reality that their bodies would let them down in this respect was shocking to both participants. They were unable to comprehend the reasons for their infertility. Not being able to control their lives, as well as their spouses', led to an emotional crisis in the lives of Denise and Claire. Here, they experienced suffering on an emotional, physical and social level. Only through the adoption process were they able to regain some sense of control and consequently a sense of happiness.

Suffering is Isolation

According to existential theory, individuals are concerned with preserving their unique identity, but at the same time have an interest in going outside of themselves to relate to other beings (Corey, 2001). In essence, human beings are relational beings and we all strive for some connectedness with others. In terms of the family systems approach, individuals are best understood within the context of relationships and interactions within the entire family. Individuals are all connected to living systems and any change in one part of the unit will reverberate throughout other parts (Becvar & Becvar, 1988). Social constructionism also focuses on the belief that humans are all interrelated but through the process of dialogue. It is through dialogue that individuals are able to make meaning in social relationships. The belief is that human life is constructed in personal and family narratives that maintain both process and meaning in people's lives. Personal stories are thus constructed only through social interactions (Anderson & Goolishian, 1988).

However, when individuals feel disconnected from others, a sense of aloneness and isolation may be experienced. Feeling separated from others and unable to count on them can lead to a sense of suffering for many individuals. This was the case for the six women participants struggling with familial breast cancer, eating disorders and infertility.

Loneliness

All six participants felt at some stage in their life as if they were alone. They felt set apart from the world, the community, family and friends at a time when they most needed to be comforted and supported. They perceived themselves as being disconnected from the world, solitary and even abandoned. An overwhelming lament by the six participants was the feeling that no one really understood what they were going through. Laura and Christel, for example, commented on how their husbands were unable to fully understand what they were feeling. Laura also complained about her family not providing her with the appropriate support. What she needed from them was not what she was receiving in terms of emotional and social support. They thus felt alienated from and misunderstood by the world in terms of their personal suffering.

In terms of the eating disorders, personal suffering was experienced predominantly through secrecy and shame. The secrecy of their eating disorders had alienated them from family and friends and both Lisa and Anita felt as if they were living a lonely and isolated life. The shame they felt regarding the bingeing, the weigh loss attempts, the weight gain and the bulimia had created a life of isolation. Both were unable to discuss their secret habits with anyone for fear of rejection and shame. Feeling lonely and detached from others was causing them much distress and suffering.

Suffering was also seen in the lives of Denise and Claire who felt most alienated, vulnerable and isolated in social situations. Because there were constant reminders of fertility, children and motherhood wherever they went, both women felt like they did not belong in specific social situations. Denise, for example, struggled to be amongst friends who were having their own children, while Claire, felt like she needed to escape situations where the only conversation was pregnancy and motherhood. Their sense of feeling apart and distant from other people led them to a deep experience of pain and suffering.

Anger

Anger is one emotion that can lead to a sense of isolation from others. Usually anger may be directed at oneself or at other people - close relatives, friends, the world and even God (Louw, 1991). The individual places blame on others and in turn begins to feel a sense of isolation and distance from those who may or may not be contributing to the anger. These feelings are, however, usually a symptom of other feelings including a sense of irritation, being upset, annoyed or hurt and may refer to some type of negative or unpleasant emotion (Baron & Byrne, 1991).

In Laura's battle with familial breast cancer, her anger was mainly directed towards family members who were unable to understand her pain and emotional struggle. This anger eventually led her to experience isolation from the family system and to cope with the pain on her own and through therapy. At some point, she actually refused to phone people and to have contact with her sister, brother and father. She also felt anger towards her mother and the inherited mutation. During my sessions with Laura I discovered that behind the anger lay much hurt and disappointment in terms of family expectations. This hurt was leading her to deal with the mastectomy and the mutation on her own.

With Christel I noticed that she still harboured anger towards her stepmother and the death of her sister with whom she had been very close. The anger she felt was keeping her from sharing personal pain with family, friends and her husband. I felt that the anger was merely a symptom for feelings of hurt, rejection and fear. She came across as strong and competent to deal with her pain on her own and was therefore not ready to open herself up to anyone. She was suffering with the breast cancer on her own.

