

**THE PSYCHOLOGICAL EXPERIENCE OF BREAST CANCER AND ITS  
RECURRENCE: FROM QUANTIFICATION TO INTERACTION**

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SUMMARY

THE PSYCHOLOGICAL EXPERIENCE OF BREAST CANCER AND ITS  
RECURRENCE: FROM QUANTIFICATION TO INTERACTION

A qualitative study exploring the experience of breast cancer recurrence, to  
the quantitative study of breast cancer recurrence and the relationship between  
general anxiety, anxiety and depression, levels of control, and information and the  
experience of breast cancer recurrence.

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## SUMMARY

### THE PSYCHOLOGICAL EXPERIENCE OF BREAST CANCER AND ITS RECURRENCE: FROM QUANTIFICATION TO INTERACTION

A pluralistic study, employing quantitative and qualitative methods, was conducted. In the quantitative analyses two groups of patients and their partners were compared on general health, anxiety and depression, locus of control, marital adjustment and the use of alternative medicine. The first group (n=40) experienced a recurrence of their breast cancer. The comparison group consisted of 94 breast cancer patients whose illness had been in remission for at least one year. Nine husbands of patients with recurrent cancer and 18 husbands of the comparison patients took part.

The patients who experienced a recurrence of their breast cancer completed five questionnaires four times over a one-year time period. They also took part in a structured interview concerning the use of complementary treatments. Comparison patients filled in the same questionnaires twice over the one year time period and partners completed four questionnaires once only.

The Statistical Package for the Social Sciences (SPSS) was used to analyse the data. At first assessment, a significant difference ( $p < .0006$ ) was found between the two groups, with the recurrence patients suffering from poorer general health. There was, however, no difference between the groups one year later.

At first assessment, it was also shown that women with recurrence suffered significantly more ( $p < .003$ ) from depression than the comparison group, but there was not a significant difference in the level of anxiety between the two groups. One year later, an

analysis of the remaining 15 recurrence patients and 45 comparison patients showed no differences in anxiety or depression.

More than half of the patients did not expect that their cancer would start again. The majority (84%) experienced the recurrence as an emotional trauma. We did not find any quantitative evidence of adverse emotional effects upon partners whose wives had been told that their cancer had recurred.

There was not a statistically significant difference on any of the locus of control dimensions between the two groups. Sixty six of the 96 patients (69%) who responded to the alternative medicine questionnaires, did not use any form of alternative treatment. The results of this study showed that women who had experienced a recurrence of their cancer was a group who suffered from more emotional morbidity than other women with breast cancer and confirmed that the news of recurrence caused emotional trauma.

Five therapeutic interviews with breast cancer patients were conducted, using an interactional analysis complementary to the quantitative analysis. Although each patient presented with her own unique style in converting her own feelings and thoughts about her experience of having cancer they all seemed to suppress their emotions, particularly anger and sadness. Some of the knowledge gained by the quantitative analysis of the questionnaire data and the structured interview, was confirmed by the information obtained from the therapeutic research interviews. Most women who have breast cancer fear that it may start again. The use of alternative medicine is not in place of traditional medicine, but rather as complementary to conventional medicine.

This study attempted to show how multifactorial and complicated the effects of the disease are on the human psyche and hopefully contribute towards the understanding of how to deal with these patients during therapy.

## OPSOMMING

### DIE SIELKUNIGE ERVARING VAN BORSKANKER EN DIE HERHALING

### DAARVAN: VAN KWANTIFISERING TOT INTERAKSIE

'n Pluralistiese studie met behulp van beide kwantitatiewe en kwalitatiewe metodes is gedoen. Tydens die kwantitatiewe navorsing is twee groepe pasiënte en hul mans vergelyk in terme van hul algemene geestesgesondheid, angs, depressie, lokus van kontrole, huweliks aanpassing en die gebruik van alternatiewe medikasie. Tydens die kwalitatiewe navorsing is terapeutiese onderhoude met vyf borskanker pasiënte gedoen en interaksioneel ontleed.

*Kwantitatiewe navorsing.* Die eerste groep (n=40) se borskanker het herhaal. Die vergelykende groep het bestaan uit 94 borskanker pasiënte wie se kanker vir minstens een jaar in remissie was. Nege mans van die vroue van groep een en 18 mans van die vergelykende groep het ook deelgeneem.

Die pasiënte wie se kanker herhaal het, het vyf vraelyste vier keer oor die een jaar periode ingevul. Hulle het ook deelgeneem aan 'n gestruktureerde onderhoud oor die gebruik van alternatiewe medisyne. Groep twee het dieselfde vraelyste twee keer oor die jaar periode ingevul en die mans het vier vraelyste een keer ingevul.

Die Statistiese Pakket vir die Sosiale Wetenskappe (SPSS) is gebruik vir die verwerking van die data.

Met die eerste toetsing is 'n betekenisvolle verskil ( $p < .0006$ ) gevind tussen die twee groepe. Die pasiënte wie se kanker herhaal het, het swakker algemene



geestesgesonheid ervaar as die wie se kanker nie herhaal het nie. Een jaar later was daar egter nie meer 'n verskil nie. Tydens die eerste meting het die eerste groep ook meer depressief ( $p < .003$ ) as die tweede groep gemeet, maar daar was nie 'n verskil in angstellings nie. Een jaar later was daar ook nie meer 'n verskil in depressie of angs tussen die oorlewende pasiënte van groep een ( $n=15$ ) of groep twee ( $n=45$ ) nie.

Meer as die helfte van die pasiënte het nie verwag dat hul kanker sal herhaal nie. Die meerderheid (84%), het die herhaling daarvan as 'n emosionele trauma ervaar. Daar was nie enige nadelige emosionele effek op die mans van die pasiënte wie se kanker herhaal het, gevind nie.

Daar was nie 'n verskil op enige van die lokus van kontrole dimensies tussen die twee groepe gevind nie. Ses en sestig van die 96 pasiënte (69%) wat op die alternatiewe medisyne vraelys gereageer het, het geen vorm van alternatiewe medisyne gebruik nie.

Die resultate van hierdie studie het getoon dat vrouens wie se kanker herhaal die nuus daarvan as 'n emosionele trauma ervaar.

*Kwalitatiewe navorsing.* Vyf terapeutiese onderhoude is met borskanker pasiënte gevoer, aanvullend tot die kwantitatiewe studie. Alhoewel elke pasiënt op 'n unieke wyse gereageer het op haar ervaring van borskanker, blyk daar tog sekere ooreenkomste te wees. Hulle was almal geneig om emosies, veral hartseer en aggressie, te onderdruk.

Die kwalitatiewe inligting verkry tydens hierdie onderhoude, het aspekte van die kwantitatiewe studie bevestig:

- (i) Die meeste vrouens met borskanker vrees dat dit mag herhaal.
- (ii) Die gebruik van alternatiewe medisyne was nie in die plek van tradisionele metodes nie, maar eerder as byvoeging daartoe.

Hierdie studie het getoon hoe multifaktoriaal en gekompliseer die effek van 'n chroniese siekte op die psige is en is 'n poging om 'n bydrae te lewer tot beter hantering van pasiënte.

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## 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.

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## CHAPTER 2

# LITERATURE STUDY: THE PSYCHOLOGICAL IMPACT OF INITIAL BREAST CANCER AND ITS RECURRENCE

### 2.1 Introduction

In this chapter, studies of the emotional impact of the diagnosis of initial breast cancer on women and their partners are presented. It describes the fear of recurrence that seems to start soon after the initial diagnosis and seems to stay with patients until death, be it from cancer, an accident or any other disease.

These studies are discussed in terms of methodology used and findings. Most of these studies were done within a medical paradigm. The description of these studies is an attempt to show that there is a need for a more comprehensive multifactorial study of the psychological impact of breast cancer and its recurrence. The understanding of the emotional experience of cancer becomes even more important, as some research shows that psychological intervention may have an impact upon initiation and recurrence of breast cancer (Levenson & Bemis, 1991; Grossarth-Maticcek, Eysenck, Boyle, Heeb, Costa & Diel, 2000).

Firstly, studies dealing with the diagnosis of breast cancer and the fear about the recurrence of breast cancer are presented. Thereafter, studies describing the psychological impact of recurrence are discussed. These are followed by discussions on the possible influence of psychological predisposition on coping with cancer and the severity of a diagnosis of a first cancer versus the diagnosis of recurrent cancer.

These are succeeded by the discussion of themes that are of importance to the retention of hope and the discussion of coping with cancer. Studies dealing with the emotional impact of the news of cancer on partner relationships will follow after that. Lastly, the difficulties in doing research with patients with recurrent cancer are pointed out.

## **2.2 Studies referring to the diagnosis of initial breast cancer and the fear of recurrence.**

Women who have been diagnosed with breast cancer often express fear that it may start again. Fallowfield and Clark (1991) described this fear as a pre-eminent worry for most women, especially during the first few years after treatment. Wong and Bramwell (1992) and Guez (1994) found that mastectomy patients experienced anxiety regarding the effectiveness of their treatment soon after they had been discharged from hospital. This fear of recurrence was not only shown by formal scientific studies, but also expressed in the media and in a particularly well written report by an English reporter, expressing the fear of recurrence vividly (Rook, 1989).

She wrote that the underlying thought that the cancer had not been totally eradicated by the treatment for the initial cancer and might recur in spite of reassurances by doctors made her feel as if:

*"There's been no battle. Braver folk than I may 'take on' and 'fight' cancer, I wouldn't dare to tempt the Unseen Enemy. I accept that it and I will play Russian Roulette for the rest of my life but just hope that its pistol remains jammed. It's presumptuous to triumph over cancer. While your luck holds and you're winning, best to shut up and just enjoy it."* (Rook, 1989).

These expectations of whether or not their disease will start again may have an

influence on the severity of the psychological impact of the news when it actually happens. Holland (1977) described this fear as a disquieting concern about the future. Cancer patients have to live with the disease and are uncertain of its outcome. Some women describe this fear as living with a time bomb inside their bodies; it just waits to explode again. Others are overconcerned about the healthy breast and will examine it repeatedly to check for lumps.

The fear of recurrence and uncertainty about the outcome of cancer seem to stay with these patients whatever treatment they receive. Lasry and Margolese (1992) found that fear of recurrence was independent of type of treatment received. They found that patients who underwent radical surgery did not manifest less fear than women who had breast conservation. In a review of ten studies comparing psychosocial outcome of different treatments of breast cancer, Fallowfield (1990) concluded that patients who underwent lumpectomy and radiotherapy rather than a mastectomy, had an advantage of body image, but found little difference between the treatment groups in terms of psychological morbidity. Whatever the treatment, they were still confronted with the fact that they had cancer which might recur. In spite of these convincing studies, some behavioural researchers still undertake studies with much smaller groups. For example, in a study of only three patients, it was found that the patient who had breast reconstructive surgery was more satisfied with general bodily appearance (Lo Castro & Schlebusch, 1998) which possibly influenced her general attitude towards cancer and its recurrence. The investigation of patients' perceptions of body image and satisfaction with treatment results, is however, another research issue.

It seems that fear of recurrence may be influenced by a patient's perception of the availability of social support. Northouse (1981) conducted a study to determine the relationship between the presence of significant others and fear of disease recurrence in



patients in cancer remission. A Fear of Recurrence Questionnaire was administered and a Significant Other Interview was conducted with thirty mastectomy patients whose cancer was in remission. There was a strong negative relationship between significant others and fear of recurrence. Those subjects reporting fewer significant others had higher fear of recurrence scores, whereas those subjects reporting more significant others had lower fear of recurrence scores. A strong negative relationship was also found between the number of significant others whom the subject identified as understanding her health concerns and fear of recurrence. It seemed thus that is not only the number of significant others that is important, but also whether they are empathic towards the patient's feelings about having cancer.

In another study on the fear of recurrence, Halttunen, Hietanen, Jallinoja and Lonqvist (1992) interviewed twenty-two breast cancer patients who were relapse-free and had no need for cancer-related treatment. They were interviewed 8 years after mastectomy in order to evaluate their feelings of being cured of breast cancer and the meaning of cancer in their lives. The study was part of a follow-up study of 57 breast cancer patients. Half of the available 22 patients still had frequent or occasional thoughts of recurrence and over two-thirds still thought they had not been 'cured' of cancer. More than half of the patients thought that the experience of breast cancer had made them more mature. Women who had fewer thoughts of recurrence belonged to a group that had gone through an eight-week group psychotherapy intervention, were less depressed and had more other illnesses than the group who had no psychological intervention.

Eight years after mastectomy, the relapse-free women had recovered well; they considered their state of health as good and were satisfied with their lives in general. However, in common with other studies, Halttunen found that a significant proportion of these women did not feel 'cured' and that they suspected recurrence every now and

then.

Munkres, Oberst and Hughes (1992) hypothesised that cancer recurrence may produce unique stressors for patients receiving chemotherapy. The objectives of their exploratory study were to:

- (i) describe perceptions of symptom distress, self care burden, appraisal of illness, and mood in patients undergoing chemotherapy;
- (ii) identify differences in these perceptions according to stage of illness (new versus recurrent cancer);
- (iii) test a theoretical model of the mediating effects of appraisal. They used the cognitive coping model as theoretical framework, according to which patients appraise their situation and act upon the personal meaning that they ascribe to it.

The subjects completed a modified Symptom Distress Scale, the short form of the Profile of Mood States, and a self-report form that included personal and illness characteristics and questions about the subjects' current situation. The 60 subjects were outpatients being treated for initial cancer (n=28) or recurrent cancer (n=32). Those with recurrence had higher symptom distress and health deviation self-care burden scores and more stressful appraisals. Munkres also stated that it was apparent from their clinical observations of many patients' positive attitudes following effective early treatment, that not all patients consciously anticipate a recurrence.

### **2.3 Comment**

Although these studies that dealt with the fear of recurrence were mostly exploratory and

used small groups, they all agreed that the majority of women with an initial diagnosis of cancer were not convinced that they had been totally cured. These studies showed that many lived with the fear that their disease might recur. According to Northouse (1981), this insecure feeling that the treatment had not been adequate seemed to be at its peak when treatment had been completed (Fallowfield & Clark 1991; Wong & Bramwell, 1992), but did not necessarily subside over time. Except in the case of Northouse, who used a fear of recurrence scale, many of the findings that dealt with the issue of "fear of recurrence" were mainly based on anecdotal evidence, as described by Schmale (1976). Other observations about fear of recurrence were made during studies that had other objectives as a major theme (Spiegel & Bloom, 1989; Spiegel, 1993; Moorey & Greer, 1989).

Although the results of these studies left many research questions regarding fear of recurrence unanswered, they confirmed that the majority of women with breast cancer experience a fear of recurrence.

## **2.4 The psychological impact when recurrence is diagnosed**

Many patients can be described as fortunate in the sense that their cancer stays in remission for years and they may die in old age or on account of some other reason. However, not all patients are so fortunate as others may experience a recurrence of their breast cancer. Studies dealing with the psychological impact of the news of recurrence are discussed in the next section. They refer to the patients' emotional reactions to such distressing news – for example, do they become more anxious and/or depressed?

### **2.4.1 Patient's expectations**

A few studies examined how a patient's expectations about recurrence influenced their



coping abilities when they actually had to deal with the situation.

Cella, Mahon, and Donovan (1990) hypothesised that recurrence of cancer can be understood and therefore treated as a traumatic event that places patients at risk for stress response symptoms. To test this hypothesis, they administered the Impact of Event Scale (a measure of response to specific stressors), the Psychological Adjustment to Illness Scale-Self-Report version, (a measure of general adjustment to illness) to 40 patients with recurrent malignancies of mixed sites. They also conducted a semi-structured interview in which the patients were asked about their reactions to and experiences surrounding the recurrence, compared with reactions and experiences of their initial diagnosis. In self-report measures and in the interview, patients clearly perceived that adjustment to recurrence was more problematic than adjustment to initial diagnosis. They pointed out that the findings were consistent with an expectation derived from the stress-disorder literature: patients who reported having been completely surprised by the recurrence and those undergoing their first recurrence, showed significantly more intrusive and avoidance stress response symptoms. They stated that, given the heterogeneity of the patient population and the relatively limited sample size, further study was needed to assess the contribution of other important mediating factors in the development of stress disorders. They suggested that because the predictors in this study (extent of surprise and number of previous recurrences) could be identified before and immediately following a recurrence, primary and secondary interventions might help prevent stress disorders in patients who may have had unrealistic expectations.

Findings from a study of Weisman and Worden (1986) also showed that patients who expected a recurrence were not surprised and, as a result, were less distressed when it happened than were patients who felt at little or no risk of recurrence.



These researchers assessed the emotional and psychological status of 102 patients with recurrent cancer. They studied the impact of recurrence and compared it with the experience of patients when first diagnosed with the disease. Six tumour types were chosen - breast, colon, lung, Hodgkin's disease, malignant melanoma, and gynaecological tumours. They found that 30 per cent of patients with recurrent cancer found the experience less traumatic than their original diagnosis. These were patients who were less surprised by the recurrence and who did not believe that they were cured. These were also patients who, at the time of recurrence, were suffering less physical distress in terms of fewer medical symptoms, and fewer health concerns. They described these patients as less threatened by recurrence and more optimistic about the future. They also experienced fewer problems accompanying the return of their cancer. The authors stated that it was as if a realistic awareness of risk was not inconsistent with optimism and with hope for another remission.

The majority of the group (66%) was completely surprised when cancer recurred and tended to become distressed sooner than at the first diagnosis. In spite of being surprised with the diagnosis, patients with recurrence reported few psychological problems.

The authors came to the conclusion that although recurrence was clearly an ominous development, they found no research evidence that it was actually more distressing than the first diagnosis. They also concluded that recurrence patients were mainly worried about health and existential issues. Although they were distressed, the principal factor seemed to be surprise at the recurrence, rather than any specific psychosocial predisposition.

Research has been done on the following factors relating to the recurrence of breast

cancer. Psychological predisposition, the severity of a diagnosis of recurrent breast cancer, the retention of hope against anxiety and depression after a diagnosis of recurrent breast cancer, the coping strategies after such a diagnosis and the effect of such a diagnosis on locus of control are discussed in the following sections.

#### 2.4.2 The role of psychological predisposition in dealing with the news of recurrent cancer

Jenkins, May and Hughes (1991) found that psychosocial predisposition played a role in coping with the news of recurrence. Psychological predisposition includes the personality of the patient. For example a person with a tendency towards depression may become even more depressed when told that her cancer has started again and may not be willing to undergo any further treatment. It also includes expectations about the development of the disease. One would expect that someone who never gave it a second thought that her cancer may return will be more shocked by the news than a person who knew that there is such a chance.

