

## CHAPTER 1

# THE PSYCHOLOGICAL EXPERIENCE OF CANCER AND ITS RECURRENCE

### 1.1 Introduction

Preliminary quantitative research has been done by the author (Falkson, 1999) on the experience of breast cancer, stressful life events, anxiety and depression. The research showed a positive correlation between anxiety, depression and the number of stressful life events of cancer patients. These results emphasized the importance of the individual's experience and reaction to stress. There was also an indication that the relationship between the onset of the recurrence of cancer and the simultaneous and relatively paired relationship with stress, was probably not a causal relation. The study concluded that the patients' psychological framework played a role in their reaction to stressful events. Regardless of these preliminary findings, the study generated more questions around an individual's experience of cancer and how that influences his or her coping with a chronic illness, than answers.

The present study took a broader perspective of the psychological impact of breast cancer and its recurrence. Two processes contributed to the present study. Firstly, additional knowledge and clinical experience were gained since the period of investigation of the previous, preliminary study. But, secondly and possibly more influential on the present study, was my own development towards becoming a clinical psychologist and postmodern thinker.

Originally, as with the preliminary study, this study was planned as a quantitative study. The aim was to compare two groups of breast cancer patients, namely those patients whose cancer was in remission and those whose cancer recurred.

In spite of including more variables for greater objectivity in the current study, I was still dissatisfied and uncomfortable with the procedures and methods to be used in quantitative research in a study of this nature. I became aware of the limitations of a quantitative approach to human sciences and the realization of why my preliminary study generated more questions regarding people's experience of cancer than answers or solutions. Although more variables were included in this study than the previous one, I also decided to venture on a different approach towards examining the psychological experience of breast cancer. This route eventually led to a pluralistic methodological approach for the present study.

Thus, the pluralistic approach towards this study was the result of my own development, both as researcher and clinical therapist.

My personal academic development brought a realization that my general way of observing the world and the lives of people and therefore also my way of thinking and doing research underwent a major shift. This shift will be explained in the chapter on methodology. It will also be shown that looking differently at research on the experience of breast cancer and its recurrence, brought a realization that one may lose depth in understanding this experience by using quantitative methodologies.

The shift was not only essential for a paradigm change in itself. I believe it was essential for me to come to an understanding of the complexities of life, of pain and illness, of the experiences of people trying to cope with chronic, if not terminal, diseases. I started to realize that the illness and experience of breast cancer is probably a continuous process. Attempting to find differences by "boxing" people with cancer into groups, did not adequately equip health professionals with an understanding to deal with the complexities they face when interacting with a breast cancer patient. In fact, it seemed to me that these pathways with the one-sided "objective" viewpoints, might do harm by providing biased material and information to

health professionals.

Although my development brought me to the understanding of the limitations of the positivistic, and as such of the quantitative approach to human research, I also believed that the results obtained from such research were not useless. Moving and shifting towards a constructivist point of view, I became part of the research and objectivity, as described by a quantitative approach, was not possible (Keeney, 1985). My tendency towards viewing my research shifted towards a principle of “both/and”. For this reason, quantitative experiments are not worthless. They are, so to speak, only one side of the coin. By turning the coin to include a qualitative experience, the outcome of the research seemed to be richer in data. In providing open-ended answers and in providing descriptive meanings to human experiences, qualitative research describes a more satisfying picture. This process brought me to an acceptance of a pluralistic approach to research.

With the pluralistic approach towards this study, I attempted to view the same phenomenon from different angles. In this way, the benefits and limitations of different research approaches could possibly be pointed out, and a clearer perspective could be obtained.

Though this study focused on breast cancer and the recurrence of breast cancer, it can also be seen as my own journey of “recovering” from my rigidity of mind, from a positivistic way of observing the world to an open view towards life in general. On a meta level, the process of the research and the change in my own development, might reflect the cancer of a rigid mind shifting towards flexibility and my journey towards a possible “cure”.

## **1.2 Personal encounter: myself and dealing with patients with cancer**

In my work with cancer patients, especially in England during 1993 to 1996, I was

struck by my inadequacy and that of others working with cancer patients, in dealing with their feelings of hopelessness and fear upon hearing that they had cancer or that the cancer had recurred. In spite of the patients' misgivings about the future, the reaction of some of the medical staff on the ward was that patients who had a recurrence had been "through it all" and needed less attention because: "They know the ropes now". With those patients who experienced a recurrence of their cancer it seemed as though the assumption from others was that they had already worked through the emotional issues of being diagnosed with cancer. They were seen as "veterans" who knew the procedures of the different treatment regimens. However, in my view, the patients themselves told a different story. They were scared and felt unable to cope with the news of the recurrence of their disease. Some of them might have been disillusioned by conventional treatment and might have opted for alternative forms of treatment. Some patients might have even prefer to die.

It was my observation that most breast cancer patients expressed the need for emotional support from care givers and health professionals. I became aware of the fact that there was an urgent need for a study that focussed on the emotional impact of a diagnosis of breast cancer and also to include patients who had a recurrence.