In terms of eating disorders, both Lisa and Anita directed anger towards themselves for not being able to control issues of weight and food. They were angry and frustrated at their inability to deal with emotional pain related to other areas of their lives. Anger towards themselves was connected to anger towards the world. Anita, for example, used food and weight as a means of showing anger and resistance towards her husband and his demands on their marriage. Lisa was angry at herself for

past relationships and the failure to succeed at university. The anger both women experienced contributed to their sense of isolation and hence their experience of suffering.

Denise and Claire also experienced suffering through the anger. Throughout her ten-year battle with infertility, Denise felt anger towards strangers, friends, women who abused or neglected their children, doctors, the medical world and God. It was extremely difficult for her to speak to individuals who were ignorant of her pain and suffering and who commented on her situation without much thought or consideration. She was also angry at the intrusion of the medical world into her intimate life, particularly the examinations and procedures she had to undergo. Not knowing what she had done to deserve the infertility also made her angry towards God and friends who were able to conceive without any difficulties. Her anger which embraced feelings of disappointment, worthlessness and hurt were all instrumental in alienating Denise from her social environment at specific times in her life.

In Claire's life, her main anger was towards herself and the possible damage she could have done to her body in terms of previous relationships. Claire blamed herself for becoming involved in relationships before her marriage that could have contributed to her infertility. However, the anger that ultimately alienated her from others was the one related to fellow colleagues in the nursing profession. She found it extremely difficult to accept that some women would have children and then go back to work immediately, dedicating themselves entirely to their jobs. She felt that the babies needed their mothers. This anger was fueled by the fact that Claire was unable to have children of her own. Claire found it hard to be herself in this environment. Her distancing from her colleagues created for her a sense of isolation and suffering.

Suffering is Emptiness

Self-concept refers to the way in which an individual sees him/herself (Louw, 1991; Van Dyk, 2001). It forms a crucial aspect of human functioning in that most individuals are concerned about who they are, how good they feel about themselves, how effectively they function, and so forth (Baron & Byrne, 1991). It entails a complex and organised idea of the person as a whole, and includes cognitive, physical

and emotional aspects such as one's self-image, self-esteem and self-acceptance. Self-image, for example, is determined by the individual's inner image of what he/she is. Self-esteem, on the other hand, refers to a personal assessment of one's traits and of one's value or worth (Louw, 1991; Van Dyk, 2001). Both self-esteem and self-image are very closely related.

The development of a self-concept is a process that continues throughout life and which usually begins at about six or eight months (Louw, 1991). If an individual's self-esteem is low, negative emotions such as depression may be experienced. People with low self-esteem are usually more affected by and concerned with social evaluations, and less capable of dealing with negative emotions (Baron & Byrne, 1991; Louw, 1991; Meyer et al., 1989). If, however, it is high, individuals are better able to perform positively or at their highest ability. Individuals with a high self-esteem are also able to deal with failure, death, anger and negative emotions in a constructive and positive manner (Baron & Byrne, 1991). They are also able to function better in interpersonal situations.

Low Self-Concept

In this study, a common factor amongst all six participants, which led to an experience of personal suffering, was directly related to low self-concept and low self-esteem. A general feeling of worthlessness and the inability to be who they really were was experienced. For example, in the familial breast cancer context, Laura felt that she was unable to be herself amongst family and friends. She felt as if they were determining her reactions and she felt powerless to stand up for herself. She blamed the low self-concept on her youth. She felt that her mother had never really given her love and acceptance and openly showed more acceptance towards Laura's brother and sister. Christel, on the other hand, did not admit to low self-concept or low self-esteem. She stated several times that she had become a confident person over the last year but only as a result of her battle with cancer. However, before the diagnosis she had never really thought much of herself and also blamed it on the emotional and verbal abuse she had received from her stepmother. Only after her battle with breast cancer was she able to begin to like and stand up for herself.