Jenkins, May and Hughes (1991) interviewed twenty-two individuals who suffered from local recurrence of breast cancer to determine psychosocial morbidity. Psychometric assessment included the Hamilton Anxiety Scale, the Eysenck Personality Questionnaire and the Montgomery Asberg Depression Rating Scale. This assessment was conducted prior to clinical evaluation and included a structured interview, the Composite International Diagnostic Interview. Current psychiatric diagnosis was established. Ten (45%) of the recurrence group had current psychiatric illness (anxiety and depression) at the time of local recurrence. Previous psychiatric illness and trait neuroticism were predictive of vulnerability to psychiatric morbidity at local recurrence. They concluded that their results showed that a significant proportion of patients with local recurrence suffered from major depressive illness.

They stated that results of their small study suggested that factors similar to those identified in patients initially diagnosed and treated for breast cancer were also significant in influencing psychosocial morbidity at the time of local recurrence. These factors included personality factors such as trait neuroticism, the presence of a previous psychiatric history and the presence or absence of supportive family and marital relationships. Their findings showed a higher prevalence of morbidity in their patient group and they recommended that screening and psychiatric consultation should routinely be employed to treat and alleviate the anxiety and depressive illness found in many patients.

Results from these studies showed concordance in that those patients who expected that a recurrence might occur, were less depressed when it actually happened, while those patients who were optimistic and believed that they were fully cured were more devastated by the news of recurrence. These results presented a difficult practical dilemma of the extent to which the patient should be made aware of the chances of recurrence of breast cancer.

#### 2.4.3 Severity of a diagnosis of recurrent breast cancer versus initial cancer

Research results of the severity of the impact of the news of an initial diagnosis of breast cancer versus the severity of the effect of the news of recurrence, are contradictory. Weisman and Worden (1986) stated that they could find no evidence that the news of recurrence was more distressing than the first diagnosis. On the other hand, Cella, Mahon and Donovan (1990) and the Jenkins, May and Hughes (1991) studies showed that patients experienced the news of recurrence as being more distressing than that of a first diagnosis and many suffered from depression. These contradictory findings may be attributed to many factors, e.g. the differences in terms used by the researchers, age and population of groups and the methodology of the research. When depression is



used as measure of the effect of the news of recurrence, the studies agree that patients who received a diagnosis of recurrence were more depressed than those whose cancer was in remission.

#### 2.4.4 The retention of hope as reaction against overwhelming anxiety and depression

In spite of the evidence that women with recurrence suffered from depression and anxiety and had existential concerns, a significant number seemed to retain hope and optimism.

Levy, Lee, Bagley and Lipman (1988) described it as: "somewhat puzzling" that a woman, who experienced recurrent breast cancer, could express feelings of being "glad", "cheerful" and "joyous". They did find, however, that some of the patients in their sample of 36 women with recurrent breast cancer reported experiencing these feelings, as measured by the Affect Balance Scale. In an effort to explain how the women could experience these positive feelings in such adverse conditions, they speculated that those items on the scale reflect hope or optimism in some dispositional sense. Bearing in mind how well some cancer patients used denial as a coping strategy; these "joyous" feelings could just as well be expressions of denial.

Munkres, Oberst, Hughes (1992) showed that although members of the recurrence group considered themselves to be more seriously ill than did members of the initial-treatment group, no differences in expectations about treatment effectiveness existed between the two groups. This suggested that those with recurrence, while having a realistic understanding of their prognosis, were able to maintain at least some hope for cure or control.

It is often difficult to distinguish this element of hope from denial when patients cling, against all odds, to unrealistic hope until right at the end. Patients' thoughts and feelings



about the implications of having experienced a recurrence of their disease can vary from moment to moment. This provides a challenge to those who attempt to study the psychological impact of the news of recurrence. New evidence suggests that the news of a diagnosis of cancer may have a physical effect on a patient's central nervous system which may have the effect of losing hope of recovery (De Brabander, Gerits, Sacre, Lamote, 1989).

#### 2.4.5 Coping with recurrence and survival from breast cancer

Some studies on recurrence dealt with the possible influence of psychosocial factors on survival. These studies aimed to determine if psychosocial factors in conjunction with the better-known physical prognostic factors had an effect on survival.

A study by Levy, Lee, Bagley and Lipman (1988) identified predictors of survival time in patients with first recurrence of breast cancer. The predictors included psychological as well as biological factors. Beginning in 1979, 36 women were treated for histologically proven recurrent disease. These women were enrolled in a prospective study. At the time of data analysis in 1988, 24 had died from their malignancy. Four factors predicted survival time in the sample:

- i) Patients with a longer disease-free interval;
- ii) those who expressed positive feelings of being glad, cheerful and joyous at baseline testing;
- iii) women whose physicians predicted that they would live longer;
- iv) those who had fewer metastatic sites tended to live longer with recurrent disease than others in the sample ( $p < 0.0001$ ).

The authors concluded that factors at a number of levels - behavioural, as well as biologic - needed to be considered in accounting for disease outcome variance.

Levy, Lee, Bagley and Lippman (1988), however, stated that the most important predictor of survival time for their sample of patients with recurrent breast carcinoma, was biological, namely the disease free interval. The second most potent factor was the report of positive mood.

In another study Levy, Herberman, Lipman, D'Angelo, and Lee (1991) reported further support for their earlier findings that psychosocial factors might have an influence on survival. Ninety women with recently diagnosed breast cancer were entered into a behavioural immunology protocol. When the disease outcome variable was defined as time to recurrent disease, the psychosocial factors were strongly predictive of the rate of disease progression for patients who had a recurrence. They concluded once again that immunological and psychological variables such as mood, contribute more to the great variation in outcome of early-stage breast cancer, than has been believed in the past.

Dean and Surtees (1989) interviewed one hundred and twenty-two women with primary operable cancer before and three months after mastectomy. The outcome of 121 of the women was assessed 6-8 years after operation. Those who were assessed three months after the operation as coping by using a strategy of denial, had a better chance of remaining recurrence-free than those women employing other coping strategies. They warned that this finding should be viewed with caution because of the inherent difficulties in measuring coping strategies, particularly on account of the fact that the patients were not consistent in the coping strategy they used before and after the mastectomy. They claimed however that psychological measures improved the prediction of recurrence-free survival beyond that achieved by other variables (e.g. histological node status,

tumour size and treatment).

In contrast to the above, Cassileth, Lusk, D.S. Miller, Brown, and C. Miller (1985) studied 155 breast cancer patients and came to the conclusion that psychological factors played a minor, if any, role in the survival of breast cancer. They followed up these patients to determine the time to relapse. Analysis of the data indicated that social and psychological factors did not influence the length of survival or the time to relapse. They concluded that although these factors may contribute to the initiation of morbidity, the biology of the disease appeared to predominate and to override the potential influence of life-style and psychosocial variables, once the disease process was established.

Worden (1989) found that among demographic variables, gender and socio-economic status did not predict distress levels, while age did. They hypothesised that the younger patients with recurrence would be among the most distressed, and this proved to be the case. The distress levels of younger recurrent patients were high, as were their existential concerns, and they were more likely to blame themselves for the recurrence of their disease. They found self-blame interesting in the light of current popular literature that espouses the need to take responsibility for the condition of one's health, whether good or bad.

#### 2.4.6 Comment

Although these studies had the same objective, namely to determine whether psychological disposition had an influence on survival, they used different psychometric measurements, different types of analysis and took different predictive factors of survival into account. These differences may well account for the contrasts in outcome. In an effort to improve on research techniques, studies of this complexity are very rarely duplicated. This makes it almost impossible to confirm or dispute previous research



findings. The answer to whether or not psychological disposition has an influence on survival time in breast cancer remains elusive.

However, more recent studies such as those by Grossarth-Maticek, Eysenck, Boyle, Heeb, Costa and Diel (2000) showed that psychosocial factors might have an effect on the causation of breast cancer and its prevention.

Furthermore, most of the above research and the interpretation of their results followed a paradigm for research from a positivistic point of view. It rests on the assumption that there is causality in effects. This viewpoint may attempt to provide answers without taking into account that a specific theoretical framework influences research. For example, most of these studies did not take a patient's religion or views on death into account, as influences on coping behaviour. When talking to someone with a terminal illness or with someone, who is dying, one realises that those are very important issues. Furthermore, the research itself may become a stress factor that influences a patient's ways of coping. For example, a study about the fear of recurrence, where measurements are taken from a group of patients whose disease is in remission, may remind them even more that the cancer may start again. Such a study in itself may add to their fear that it may start again. This line of thought is revisited in the last chapter where the merits of a medical model of research in psychological investigations are discussed.

## **2.5 The emotional impact of the news of breast cancer on partner relationships**

It seems that relatively stable and good quality marriages enhance mental health according to studies done by Hughes and Gove (1981) and Gove, Hughes and Style



(1983). It also improved adjustment to cancer according to Friedman, Baer, Nelson, Montague, Smith and Dworkin (1988). It showed an increase in survival time in cancer patients according to studies done by Goodwin, Hunt, Key and Samet (1987); Funch and Marshall (1982) and Marshall and Funch (1983). According to Manne (1999) criticism and avoidance from partners seemed to have a negative effect on patients' adjustment to cancer.

The interaction between patients and their partners thus seem to be an important aspect in coping with cancer. Living with cancer does not have an effect on the patients only; it also has an emotional effect on their partners (Fallowfield, 1995; Northouse, Laten & Reddy, 1995; Barraclough, 1994; McCorkle, Yost, Jepson, Baird, & Lusk 1993; Gotay, 1984). It may even have a physiological effect on those persons close to them, such as husbands and partners according to Baron, Cutrona, Russell, Hicklin and Lubaroff (1990).

A study by Hilton (1993) showed that a diagnosis of cancer caused disruption in marital relationships, but the emotional distress experienced by partners has not received much attention in the literature. Moorey and Greer (1989) stated that it seemed as if the patient's problems have overshadowed those of the spouse.

Compas, Worsham and Epping-Jordan (1994) confirmed that spouses reported similar levels of distress as patients at the time of diagnosis. Spouses and other family members also reported uneasiness and difficulty in communication with cancer patients in a study done by Krant and Johnston (1977).

A variety of complications in communication or sexual relationships may begin as adjustments have to be made as couples adapt to the emotional demand of living with cancer. For example Leiber, Plumb, Gerstenzang, and Holland (1976) reported that

patients and spouses of both sexes experienced an increased desire for physical closeness, but a decrease in the desire for sexual intercourse. Zarcone, Smithline, Koopman, Kraemer and Spiegel (1995) found that the majority of their patients with metastatic breast cancer and their spouses were interested in experiencing sexual pleasure, but less than a quarter of them reported experiencing sexual pleasure. Patients and their spouses may find it difficult to talk to each other about the cancer. Chaitnik, Kreidler, Rapaport and Algor (1992) found that communication between patients and spouses was good only where patients were well informed about their disease.

Those patients who reported strong family ties (Mc Corkle, 1993), and interpersonal support (Grassi, Rosti, Lasalvia and Marangolo, 1993; Ell, Mantell, Hamovitch, & Nishimoto 1989; Bloom & Spiegel, 1984; Gayle, Taylor, D. & Taylor, S.E., 1990, Zemore & Shepel, 1989) tended to adjust more positively to living with cancer. This emphasised the importance of healthy social and particularly marital relationships. When people who were emotionally close to patients reported poor psychological functioning, it was associated with patients mentioning more physical symptoms, according to a study done by Ell, Nishimoto, Mantell and Hamovitch (1988).

Schaefer, Coyne and Lazarus, (1981) also warned that a formal social relationship such as marriage, did not guarantee social support but could actually add stress to people's experience. Houts, Yasko, Kanhn, Schelzel and Marconi (1986) found that patients expressed a need for help in dealing with emotional problems. Some reported that support given to them was often inappropriate, according to Revenson, Wollman and Felton (1983). Peters-Golden (1982) found that healthy persons often misunderstood the concerns patients had. For example, patients who had a mastectomy might be more concerned with the life-threatening implications of having cancer than the fact that they

had lost a breast. Data from a study by Gayle, D. Taylor and S.E. Taylor (1990) showed that patients found emotional support to be "the most helpful" type of support they received from spouses; that they valued their spouses physical presence (just being there); and their spouses calm acceptance of the illness. Wortman (1984) found that patients who did not experience emotional support, might fear that they would be rejected and abandoned by friends and family.

Spiegel (1993) found that certain types of family interaction at home predicted how well the sick members of the family felt over time. Open discussion about the cancer and the problems it caused as well as shared problem solving had a positive effect on the emotional well being of patients and family members.

Very few studies described the effect of the news of recurrence on partner relationships. Silberfarb, Maurer and Crouthamel (1980) studied 146 breast cancer patients representing three different treatment regimens by means of a structured interview, open ended questions, and a modified Psychiatric Status Schedule. They found that the most emotionally disturbing time was the first recurrence of the breast cancer, and the most common disturbance reported was in the area of mate role functioning.

They found that it was at the recurrent stage that patients articulated most concern for "how much longer" as well as expressing apprehension about other family members and of being a burden on them both financially and physically.

Checkryn (1984) reported a descriptive correlational study about the meaning of cancer recurrence to patient and spouse and the communication they exchanged about it. Twenty-two subjects, 12 women with cancer recurrence and 10 spouses, participated in separate interviews and completed a standardised measure of marital adjustment.



Their findings indicated that cancer recurrence posed individual and family hardships. It also caused difficulties with closure, uncertainty, grief, feelings of injustice, fear, anger, a concern with coping, a concern with the impact on the family, and an absence of a communicated shared understanding between patient and spouse about the cancer recurrence. They reported that a substantial number of subjects said that they did not talk with their spouse about the recurrence. Furthermore, those who said they did talk about it, did not share their spouse's understanding of the recurrence. Nevertheless, patients attributed a significant degree of support from spousal communication. The lack of a communicated-shared understanding did not suggest dysfunction as measured by the marital adjustment scale.

It was, however, clear from previous studies such as those done by Silberfarb et al. (1980) and Hall, Fallowfield and A'Hern (1995) that the news of recurrence of cancer caused psychological morbidity in the patients and one would expect it to have a relative detrimental effect on partner relationships.

Another question, from another viewpoint, can be asked. If the recurrence of breast cancer has the effects as discussed above, do the treatments and/or complementary treatments play a role in the patient's reactions to the diagnosis of recurrent breast cancer? It is thus important to investigate the literature concerning the treatment and complementary treatment with regard to breast cancer.

## **2.6 Other factors influencing the experience of the recurrence of breast cancer**

Researchers who investigated recurrence of cancer also found that the following factors influenced the experience of recurrence of breast cancer.



Schaefer, Coyne and Lazarus (1981) found that the availability of nurse counsellors, created an opportunity for patients to express their feelings upon learning their diagnosis. This opportunity had an influence on the coping ability of patients. Patients in units where there were no counsellors available did not cope as well as patients in those units where counsellors were available.

Schmale (1976) emphasised that it was important for the patient to know that the physician was not going to abandon them or their family, but would remain available to discuss concerns and would provide comfort during the final stages of the illness.

Silberfarb (1980) found that it was at the recurrent stage that patients articulated the most concern for "how much longer?" as well as expressing concerns about other family members and of being a burden on them both financially and physically. He recommended that routine psychiatric evaluation might be appropriate at the stage of first recurrence.

Mahon (1991) emphasised the challenge that patients who experienced a recurrence of malignancy presented to nurses. She remarked that one of these challenges was to assist patients in coping with the psychosocial impact of a recurrence of malignancy. She found that the patients clearly expressed their dependency on the nurse and although the role of medical staff was not a primary focus of their study, the subject of emotional support by medical staff often cropped up during interviews.

Munkres, Oberst and Hughes (1992) also emphasised the importance of communication with patients. She stressed that people being treated for recurrent disease needed different pre treatment educational interventions than those receiving initial treatment. Providing a reasonable set of expectations about symptoms might help patients to set more reasonable activity goals.

Checkryn (1984) pointed out the responsibility of nurses to recognise grief as a normal response to the lost "cured" status. They can assist patient and family by acknowledging their grief. In so doing, nurses can help families feel comfortable about expressing their losses and sharing their grief.

In a prospective study on the psychological impact of recurrence of breast cancer, Hall, Fallowfield and O'Hern (1995) also emphasised the importance of the communication between doctor and patient, particularly at the interview when the diagnosis of recurrence is given. They found that women with recurrence were significantly more likely to suffer from anxiety and depression after the diagnosis had been made than the comparison group. This difference was absent before diagnosis with recurrence. The importance of two way communication was further emphasised by the results of this study, that showed that psychiatric morbidity appeared to be more closely related to the interpretation that patients gave to the information given to them, than with the accuracy of the information.

## **2.7 Difficulties in research with recurrence patients**

Previous research showed that where cancer recurred, patients seemed to be a problematic group.

Weisman and Worden (1986) reported that it was much more difficult to enlist patients whose cancer recurred for research and intervention purposes. These patients reported few psychosocial problems and wanted only to get on with the cancer treatment. Family and friends tended to discourage the patients' participation in a research program or in an intervention study. They also found that physicians who had referred newly diagnosed or extremely vulnerable patients in the past, also seemed disinclined to

suggest that their team see the patients during recurrence. The most common reason given was that nothing would be gained.

They noted that many patients whose cancer had recurred and who consented to take part in research, gave only perfunctory answers to their questions. They seemed preoccupied, even indifferent, and far less eager to admit to problems than were first-diagnosed patients. When asked to return for subsequent interviews, the recurrence patients' rate of refusal was high, exceeding that of first-diagnosis patients. In the Spiegel (1993) study, where patients were randomly assigned to two groups who would either receive psychological support in support groups or not, 18 of the 109 patients who were approached to take part in the study, refused. An additional problem with studying patients with advanced disease is that a high number of patients are impossible to follow up during the study period because many are lost because of death or are too ill to be psychologically assessed. In Spiegel's study, only 24 of the 50 patients in the experimental group survived long enough to fill in at least one follow-up questionnaire, (which was done at four-month intervals), after the commencement of the study.

Checkryn (1984) also found that it was difficult to examine patients whose cancer had recurred and their families. Their sample consisted of 22 subjects: 12 women patients and 10 spouses. The unequal number of subjects was due to the fact that two women agreed to participate, but later refused the investigator permission to approach their spouses.

Hall, Fallowfield and A'Hern (1995) who undertook a three year prospective study of breast cancer patients interviewed them at one year intervals. They also incurred the problem that many patients died before they could be interviewed. Hall suggested that, to maximise in research projects the number of patients whose cancer had recurred,



would be to conduct follow-up interviews more frequently.

One should start out with large numbers of patients whose cancer had recurred if the study requires assessment over a long period because there will be many deaths during the study period. It may also imply that the "survivors" had a better prognosis at the beginning of the study and the doctor may have told them so. This information may have softened the blow of the news of recurrence considerably. To add to these confounding factors in measuring psychological morbidity of recurrence patients, Hall also showed that there were differences in psychological morbidity, depending on the way that women interpreted the information conveyed about their prognosis.

Difficulties in research with patients whose cancer has recurred do not lie only in aspects such as the declining number of patients available for follow-up interviews but also in the availability of suitable psychological measuring instruments. The instruments used currently are mostly measurements of general anxiety and depression and do not deal with the impact of the news of recurrence directly.