The patients, with whom I worked on a daily basis, convinced me that a study that dealt with the emotional experience of breast cancer and its recurrence was needed. I spoke to a patient on the ward who heard that her cancer had recurred and she said: *"Although I expected it, I thought, well perhaps I will be lucky and get away with it. Of course I didn't, and then I thought, oh well, here we are again. The other half of me did expect that it would happen. I didn't feel that I would have much of a chance the second time. I thought: That was it. Just a matter of waiting for me to dwindle away and that will be the end of me. This time I got very aware of my own mortality."*

A patient who had a second mastectomy, found it very hard to carry on with her daily

activities:

*"I wish I could feel more confident. Perhaps as time goes on I will. I really don't know if it's gone. I kind of feel that it is lurking about inside still."*

I also discovered that it was not possible to predict the reaction of an individual patient when they receive the news of a diagnosis of cancer. There were many factors that influenced such reactions and behaviours, for example, the socio-economic status of the patient, the availability of social support at the time, the way and by whom the "bad news" was conveyed to her. Her attitude towards the doctors and vice versa and the conventional treatment methods might also have an influence on her emotional experience of a diagnosis of cancer. This complicated research that attempted to explore the way in which these patients reacted to and lived with a life threatening disease.

Working with cancer patients, I was struck by the immensity of the fear, anger, and uncertainty with which they lived, almost on a daily basis. Doctors and patients told me, and my own observations confirmed, that the diagnosis of cancer caused an emotional crisis for patients.

A cancer patient, who was a medical doctor, told me that she knew it was the end of the road. She died three weeks later, although her medical prognosis was much better than that. She told me directly that she did not want to go on with treatment and preferred to die.

A similar case presented itself at a hospital in South Africa, when a woman was operated for cancer of the stomach. Her life expectancy was at least six months. Regardless of this prognosis, she conveyed to me that she would not be able to cope with being in pain and with the emotional strain her illness would cause her family. She died that same evening. Although there might be various other and medical reasons for her sudden death, it seemed as though patients might have control over

when they were ready to die, and/or that they might decide to choose death as an option, or choose to live with their illness.

These observations allowed me to discover through literature, what the academics and researchers have to say on this complex phenomenon.

### **1.3 Basic accounts on research**

In the following section, as in the follow-up chapters, the basic “factual” ingredients on breast cancer are presented. The reader will see that most of these factual accounts are based on theories and research that were in essence positivistic in nature. The research on cancer, mostly from medical quantitative measurements, will be included to provide a framework of knowledge and as a point of departure for the follow-up process research. This perspective will possibly lead to an understanding of the complexities of life of people suffering from a chronic illness, in these research cases, of women with cancer.

Upon receiving a diagnosis of cancer, the majority of patients felt extremely threatened (Haltungenen, Hietanen, Jallinoja & Longqvist, 1992). They seemed to fear that death was inevitable and that the process of dying would probably be long and painful. They also feared the side effects of current conventional treatments (Munkres, Oberst & Hughes, 1992) such as chemotherapy and radiotherapy. It is generally known that chemotherapy is associated with hair loss and nausea and radiotherapy is feared for the disfigurement and damage it may cause to other organs.

For those cancer patients who received treatment and whose disease went into remission, the shock of hearing that it has started again (often after years of complete remission), seemed immense. Feelings such as anger, disbelief, resignation, and acute depression were common (Fallowfield & Clark, 1991). Some patients reacted to the news of recurrence by becoming depressed and seemed to fulfil some of the

criteria of depression, as described by Kaplan, Sadock and Crebb (1994).

These different feelings might also occur in the same individual over a period of time. For those people who had been diagnosed with cancer, who received treatment and whose disease went into remission, often lived with the fear that it might return. Even though it might never return, it was as though they constantly lived with a belief that cancer may recur again.

In the case of breast cancer, the patient lost not only a physical or biological part of her body but more than that, a loss of the meanings associated with that body part. These included the patient's concepts of femininity, motherliness and sexuality. In fact, the breast might be seen as a woman's understanding of her total womanhood.

Evaluations for the recurrence of cancer, often meant that complete recovery could not be reached (Spiegel, 1993). This study also concerned itself with how patients whose cancer was in remission, lived with the ever present threat that it might start again.

Although medical research seems to make progress in the treatment of cancer, recurrence may still happen. The layman generally considers recurrence a sign of poor prognosis. In reality, patients with a local recurrence of their breast cancer, meaning a recurrence in or close to the scar tissue, still have a good prognosis. Those patients diagnosed with a second primary cancer are also usually told that their prognosis is still good. In spite of having a good prognosis, patients whose cancer recurred seemed to regard the future as less bright than the future of other patients whose disease had been in remission for years and who succeeded in carrying on with their daily activities (Moorey, Greer, 1989; Cella, Mahon & Donovan, 1990).

## 1.4 Previous research on breast cancer and its recurrence

My literature search that will be discussed in subsequent chapters, made it quite clear to me that extensive research had been done on the experience of a first diagnosis of cancer, but that less research had been done on the emotional impact of a diagnosis of recurrent cancer. According to Schmale (1976) the most common psychological reaction to the first recurrence of disease of any kind, was a feeling that something had gone wrong and that things were out of control. The patient might think that the previous therapy had been inadequate or that the disease was more powerful than previously expected. Fifteen years later, Fallowfield and Clark (1991) also noted that the impact of recurrence might be devastating. These patients' hopes and confidence that the initial treatment had been successful would be shattered and the situation demanded rethinking of the future.