Low self-concept was predominant in the stories of Lisa and Anita. Lisa felt that she had no self-confidence or self-worth. It was exacerbated by the fact that she felt overweight. She evaluated herself constantly by the opinions of family and friends and needed their approval to feel worthy or special. She mentioned how her needs were always neglected and how putting people first was her main concern. Anita also demonstrated low self-concept, particularly in relation to her husband. She felt worthless as a wife, mother and daughter and followed the expectations of others. She tried to lose weight to be accepted by others but eventually landed up being self-destructive and negative. Both women tried to increase their low self-concept and self-worth through dieting and losing weight. Unfortunately, their inability to do so only made their self-esteem and self-concept disintegrate even further.

In the infertility context, both participants also mentioned difficulties with self-concept and self-image. Both Denise and Claire had, during their ten-year struggle with infertility, identified their self-concept and self-esteem with a healthy and well-functioning body. Their self-esteem and self-worth were threatened when their bodies were unable to conceive a child. Both experienced a wide range of feelings detrimental to their self-esteem and self-image. These included feelings of being damaged, defective and inadequate not only as individuals but also within the social context. By placing blame on their impaired bodies, their confidence, worth, image and esteem were further destroyed.

Sadness/Depression

A further factor contributing to a sense of suffering is that of sadness and/or depression. The experience of feeling sad or depressed was seen in the stories of all six women at some point in their lives. From a humanistic-existential viewpoint, depression is characterised by an individual who fails to live a complete and authentic life. Such an individual usually feels fear of aloneness and guilt for not fulfilling his/her true potential (Phares, 1992). The cognitive viewpoint, however, describes depression as the way people think of themselves. Usually, the tendency is to devaluate themselves and to see their world and their future in negative terms. Their lives are filled with hopelessness and helplessness (Phares, 1992).

In this study, Laura felt most depressed at the beginning stage of her journey with familial breast cancer. She had just found out that she carried the genetic mutation and would have to consider the removal of her breasts. She not only felt fear in terms of her future but an intense feeling of sadness and depression. Her depression was linked to her view of herself as worthless once her breasts had been removed. The emphasis on the breasts as symbols of femininity and sexuality was also seen in Christel's experience with breast cancer. The time when she experienced a deep sense of sadness was when she had to remove her breasts. She also felt sad about the way people pitied her and the times when she felt most alone.

The participants in the eating disorder context also expressed depression, helplessness and hopelessness in not being able to control their weight and eating patterns. For Lisa the depression had already manifested itself in America and had become worse in South Africa where she found herself more and more powerless to control her weight. She also felt depressed knowing that she was unable to do better in her studies and become involved with someone in a meaningful, long-term relationship. Anita also expressed depression not only in terms of her obesity but also in her marital relationship. She was unable to determine if the marital problems had led to the weight gain or vice versa. She did feel, however, that the depression was due to her feeling inadequate as a wife, mother and daughter.

Finally, in the infertility context, both Denise and Claire experienced depression in terms of ideals and dreams that would never be met. Although they had adopted children, they still felt sad that they were unable to conceive and give their husbands children of their own. They felt depressed about their physical inadequacies and their failure to be mothers. The depression was experienced primarily during their childless years when issues of meaninglessness, despair and pessimism dominated their lives.

As seen in the above section, an attempt to describe the term *suffering* was provided by considering the co-constructions that emerged in the sessions between the six women and myself. It was my aim, during the interviews, to elicit as many meanings possible regarding the women's perceptions of personal suffering within the contexts of familial breast cancer, eating disorders and infertility. Themes were

chosen according to my personal framework, while previously held ideas, personal epistemological assumptions, frames of reference and my experience in the field of therapy guided the punctuations. These meanings were discussed on a meta-level and were briefly linked to the theoretical perspectives presented in the previous chapters. One final co-construction that emerged in the sessions was the significance and meaning of suffering. Since the six participants had shared personal information regarding their pain and suffering, I felt I needed to give them something back by encouraging them to find meaning in their personal suffering. The following section considers the personal meanings the six women gained from the sessions.