These difficulties in conducting a psycho-oncological study should not deter scientists from conducting studies, but rather motivate them to find more answers to a complex phenomenon. As Schlebusch (1998) pointed out, there have been some answers to the complex relationship between health, behaviour, stress, physiological responses and immunity but much still needs to be clarified regarding cancer. These challenges in research can only be met by a multidisciplinary team, as indicated by Holland (1991) in a review of the progress in oncological research from the fifties to the nineties. The advantages of the improvement in quality of life that insight and understanding provide to the patients, far outweigh the difficulties inherent in this type of research.



## CHAPTER 3

# CANCER AND APPLIED THEORETICAL FRAMEWORKS: STRESS, SOCIAL LEARNING THEORY AND LOCUS OF CONTROL

### 3.1 Introduction

Within the framework of a pluralistic study, different theories seem appropriate. To come to an understanding of the experience of a diagnosis of breast cancer, it is necessary to understand a variety of concepts involved in human adaptation to a severely stressful situation such as having cancer. An outline of theories of stress is given to provide a theoretical framework against which the experience of cancer as a chronic stressor can be intellectualised. One of the possible ways of making sense of an event such as cancer has to do with one's sense of control. The development of social learning theory from which concepts such as locus of control evolved is discussed in this chapter. In Chapters 4 and 5 the other applied theories applicable to this study are discussed.

To assist in the understanding of how people learn to react to stress, a brief outline of the social learning theory of Bandura (1977) is given. With its emphasis on self-sufficiency, this theory is applicable in the field of health psychology. Rotter's work (1966) that is also based on social learning theory, provides a framework for the understanding of the different pathways a person may follow to gain control over the situation. It follows that these theories behind the concept of locus of control also form the background against which the studies, regarding breast cancer and locus of control, have been done.

Within the field of psycho-oncology theories are constantly applied and redefined. Particularly in the case of locus of control, this is well illustrated. The concept of locus of control developed from social learning theory. Locus of control seemed to be a useful construct in understanding how patients react to the news of a diagnosis of cancer and its recurrence. In the case of those patients who experience recurrence of their cancer, one of the possible options that may be followed, is the use of alternative medicine rather than conventional medicine that has failed to cure. This option has been examined in this study and the theory and its application is discussed in this chapter. Lastly, the integration of locus of control with the other theories used in this study is presented.

### **3.2 Stress**

In my initial study on stress and cancer (Falkson, 1999) I emphasised that the individual's emotional reaction to stress played an important role in coping with cancer. In the present study, this subject is explored further to incorporate aspects such as locus of control.

Even before describing theories surrounding coping and control, it is important to look at the concept of stress and more specifically chronic disease as a stressor to understand what it is that these patients experience and what they have to cope with. The author dealt with this concept in more detail in the aforementioned research, but a short review of the literature provides the necessary background to this study. It also provides the definitions of how the concept of stress was used in these studies.

Traditional theories failed to account for individual differences in human response to potentially aversive conditions and characterised the stressed organism as a passive

recipient of external forces. Janis (1974) stated that the experiments provided reliable data, but that the value of the data for extrapolating to actual life stress was dubious because human behaviour involves more than just instinctive behaviour.

Selye (1976) gave a useful definition of stress as the non-specific response of the body to any demand. All endogenous or exogenous agents that make such demands are called stressors. It is immaterial whether the situation is pleasant or unpleasant, what is important is the intensity of the demand for adjustment.

A confusing aspect of stress is that a distinction is often not made between psychologically based stress and physiologically based stress. In the case of cancer, both types are relevant. The cancer itself causes physical stress reactions, especially in secondary cancer where back pain, for example, may become an everyday problem. Furthermore, there are the noxious side effects of chemo- and radiotherapy, which cause different degrees of physiological stress. Psychological stress seems to be caused by living with the knowledge of having a life threatening disease and the fear of recurrence. Once the recurrence has occurred the stressful situation seems to be: "*How long do I have to live?*"

During therapy with cancer patients it seems clear that stress cannot be described exclusively by a single stimulus - response observation. A theory suitable for studying the experience of being a cancer patient should accommodate multifactorial aspects of coping and a thorough understanding of what the stress of having cancer means to the individual. Differences among individuals in cognitive appraisal are important determinants of affective and physiological responses to potentially threatening events.

Miller and Leary (1993) pointed out that each individual within his or her specific situation and psychological make up, interprets the stress situation and reacts according to that



interpretation. In a psychoanalytic study of the stress associated with having to undergo surgery, Janis (1974) also emphasised the importance of individual differences in reaction to stress. He described aspects such as family situation, occupation and daily activities as essential contexts necessary for the most elementary understanding of why one person reacts differently to another. In practice, it is very often difficult to interpret the resulting behaviour in terms of the stressful situation. For example, it is not uncommon to find patients with recurrent cancer who have low anxiety and depression levels. They confirm that they regard themselves as fortunate individuals because they have had good lives, and have lovely children and grandchildren who take good care of them. They do not appear to experience emotional pain and carry on with their lives. They seem to cope better than one may assume the situation warrants. The fact that some people apparently cope so much better than others confronted with the same stressor, may lie in differences in their personality, socio-economic status and social support, amongst others. As Lazarus (1966) confirmed, the important role of personality factors in producing stress reactions requires that we define stress in terms of transactions between individuals and situations, rather than either one in isolation. Because it is also a relational theory, this particular theory of coping also corresponds to, or complements, the interactional theory of research therapy that was used as framework for the qualitative research.

Lazarus (1966) suggested that stress may be treated as an organising concept for understanding a wide range of phenomena in human adaptation. Many factors in the environment and aspects within an individual combine to generate stress. Stress should not be understood as a variable but as a rubric, consisting of many variables and processes. Selye (1976) also pointed out that a real understanding of stress is dependent upon a holistic and integrative approach; no aspect of it can be analysed in



depth without a full realisation of where and how it fits into the whole picture. A study, by Chen and Craske (1998), years later, showed the intricate relationship between anxiety and stress and confirmed that these factors cannot be studied in isolation. In the same line of thought, Mc Gill (1998) proposed a unified model for studying stress and coping. A multifactorial analysis seems to be the right approach to follow in examining the psychological impact of recurrence of breast cancer, because there are many variables that cause stress in these patients and it is not possible to reduce this to just one variable called "stress". In order to keep individual differences of the psychological reaction to the stressful situation of having cancer in mind, it is imperative to include as many variables as possible, for example, demographic factors, social support and locus of control in the final analysis. A study using a systematic theoretical framework for examining the psychological impact of cancer and by comparing levels of depression, anxiety and general health between a group of women with recurrent breast cancer and a group of women whose breast cancer was in remission for at least one year, should add to our understanding of the concept of stress. It should also provide information on how to improve therapy with cancer patients. Such a multifactorial approach should allow for interactions between the many variables involved in human behaviour.

One way of reacting to a stressful situation may be to take control of the situation. Particularly in the case of a life threatening disease such as cancer, the concept of locus of control seems to be a construct suitable for studying the way a person reacts to the news that she has breast cancer or that it has recurred.

### **3.3 Social learning theory and locus of control**

An important part of the emotional experience of breast cancer and the stress involved in its diagnosis, has to do with a person's sense of control over events. The more control a

person perceives to have, the better the coping. When a person is diagnosed with cancer and then rediagnosed with recurrence, it can be expected that issues around control will be prominent. In the case of the recurrence of breast cancer, there may be doubt regarding the health practitioners' ability to control the disease and patients may opt for alternative forms of treatment.

Although control is studied within the more integrative theoretical framework of the process coping theory of Lazarus (1966, 1993), a broader theoretical background to the concept is given in this chapter.

The concept of locus of control originated in behavioural psychology. Behavioural psychologists have always acknowledged the importance of reinforcement, reward, or gratification in the acquisition and performance of skills and knowledge. The strict stimulus response theory of the behaviourists, however, did not take individual differences in behaviour into account and was criticised by both Rotter (1966) and Bandura (1977). They became advocates of social learning theory, which is based on the principle that an event regarded by some persons as a reward or reinforcement, may be differently perceived and reacted to by others. One of the determinants of this reaction is the degree to which the individual perceives that the reward follows from, or is contingent upon, his own behaviour versus the degree to which he feels the reward is controlled by forces outside of himself, independent of his own actions. Social learning theory differs from behaviourist theory in the premise that the effect of a reinforcement following some behaviour on the part of a human subject, is not a simple stamping-in process. It depends upon whether or not the person perceives a causal relationship between his own behaviour and the reward. This implies an interaction between the environment and the person, rather than the outcome being dependent upon one or the other. Behaviour, personal factors and environmental factors all operate as interlocking

determinants of each other. Bandura (1966, 1977) pointed out that the relative influences exerted by the interdependent factors, differ in various settings and for different behaviours. He showed that there are times when environmental factors exercise powerful constraints on behaviour and other times when personal aspects the override determinants over the environmental factors. This means that in social learning theory, people are neither driven by inner forces nor buffeted by environmental stimuli. Behaviour is rather explained by a continuous interaction between the two.

Bandura (1977) used this theory to show how symbolic, vicarious and self-regulatory processes assume a prominent role. I found this view to be particularly applicable to patient behaviour and again it compliments the other relational theories used in this study.

Bandura (1977) showed how people not only learn from direct trial and error basis but also vicariously by observing other people's behaviour and its consequences. This ability of people to learn from observations, enables people to acquire large, integrated patterns of behaviour which saves them a great deal of effort in acquiring knowledge by trial and error. Particularly in the cancer field, this ability may be of critical importance, for example, where one woman can learn from another cancer patient about ways to adjust more comfortably to the loss of a breast and the side effects of treatment, such as hair loss.

Another distinguishing aspect of human learning behaviour according to social learning theory, is our ability to use symbols as a powerful means of dealing with the world. Through verbal and imagined symbols, we process and preserve experiences in representational form as references for future behaviour. A practical use of this ability of humans in psycho-oncology is, for example, to use images to help with pain relief.



Several relaxation techniques proved to be useful in pain relief with patients. When these techniques are applied, the patient can, for example, be asked to imagine a restful place, or to imagine her body floating without any pain.

Another strong feature of social learning theory is the important role it assigns to self-regulatory behaviour (Bandura, 1977). By arranging environmental inducements, creating cognitive supports and regulating consequences for their own actions, people manage to gain some control over their behaviour and events that happen to them. In the oncology field, this ability to reinforce one's own behaviour has the benefit of creating a sense of control over a potentially overwhelming situation.

Bandura (1966) stated that there are three essential components of successful reinforcement procedures. Firstly, the reinforcements must be powerful and durable to maintain responsiveness over long periods, while patterns of behaviour are stabilised. Secondly, reinforcing agents must be made contingent upon the desired behaviour and thirdly, a reliable procedure for eliciting desired behaviour is essential.

Bandura also elaborated the concept of self-efficacy as a central part of social learning theory (Zimabardo, McDermott, Jansz & Metaal, 1993). Self-efficacy is the belief that one can perform adequately in a particular situation. One's sense of self-efficacy influences one's belief of whether one will be successful in a given situation or not. The result is that self-efficacy has an influence on motivation and self-confidence. It is self-evident what the implications of this theory are for the field of psycho-oncology, where it is so important that the patient should believe that the treatment will have the desired outcome in order to remain motivated to complete the often difficult regimens. This does not mean an unrealistically optimistic view, but the will to survive and the motivation to try everything in one's power to promote the healing process. One's self-efficacy



influences persistence when faced with difficulty and is therefore an important aspect of self, particularly in cancer, which is a chronic disease.

Social learning theory as elaborated by Rotter (1966) provides the general theoretical background from which the idea of locus of control developed. In social learning theory, reinforcement acts to strengthen expectancy that a particular behaviour or event will be followed by that reinforcement in the future. Rotter stated that once expectancy for such a behaviour reinforcement sequence is created, the failure of the reinforcement to occur, would reduce or extinguish the expectancy. As an infant develops and acquires more experience, he differentiates between events that are causally related to preceding events and those which are not. Rotter deducted a general hypothesis that when the reinforcement is seen as not contingent upon the subject's own behaviour, that its occurrence will not increase expectancy as much as when it is seen as contingent. Conversely, its non-occurrence will not reduce expectancy as much as when it is seen as contingent. It seems likely that, depending upon individuals' history of reinforcement, they would differ in the degree to which they attributed outcomes to their own actions.

He described their basic hypothesis as the following: if a person sees reinforcement as being the result of his previous behaviour then he may repeat that behaviour. If he perceives something as outside his own control or not contingent upon his own behaviour, but dependent upon chance, fate, powerful others, or unpredictable, then the preceding behaviour is less likely to be strengthened or weakened. Rotter (1966) stated that an individual who has a strong belief that he can control his own destiny is likely to :

- (a) be more alert to those aspects of the environment which provide useful information for his future behaviour;
- (b) information for his future behaviour;

- (c) take steps to improve his environmental condition;
- (d) place greater value on skill or achievement reinforcements and be generally more concerned with his ability, particularly his failures; and
- (e) be resistant to subtle attempts to influence him.

### 3.3.1 Defintions of control

According to Syme (1989) one should keep in mind that, although so many investigators have suggested the importance of control for health and well being, few studies are comparable, because they did not use the same concept in exactly the same way.

Syme described control as a complex concept seen differently by different researchers. Some think of control as a personal 'state of being' (of being in control) while others see it as a 'condition' (where things are under control).

Control is a multifaceted construct and Wallston (1989) cautioned that one should be clear about which aspect of control one wishes to study and why one wishes to do so. One should distinguish between "perceived control" as opposed to "actual control" in health-related research. Wallston described perceived control as a belief that one can determine one's own internal states and behaviour, influence one's environment, and/or bring about desired outcomes. He stated that the definition perceived control as a belief, indicates that it is an individual difference construct; something which, when assessed, varies among individuals and within the same individual over time. In contrast, actual control is conceived of as a property of the situation and setting.

Thompson (1981) also defined control as the belief that one has at one's disposal a response that can influence the aversiveness of an event. She pointed out that this definition had the advantage of being general enough to include all types of control. It

also recognised that control did not need to be exercised for it to be effective and it did not even need to be real, just perceived, to have effects.

### 3.3.2 Development of a theory of multidimensional health locus of control

B. S. Wallston, K. A. Wallston, Kaplan and Maides (1976) and K. A. Wallston, B. S. Wallston and Vellis (1978) developed the original Health Locus of Control scale (HLC) as part of a theory of multidimensional health locus of control. The scale is a unidimensional measure of people's beliefs that their health is or is not determined by their behaviour. Individuals with high scores on the 11-item HLC scale are "health-externals". This means that they are presumed to have generalised expectancies that the factors which determine their health are such things as luck, fate, chance, or powerful others, all factors over which they have little control. At the other end of the dimension are the health internals, who believe that the locus of control for health is internal and that one stays or becomes healthy or sick as a result of one's own behaviour.

The theory and the original scale have been criticised, however, because both Powerful Other Health Locus of Control (PHLC) and Chance Health Locus of Control (CHLC) are external dimensions. Wallston (1989) pointed out that scoring high on the PHLC dimension does not necessarily indicate low perceived control. Particularly in the case of cancer, when patients are chronically ill and under long treatment regimens, it is realistic to believe that other people's actions can influence one's health status. He also stressed that it may be beneficial to hold these beliefs, particularly if the 'powerful other' people are expert practitioners who have only one's best interests at heart. Scoring high on the CHLC dimension usually does mean low perceived control (except if one truly believes one can control random events); however, moderately high CHLC beliefs may be advantageous in certain circumstances when, in fact, there is little one could actually do to change one's health status.



### 3.3.3 Multidimensional health locus of control

Levenson (1974) also questioned the conceptualisation of locus of control as a unidimensional construct and argued that the understanding and prediction of locus of control could be further improved by studying fate and chance expectations separately from external control by powerful others. She attempted to develop a conceptually “cleaner” instrument, than the Wallston I-E scale.

Levenson (1974) did a study on activism. She hypothesised that the reason the I-E scale did not meaningfully differentiate between those who are involved and those who are not involved in activism, is because of the broad definition of externals as those with expectancies that fate, chance, or powerful others will control events.

She constructed three new Lickert type scales (Internal, Powerful Others, and Chance - I, P, C) in order to measure belief in chance expectancies as separate from a “powerful others” orientation. According to Levenson, it seemed that those orientations reflected quite different beliefs and therefore should not be grouped together under the rubric of external control. The rationale of the finer differentiation stemmed from the reasoning that people who believe the world is unordered (chance) would behave and think differently from people who believe the world is ordered, but that “powerful others” are in control. In the latter case a potential for control exists.

To test the discriminant validity of the I, P, and C scales, they were administered to 329 male undergraduate students enrolled in an introductory chemistry course at a Texas University. A factor analysis of the data confirmed that the refinement of the I-E scale into the three orientations of “internal”, “powerful others”, and “chance” was justified.

Since its construction, the Multidimensional Health Locus of Control Scale (MHLC) had been widely used and Wallston (1989) commented that the MHLC Scale still



predominated in the literature as the preferred means of assessing control in health-related settings. He warned, however, that it was not always used well or wisely in the erroneous belief that a single measure of a single construct will somehow magically help explain a significant amount of the variance in health behaviour and status. Health behaviour is multidetermined and locus of control should be used with other measurements to predict health status.

#### 3.3.4 Locus of control and adjustment

Locus of control should not be seen separately from a person's total behaviour but only as one more construct in human coping behaviour. Particularly in sick role behaviour locus of control seem to be relevant in order to understand patient behaviour. B. S. Wallston and K. A. Wallston (1978) already found evidence, in their review of the literature in 1978, evidence that the construct of locus of control is relevant to the prediction of sick role behaviour, particularly behaviour which will be important in this study such as compliance with treatment. They commented that internals generally showed more positive behaviours but warned that there are many factors other than locus of control which influence behaviour and this may lead to inconsistent results.

Folkman (1984) warned that the relationships between personal control and stress, coping, and adaptation outcomes are complex. She said that believing that an event is controllable does not always lead to a reduction in stress or to a positive outcome, and believing that an event is uncontrollable does not always lead to an increase in stress or to a negative outcome. A more integrated approach towards studying these factors may shed more light on the relationships between them.

### 3.3.5 Effect of a diagnosis of cancer on locus of control

One would expect that the news of breast cancer will have an impact on a person's sense of control over her life. Once again she becomes a patient who has to undergo an operation or receive chemotherapy which result in feeling unable to cope with daily demands and of being dependent on doctors, family and friends. Some patients also realise that they cannot be cured and that they will not survive. A natural reaction to such devastating news would leave a patient at least initially anxious, depressed and feeling helpless.

Syme (1989) stated that the importance of the concept of control to researchers in the health field, is that it has practical value as a concept that deals with behaviour that may be amenable to intervention and it involves behaviour which hopefully we can do something about.

Spiegel (1993) also emphasised the practical value of locus of control as a concept and underlined the possibility of enabling patients to regain control. He confirmed that patients with cancer often feel sick and helpless. They are in desperate need of being in control of their personal lives and illness and he suggested that control could be enhanced in the mental, physical and social domains. The illness cannot be undone, but an active approach can control the current situation. By understanding how patients perceive control in a situation where they clearly express feelings of fear and dependency, we may be able to assist them in regaining some control. This may lead to better emotional well being.