Other research indicated that this was a time when a feeling of hopelessness might take over, that might well have an adverse affect on these patients' health outcome. In a study of hopelessness and the risk of mortality in cancer patients, this finding seemed apparent. Everson, Goldberg, Kaplan, Cohen, Pukkala, Tuomilehto and Salonen (1996) found that hopelessness was a strong indicator of adverse health outcomes. Jenkins (1996) confirmed that a positive attitude should be part of the process of combating chronic illness.

Spiegel (1993) found in his experience of support groups for patients with breast cancer, that those with recurrence had to confront themselves with the fact that they now had a chronic illness. When they dealt with the physical and mental changes that the progression of their cancer and its treatment produced, they were much more concerned with issues of dying and death than newly diagnosed women. In a discussion of cancer patients' needs for rehabilitation at different stages of the disease, Ganz (1990) also said that where cancer recurred, the psychological impact



was one of distress. This feeling of distress was enhanced by the knowledge that they might not be cured. Moorey and Greer (1989) who counseled patients after cancer recurred, found that they often felt demoralized because their cancer had not responded to treatment.

Moorey and Greer's study on the experience of breast cancer, took the view that cancer is a chronic disease that may go through different stages. They said that a patient's experience of a first diagnosis of cancer might be different from the experience of a recurrence of breast cancer. Knowledge of the differences may be important in therapy with these patients.

## **1.5 The pluralistic approach of the study**

The study followed a pluralistic approach methodologically, in the sense that both quantitative and qualitative methods were used. The reason for this was to provide a complete as possible picture of the consequences of a diagnosis of breast cancer on the psychological functioning of patients and their partners.

The study developed into two stages. The first stage followed a quantitative approach towards examining possible differences between breast cancer patients whose illness was in remission and another group of patients whose breast cancer had recurred. This part of the study included partners of the cancer patients. The second part of the study followed a qualitative approach and comprised of breast cancer patients with whom in depth interviews about their psychological experience of breast cancer were undertaken. The pluralistic approach also included my own observations and experiences during the process of research.

The goal of the research is not only to provide more information to add to more academic knowledge, but rather to provide insight and understanding of issues that may be used to assist patients in general and in psychotherapy or other forms of

treatments during an illness such as cancer. As Passik, Theobald, Donaghy, Heminger and Dugan (1998) pointed out, research in psycho-oncology aims to clarify issues for patients and family members to assist them in evaluating management strategies for treatment and to provide better total care for these patients.

## **1.6 The aims of the study**

The study aimed, through a process of pluralistic research, to uncover and discover experiences of patients with breast cancer. The goals of the research were not only to provide specific facts about the experience of breast cancer, but to provide an understanding of women's personal, human and emotional encounter with breast cancer and its recurrence.

Lastly, the process and development of the research was linked to my own development as psychologist and researcher. The last aim of this study was to describe the evolvment of my development.

## **1.7 The research: hypotheses and analyses**

### 1.7.1 Quantitative study: hypotheses

For the quantitative phase of the study the following hypotheses were formulated:

- (i) Patients with recurrent disease would have lower perceptions of their general health than the comparison group.
- (ii) Patients who experienced a recurrence of their breast cancer would be more anxious and depressed than a comparable group of breast cancer patients whose illness was in remission.
- (iii) Patients' first reaction to recurrence of cancer would relate to their expectation of whether they have been cured from their initial cancer or not. Those who

expected it to recur would experience it as less of an emotional shock than those who believed themselves cured.

- (iv) The partners of recurrence patients would have lower measures of general health, would be more anxious and depressed and would experience more discord in their relationships with their partners.
- (v) Patients with recurrent cancer would be more inclined to make use of alternative treatments than patients whose disease was in remission. Those patients with a high internal locus of control would be more inclined to use complementary treatments than those who were higher on the other types of locus of control.

#### 1.7.2 The qualitative study: a descriptive analysis

For the qualitative part of the research, the focus was on describing the individual experiences of patients with breast cancer. An attempt was made to analyze these experiences which should bring an understanding of the emotional and personal impact of breast cancer on women's lives.

#### 1.7.3 Pluralistic study: Integrative findings

As a final analysis, the results of the quantitative study as well as the analysis of the qualitative study will be integrated and a both/and view will be presented.

### **1.8 Study outline**

An overview of the literature dealing with the psychological impact of cancer including recurrence of cancer is presented in Chapter 2. Chapters 3, 4 and 5 deal with theoretical concepts such as stress, social learning theory, locus of control and the applied theoretical frameworks of coping. Personality theories, the description of a process theory, the explanation of an integrative approach and the theoretical

framework of interactional psychology was also presented. Chapter 6 describes the research methods, followed up by the research findings in Chapter 7. Chapter 8 draws conclusions and makes recommendations for further research.

LITERATURE

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