Meaning in Suffering

Suffering related to physical, emotional and social problems or disabilities may destroy an individual's reason for living. It may at times stimulate an exploration of one's views regarding specific issues and sustain or alter one's perspective on life (Reed, 2003). As individuals submit to the suffering, many begin to deal with issues of its significance. It was my aim at the end of the sessions to see if the six participants had been able to make sense of their personal suffering.

According to Reed (2003) suffering itself has no meaning. Individuals, however, tend to interpret their life circumstances through the application of meaning. It seems that suffering is better endured when meaning has been ascribed to the particular situation, particularly because meaninglessness makes the suffering unbearable. Ascribing meaning and finding significance in the suffering is, however, a very unique experience. Discovering how an individual finds significance in his/her suffering and how meanings are constructed can only be determined by listening to patients and by being involved with them within a context of language (Anderson & Goolishian, 1988; Reed, 2003). The view that emerges will then enable the individual to either move towards or retreat from acceptance and understanding.

According to the existential perspective and, in particular logotherapy, an individual's quest in life is to discover meaning, purpose and direction (Frankl, 1986; Meyer et al., 1989; Phares, 1992; Shantall, 2003). It is based on the premise that life has meaning under all circumstances, not only in opportunities and joys, but also in

pain and suffering (Shantall, 2003). With the existential approach, individuals are encouraged to reflect on life, to recognize their range of alternatives, and to consciously shape their own lives. It is a process of searching for the value and meaning in life and exploring options for creating a meaningful existence (Corey, 2001). Finding meaning in the circumstances of the six women participants became an important personal quest towards the end of my sessions. Since meanings are discovered and not invented, and because individuals can only experience the meaning of life by living it (Shantall, 2003), my aim in the sessions was to see if the six women had indeed discovered meaning in their personal circumstances. This transpired through the process of dialogue where personal perspectives, resources and unique experiences were elicited through the process of language.

As mentioned previously, social constructionism is interested in the generation of new meanings in the lives of individuals. Social constructionists seek to elicit perspective and focus, facilitate the discovery of new options, and co-construct solutions unique to the individual or family (Anderson & Goolishian, 1988; Corey, 2001). Collaboration, compassion, reflection, and discovery characterize the interactions of therapist and client (Corey, 2001). Based on these assumptions, it was my aim to discover meaning in the women's lives through such lenses.

In the familial breast cancer context, Laura expressed that she had only gained meaning in suffering once the mastectomy and breast reconstruction operations had taken place. She realised that she was worthy and strong enough to be able to cope with her suffering. She also stopped seeing herself as a victim and started to see the importance of being a more active participant in her life. She had gained courage to meet her own needs and to express how she felt about specific issues in her life, particularly towards her family and husband.

Christel's quest for meaning was mostly related to past issues. She realised that the breast cancer had allowed her to see that she had unresolved pain in her life, particularly feelings of anger that had never been dealt with at the time. She felt that she needed to deal with her current issues of suffering in order to avoid pain at a later stage in her life. She believed that she gained tenacity in the suffering and that she had become a braver person. Christel also mentioned that her self-confidence had

increased and that she had found a 'better person' in herself. She felt that her own struggle with breast cancer could act as an example to other people. She had handled the pain with dignity and strength and was proud of herself as a human being. Meaning was also achieved in terms of shifting her priorities. Before she had been over concerned with minor issues in her life. Her struggle with breast cancer had allowed her to become more relaxed and to rather concern herself with more serious issues.

In the eating disorder context, Lisa achieved meaning in terms of becoming aware of the emotional reasons for her eating behaviour. Before therapy she had been unable to understand why she lacked control with her weight and eating patterns. The meaning she gained from her whole experience involved a greater awareness of her emotional and physical anxiety and how this contributed towards emotional hunger. Anita was also able to understand the connection between her emotions and her eating patterns. She was now able to connect her feelings of worthlessness and low self-esteem to the amount of food she ate and the control she exhibited over her weight. Anita also realised that her reasons for wanting to lose weight were to satisfy her husband and not necessarily herself. Despite knowing this, however, Anita was still determined to have the duodenum operation.