Particularly in the case of cancer patients, the feeling of being in control may improve well being. In many ways, patients are deprived of the ability to exert control. This perceived absence of the ability to control is debilitating. When there are good reasons

why it is either undesirable or impossible to remove restrictions on freedom, that is, when it is not possible to enable the exercise of real control, Langer (1975) suggested that it might be advantageous to induce the illusion of control. For example, by allowing patients in the hospital to decide whether he wants an injection of penicillin or a penicillin tablet (when the difference in the amount of time it takes to get into the bloodstream is not important), he has been given the opportunity to exercise control, although the important decision - that he is going to have penicillin - has already been made. Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, and Grunzen (1993) agreed with the view that it is important to maintain perceptions of control in low control situations by allowing control in day-to-day activities. They found that even patients who were physically or psychosocially worse off, were better adjusted if they had higher perceptions of control.

Taylor, Helgeson, Reed and Skokan (1984) found a positive correlation between belief in self-control and adjustment. They also found a positive correlation between belief in the control of others and adjustment, which is explained as understandable in the case of cancer patients where the physician is in control. Years later Taylor, Helgeson, Reed and Skokan (1991) confirmed that a sense of control was adaptive and reduced psychological distress. They found, however, in their later study that although patients with good prognosis benefited psychologically from a belief in the control of powerful others, those with poor prognosis did not.

Grassi, Rosti, Lasalvia, and Marangolo (1993) investigated the role of psychosocial variables such as social support and locus of control on adjustment to cancer. They found that external locus of control and inadequate interpersonal support was associated with less effective strategies of adjustment to cancer. They concluded that a high internal locus of control may influence a "better mental adjustment" to cancer. They



defined this "better mental adjustment" as a tendency to have a positive attitude towards illness, to perceive it as a challenge, and to take an active role in his/her own recovery. They described those patients with an inadequate social support and external locus of control to have a tendency towards helplessness and despair, and to a fatalistic attitude, with absence of active strategies to deal with illness and treatment.

Lewis (1989) examined the effects of attributed control over one's health and experienced meaning of one's situation on anxiety and self-esteem in 57 adults with advanced cancer. Although he found that the extent to which the patients attributed meaning to their situation was a significant predictor of both higher self-esteem and lower anxiety, he did not find that patients' locus of control affect either their self-esteem or their anxiety. Contrary to this hypothesis, no significant relationship between control over one's health status and self-appraisal and anxiety was found. He gave a plausible reason for this result in stating that these patients had advanced disease and realistically experienced their cancer as uncontrollable. He suggested that in late-stage cancer, the emphasis as far as psychological support should not be on responsibility and control over health status but rather on perceived meaning and purpose.

Hilton (1989) did a descriptive correlational study to investigate the relationship between factors such as uncertainty about the cancer situation, control of the cancer situation and a set of coping strategies used by women to cope with breast cancer. She accommodated many influencing variables in the design of her study in order to reflect the complexity of real-world stress and coping. The group consisted of 277 non-hospitalised women with breast cancer. Women who had high control used systematic problem solving, escape avoidance, positive reappraisal and self-controlling strategies. This study seem to confirm that those patients who experience high control will actively use problem solving behaviour and may well engage in the use of alternative treatments



if they believe that it may enhance their chances of a cure or better their quality of life as we hypothesised in our study. Norman, Bennett, Smith and Murphy (1998) stressed that locus of control should be studied in relationship to other health behaviour and not as a phenomenon on its own.

### 3.3.6 The use of complementary treatments as a means of taking control

Conventional or mainstream cancer treatment usually consists of a combination of chemotherapy, radiotherapy, pharmacology and surgery. Each patient is, however, treated in an individualised way depending on the stage of her disease (Fallowfield & Clark, 1991). The side effects of these types of treatments such as the scarring and disembodiment of the surgery, the hair loss and nausea of chemotherapy and the nausea, fatigue and burns of radiotherapy, often cause varying degrees of distress. Patients often say that cancer itself is painless, but that the side effects of the treatment make them feel sick to the point of giving up. Many actually stop treatment before the cycle has been completed because they cannot endure the side effects. Those patients whose cancer recur, often feel that they cannot even contemplate the idea of treatment again and may seriously consider into using alternative forms of treatment. A very moving account of the day to day life of a cancer patient is described in the e-mail messages of Picardie (1998) where the ill effects of treatment such as the loss of hair is poignantly detailed.

The media in the modern Western World have given significant publicity to the possible advantages of complementary treatments for various diseases. Ernst (1995) stated that it had gained medical, economical and sociological importance and that there was a general disenchantment with mainstream medicine. According to Alberts (1993) this interest of the patient population in alternative forms of treatment was widespread, in spite of technological advances in conventional procedures. There is also an increasing

awareness of patient choice in decision making regarding medical procedures, for example mastectomy versus lumpectomy. According to Conrad (1985) patients assumed more responsibility regarding their own health. Against this background we thought that there might be a positive relationship between a high internal locus of control and the use of complementary treatments. We hypothesised that patients with recurrent breast cancer might be disillusioned with mainstream medicine and search for alternative treatments. It is of importance to determine how many patients use complementary treatments and which types they use. Some of these treatments may be harmful and patients should be warned against their use. Other complementary treatments, for example aroma treatment, may have a relaxing effect on the patients. These may be beneficial to their general feeling of well being although they do not cure the cancer.

There is a wide variety of treatments and a plethora of literature available in most bookstores. Maher and Young (1994) pointed out that studies on the use of complementary medicine in breast cancer varied considerably regarding the definition of complementary treatments, with some including support systems such as telephone help lines and counselling.

Ernst (1995) described complementary medicine as the diagnosis, treatment and/or prevention, which complements mainstream medicine by fulfilling a demand not met by orthodox medicine. Complementary medicine attempts to involve the patient's wishes in the treatment. Cassileth (1986) in a thorough overview of unorthodox approaches over time, concluded that complementary treatments have three main characteristics. Firstly, it is not based on pills or potions but on life-style orientated changes such as exercise, diet and stress management. Secondly, there are no more "secret formulas". Patients

want to understand the rationales behind the cures. Thirdly, the treatments often carry an aura of respectability or scientific proof.

Although the term “adjunctive therapies” has also been used to describe therapies that are used in conjunction with established therapies, I use the term “complementary”.

### **3.4 Conclusion**

This chapter gives an overview of cancer and the applied theoretical frameworks of stress and social learning theory. It also discusses locus of control and the use of alternative treatments. The next chapter focuses on cancer and the theoretical frameworks of coping, applicable personality theories, and process theory.

## CHAPTER 4

# CANCER AND APPLIED THEORETICAL FRAMEWORKS: COPING, PERSONALITY AND PROCESS THEORY.

### 4.1 Introduction

The experience of breast cancer and/or the recurrence of breast cancer seem to depend largely on how people react to the diagnosis. This reaction is closely related to their coping mechanisms and possibly their personalities. In the previous chapter an outline is given to provide a broader understanding of how people learn within a social world. In this chapter, a more specific outline of theories explaining how people cope and what factors influence this coping behaviour, is presented.

To come to an understanding of coping, a brief description of the development of coping theories is given to illustrate why a specific coping theory has been chosen as theoretical framework to study the experience of breast cancer and its recurrence. Emphasis is placed on theories that may be applicable to coping with a chronic disease such as cancer. Theoretical issues underlying behaviour such as denial and information seeking behaviour, which are prominent in coping with cancer, are discussed. In psycho-oncological research theories are formulated alongside practical findings from studies. It is difficult to separate the two and a better understanding of how a specific theory is chosen above another is better illustrated by showing how conclusions from one study lead to a more refined theory which is better suited to the study of the experience of being a cancer patient.

Reasons for studying theories about coping are numerous. Newman (1990) stated that researchers study coping behaviour in an attempt to make sense of the different responses to illness and stress as well as differences in outcomes in the disease



process. A better understanding of the concept might permit the development of appropriate interventions to enhance constructive coping styles and ameliorate problems experienced by people whom employ maladaptive or ineffective strategies.

## 4.2 Coping: overview of state/trait approach

There are mainly two broad approaches describing the theoretical concept of coping. The first emphasised style (Pettingale, Burgess & Greer 1988; Eysenck, 1985; Weinberger, Swartz & Davidson, 1979). They described coping as a personality characteristic. The other theory, described by Lazarus (1993) emphasised process; that is, efforts to manage stress that change over time and are shaped by the adaptational context out of which it is generated. The process theory of Lazarus is also more applicable to the qualitative approach of this study, which emphasises the relationship between the individual and herself; the individual and others around her; the individual and the disease.

As with stress, coping has been defined in many different ways. Although the process theory of Lazarus (1993) is the theoretical framework against which the psychological impact of the news of recurrence is studied here, an overview of other approaches as applied to the way patients react to the news that they have cancer, is given. A critique of other approaches to coping is done to illustrate why the Lazarus theory seems to be the most suitable theory to examine coping with cancer.

An approach that separated the coping behaviour of individuals into different strategies which are described as fixed ways of dealing with cancer, were used by Greer and Watson (1987). They defined mental adjustment to cancer as the cognitive and behavioural responses made by an individual to the diagnosis of cancer. Mental adjustment comprises firstly appraisal, that is, how the patient perceives the implications of cancer, and secondly the ensuing reactions which entails what the

patient thinks and does to reduce the threat posed by cancer. These fixed ways of dealing with the threat posed by cancer might also have an influence on the eventual outcome of the disease. Greer and Watson developed a mental adjustment to cancer scale, which followed the original work done by Morris, Greer, Pettingale and Watson (1981), Watson, Greer, Young, Inayat, Burgess and Robertson (1988) and Osborne, Elsworth, Kissane, Burke and Hopper (1999), who refined the scale further. This scale groups mental adjustment to cancer into four broad categories, namely:

- (i) Fighting spirit. This categorises people who fully accept a diagnosis of cancer, have an optimistic attitude towards it and are determined to fight it.

Fallowfield and Clark (1991) found many examples of fighting spirit in one thousand in-depth interviews conducted with cancer patients. An example from their book on breast cancer is *"I'm not giving in, whatever happens. I'm going to fight this thing"* (p 41).

- (ii) Denial. The patient either rejects the diagnosis of cancer or denies/minimises its seriousness. Denial is something that I encountered many times in my work with cancer patients. They would, for example, say: *"Well, I don't think that these experts always know what's going on and just to be on the safe side they prefer to treat breast lumps as serious, just in case"* (Fallowfield & Clark, 1991, p 41).

- (iii) Stoic acceptance. The patient accepts the diagnosis, does not seek further information and has a fatalistic attitude. An example of such an attitude would be: *"I knew what he was going to say. I was quite prepared. I know that it's out of my hands - what will be, will be. It's pointless worrying"* (Fallowfield & Clark, 1991, p 42).

(iv) Helplessness/hopelessness The patient is overpowered by the knowledge of the diagnosis and her daily life is disrupted by the preoccupation with cancer and dying. Another quote from Fallowfield and Clark (1991) illustrated this attitude as follows: "*We're not lucky people in our family - my Dad died of cancer, and my Mum. I know I'm going to go that way too. The only thing I like is my garden, but I haven't planted any bulbs even - what's the point? I won't see them will I?*" (Fallowfield & Clark, 1991, p 41).

Using the Mental Adjustment to Cancer Scale (MAC), Greer and Pettingale (1979) reported results which indicated that psychological response to cancer diagnosis, assessed three months post-operatively, were related to outcome five years later.

Ten years later, Pettingale, Morris, Greer, and Haybittle (1985) re-examined the association between psychological response and outcome in their cohort of patients. They found, once again, a more favourable outcome in those patients described as exhibiting fighting spirit and denial than among those who showed stoic acceptance or a helpless/hopeless response. They came to the conclusion that the effect of mental attitude is independent of other prognostic factors and should be included as an additional prognostic indicator for patients with breast cancer.

Burgess, Morris and Pettingale (1988) did further research that confirmed the existence of these four broad categories. Their analysis of cognitive responses and the other psychological variables combined, also revealed that four broad coping styles could be delineated: positive/confronting, fatalistic, hopeless-helpless and denial/avoidance. These categories corresponded to their previously described categories. Lower psychological morbidity was associated with a positive/confronting response to diagnosis and with high internal locus of control, while higher anxiety and depression scores were associated with a hopeless-helpless response to diagnosis and with low internal locus of control.



Other researchers also used the same categorisation of mental adjustment to cancer. Grassi, Rosti, Lasalvia and Marangolo (1993) investigated the role of psychosocial variables and psychological vulnerability on adjustment to cancer. Their study was undertaken on 157 cancer patients. Assessment of adjustment to cancer was carried out with the Mental Adjustment to Cancer, (MAC) scale. The results indicated that the MAC dimension Fighting Spirit (FS) was related to low External locus of control (ELC) and high social support, while an opposite association was shown for Helplessness (H) and Fatalism (F). According to MAC cut-off scores, 'cases' reported higher ELC and lower social support than 'non-cases'. Their findings seem to confirm the utility of the MAC in oncological settings and the adverse effect of prior psychological problems, present emotional disorders, external locus of control and inadequate interpersonal support on strategies of adjustment to cancer.

Another study, by Ralph, Clemente and Temoshok (1985) used the same theoretical framework for studying adjustment to having malignant melanoma as a predictor of follow-up clinical status. The study involved 117 patients who were followed up longitudinally. A clinical psychologist interviewed patients on their first clinic visit following diagnosis. The interview included questions regarding the patients' adjustment to the disease. Two independent researchers, using two categorization schemes, coded the patients' responses to the questions concerning their reaction to malignant melanoma. The Greer and Watson (1987) categorisation assigned patients to one of four mutually exclusive adjustment categories (denial, fighting spirit, stoic acceptance and feelings of hopelessness/helplessness). The second procedure derived a quantitative measure for each of the four categories, thus yielding a profile of scores. Contingency table and logistic regression analysis identified two statistically significant gender-specific predictors of clinical status. Response characteristics of stoicism among women and helplessness/hopelessness among men were significantly associated with unfavourable outcome. Their findings support



previous research, suggesting that psychological adjustment, even when known biological and epidemiological prognostic determinants are evaluated in the analysis, may be a significant predictor of clinical status.

Coping strategies that have been studied extensively and separately from the Greer and Watson categorisation are denial versus confrontation and information seeking versus information-avoiding behaviour.

### 4.3 Denial

As with the other coping strategies, denial has been studied in its relationship to the outcome of disease. The majority of these studies (Grassi, Rosti, Lasalvia & Marangolo 1993; Schetter, Feinstein, Taylor & Falke 1992), agree that denial and various forms of repression are associated with generally unfavourable outcomes in cancer, such as faster disease progression, heightened emotional distress, and shorter length of survival. Other researchers, (Manuel, Roth, Keefe & Brantley, 1987; Felton & Revenson 1984; Derogatis, Abeloff & Melisaratos, 1979; Achterberg, Matthews & Simonton, 1977; Silverfarb & Greer, 1982), also found that responses to cancer that are assertive, self-reliant, information-seeking, openly expressive, confrontational, and even hostile are related to favourable outcomes.

One of the most well known researchers and authors on death and dying is Kubler-Ross (1995, 1997). She found that many patients go through different stages before eventual death. These stages are: (a) Denial and isolation (b) Anger (c) Bargaining (d) Depression (e) Acceptance. She warned, however, that one should not see these stages as a rigid one-way process but rather use them as guidelines to understand patient behaviour. She saw denial as the first stage because this is where the patient would say: "*No, this is not happening to me*". She described it as a temporary

defence and said that the patient should be allowed to keep this defence as long as it was practically possible and needed to alleviate anxiety.

Schetter, Feinstein, Taylor and Falke (1992) found that coping through social support, focusing on the positive, and distancing was associated with less emotional distress, whereas using cognitive and behavioural escape-avoidance was associated with more emotional distress.

In contrast to the above-mentioned studies, Silverfarb and Greer (1982) suggested that denial might be adaptive in the early stages of cancer and Greer and Pettingale (1979) associated denial with favourable prognostic outcome.

In these studies of denial, there was a tendency, to view it as a static quality, which was measured only once. This research method did not take into account that denial functioned as a cognitive act and varied from moment to moment with the ebb and flow of negative emotion. Lazarus (1966) also emphasised that its operation might depend on situational factors. He stressed that, denial, as a theoretical concept in the study of patients' coping with having cancer, had to be defined in terms of "what" it was that patients denied and to what extent. This could vary from patient to patient and over different time intervals. Contrary to initial thinking, denial might be useful for adaptation under certain definable circumstances. According to Wool (1988) in the area of cancer, the act of denial could result in unconscious negation of symptoms of illness and cause a disruption of the help-seeking response. On the other hand, denial is, described as neither good nor bad in itself. What is seen as important to the oncology clinician is the way in which it may assist or impede an individual's adjustment to cancer. Moorey and Greer (1989) also stated that one should not automatically challenge denial during therapy, because it may be an adaptive way of coping.

When dealing with denial one should distinguish its various forms. One may deny facts, the true meaning of information and/or its likely future consequences, or one's emotional state. Lipowski (1970) confirmed that evaluation of denial must always include a consideration of what is denied, in what situation and by whom.

Findings by Feifel, Strack and Nagy (1987) supported the theory that conceptualised coping behaviour in dealing with life-threat as being shaped more by situational context than by personal style. Their results indicated that life-threatened patients used confrontation significantly more than did non-life-threatened patients in dealing with their illness.

Lipowski (1970) also confirmed the importance of the situational context in which denial should be interpreted. He viewed denial of illness or passive surrender to it as possibly adaptive during the acute phase of a severe illness, but as maladaptive in its later stages, when recognition of facts and active coping would be more appropriate. Morris, Blake and Buckley (1985) also confirmed that denial might at least be pragmatic adjustment in situations where little or nothing can be done instrumentally.

Lazarus and Folkman (1984) had an operational view towards the study of denial that takes situational factors into account. He pointed out that the meaning of denial posed a methodological problem because it is usually described as the rejection of reality. He offered the following principles for the specification of the conditions under which denial and denial-like forms of coping might have favourable or negative outcomes.

- (i) When there is nothing constructive people can do to overcome a harm or threat, that is, when there is no direct action that is relevant, denial and denial-like processes contain the potential for alleviating distress without altering functioning or producing additional harm.



- (ii) Denial and denial-like processes may be adaptive with respect to facets of the situation, but not the whole. Patients with diabetes can deny the seriousness of the situation as long as they also continue to give vigilant attention to diet, activity level, and insulin. The distinction between denial of fact and denial of implication is also relevant here. For example, it is probably more dangerous to deny that one has cancer than to deny that the diagnosis implies a death sentence. Denial of implication may be more akin to illusion, positive thinking, or hopefulness, which all of us experience occasionally. The capacity for these mechanisms may be a valuable psychological resource, rather than a distortion of reality.
- (iii) In chronically uncontrollable (and unchangeable) situations, denial may be the strategy that effectively reduces both arousal and concomitant processing of information from the environment.
- (iv) The timing of denial and denial-like forms of coping may be of major significance. Denial may be less damaging and more effective in the early stages of a crisis, such as sudden illness, incapacitation, or loss of a loved one, when the situation cannot yet be faced in its entirety, than in later stages (Lazarus & Folkman, 1984).