Denise and Claire also gained meaning in their struggle with infertility but only after they adopted Robert and Keslyn. Denise, for example, found meaning in her suffering believing that if she had fallen pregnant, Robert would never have been adopted. She believed that Robert had been sent to them for a specific reason. If they had conceived their own child, Robert would never have had the opportunity to live with them. Her meaning in her suffering was, and is today, completely based on her relationship with Robert. It is this relationship that gives her strength to deal with her pain and that now makes her life worth living.

For Claire, meaning was also achieved only after applying for adoption, moving to Botswana and doing the Family Life Course. She was able to grieve and mourn only in Botswana. Here, she was able to re-identify herself, assess her support systems, focus on her marital relationship, be aware of her personal coping skills, enhance her self-esteem, create a positive self-image and extend her areas of strength.

Doing this away from her home and work environment had been beneficial to Claire's search for meaning. Finally, meaning was enhanced with the adoption of Keslyn. Her needs for motherhood had been met and she was now able to move forward with her life.

Conclusion

Common themes of suffering that were co-constructed in the interviews between the six women participants and myself form the basis of this chapter. The aim was not to generalise the experiences of the participants, but rather to see their experiences as valuable and important in understanding the nature of suffering. The women's meanings were made possible through the process of social constructionism and dialogue. These punctuations involved the sharing of meanings about suffering as related to familial breast cancer, eating disorders and infertility. The elicited co-constructions illustrate the importance of language as a meaning-generating tool.

To summarise the findings of the above chapter and the thesis as a whole, a concluding chapter of the meaningfulness of the research process will be provided next.

CHAPTER 8

CONCLUSION

"Where shall I begin, please your Majesty?" he asked.
"Begin at the beginning," the King said, gravely,
"and go on till you come to the end: then stop."
(Alice's Adventures in Wonderland)
(Lewis Carroll)

This thesis has punctuated the meaning of suffering within the contexts of familial breast cancer, eating disorders and infertility. It has dealt with themes and co-constructions that emerged in the conversations between six women and myself as part of the interviewing context. Through the process of language, personal realities and meanings were discussed and shared to provide the reader with a greater understanding of the nature of suffering. In this concluding chapter, the present study will be evaluated according to its principal objectives, findings and limitations. Recommendations for future research will also be proposed.

General Discussion of the Study

In Chapter 1 the notion of suffering was introduced and the motivation for the study discussed. Chapter 2 provided a description of the research process and research method that would form the basis of this study. This chapter focused primarily on the qualitative and social constructionist approaches. Chapter 3 provided the reader with a brief understanding of how the body has been viewed historically through the lenses of various perspectives. Issues regarding the body were discussed within a framework of existing literature. Chapters 4, 5 and 6 included the conversations between the six women participants and myself in verbatim form. Theory was also discussed to provide the reader with a more comprehensive understanding of familial breast cancer, eating disorders and infertility. In Chapter 7 the elicited co-constructions of meanings regarding personal suffering were presented based on my personal assumptions and frame of reference. Similarly, it is hoped that

the reader will also infer his/her own distinctions and meanings regarding the nature of suffering as well as suffering pertaining to the familial breast cancer, eating disorder and infertility contexts.

Objectives of the Study

The main objective of the study was to provide the reader with a more comprehensive understanding of personal suffering as experienced by women struggling with bodily issues. The aim was to explore the concept of suffering in three contexts – familial breast cancer, eating disorders and infertility, and to see if a comprehensive understanding of suffering could be gained. Each context involved a physical problem related to women's health.

A second objective in gaining a more comprehensive awareness of suffering was and is to enable therapists, counsellors and individuals working with familial breast cancer, eating disorders and infertility to better understand the individual's personal suffering. Understanding the nature of suffering may provide individuals with a greater awareness of specific meanings and emotions that should be dealt with in the therapeutic context.

A third objective was to elicit different and unique meanings of suffering through a process of dialogue and conversation. I hoped to gain as much information as possible regarding suffering through differing personal epistemologies, wider social discourses and frames of reference. Through the process of dialogue, co-constructions of suffering would emerge amongst all six participants. A qualitative and social constructionist approach was therefore preferred for this study. The aim would not be to quantify or explain the women's experiences and meanings in terms of measurable data. In essence, they would not be seen as objects, but rather as active participants.