By using denial and denial-like processes Lazarus successfully illustrated that: (a) no strategy should be labelled as inherently good or bad; (b) the context must be taken into account in the judgement of coping; and (c) principles must be developed with which to judge whether a particular coping process suits both personal and situational aspects of the transaction. This is the approach that seems to be the most useful for the purposes of psychological research and should be used not only for denial, but should also be considered for coping.



#### 4.4 Information seeking versus information avoiding.

Personal experience and literature indicate that some cancer patients will actively seek every piece of information they can find about the disease in order to understand it better and to cope more effectively. On the other hand, there are those who avoid knowing too much and “leave it up to the doctors”. This behaviour would probably be relevant as additional information on the way patients cope with cancer and may be used during therapy. For example, those who actively seek information could be provided with books that can be discussed during therapy. In this chapter, the theories addressing coping and information seeking behaviour are described.

There are contrasting theories about whom should show better adjustment to breast cancer, information-seekers or information-avoiders. Safety signal theory, preparatory-response theory and information-seeking theory predict better adjustment for the information-seekers, because information allows one to discriminate the safe from the unsafe, to make the appropriate preparatory responses, and to reduce the inherent aversion to uncertainty. However, according to the blunting hypothesis, one cannot be upset by events to which one is not attending. Zemore and Shepel (1987) hypothesised that since information-seekers were more likely to be attending to threatening events than information-avoiders, information-seekers should show more emotional upset than information-avoiders.

To test whether information-seekers showed better adjustment than information-avoiders Zemore and Shepel (1987) did a study on 301 patients with breast cancer who had undergone a mastectomy between 1 and 26 months earlier. They administered the Social Adjustment Scale and a 47-item emotional adjustment scale, with four questions designed to measure information seeking.

Analysis showed a statistically significant correlation between information seeking and adjustment. Patients with breast cancer who scored high on information-seeking,

as indicated by their self-ratings of knowledge of breast cancer, amount read, and number of people with whom they talked to about breast cancer, also scored high on social adjustment and emotional adjustment. These findings are consistent with the safety signal, preparatory -response, and information-seeking theories, and inconsistent with the blunting hypothesis.

Hopkins (1986) developed an Information Preference Questionnaire (IPQ). In the process of developing this scale, which is an instrument to measure information seeking, 58 subjects were interviewed about their information-seeking practices. They were asked to complete the IPQ and two standardised instruments selected to measure how well the patient was adapting to the chemotherapy treatment experience. Information seeking was found to be negatively related with subjects' age and the severity of disease. No significant relationships were identified between information seeking and the adaptational outcome measures of mood states and level of functioning.

From a practical standpoint, the data from these studies suggest that a two-pronged approach should be followed to information delivery in medical contexts. Miller, Combs and Stoddard (1989) suggested that for high monitors/low blunterners, voluminous preparatory and sensory information should be made available, with an opportunity to express emotion and a focus on explicit reassurances about the external sources of competence available. Conversely, for low monitors/high blunterners, more minimal procedural information should be made available, with an emphasis on the patient as an important self-resource in the situation.

#### **4.5 Personality and behavioural factors**

One would assume that a person's basic personality structure have an influence on the way that person will cope with a chronic disease such as cancer. The theories

that attempted to explain coping behaviour from this perspective are called the state/trait theories.

The state/trait approach to coping includes a description of personality factors as traits that have an influence on development of and prognosis of cancer. These theories attempt not only to explain coping with cancer, but also to find a correlation between certain personality types and the development of cancer. They also attempted to show differences in coping with cancer between certain personality types.

The idea that certain personality types might be more prone to develop cancer is not new. In an introduction to their own work on this subject, Greer and Watson (1985) referred to a second century Roman physician, Claudius Galenus, who said that melancholic women were more prone to develop cancer than those of sanguine temperament.

Although the description of personality types had changed, the theory still exists that psychological factors contribute in some individuals, through interactions with biological homeostatic mechanisms, to the promotion of certain cancers. Fox, (1981), Bovbjerg (1991) and Baltrush, Stangel and Titze, (1991) wrote excellent reviews on those studies that dealt with psychological factors, the immune system and cancer.

Eysenck (1985) was one of the founders of the trait theories of personality. By applying factor analysis he identified common patterns which he defined as personality traits. In his work with cancer patients Eysenck (1988) identified two major personality traits which appear to characterise the cancer-prone personality. The first trait is a helpless/hopeless reaction to stress, involving a failure to cope with a stressful situation, and secondly a rational non-emotional, repressed reaction to life events, that would normally produce strong reactions, such as fear or anger.



Greer and Morris (1975) found an association between the diagnosis of cancer and a behaviour pattern of extreme suppression of anger throughout adult life. This correlation reached statistical significance only in women under 50. Similar findings were obtained in a second group of women with breast tumours where they reported a significant association between a diagnosis of breast cancer and an abnormal pattern of emotional behaviour, particularly the extreme suppression of anger.

Three other investigations done by Jansen and Muenz (1984) and Wirsching M, Stierlin, Hoffman, Weber and Wirsching, (1982) and Morris (1980) found expression of anger to be significantly less frequent among breast cancer patients than among controls.

Results of a prospective study done by Scherg and Hum (1987) showed that breast cancer patients, when compared with women with benign breast disease, showed less anxiety and a less pronounced Type A behaviour. They were described as more committed to social and religious norms and data on the Social Desirability scale indicated that cancer patients put off their own wishes in favour of a more socially desirable behaviour.

Grassi and Molinari (1988) investigated the relationship between suppression of negative feelings and psychological reaction to cancer. A series of breast cancer patients were studied preoperatively (n=35), a week after mastectomy (n=32) and six months later (n=12). Six months after surgery, hostility (SQ Hostility scale), inability to express feelings to others and a tendency to perceive the somatic effects of the illness, were associated with emotional repression.

Cheang and Cooper (1985) also confirmed this trait in cancer patients of not expressing feelings. They claimed that the concealment of feelings is the one distinguishing feature of breast cancer patients.



Jensen (1987) studied 52 women with a history of breast carcinoma and 34 healthy women prospectively. A multiple regression analysis which controlled for disease stage at original diagnosis, age, total length of disease course, haematological factors and blood chemistries at study onset, showed neoplastic spread to be associated with a repressive personality style, reduced expression of negative affect, helplessness-hopelessness, chronic stress, and comforting daydreaming. They suggested that further research should be done to examine the role of psychological functioning upon health-relevant behaviours that might blunt the benefits of health care.

The description of psychological factors which might have an influence on the initiation and development of cancer led to a theory of a pattern of psychological attributes called "Type C" behaviour.

#### **4.6 Type C" behaviour**

Morris (1980) stated that suppression of emotional responses, particularly anger, appears to be central to the "Type C" behaviour pattern. Greer et al. (1985) tested the importance of this behaviour pattern as a prognostic indicator, in patients with malignant melanoma, and found it to be significantly associated with thicker and more invasive tumours in the under 55 age group. "Type C", behaviour was also associated, in this study, with a "defensive" response to stress, defined as being "high on both self-reported social desirability and anxiety". They suggested that it was suppression of behavioural responses rather than repression that was important. Subjects were aware of their negative emotions, as evidenced in self-reports, but suppressed behavioural reactions.

According to Weinberger, Swartz and Davidson (1979) breast cancer patients tend to control their emotions and adopt a rational, non-emotional approach to life. Their data

validated the tendency towards emotional control: i.e. the breast cancer group was rated as less expressive than the control group.

Pettingale, Burgess and Greer (1988) described the effect of this type of psychological response as having an influence on prognosis, independent of other known prognostic variables.

Cooper and Farragher (1992) did a prospective study of 2163 women attending a breast-screening clinic, or attending a routine medical check-up. They found a statistically significant relationship between the methods used to cope with stressful situations and breast disease. The group of women who fared "best" in this study (i.e. had a diagnosis of either no disease, or benign disease) used more coping strategies than their counterparts. Their strategies were positive in the sense that they either sought external social support or increased their internal strengths by improving their perceived locus of control.

Renneker, (1981) who did psychotherapy with cancer patients, emphasised the "pathological niceness syndrome" of cancer patients. They appeared to be compliant, submissive, passive, selfless and anxious. They tended to please in order to avoid being disliked. Cancer patients viewed themselves as being externally controlled. They perceived their illness as an anonymous blow and showed a low sense of control and marked helplessness regarding their ability to influence their own lives and health.

#### **4.7 Critique of fixed coping styles**

In view of the more flexible approach towards psychological reaction to stress as described in Lazarus's (1984) theory, it seems imprecise to describe behaviour into categories such as "Type A" or "Type C" behaviour. Syme (1989) described the category approach as an over-simplification of terms, that limits research within that

framework with the result that the multifactorial nature of coping behaviour is lost. Hilton (1989) underlined the importance of multifactorial research in her correlational study of the relationship between commitments, uncertainty about the cancer situation, threat of recurrence, and control of the cancer situation and a set of coping strategies. She stressed that the real world is complex, with many influencing variables, and it seemed that a broad perspective might better account for major variables in coping with breast cancer.

A review by Levenson and Bemis (1991) of the literature on cancer and its potential connections to affective states, coping/defensive styles and personality traits, behaviours, and stressful life events showed that much of the research was flawed by poor study design. While some psychological factors can be associated with cancer onset and progression, no direct links have been established. In his review of the current theory of psychogenic effects on cancer incidence and prognosis, Fox (1983) concluded that there was not enough evidence to support the theory that psychological factors had an influence on cancer incidence. Almost ten years later, Mulder, Pompe, Spiegel, Antoni and Vries (1992) also came to the same conclusion in their review of the influence of psychosocial factors on the course of breast cancer.

Persky, Kempthorne-Rawson and Shekelle (1987) undertook a prospective 20 year follow-up study done of 2018 middle aged men using the Minnesota Multiphasic Personality Inventory (MMPI) and the Cattell 16 Personality Factor Inventory (16PF). The data did not support the hypothesis that psychological repression was associated with the risk of cancer. The importance of this study is that when a prospective study is done on a big group, the trait theory does not always seem to hold.

Further evidence that psychological repression might not have an influence on the initiation of cancer, came from a study of S. Kreitler, Chaitnik and H. Kreitler (1993).



They examined levels of repression in three groups of women pre- and post surgery for breast cancer. The three groups were healthy women (n=40), those whose biopsy showed they had breast cancer (n=32) and women who underwent surgery unrelated to breast cancer (n=26). The results of their study of these 98 women indicated that repression could be a response to the threat posed by a cancer diagnosis and is a means for keeping anxiety at a tolerable level, rather than a personality trait of cancer patients.

In considering a chronic stressor such as illness, it is also possible that some individuals with long-standing disease may not use any particular style of coping. Newman, Fitzpatrick, Lamb and Shipley (1990) warned that attempts to force the data to place subjects onto dimensions such as emotion focused or problem focused coping styles, might lead to a deceptive picture of individuals' overall coping strategies. Jarrett, Ramirez, Richards and Weinman (1992) who found that the majority of patients use a wide repertoire of coping responses, confirmed this view.

It is also difficult to conceptualise how two such contradictory coping strategies as "fighting spirit" and "denial" are described as strategies resulting in longer survival. A fighting spirit strategy, requires an individual to accept the fact that she has cancer and "fight" it, while denial means not accepting the real situation. Moorey and Greer (1989) dealt with the complexity of denial and its implications in terms of coping with cancer, by stating that denial should not automatically be challenged because it might be an adaptive way of coping. It should, however, be questioned during therapy in certain situations. For example, if denial prevents the patient from undergoing treatment, if denial causes communication barriers with the spouse or when it is not effective as a coping strategy and anxiety and depression may occur. In the application of psychological therapy as adjuvant treatment for patients with cancer, Moorey and Greer (1989) moved away from the rigid approach towards coping strategies, towards a more flexible approach which suits the needs of the

individual patient and enable patients and spouses to deal in more effective ways with the threat of cancer.

Meyerowitz (1983) found that denial was the variable most strongly associated with post-mastectomy distress. Denial was more important in explaining distress than the availability of social support, age, or time since operation. Data from a study of Carver, Pozo and Harris (1991) also contradicted the finding that denial may be adaptive. They found, in their one year prospective study of 59 breast cancer patients that acceptance predicted less distress and denial predicted more.

The fixed theories described in the literature review do not accommodate for a more flexible approach towards coping where an individual copes with a situation according to the requirements of that situation at a specific time. The same breast cancer patient may deny feelings of being tired while at work, but may well spend much more time in bed to enable her to cope with her illness. There seems to be evidence of both variability and stability in coping behaviour and research designs should accommodate this.

The psychoanalytic approach that many of these personality theories adopt to illustrate how some individuals are predestined to develop cancer, does not explain how many people with similar unhappy childhood experiences and similar coping strategies do not develop cancer. Somerfield (1992) mentioned the pragmatic advantage of adopting a state, rather than trait, approach to coping. In terms of intervention, it may be easier to change a person's way of coping within a specific situation (what they do) rather than change a coping trait (the way they are). Adjuvant psychological treatment seemed to prove this point, as is illustrated in the following study.

Spiegel's (1993) pioneering study, demonstrated with his pioneering study that women with breast cancer who received adjuvant psychological and social support in



group therapy sessions, suffered less from depression and anxiety and reported that they experienced less pain than a control group of breast cancer patients. Four years after commencement of the study, he found that the average survival time for the control group was 18.9 months and 36.6 months for the experimental group. This meant that, from the time that they entered the study, the women in the experimental group lived twice as long as those in the control group. This work gave further evidence that was confirmed by Leszcz and Goodwin, (1998), that the adoption of a pragmatic approach towards the enhancement of a patient's coping skills may well work towards a better quality of life and possibly a longer life than the use of a theoretical framework where patients coping strategies are described as personality traits which may be difficult to change.

Heim, Augustiny, Schaffner and Valach (1993) came to the conclusion, after their five year prospective study on coping with breast cancer, that there was evidence of constant dimensions as well as variability in coping. It seems that coping is an elusive concept that needs further refinement through long-term follow-up procedures and repeated measures. Current group psychotherapy with patients with cancer, attempt to enhance coping by finding meaning in the experience of having a chronic illness (Greenstein & Breitbart, 2000).

In spite of methodological differences, Glanz and Lerman (1992) found in their review of recent literature on the psychosocial impact of breast cancer, that they agreed that as many as one-quarter of women with breast cancer suffered psychological morbidity. Hopwood, Howell and Maguire (1991) found that one third of their group of two hundred and twenty-two women suffered from affective disorder. Plumb and Holland (1977) found that about a fourth of 97 cancer patients were moderately or severely depressed. Bukberg, Penman and Holland (1984) recorded that 42 percent of 62 oncology patients met criteria for non-bipolar major depression, using the DSM-



III diagnostic criteria. Hopwood et al. (1991) reported that 39 per cent of 75 women who underwent mastectomies had serious anxiety, depression, or sexual difficulties.

If the diagnosis of an initial breast cancer is so devastating to many patients, it seemed important to study the psychological impact of the news of recurrence. Greenberg (1992) stated that the diagnosis of serious and treatable disease was essential to competent medical care and to leave undiagnosed and untreated depressive disorder in cancer patients was "unconscionable". In spite of the fact that it seems so obvious that patients must be devastated by the news of recurrence, very little has been done to explore their reactions so that behavioural interventions to improve psychosocial adjustment can be developed. Hall and Fallowfield (1995) found, in their study on psychological morbidity of patients with breast cancer, that of the 38 women with recurrence, only 8 were offered some form of support by a specialist nurse or hospice nurse.

In studying responses to a diagnosis of cancer, a number of criteria need to be taken into account, including the extent to which the overall pattern of the person's psychological responses enables him/her to:

- (i) regulate or avoid persistent painful emotion;
- (ii) co-operate with medical recommendations;
- (iii) achieve a position which facilitates the optimum adjustment of close others to his/her predicament; and
- (iv) maintain cherished values.

## 4.8 A process approach towards coping

It seems clear from the above critique, that the explanation of the psychological experience of cancer in terms of a fixed trait personality theory, does not leave enough room for satisfactory explanation of the complexity of the individual experience of cancer. A theory, which accommodates the ever-changing nature of human experience, seemed to be more appropriate for the type of study intended here. The coping theory of Lazarus (1991) seems applicable to the description of the multifaceted aspects of the psychological experience of cancer. Although his theory is mainly a coping theory, it also encompasses the wider perspective of the total psychological experience of the disease and it emphasises the relational interactions that take place.

Lazarus (1991) described coping as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. In line with this description, Lipowski (1970) defines the coping of a patient with his illness, as all cognitive and motor activities which a sick person employs to preserve his bodily and psychic integrity, to recover reversibly impaired function and compensate to the limit for any irreversible impairment. He describes coping behaviour as a result of multiple factors reflecting a patient's specific disposition, as well as characteristics of his total situation during a given episode of illness and its different phases. The way in which the patient copes with his illness spells the difference between optimum recovery and psychological invalidism.

The conceptual framework for this study of the psychological impact of the knowledge of a recurrence of cancer and the way patients cope for one year after such a diagnosis, is derived from the coping theory of Lazarus (1984). It was a development in coping theory and research in which the hierarchical view of coping,

with its trait or style emphasis, was abandoned in favour of an approach that treated coping as a process. From a process perspective, coping changes over time and in accordance with the situational contexts in which it occurs.

Lazarus does not exclude the idea of traits totally. He proposed a combined intra- and inter-individual research design to allow the study of coping in both its state and trait aspects. State, according to Lazarus, represents instability (flux) or change. Trait represents stability or consistency across diverse conditions. If coping consistency over time and across encounters is emphasised, we are dealing with the trait concept; if we emphasise contextual influences and coping inconsistency over time and across encounters, we are dealing with the state concept or process. Lazarus described these as two sides of the same coin, and both sides are usually relevant. Confirmation of this argument of both variability and stability in coping behaviour over time and situation comes from a study by Heim, Augustiny, Schaffner and Valach (1993). They found in their study of 74 breast cancer patients followed for 3-5 years at 3-6 monthly intervals, that three dimensions of coping appeared to be constant, namely, support and acceptance; denial; and diversion by thought and action. They found evidence of variability in the potential range of coping modes used. This variability in coping was further increased when coping was assessed over predefined stages of illness, that were described as different clinical situations.

The purpose of this study is to determine how different individuals experience the stressful situation of having a recurrence. Coping is studied as the process through which the patient manages the emotional demands that recurrence places on the person and her relationship with her husband.

Lazarus's (1991) process approach to coping has three main features, which have all been taken into account in the planning of this study.