Main Findings

Meanings and perceptions that arose from the literature study and interviews with the six participants regarding the body, familial breast cancer, eating disorders and infertility were the following:

- Personal suffering can be only be defined and characterised by the individual him/herself. Suffering remains a personal issue depending on the life circumstance, the problem at hand, the individual's personality, past and present experiences, and the surrounding social environment. Each individual has his/her own particular epistemology and view of the world (Bateson, 1972; Keeney, 1983). Personal values and meanings are attached to an individual's ideas, actions and perceptions about life. The interviewing process with all six women demonstrated that each hold varying views of the world, and specific and personal meanings about problems relating to suffering. An explanation or understanding of suffering can therefore only be fully understood when personal epistemologies are listened to and discussed within a social constructionist perspective. The findings in this research study are therefore not finite nor the complete truth. They merely remain a co-construction of personal meanings and epistemologies as shared by six women. Interviewing more women, or interviewing women with other bodily problems would have elicited other explanations of personal suffering.

- A second finding in this study relates to the nature of suffering as evoking various themes. The main themes of suffering that emerged in the interviews, and that were discussed in detail in Chapter 7, refer to suffering as an experience of loss, isolation and emptiness. Any form of loss, in particular, one's loss of identity and control over life circumstances is a contributing factor to an experience of personal suffering. Suffering is also experienced when an individual feels isolated from others and from the world. Usually the isolation is seen in an individual's sense of loneliness or in his/her anger towards significant and non-significant others. Suffering also entails a sense of emptiness that encompasses feelings of worthlessness, low self-concept,

and low self-esteem. Emptiness also includes lack of happiness, joy and contentment with one's life, and feelings of sadness and depression.

- A third finding is that personal suffering encompasses three main levels – the physical, emotional and social. All three domains, although different, are interrelated to one another and cannot be separated. An individual encountering pain and suffering in the body will be affected emotionally and socially. Similarly, emotional suffering will impact on the physical and social domains. Personal suffering can therefore not be disconnected or seen in isolation from the physical, emotional and social domains.

- Understanding the nature of suffering and its influence on the physical, emotional and social domains may be useful for the therapist, counsellor or individual working with familial breast cancer, eating disorders and infertility. He/she will have to consider the physical, emotional and social impact on the individual and deal with all three areas holistically. Dealing only with the physical, emotional or social without considering the impact they have on each other is simplistic and reductionistic. Viewing the impact of suffering in all three contexts will aid the therapist or counsellor help the individual in a more effective manner.

- Suffering entails a deeper and far more complex experience of pain. It is not simply an experience of a challenge or a difficulty, but rather a deep sense of struggling. Suffering is far more painful and burdensome. It entails pain, loss and emptiness on a social, emotional and physical level and cannot be equated to difficulties that are experienced on a day to day basis or which can be easily resolved and overcome. Instead, suffering goes to the core of an individual's soul, mind and body. It is experienced on a far deeper level, able to transform and modify previously held beliefs, values and epistemologies. An individual's world is transformed radically, in such a way, that the individual is unable to remain the same. The individual also remains consumed in that suffering for a period of time. It is an intense and debilitating experience, and any attempt to return to a normal state will be difficult or near impossible (Reed, 2003).

- One way of transcending one's suffering is to find meaning in the suffering. When the individual is able to find and experience meaning in his/her suffering, then he/she has achieved the freedom to rise above conditions that were once so debilitating (Frankl, 1986; Meyer et al., 1989; Shantall, 2003). Furthermore, meaning regarding personal suffering is not something one can create or invent, but rather it is found, discovered, detected, discerned and experienced. As individuals we find meaning by discerning what each situation is requiring of us and what we are called upon to do or be (Shantall, 2003). Only when an individual is able to find that meaning, can he/she be freed from self-destruction and self-preoccupation. The individual is then able to experience a sense of self-worth, a sense of being a responsible, spiritual individual, a sense of having a unique destiny to fulfil, and a sense of power to strive towards living one's life more fully (Shantall, 2003).