Firstly, observations and assessment are concerned with what the person actually thinks or does, in contrast with what the person usually would do, or should do, which is the concern of the trait approach. In this study, the assessments cover the actual behaviour, thoughts and emotions of the patient and her family.

Secondly, what the person actually thinks or does is examined within a specific context. Coping thoughts and actions are always directed towards particular conditions. To understand coping, and to evaluate it, we need to know with what the person is coping. The more narrowly defined the context, the easier it is to link a particular coping thought or act within a contextual demand. This study covers coping behaviour of cancer patients with the diagnosis of breast cancer and recurrence.

Thirdly, a coping process entails change in coping thoughts and acts, as a stressful encounter unfolds. Coping is, thus, a shifting process in which a person must, at certain times, rely more heavily on one form of coping, say defensive strategies, and at other times on problem-solving strategies, as the status of the person-environment relationship changes. A study by Edgar, Rosenberg and Nowlis (1992) on coping with cancer during the first year after diagnosis showed that the emotional coping of patients improved over that time. Time itself leads to changes in coping behaviour. Folkman (1984) maintained their coping theory as a description of two processes: namely coping as appraisal and coping. These processes are mediated by stress and are now used to focus attention on an important aspect of coping.

As Lazarus points out, the importance of studying coping behaviour is to determine if some coping patterns are more serviceable than others in given types of people, for given types of psychological stress, at certain times, and under known conditions. The study of coping as a process is a new approach compared with studies on coping within the trait approach.

According to the process theory, both cognitive appraisal and coping are critical mediators in stressful encounters. The individual evaluates first whether anything is at stake in an encounter (primary appraisal). Then the individual evaluates whether anything can be done (coping responses) to overcome the threat and prevent harm (secondary appraisal). Primary and secondary appraisals are influenced by personal and environmental variables. Personal variables include values, commitments, and beliefs; environmental variables include situational demands, constraints, and social resources. If an encounter is perceived to be threatening, coping responses are activated. The first function of coping is to control the problem causing the distress, and the second function is to minimise emotional distress.

As the personal and environmental variables of Lazarus and Folkman's theory suggest, every person interprets and appraises the recurrence in a slightly different manner, because of previous experiences and support available at the time of recurrence. In this study coping is a psychosocial issue, which refers to an interaction between intrapersonal and interpersonal events. Adjustment concerns the response to the environment in an adaptive manner. Dobkin and Morrow (1986) stated that psychosocial adjustment in oncology referred to the way in which the experience of having cancer is handled by the individual.

Folkman (1984) summarised their coping theory as a description of two processes, namely cognitive appraisal and coping. These processes are mediators of stress and stress-related adaptational outcomes. An important aspect of coping within this theory is control. In the context of this theory control can be approached in two ways: as a generalised belief of an individual concerning the extent to which he or she can control outcomes of importance and as a situational appraisal of the possibilities for control in a specific stressful encounter.

According to Folkman (1984) process theory described a stage of primary appraisal where the individual appraises the harm, loss, threat or challenge involved in the stressful situation. If the person interprets the situation as threatening or harmful, emotions such as anger, fear and resentment usually occur. When the situation is interpreted as a challenge emotions are usually pleasurable such as eagerness and excitement are involved. Folkman also pointed out that generalised beliefs about control, which concern the extent to which individuals assume they can control outcomes of importance, influence primary appraisal. Rotter (1966) said that generalised control expectancies have their greatest influence when a situation is ambiguous or novel.

Secondary appraisal comprises the evaluation of coping resources and options. Folkman (1984) described secondary appraisal as addressing the question, "What can I do?" and it becomes critical when there is a primary appraisal of harm, loss, threat, or challenge. Situational appraisals of control are part of secondary appraisal and refer to one's belief about the possibilities for control in a specific encounter.

#### **4.9 Conclusion**

This chapter describes theories that may enhance understanding of how patients may experience a chronic disease such as cancer. It discusses previous studies done within the frameworks of those theories. It seems as though most of those studies were done using a more positivistic approach, than suits the medical model. The quantitative phase of this study could be compared to those studies, but it employs a different approach to the psychological experience of breast cancer.

In order to obtain a different point of view on the same phenomenon, a more qualitative approach is followed to examine the experience of persons with breast



cancer. The qualitative approach leans heavily on interactional theory, which is discussed in the next chapter.

## INTERACTIONAL THEORY

### 5.1 Introduction

The aim of the study is to take a broad integrative view of the experience of living with cancer. This means that to do this as properly as possible on how patients experience living with cancer, no one theory or just one method could be followed. To this end, quantitative as well as qualitative methodological approaches were used. The qualitative approach is explained in the example chapter and in the next chapter. The discussion in this chapter shows the view of the theory upon which the qualitative research was based and the reasons for the inclusion of therapeutic interviews as method of inquiry in this study.

In order to understand the living with cancer for an individual starting at the beginning of experience of having cancer, one is forced to remain aware of different psychological theories as well as the nature of the disease. Different psychological theories such as social learning theory, coping theories, theories of locus of control and self-efficacy, all have a relevance and are discussed in greater chapters. Psychological theories however, deal with intellectual ways of thinking about man and life itself. When it comes to people's experience of illness and specifically a disease such as cancer, specific psychological theories need to be addressed if research in the field of psycho-oncology (Guex, 1994) is to be undertaken.

Bandura (1966, 1977) pointed out that the relative influences exerted by interdependent factors, differ in various settings and for different behaviours. He showed that there are

## CHAPTER 5

### INTERACTIONAL THEORY

#### 5.1 Introduction

The aim of the study is to take a broad integrative view of the experience of breast cancer. This meant that, to obtain a picture as complete as possible on how patients experience having breast cancer, no one theory or just one method could be followed. Therefore, quantitative as well as qualitative methodological approaches were used. In the previous chapters, theories relating to, for example, coping and locus of control, are discussed. In this chapter, an overview of the theory upon which the qualitative research was based and the reasons for the inclusion of therapeutic interviews as method of inquiry, is given.

In order to arrive at a theoretical framework for an understanding of the psychological experience of having cancer, one is forced to remain aware of different psychological theories, as well as the nature of the disease. Different psychological theories such as social learning theory, coping theories, theories of locus of control and self-efficacy are all directly applicable and are discussed in previous chapters. Psychological theories, however, deal with hypothetical ways of thinking about man and life itself. When it comes to people's experience of illness and specifically a disease such as cancer, specific psychological theories need to be addressed if research in the field of psycho-oncology (Guex, 1994) is to be undertaken.

Bandura (1966, 1977) pointed out that the relative influences exerted by interdependent factors, differ in various settings and for different behaviours. He showed that there are

times when environmental factors exercise powerful constraints on behaviour and other times when personal aspects are the overriding determinants over the environmental factors. This means that in social learning theory, people are neither driven by inner forces, nor buffeted by environmental stimuli. Behaviour is rather explained by a continuous interaction of the two. The particular theory of coping discussed in previous chapters (Lazarus, 1966; Lazarus & Folkman, 1984; Lazarus, 1991) also complements the interactional theory of research therapy that will be used as framework for the qualitative research. Although a wide variety of theories have been used during this research, they share the quality of being relational.

## **5.2 A personal attempt to arrive at a theoretical understanding of the experience of breast cancer**

Knowledge of all the above mentioned and other theories and the disease itself is a requirement for doing research in psycho oncology. Being a researcher and a therapist, enables the researcher to find her own way of making sense of data presented by her own and other studies. The researcher is also placed in a more personal environment, where direct contact with patients is necessary in order to obtain qualitative data through therapeutic interviews and therapy sessions.

Being with a patient who underwent a bilateral mastectomy a few days previously, confronts one with not only the patient's emotions, but also with one's own emotions. During these therapeutic interviews I realised once again that the researcher is part of the research process. It is impossible to describe the patient's experience of having cancer, without taking account of the fact that she expressed her experience of having cancer within her relationship towards me as researcher within that particular "here and now" situation. One cannot do research in this way without becoming part of the



process, including one's own thoughts, feelings, experience, one's own view of therapy and theory, one's own feelings and thoughts on death and illness. One has to be able to become part of it, but then also be able to retreat and reflect on what has happened during an interview. Only by being part of the patient's world, is it possible to get a glimpse of what it is to have breast cancer. Only then, can one reflect and analyse.

In the qualitative research process I found it of extreme value to discuss the interviews with a second "observer", my supervisor, who could also enter this world because it is not foreign to him. As a researcher, psychologist, but also as a cancer patient, he experienced this "going in and becoming part of" and the "distancing and analysing" process.

While listening to these patients expressing their emotional experience of having breast cancer, I could rely on my knowledge of the disease and its different treatments and side effects. This knowledge saved them from having to explain, for example, the side effects of chemotherapy or radiotherapy. I understood the different stages of having cancer. That meant that I knew that after a year, many mastectomy patients found a way of living with cancer. I could also recognise the different defence mechanisms, such as distancing, when sadness became too overwhelming. I had the knowledge of the results of the quantitative study to assist me in understanding what the patients were trying to convey to me about their individual experiences of having cancer.

Although this approach towards research felt unique and valuable to me as a researcher, the idea that the researcher is part of the process has been acknowledged by previous philosophers and researchers (Buber, 1947; Sullivan, 1954; Stolorow, Atwood & Brandchaft, 1994; Carkhuff & Berenson, 1967; Esser, 2000; Hoskins, 2000).

With all the available theories already discussed in previous chapters and the knowledge gained from my personal experience and those of my supervisor, one theory seemed to be particularly well suited in describing patients' experience of having cancer. Being trained in interactional therapy and finding this a style of therapy with which I feel comfortable, I chose interactional therapy research for the qualitative part of the study.

### **5.3 Development of interactional therapy**

Interactional psychology is more an approach than a specific theory employing specific techniques (Carkhuff & Berenson, 1967; Swart & Wiehahn, 1979; Hychner, 1991). The interactional therapist uses tools from different theories as they are needed and is therefore not restricted. The techniques are used as the therapist finds them useful to bring about changes in the therapeutic relationship, which would achieve the goals of therapy for that specific client. However, this orientation or epistemology did not happen overnight, but was the result of a development of different paradigms from which interactional research became possible. In order to function in an interactional way and to implement this in the way research is conducted, one needs to think about the world in a specific way, one needs a personal belief system or epistemology according to which one operates on a day to day basis which provides one with a vision through which one constructs and gives meaning to one's life (Becvar & Becvar, 1988). This belief system or epistemology is a socially constructed meaning and therefore not fixed or rigid (Marques, 1999). The theory of interactional psychology developed through different scientific movements and practical attempts at finding ways to deal with human problems. It was a move away from the pure scientific way of thinking of the world but used some of its concepts.

### 5.3.1 Development of an interactional view

As already stated, the importance of interpersonal relations in psychology is not new. Sullivan (1953) brought it to the foreground. He stressed the importance of the interpersonal situation in understanding the phenomena with which psychology deals. He stated: *“Every constructive effort of the psychiatrist, today, is a strategy of interpersonal field operations which (1) seeks to map the areas of disjunctive force that block the efficient collaboration of the patient and others, and (2) seeks to expand the patient’s awareness so that this unnecessary blockage can be brought to an end”* (p. 376). In psycho-oncology, it is the work of the therapist to use the relationship with the patient to determine these “blocks” to healthy emotional functioning and to use the relationship as the healing tool. For example, one often finds that patients find it too difficult to talk about their feelings of anger, fear and resentment because other people expect them to be brave and to keep a positive appearance. They become incongruent in their behaviour and more anxious because they cannot express their emotions. Within the therapeutic relationship, a climate is established where they can feel safe enough to express these emotions and that in itself has a healing effect upon them

Sullivan (1954) described the field of psychiatry as the field of interpersonal relations and said that: “since it has been alleged that this is a perfect valid area for the application of scientific method, we have come to the conclusion that the data of psychiatry arise only in participant observation” (p. 3). The idea that therapeutic interviews where the observer is just as much part of the research process as the participant, has thus also become part of the modern psycho-analytic approach (Stolorow, Atwood & Brandchaft, 1994; Sedgwick, 1994) and it is fundamental to interactional therapy (Carkhuff, & Berenson, 1967). The two-way relationship with particular emphasis on warmth and empathy had also been described and practised by Rogers (1942). Textbooks



(Brammer & Shostrom, 1977; Shertzer & Stone, 1974) prescribed during my training at pre-graduate level, set the fundamentals of the importance of the relationship in my own training. This was followed up much later, by my training as a clinical psychologist with a personal inclination towards interactional psychotherapy and a special interest in research based on this approach.

One of the fundamental concepts in interactional psychology is the concept of cybernetics. This is a word used by Plato to describe the art of steering men and it was in a political sense, referring to different strategies that might be used (Keeny & Ross, 1985). There is thus a historical link between politics and interactional psychology. They share the common underlying notion of communication that includes “who-does-what-to-whom-when” (Keeny & Ross, 1985). The same authors also showed how the strategic, political, functional and interactional consequences in communication are emphasised rather than giving the content.

Cybernetics implicate a relationship between change and stability and was defined as “all change can be understood as the effort to maintain some constancy and all constancy as maintained through change” (Keeny & Ross, 1985). The important role of the person who observes and the role of objectivity came into play when it was realised that the observer becomes part of the process. The idea of second order cybernetics developed, which postulated that there cannot be such a thing as a separate observed system. The way the observer describes his observations is coloured by his own culture, family and language (Boscolo, Cecchin, Hoffman & Penn, 1987).

The different points of view of how it is possible for a researcher to describe what he perceives, is also fundamental to the understanding of the development of interactional theory and research. Answers on how the viewpoint that the researcher is part of the

process, established itself can be found in the development of phenomenological philosophy. Of particular interest, is the notion of the philosopher Husserl, who moved away from the notion that researchers can objectively and separately describe the world (Iturrate, 1976). He described consciousness as: *“the actualization of a kinship that binds subject and object together as codeterminants of experience”* (Iturrate, 1976, p.100) .

Forthcoming from the philosophical and scientific fields, the strategic approach developed. The main figures in this movement were people such as Bateson, Jackson, Weakland and Haley (Grove & Haley, 1993; Kotze, 1983; Becvar, D.S. & Becvar, R.J., 1996). These people were familiar with the concept of cybernetics in the 1940's and started to focus not only on content, but also on patterns of communication.

Of particular interest during this time was the work of Bateson whose goal was to find an appropriate framework for the behavioural sciences. During 1953 he was joined by Jay Haley and John Weakland who formed a research team that became well known for their analysis of the communication patterns of schizophrenic patients. They formulated the double bind hypothesis (Becvar, D.S. & Becvar, R.J., 1996). The importance of this theory is that it moved away from the notion that insight is a prerequisite for cure or change and described schizophrenia as an interpersonal and relational phenomenon. According to Becvar and Becvar (1996) the bridge between intrapsychic and systemic approaches to therapy was made by Ackerman, who combined psychodynamics and the social role of an individual to describe the ongoing maintenance of change and stability in the person, the family and the culture.

During the 1960's a group called the Mental Research Institute (MRI) was established, with Don Jackson as one of the leading communication researchers (Becvar & Becvar,

1996). His contributions were in the establishment of basic rules of communication and the concepts of homeostasis in families. During the 1960's and 1970's Jay Haley was a leading figure at the Philadelphia Child Guidance Clinic where the social context of human problems were emphasised (Haley 1963; Haley & Hofman, 1967). Other important members at this institute who contributed to the interactional approach, were Watzlawick and Weakland who developed a briefer form of therapy with the aim of finding efficient solutions to presenting problems (Weakland, Fisch, Watzlawick & Bodin, 1971; Watzlawick, 1983; Nardone & Watzlawick, 1993). They postulated that in order to solve problems, one has to understand how problems are created and maintained. Of importance to this study, however, is more how this paradigm is applicable to the way research is conducted.

### 5.3.2 The interactive relationship between researcher and patient

Buber (1947) a philosopher, said: *"I cannot depict or denote or describe the man in whom, through whom, something has been said to me. Were I to attempt it, that would be the end of saying. This man is not my object; I have got to do with him"* (p.27). This quotation described my feelings aptly after talking to patients with breast cancer. One cannot distance yourself, you have to be with the patient in order to understand. This perspective that emphasises the researcher's participation in constructing what is observed, is called "constructivism" (Keeny & Ross, 1985; Hoskins, 2000). Although the focus of these interviews was on the experience of breast cancer patients, my own subjectivity was part of the interview and also of the interactional descriptions of experience. The study is thus an intersubjective interpretation of the relationship that took place during the interviews. This intersubjective interpretation of the interviews was further broadened by additional views of my supervisor who listened to the recorded versions of the interviews.



It is important to be aware of being part of the process to be able to distinguish between one's own needs and that of the patient during the process. Kahn (1991) described this dilemma of being part of the process aptly, when he said: "*What seems important is that we think through the implications of each strategy we explore, that we pay attention to the effects on the client, and above all, that we scrupulously consider whether what we do is for the client or for ourselves*" (p. 146).

In interactional psychology, the aims of therapy are clarified and the relationship is used to reach these goals. Seen from another angle, interactional psychology can also be called relationship psychology (Beyers, personal communication, 1999). Swart and Wiehahn (1977) stated that there are manoeuvres on the part of the psychotherapist in interaction with the patient that change the relationships of the patient. Although the therapist is part of this process it is said that he is more "in control" of the process than the patient (Grove & Haley, 1993). With clear aims and the strategies to realise them, this form of therapy becomes a tool for research purposes and can become measurable.

#### **5.4 Research using interactional analysis as framework**

This manner of interactional therapy and doing research becomes an art, with the therapist having to adapt to the demands of the relationship constantly. Using the relationship as the main tool of therapy, it is immaterial whether the therapeutic interview was conducted in my office, a hospital room or the patient's home. There is no attempt to create an impression of standardisation. Yet, the context will also be taken into account, as the context has an influence on the nature of the relationship.

The researcher should keep an open mind towards the process of which he is part and should always heed the warning of Buber (1947) who said :"*I always have been to*

*admire genuine acts of research, when those who carry them out know what they are doing and do not lose sight of the limits of the realm in which they are moving” (p. 29).*

In qualitative research, concepts such as reliability and validity are not found in the research methods or the number of cases studied, but contained in the description of the researcher who is part of the research process. This idea of the responsibility of the researcher was already described by Buber in 1947 when he stated: *“The idea of responsibility is to be brought back from the province of specialised ethics, of an “ought” that swings free in the air, into that of lived life. Genuine responsibility exists only where there is real responding.*

*Responding to what?*

*To what happens to one, to what is to be seen and heard and felt. Each concrete hour allotted to the person, with its content drawn from the world and from destiny, is speech for the man who is attentive. Attentive for no more than that is needed in order to make a beginning with the reading of the signs that are given to you. For that very reason, the whole apparatus of our civilization is necessary to preserve men from this attentiveness and its consequences. For the attentive man would no longer, as his custom is, “master” the situation the very moment after it stepped up to him: it would be laid upon him to go up to it and into it. More-over, nothing that he believed he possessed as always available would help him, no knowledge and no technique, no system and no program, for now he would have to do with what cannot be classified, with concretion itself. This speech has no alphabet, each of its sounds is a new creation and only to be grasped as such.*

*It will, then, be expected of the attentive man that he faces creation as it happens. It happens as speech, and not as speech rushing out over his head but as speech directed precisely at him. And if one were to ask another if he too heard and he said he did, they*

would have agreed only about an experience and not about something being experienced "(p.34).