Anderson and Goolishian (1988) place importance on human systems as capable of generating meanings through dialogue. In terms of my own assumptions and meanings, it was only through this process that previously held ideas about suffering were challenged and modified. As my meanings and beliefs evolved and emerged within the interviewing contexts, I became aware of the impossibility of outcome prediction and the inference of objective truths regarding issues of suffering. The meaningfulness of the social constructionist perspective to human relations, problems and solutions was highlighted as valuable and necessary in this research topic.

Recommendations

The nature of suffering has been extensively described and understood within religious and medical fields. From the literature, much information has been written regarding the *meaning* of suffering. However, I feel that a greater understanding is needed in terms of "What is suffering?" "How are individuals affected by it?" "How do individuals cope with it?" and "How can one assist the individual in finding meaning in suffering?" However, based on the above findings, it is recommended that future research be carried out on the nature of suffering within the psychological

and therapeutic fields. It is also important that therapists and counsellors be more aware of their patient's suffering when therapy is sought. This entails an understanding of what the patient is experiencing on a physical, emotional and social level. It also means that the therapist should elicit a description of the patient's suffering as well as a detailed story about the specific problem. The specific problem should be dealt with in terms of when it began, what lead to its occurrence, what solutions were attempted, the reactions of different family members to the problem, coping behaviours, and so forth. At the same time, however, it is important for the therapist to also move beyond the nature of suffering towards an exploration of its meaning and significance. Focusing on its significance and role in the patient's life can be seen as therapeutic and restorative. Finally, it is believed that suffering is an individual and unique experience and that personal meanings and co-constructions of suffering may lead to a greater understanding of what it is. It is important to realise that such an understanding can only come about when suffering is considered within the framework of personal and social discourse.

Limitations of the Study

The choice of research for this study is qualitative and based on social constructionist principles. This implies that the study will be personal, subjective and idiosyncratic. As a result, the study does not render verification and proof of findings possible. From a social constructionist perspective, meanings and findings are co-constructed in social discourses that reflect one reality among many possible realities. From a traditional, quantitative and statistical perspective, however, such a lack of future replication may be considered a limitation for research (Fourie, 1996; Lincoln & Guba, 1985).

A second limitation is found in the number of women who were interviewed. It was decided to only interview two women per context because of time and space limitations of the study. Although interviewing more women could have elicited more meanings and assumptions about the research topic, it was decided to only include the experiences of six women. The aim would then be to gain a more richer description of their experiences with suffering.

A further limitation involves the nature of the transcripts. Although proper analysis was done in terms of writing down in detail what occurred in the sessions, important information could have been left out. This information relates to numerous details such as intonation, voice pitch, non-verbal gestures and facial expressions (Peräklya, 1997). Rich transcriptions have, however, been extracted from the case studies so that the reader is able to make his or her own personal inferences as adequately as possible.

Conclusion

When discussing the nature of suffering, it must be noted that the distinctions and meanings that have been discussed do not represent an objective or universal truth. This thesis represents one possible way of understanding personal suffering and is in no way a single truth. Presenting the topic as such allows the reader to infer his/her own personal meanings and distinctions regarding issues of suffering. By providing a descriptive account of suffering this study aims to provide valuable information that will aid individuals understand the nature and meaning of suffering more fully.

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APPENDIX A

CONSENT FORM

Title of the study: A therapeutic understanding of women suffering through their bodies.

Purpose: To explore the stories of women who have endured personal suffering through their bodies either through familial breast cancer, eating disorders or infertility.

Role of the Participant: Women who are over the age of 25 and who are currently struggling or have previously struggled with familial breast cancer, eating disorders and infertility.

Information: The information shared during the interviews will be used as the basis for a doctoral thesis in psychology.

Researcher: It will be my aim to protect the anonymity and confidentiality of the participant and the information shared. It is, however, possible that personal stories may be recognised by other individuals from the local context. I understand that the participation of the participant is completely voluntary. The participant may withdraw from the study at any time.

Name of Researcher: _____

Signed: _____

Date: _____

Name of Participant: _____

Signed: _____

Date: _____