The above quotation expresses my own thoughts and feelings while being part of the qualitative research process. I was aware of being responsible for the quality of the research process and realised that I, (myself) and my supervisor had to become transparent in this research process in order to report responsibly what was experienced during the interviews. It was important to be aware of our own experience and thoughts because only by being aware of our subjectivity could we report what was found in the investigation. In other words : *"Transcendentalism contends that the "objectively true world" of science is a constitution of higher degree, grounded on experience and on pre-scientific thought, and that, consequently, only a radical investigation into subjectivity, the source of all validity, can arrive at the ultimate meaning of being in the world"* (Iturrate, 1976).

Within this basic understanding that the researcher is part of the research process different options of doing therapy research were open. In order to decide on how to conduct the research interviews, a broader understanding of therapeutic research was necessary.

## **5.5 Psychotherapy research: the process**

The type of qualitative research administered in this study can be described as psychotherapeutic research. The aim of this type of research is not only to gather information, but also to systematically attend to the relationship to understand what type of change had taken place during therapy or during the process of interviewing. Psychotherapy research requires judgement of the therapist that goes beyond the direct



application of knowledge obtained (Polkinghorne 1999). In this study, the aim is not only on information gathering as to how the patients experienced the news that their cancer had recurred, but also how they deal with this experience during the interview. The outcome of this research with patients will probably influence therapy.

There are different ways of doing psychotherapy research (Mahrer, 1999; Kvale, 1996). One could, for example, study the significant change processes as described by Greenberg (1999). This involves the observation, measurement and description of critical changes that take place during therapy. Another method of psychotherapy research is called "Discovery-Oriented Psychotherapy Research (Mahrer & Boulet, 1999). This way of doing psychotherapy research starts by asking questions such as: *"What are the impressive, significant, or valued changes or events that can occur in psychotherapy sessions?"* (p. 1481). These questions are then answered systematically way by a panel of judges who listen to tape recordings made during therapy sessions. Another method of psychotherapy research proposed by Honos-Webb, Lani and Stiles (1999) is to determine markers that indicate different stages in psychotherapy. These stages will indicate progression towards the goals of psychotherapy.

To avoid the trap of falling into subjectivity in therapy research, some researchers have developed extravagant models to be able to quantify results (Mahrer & Boulet, 1999; Edwards, 1998). Others used a more descriptive technique by analysing the discourse that took place (Labov & Fanshel, 1977).

Smith (1999) warned against a "naive pragmatism" in research which leads only to the study of "what works" (p. 1496). In order to prevent this study from falling into the trap of unsystematic research the interactional model of doing research will be adhered to. This method of doing research is discussed in the following section.

### 5.5.1 Interactional psychotherapy research: guidelines for describing therapeutic interviews

Interactional psychology is concerned with happenings between people rather than within a person. It focuses on the interaction between individuals, themselves, and their world in the “here and now”. Each person develops one or more styles of interaction with other people and his world and has to fulfil many different roles such as mother, child or the role of the cancer patient (Beyers & Vorster, 1991). Interactional psychology studies the interactional patterns an individual exhibits and its aim is to enable an individual to adapt her interactional styles in order to cope successfully with demanding situations (Yalom, 1974). For example, a breast cancer patient whose illness has been in remission for the last five years, may still assume the “sick” role of a cancer patient. She benefits from the sympathy of others and is reluctant to take on normal responsibilities. Within the interactional relationship with the therapist, such a patient may become aware of her interactional style and may adapt this in order to cope better with the demands of her other roles, such as that of a wife for her husband or mother for her children. The role of the therapist is to understand the patterns of interaction of the individual before it can be changed. The therapist acts as a sounding board or a mirror to the patient, who becomes aware of her own interactional styles. The therapist adapts his/her style to remove reinforcement for dysfunctional patterns of behaviour in order to diminish those behaviours of the patient. Using the same example of the patient with breast cancer whose disease has been in remission for five years but who still acts pathetically or helplessly in order to gain sympathy from others, will not get sympathy from the therapist but will be supported whenever she shows assertive behaviour. Within the safe therapeutic relationship, the patient will feel secure enough to change from exhibiting dependent behaviour towards more independent self-actualising behaviour.

As with all psychotherapies, the relationship between the therapist and patient is of utmost importance (Yalom, 1974; Swart and Wiehahn, 1979; Kahn, 1991). Interactional therapy is not a mechanistic approach, it can only be successful within a warm, emphatic and safe relationship between patient and therapist.

Nardone and Watzlawick (1993) further developed the understanding of the interactional patterns of individuals within this relationship. They focussed on the following questions:

- i) What are the client's observable behaviours and usual behaviour patterns?
- ii) How does the client define the problem?
- iii) In whose company does the problem manifest itself?
- iv) In whose company does the problem appear, worsen, disguise itself, or disappear?
- v) Where does it usually appear?
- vi) How often does it appear and how serious is it?
- vii) What has been done so far to solve the problem?
- viii) Who would be most affected by the disappearance of the problem?

The Swart and Wiehahn (1979) and Beyers and Vorster (1991) approach of analysing psychotherapy, and more specifically psychotherapeutic research descriptively, seems more to the point and useful. This was the approach used for the analysis of the therapeutic interviews.



## 5.6 Conclusion

The plurality of methods used in this study should provide answers to the formulated hypotheses. The value it places on the diversity of human nature will hopefully provide suggestions on how to improve our understanding of and behaviour towards patients with cancer. It is an attempt to clinically valid and meaningful research that complements the more traditional way of practising research.

The following chapter contains a discussion of the methods followed in conducting this study.

## CHAPTER 6

### RESEARCH METHODOLOGIES

#### 6.1 Introduction

Chapter 1 explains that this research followed a pluralistic approach towards the study of the experience of breast cancer and its recurrence. The literature review showed that most studies done on the psychological experience of breast cancer and its recurrence, used mainly a quantitative approach. These studies seemed to provide limited answers towards the question of how women experience breast cancer. It was thus important to conduct this study using a wide theoretical lens, including those theories already discussed in previous chapters; keeping the physical aspects of the disease and its treatments in mind; but always remembering that each patient also experiences her illness from her own individual frame of reference. This could only be attempted by using both quantitative and qualitative techniques. Using both quantitative and qualitative approaches may be compared to showing the other side of the coin to gain a more complete picture.

The research instruments were chosen within the framework provided by the different theories. For the quantitative approach, the General Health Questionnaire (GHQ) was used as a measure of health status of the patients. As discussed in Chapter 6, it gives an indication of non-psychotic psychiatric disturbance and was described by Goldberg and Williams (1991). This is a questionnaire that falls within coping and stress theories such as that of Lazarus (1966) discussed in Chapter 4. The Hospital Anxiety and Depression Scale (HAD) developed by Zigmond and Snaith (1983) was used to

measure levels of anxiety and depression. Anxiety and depression also fall within the framework of coping theories, as both are expressions of how well an individual is coping within a stressful situation such as having breast cancer.

Still within the general framework of coping, is the way in which an individual perceives control within a specific situation. The questionnaire used to measure this is the Multidimensional Health Locus of Control Scale (MHLC), developed by Wallston, B.S., Wallston, K.A., Kaplan and Maides (1976). The theories related more specifically to control, are social learning theory as described by Rotter (1966), and discussions on self-regulatory behaviour (Bandura, 1977). These theories have been discussed in more detail in Chapter 3. One possible way of taking control may be to use an alternative form of treatment. To test whether patients considered this possibility a semi-structured interview was conducted with them, based on information provided by BACKUP, an organization that aims to provide relevant information to women with breast cancer.

Background to the use of alternative treatments has been discussed in Chapter 3. To describe findings of the qualitative research interviews, an interactional model described by Swart and Wiehahn (1979) was used. This descriptive method and the interactional theory (Carkhuff & Berenson, 1967; Swart & Wiehahn, 1979; Hychner, 1991) were described in Chapter 5. The theories discussed and the instruments used formed parts of a picture as complete as possible about the psychological experience of breast cancer.

To illustrate this point further a short discussion of the different research approaches and the methodology of this study follows.



## 6.2 Therapeutic research as complementary to quantitative research

There are certain limitations in doing only a quantitative investigation in psychological research projects. The first of these limitations as named by Slife and Gantt (1999) is empiricism. The assumption is that only the empirical or observable may be seen as reliable information. For example, in this study that would implicate that the behaviour of those patients who did not use alternative forms of treatment after their recurrence, still trust conventional treatments. Although their behaviour certainly confirmed this conclusion based on structured interview data, many patients would say that they still go to hospital because they do not trust alternative treatments either. Some patients expressed grave concern that they were afraid that previous treatment had failed and that they realized that their chances of long term cure was very limited. This additional knowledge could not be accommodated by empirical research methods. From a therapeutic perspective, however, this is very important information on how patients deal with the experience of cancer. One might even go as far as claiming that the empirical research may lead to the wrong interpretations of results.

The second limitation of quantitative research is the fact that everything is measured. There are things in human experience that cannot be quantified. Trying to classify emotional experience into quantifiable scales, for example, by asking: "On a scale of one to ten, how stressful did you experience the diagnosis of a recurrence of your breast cancer?" limits the amount of knowledge we gain. Quantification oversimplifies and limits information. Quantifiable information can be analysed by statistical means, but loses the depth that is needed in psychological research.

Slife and Gantt (1999) described the third limitation of traditional research as the assumption that scientific knowledge should be universally applicable, fixed and

unchangeable across time and space. Again this is not applicable to psychological phenomena. For example, the emotional experience of a diagnosis of cancer changes with time and varies according to circumstance. In order to find practical implications on how to deal with these situations one cannot ignore the fact that most psychological phenomena are individual experiences and do not only vary between individuals, but also within the same individual.

The last limitation described by Slife and Gannt (1999) is naturalism. This assumption assumes that psychological phenomena are determined by certain laws. It implicitly assumes a cause-effect relationship that excludes the possibility of free will. Within the therapeutic research procedure the possibility of some control and choice within the individual is accepted. In the cancer field the manifestation of this control is clearly illustrated with some patients taking control and managing their illness, while others just give up the responsibility of their health and allow others to take full responsibility. A practical example of this is where a patient herself did not know what medication to take, but her husband knew exactly what pills to give to her at what time.

Quantitative studies are not programmed to deal with individual differences between patients. However, when one needs to intervene it is usually at an individual level. Examples of primary concerns of patients that quantitative research did not adequately address are: fear of being dependent on others and a burden to their families and fear that they might experience pain. Furthermore, none of these studies described how this "fear" or "worry" affected the women in their daily lives. For example, were those who underwent a mastectomy overconcerned with the occurrence of a lump in the other breast, did they check for it more often than the situation warranted, or not?

Given the limitations of traditional research, qualitative research should aim at providing

an additional perspective to the answers provided by qualitative research methods. Psychotherapy research provides the practical answers to enable clinicians to enhance their psychotherapeutic skills. It bridges the gap between science and practice (Golfried, Borkovec, Clarkin, Johnson, & Parry, 1999; Miranda, & Borkovec, 1999).

In order to add to our understanding of psychological phenomena that could not be provided by quantitative analysis of the data, qualitative approaches of research aim to ask questions in ordinary language, towards which patients may respond in ordinary language. They are not requested to transform their experiences into quantifiable scales. The assumption of universalism does not exist in qualitative research. It is assumed that psychological phenomena may be limited to a specific context. Qualitative research does not ascribe meaning, but strives to understand the meaning a person ascribes to his/her own experience.

## **6.3 Pluralistic approach of this study**

### **6.3.1 Introduction**

The psychological aspects examined in the quantitative analysis are perception of general health, anxiety and depression, locus of control and the use of alternative treatments for cancer. I also examined the psychological impact of the news of recurrence on the partners of those patients whose cancer recurred, by comparing their measures of general health, anxiety and depression and marital relationships with the partners of the comparison group.

I obtained approval for the quantitative study from the Ethical Committee of the South East Kent Health Authority in the United Kingdom. This allowed me to assess patients at the breast care clinic within the first few days after hearing that their cancer had



recurred.

A qualitative investigation was undertaken by conducting therapeutic interviews with patients in South Africa. Approval for this part of the study was obtained from the Ethical Committee at the Academic Hospital in Pretoria. The therapeutic interviews conducted were interpreted using the structure of interactional psychology as described by Swart and Wiehahn (1979).

### 6.3.2 Quantitative approach

Three groups were used for this part of the study. The first group of patients consisted of patients whose breast cancer recurred, the second group were breast cancer patients whose disease had been in remission for at least a period of one year. The third group was husbands of these patients. After a description of the groups, a discussion of the method of statistical analysis follows as well as a description of the quantitative measures used.

The hypotheses for the quantitative approach were the following:

- (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.

#### 6.3.2.1 Groups

##### **Patients with recurrence (N=51)**

This group included all patients diagnosed as having a first recurrence of their cancer at the William Harvey Hospital in Ashford, Kent, from September 1992 to May 1994. Recurrence included local recurrence in the breast or distant metastases. Patients with breast cancer, who developed a new cancer located in the other breast or any other area of the body such as the liver or lungs, were also included.

The consultant surgeon or breast care nurse asked eligible patients for their consent to take part in the study. Only patients judged by the consultant surgeon as having a prognosis of at least one year, were seen.

Patients were introduced to the researcher, who explained the procedure. The first set of questionnaires were administered at the breast clinic or on the ward if women had had an operation and had to stay in hospital for a few days. In those cases where the

patients could not be approached directly at the hospital, the researcher contacted them at home by telephone, explained the research procedure and sent the first set of questionnaires by post.

Of the 51 patients who were approached, 40 patients participated. Three patients died without completing the first assessment, 2 patients refused, 2 were excluded because they had a history of depression prior to their initial diagnosis of breast cancer and 2 had incomplete or spoilt questionnaires. One patient was excluded because she did not believe the cancer had recurred, in spite of being told by both the consultant surgeon and the breast care nurse. Another patient went to Mexico for alternative treatment and was admitted to the psychiatric unit of the hospital shortly after her return.

### **Comparison group (N=94)**

The comparison group was breast cancer patients, whose illness had been in remission for at least one year. They were of similar age, type of original cancer, stage of cancer and time of first diagnosis as the recurrence group.

The researcher at the breast clinic approached them when they came in for follow-up visits. She explained the purpose of the research and the procedure, asked for their consent to take part and gave them the first set of questionnaires to be filled in at home and returned by post in a pre-stamped envelope.

Of the 94 patients who were invited to participate, only one patient refused to take part, 18 did not return their questionnaires and 8 returned incomplete and spoilt questionnaires. Therefore, the statistical analysis on this group was performed on 67 patients.

The demographic data of the two groups are shown in Table 1.



**Table 1: Demographic characteristics**

	Recurrence (N=40)	Comparison (N=68)
<b>AGE</b>		
Mean	62 years	58 years
Range	35-85 years	27-80 years
<b>MARITAL STATUS</b>		
Married	26	39
Widowed	9	19
Divorced	2	1
Separated	2	3
Single	1	4
Live together	0	2

There was not a significant difference in age between the groups. The mean number of days since initial diagnosis of cancer for the recurrence patients were 1843 days and for the comparison patients 1831 days (about five years). The majority of women in both groups were married or widowed with few being single, separated or living together.

The groups were also comparable in terms of treatment for first diagnosis, adjuvant treatment, histological type of tumour, and menopausal state as can be seen in Table 2. However, the Mann Whitney test showed that the two groups differed significantly in number of lymph nodes involved at first diagnosis ( $p=0.01$ ).

**Table 2: Physiological characteristics**

	Recurrence	Comparison
Primary treatment		
Mastectomy	23	27
Wide excision	16	36
Tamoxifen only	1	5
Adjuvant treatment		
Chemotherapy	6	6
Radiotherapy	3	1
Endocrine	16	27
No treatment	11	30
Radio and chemo	1	2
Radio and endocrine	1	1
Radio, chemo, endocrine	1	1
Missing	1	0
Menopausal state		
Over 50	29	56
Under 50	11	12
Histological type of tumour		
Infiltrating carcinoma	34	58
Other	1	5
Not recorded	5	5
Number of nodes affected		
0	18	49
1-3	12	14
4-15	6	3
Not recorded	4	2
Tumour size in centimetres		
<2	7	22
2-5	23	40
>5	5	2
Not recorded	5	4

The different types of recurrence are shown in Table 3. Most women experienced local recurrence.

**Table 3: Type of recurrence**

Liver metastases	1
Brain metastases	1
Bone metastases	10
New primary	7
Local recurrence	14
Lymph nodes	6
Lung	1

## Partner groups

### (Recurrence N=9) (Comparison N=18)

The researcher asked patients who gave their consent to take part in the study to hand over sets of questionnaires to their partners. Although the patients themselves were very co-operative and willing to take part in the study, it was evident that it would be difficult to obtain sufficient numbers of partners to take part in the study. Upon request to hand over questionnaires to partners, patients replied with comments such as: “*My husband is much too old to fill in questionnaires*”; another said: “*My husband is too ill too fill in questionnaires*” or “*too busy*” and another said that her husband would get his secretary to fill in the questionnaires. In those cases where the partners accompanied the patients to the out patient clinic, the researcher asked them personally for consent to enter the study.

As indicated in Table 4, the majority (65%), of the recurrence patients was married at the time of assessment. The comparison patients were similar, with 57% married. Thirty-nine of the comparison patients and 25 of the recurrence patients completed the marital relationship scale (GRIMS).

**Table 4: Marital status of the patients**

	Recurrence	Comparison
Single	1	4
Married	26	39
Divorced	2	1
Separated	2	3
Widowed	9	19
Live together	0	2



Nine husbands of patients with recurrent cancer took part in the study and 18 husbands of comparison patients. All these husbands had been married for at least five years and most of them had very long marriages, with a median duration of marriage of 35 years. Both the average age of the husbands and the median age were 59 years.

See Table 5 for a distribution of husbands' ages.

**Table 5: Age of husbands**

Age	Recurrence	Comparison
30-40	1	1
41-50	0	1
51-60	5	6
61-70	2	4
71-80	1	4
TOTAL	9	18

### 6.3.2.2 Statistical analysis

The Statistical Package for the Social Sciences (SPSS) (Frude 1987; Norusis 1991) was used to analyse the data and mainly non-parametric procedures as described by Siegel (1988), were applied.

### 6.3.2.3 Quantitative methods

#### 6.3.2.3.1 Introduction

Recurrence was defined as local recurrence or distant metastasis, or both, with histological or radiological confirmation and timed from the month when clinical symptoms began. The consultant surgeon confirmed the presence of recurrent disease. Either the surgeon or the breast cancer nurse explained the purpose of the study and obtained consent from the patient to take part. They were told that the researcher who would provide more details about the study would contact them. Although the

researcher was often present on the day that the news of recurrence had been given some patients were too distressed to be approached. They were contacted by telephone or visited on the ward within three weeks after the news had been conveyed. During the telephone call or visit the full research procedure was explained and permission obtained to visit them at home within three months to conduct an interview on the psychological impact of recurrent cancer and the use of alternative treatments. They were asked to fill in the first set of questionnaires that were handed over to them in the ward or sent by post in the case of those who were contacted by telephone.

Interviews were done three months after the news of having cancer had been broken and another set of questionnaires was handed over at the same occasion. Two more sets of questionnaires were sent six months later and again after an interval of one year.

The recurrence patients completed the questionnaires four times during the following time intervals.

First assessment - Within three weeks of being diagnosed with recurrence

Second assessment - Three months later

Third assessment - Six months later

Fourth assessment - One year later

Members of the comparison group were recruited concurrently with the recruitment of the recurrence patients and they filled the questionnaires in twice.

First assessment - Within a week of giving consent to take part in the study

Second assessment - One year later

### 6.3.2.3.2 Semi-structured Interviews

Thirty three of the forty recurrence patients were available for interviews three months after the first assessment. The reasons for failure to interview were either because the patient was too ill or had died before the interview could be arranged. One patient, who consented to take part in the study, subsequently refused to be interviewed.

The thirty three recurrence patients who were interviewed were also asked questions about the use of alternative treatments for breast cancer. The comparison patients were sent a questionnaire containing the same questions regarding their use of alternative treatments. A list of the treatments is presented in Chapter 5. This list was obtained from the British Association of Cancer United Patients (BACKUP), Clement-Jones (1985).

The questions relating to expectations and impact of recurrence, were the following:

What do you think caused your cancer to recur?

Did you expect that your cancer would recur?

Did you experience the recurrence as a great shock emotionally?

### 6.3.2.3.3 Questionnaires

#### (i) The Hospital Anxiety and Depression Scale (HAD)

The HAD was used to measure levels of anxiety and depression. It is a self-assessment scale that was developed by Zigmond and Snaith (1983) as a reliable instrument for detecting states of depression and anxiety in a hospital outpatient clinic. These researchers compared the validity and reliability of the scale against psychiatric ratings of patients by using Spearman correlations. The results were  $r = 0.70$  for depression and



$r = .74$  for anxiety. Both those figures are significant ( $P < 0.001$ ), which means that both measures are valid and reliable indications of anxiety and depression. The HAD was developed as a screening instrument in busy hospital settings to identify those patients with emotional disorders who are in need of emotional support (Aylard, Gooding, McKenna, Snaith, 1987).

Patients find the scale easy to complete and it only takes a few minutes. It provides two separate measures of anxiety and depression. For each construct a score below 8 is in the normal range, 8-10 is "borderline" and above 10 indicates a probable disorder of anxiety or depression.

Moorey and Greer (1989) used the HAD in their research projects that involved the development of a cognitive approach towards psychological therapy with cancer patients. They pointed out that the HAD has the advantage of not containing any somatic items which means it gives an indication of anxiety and depression independent of somatic symptoms such as tiredness which might be caused by, for example, chemotherapy received by cancer patients.

A comparison was made between the two groups in levels of anxiety and depression to determine the psychological impact of the news of recurrence within three weeks after the patients had been told. The groups were compared again a year later to determine if possible differences in anxiety and depression persisted after a year of "living" with recurrence. A score of 10 and higher was used to indicate "caseness".

Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson and Bliss (1991) as well as Hopwood, Howell and Maguire (1991) confirmed the factor stability of the Hospital Anxiety and Depression scale and showed again that it is a useful instrument in determining emotional disturbance in cancer patients.

## (ii) The General Health Questionnaire (GHQ)

The GHQ was used as a measure of health status of the patients. It gives an indication of non-psychotic psychiatric disturbance and was described by Goldberg and Williams (1991). The scaled version of the GHQ-60, called the GHQ-28 was used in this study. It was developed on the basis of the results of a principal components analysis of the sixty-item version of the GHQ and is particularly useful for research purposes. It measures the following: Somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. It also gives a total score as an indication of general health.

Morris and Goldberg (1989); Goldberg and Hillier (1979) and Rand, Badger and Coggins (1988) confirmed the validity of the GHQ-28 as an effective screening instrument for psychiatric disorders. Griffiths, Meyers and Talbot (1993) validated the GHQ-28 against the Clinical Interview Schedule (CIS) and found an optimum sensitivity 0.81 and specificity of 0.82 when using a cut-off score of 3/4 (0011 scoring method).

The GHQ-28 was validated for use with patients with breast cancer by Hughson, Cooper and Mc Ardle (1995) who found the scale to be valid ( $r = .73$ ) when compared with observer ratings. They suggested a threshold score of 10 for clinical morbidity. Threshold scores for the subscales were determined as: anxiety and insomnia 6/7; severe depression 2/3; somatic symptoms 6/7; and social dysfunction 7/8.

## (iii) The Multidimensional Health Locus of Control Scale (MHLC)

As measurement of locus of control, the Multidimensional Health Locus of Control Scale (MHLC) developed by Wallston BS, Wallston KA, Kaplan and Maides (1976) was used. The scale reflected three dimensions of health locus of control beliefs as explained by Wallston KA, Wallston BS and Vellis (1978) as: Internality (IHLC); powerful others

(PHLC) and chance (CHLC) externality. The scale determines whether individuals perceive that they have control over their health (internal); whether others have control over their illness (powerful others) or whether the occurrence and course of their illness is determined by chance (chance).

Levenson (1974) also questioned the conceptualisation of locus of control as a unidimensional construct and argued that the understanding and prediction of locus of control could be further improved by studying fate and chance expectations separately from external control by powerful others. She attempted to develop a conceptually cleaner instrument than Wallston's I-E scale.

Since its construction, the Multidimensional Health Locus of Control Scale (MHLC) had been widely used and Wallston KA, Wallston BS, Vellis, (1978) commented that the MHLC Scale predominate in the literature as the preferred means of assessing control in health-related settings.

#### (iv) The Golombok Rust Inventory of Marital State (GRIMS)

The Golombok Rust Inventory of Marital State (GRIMS) developed by Rust, Bennun, Crowe and Golombok (1988) is a questionnaire which measures the overall quality of the relationship between a married man and women or a couple who are living together. It can be used to assess the impact of psychological or medical factors on a relationship. The authors tested the validity and reliability of the instrument against observer ratings and found the scale to be both valid, with a correlation coefficient of .77, and reliable, with a split-half reliability of 0.91 for men and 0.87 for women.



## 6.4 Qualitative approach

A useful approach to psychotherapy and more specifically psychotherapeutic research, is descriptive interactional analysis, slightly adapted as described by Swart and Wiehahn (1979, p. 51). This approach was used for the analysis of the therapeutic interviews. They proposed the following five steps in order to arrive at a good understanding of the client's interactional style. When the interactional analyses were interpreted for patients with cancer, these five factors were taken into account:

### 1. *How does the patient talk to the therapist?*

The therapist determines whether a client's speech is coherent, logical or whether there is the possibility of a thought disorder. Does the individual express herself clearly? What emotions, such as aggressiveness, ambivalence, anxiety, depression, or sympathy are expressed? Notice should also be taken of non-verbal cues that may confirm or contradict the verbal communication.

In Swart and Wiehahn (1979) the emphasis is on psychotherapy. In this study the analysis is used as a method of research. Thus, the way in which the patient talks to the researcher is described. It must also be noted, because of the nature of the open-ended research interview as required for the qualitative approach, the interview takes on many characteristics of what is usually described as therapy. For this reason, ethical considerations came into play and all patients gave their consent for the publication of the content of the interviews.

### 2. *How does the patient talk about her problem?*

Is there blaming, anger, denial, intellectualization or vagueness on behalf of the person? In this study, the "problem" is more the description of the patient's experience of

having breast cancer and formulated as: "How did she speak about her experience of having breast cancer" ? It may, however, also include general problems or any other problems related to the issue of cancer, e.g. the way her family reacts towards her cancer.

### **3. *What is the nature of the relationships of the patient ?***

Aspects to note here, would be, for example, whether the patient is cold, neutral, warm, distanced or controlled. At this stage of the descriptive analysis, it is also important to listen to the manner in which the person talked about her other relationships? How do the relationships help maintain the behaviour in the here-and-now situation? The analysis of the way the client interacts in the relationship with the therapist leads to further understanding of a patient's interactional patterns. Labuschagne (1997) described this interaction as the most important source of information of a client's interactional patterns, because that is the reality of the here-and-now that the therapist has in front of her.

For the purposes of the research, I took note of the way the patient spoke about her important (or not so) others, e.g. her relationship with her husband, children, extended family or friends.

Secondly, the relationship between myself and the patient, during the interview, was analysed, that is, how did she relate towards me, what effect did she have on me and vice versa; how did she come across as a person?

### **4. *What does the patient achieve with her behaviour and symptom?***

This aspect of the analysis created some form of ambivalence and difficulty for me. When I was confronted with a person with terminal illness, an emotional reaction on my

part had to be overcome. The emotional reaction was related to my rejection of the possibility that a person in a state of fighting cancer, or even dying, could possibly be in the position of “achieving” something with her behaviour or symptoms. Although I accept that all behaviour, as defined by interactional theory have effects and reciprocal effects (for that reason also my own aversion to the analyses of this part of patient behaviour), I had difficulty in formulating these as “achievements”, or manipulations. The concept of manipulation is defined here in a therapeutic sense: the withdrawn, shocked person, or the one who radiates a message of: “don’t come closer, leave me alone” sends messages which can be defined as manipulations and/or achievements.

Symptoms usually have a function and often have an effect on other people. If the effect that it has on other people benefits the client the symptom will probably continue. For example, sick role behaviour may often have the effect of eliciting sympathy from others, or it may have been used to get attention from others or may lead to becoming too dependent. If the significant others change their behaviour by for example not being overly sympathetic or not giving too much attention, the individual will probably become more assertive and less dependent on others.

When listening to the magnetic tape recordings of the interviews in order to overcome my own possible rejection of the ideas stated above, the promoter assisted me in defining this part of the interactional analysis. He stated: *“You have to recognize, because of your own vulnerability as therapist and researcher you are vulnerable within the relationship with a patient with a terminal illness. You have to recognize your own humane feelings, in order to become part of an exceptionally sensitive context. This means that conducting research in this manner, your ethics should include openness towards your own mind. You have to be aware of your way of interacting with the patient, your manner of communication, your attitudes as well as an openness to*



*convey what you have done, to report it in your research as clearly as possible. In this way, your research becomes a responsible event*". (Personal communication, Professor Beyers, 2000, Head of Psychology Department, University of Pretoria).

Finally, the emphasis is on the researcher's, that is, my attitude. As Swart and Wiehahn (1979, p. 29) put it: *"In this evaluation, the therapist will place himself in a direct open relationship towards the patient, without bias or prejudice. Only by moving out of his own frame of reference will the therapist be open and free to evaluate the patient"*.

##### **5. In what context is the therapist in the relationship with the patient?**

It is essential to describe the context as it may influence or determine how a person behaves. The context of home versus hospital may influence how a person talks and functions. Thus, context is an important influential factor in the final consideration of the interactional analysis.

The context applicable to this study was that of a patient diagnosed with breast cancer interacting with a psychologist within a hospital environment. The role of the psychologist was to create a safe relationship wherein the patient was free to explore the result of her diagnosis on her interaction with herself and others. The research was adapted to the context of the individual, where her specific needs were respected. Although there may be similarities and even "stages" some cancer patients go through, the researcher was guided by the context that the patient creates within the relationship and not by a preconceived idea of how the interview should progress.

This initial interview was thus interpreted using the interactional model as underlying theory. The interview itself was not used as an attempt to apply any interventions but it

showed possible aims for ensuing therapy with those patients. Although the therapy was outside the scope of this study, it was a natural progression from these interviews. This illustrates how research and therapy practice may become part of a process and not two total separate entities. This underscores the systemic or circular approach that is the basic paradigm towards this study.

## 6.5 Conclusion

In this chapter, an attempt is made to combine qualitative and quantitative measures to obtain a broad perspective on the way patients and their partners react emotionally to the news that the cancer had started again. The research results will be presented in the next chapter.

## CHAPTER 7

### RESEARCH FINDINGS

#### 7.1 Introduction

In this chapter, the results from both the quantitative and qualitative analysis of the data are presented. Quantitative results regarding differences between the two groups in terms of general health status, anxiety, depression and locus of control are given. Thereafter, the results from the semi-structured interviews about the causes for cancer, as seen by the patients, and their expectations about recurrence are discussed. The use of alternative treatments in these groups is also shown. Lastly the analysis of the qualitative therapeutic research interviews is presented and the main themes emerging from these interviews are discussed.

#### 7.2 Quantitative results

As mentioned in the previous chapter, forty patients, who experienced a recurrence of their breast cancer, took part in this study. There were sixty seven patients in the comparison group. However, a number of patients omitted certain responses on the questionnaires and a number of patients responded twice to the same question. This meant that those questionnaires were disregarded. For example, in the case of the Hospital and Anxiety Questionnaire (HAD) only 38 questionnaires of the recurrence group were used and 39 for the Multidimensional locus of control scale.

The results obtained from the quantitative analysis of the questionnaire data are the following:



### 7.2.1 General health

At first assessment, the Mann Whitney test indicated, a significant difference ( $p < .0006$ ) between the two groups with the recurrence patients ( $N=40$ ) suffering from poorer general health than the comparison group ( $N=76$ ). There was, however, no difference between the groups one year later.

At the first assessment, 8 recurrence patients could be classified as “cases”, i.e. the thresholds were high enough to suggest that they were suffering from psychological morbidity. At 12 months, one patient still had a score suggestive of caseness, 4 women did not take part and 3 did not reach the threshold for psychological morbidity. There were three new cases at twelve months who were not classified as cases at baseline.

### 7.2.2 Anxiety and depression

The Mann Whitney Test showed that the recurrence patients ( $N=38$ ) were significantly more depressed than the comparison group ( $N=67$ ), ( $p < .003$ ) but there was no difference in anxiety between the two groups at the time of the first assessment. One year later, the number of patients with recurrent cancer had fallen to only fifteen. Some had died, some were too ill to fill in the forms and a number had moved house. Of the 67 comparison patients, 23 did not return their questionnaires at the one-year interval assessment. An analysis of the remaining 15 recurrence patients and 45 comparison patients showed no differences in anxiety and depression.

When the data was analysed according to caseness at first assessment, it showed that 11 per cent of patients with recurrence and 9 per cent of comparison patients had depression or were borderline cases. Borderline cases mean that they did not quite meet the criteria for depression but verged on it. In terms of anxiety 42 per cent of recurrence

patients suffered anxiety, whilst this occurred in 28 per cent of comparison patients. The classification of patients as cases and non-cases can be seen in Table 6. These results are in accordance with the studies mentioned in the literature review. It is clear that a high percentage of breast cancer patients suffer from emotional disorder.

**Table 6: Hospital and Anxiety and Depression Scale (HAD) Scale Scores**

	HAD Scale scores	Recurrence (N=38)	Comparison (N=67)
HAD Depression			
Non-cases	0-7	34 (89%)	62 (91%)
Borderline	8-10	3 (8%)	3 (4%)
Cases	11-21	1 (3%)	3 (4%)
HAD Anxiety			
Non-cases	0-7	22 (58%)	48 (72%)
Borderline	8-10	7 (18%)	10 (15%)
Cases	11-21	9 (24%)	9 (13%)

### 7.2.3 Locus of control

Table 7 shows that the mean scores of both groups do not differ significantly on the three dimensions. Patients who scored high on the Internal Health Locus of Control (IHLC) also scored highly on the Powerful Others Health Locus of Control (PHLC) and Chance Health Locus of Control (CHLC).

**Table 7: Mean scores on the Multi Dimensional Health Locus of Control Scale**

Recurrence patients (N=39)			Comparison patients (N=65)		
IHLC	CHLC	PHLC	IHLC	CHLC	PHLC
22.28	19.33	21.87	23.72	20.45	22.53

The raw scores obtained by the two groups are shown in Table 8.

**Table 8: Frequencies of raw scores on Multidimensional Health Locus of Control Scale (MHLC)**

Scores	Recurrence (N=39)			Comparison (N=65)		
	IHLC	PHLC	CHLC	IHLC	PHLC	CHLC
5-10	-	-	1 (2%)	-	3 (5%)	5 (8%)
11-15	4 (10%)	7 (18%)	9 (23%)	3 (5%)	5 (8%)	24 (36%)
16-20	10 (26%)	9 (24%)	15 (38%)	14 (22%)	18 (27%)	14 (21%)
21-25	13 (33%)	12 (31%)	11 (28%)	23 (35%)	17 (26%)	24 (36%)
26-30	9 (23%)	8 (20%)	3 (7%)	21 (32%)	13 (20%)	10 (15%)
31-35	3 (8%)	2 (5%)	1 (2%)	4 (6%)	7 (11%)	3 (5%)
36-40	-	-	-	-	2 (3%)	-

Internal Health Locus of Control (IHLC)

Powerful Others Health Locus of Control (PHLC)

Chance Health Locus of Control (CHLC)

There was no statistical between the two groups on any of the locus of control dimensions.



#### 7.2.4 Emotional reaction of partners

Results of Mann Whitney tests do not show any differences in anxiety and depression, general health or differences in marital relationships between the husbands of the recurrence patients and the husbands of the comparison groups.

A high percentage of husbands (39%) and of women (43%) scored a value of 1 on the GRIMS. This can be interpreted that the couples are exceptionally well adjusted in their marriages but a low score such as 1 may also be interpreted as “undefined “ and as an attempt to conceal problems in the relationship. However, many of the husbands (52 %) as well as the same percentage of the women scored between 2 and 5 on the GRIMS, which indicates very good to average relationships. Bearing in mind that the average length of marriage was 33 years and the median 35 years, one may conclude that the undefined score of 1 may rather indicate really good relationships than an attempt to conceal problems. Table 9 shows the duration of marriages of those husbands who took part in the study. Only 2 of the 23 husbands who took part (9%) and 13 of the 54 women (24%) scored between 6 and 9 on the GRIMS, an indication of poor relationships. Further confirmation of the fact that the marital relationships may well have been good, was that none of the recurrence patients had divorced their husbands since the initial diagnosis of their cancer. In the control group, only one person had divorced her husband since her initial diagnosis.

**Table 9: Duration of marriages of partners who took part in the study**

Years	Recurrence (N=9)	Comparison (N=16)
5-15	0	2
16-25	2	2
26-35	4	5
36-45	2	5
46-55	0	1
56-60	9	16

### 7.2.5 Causes for cancer, as seen by the patients

During the interview, patients were asked what had caused their cancer to recur. Their answers are categorized in Table 10. The majority could not think of any reason. Four patients blamed marital issues such as separation or the unfaithfulness of their husbands. Three patients thought recurrence could be related to hormonal changes. Two thought that it was related to a bump or knock on the breast and two others thought it was just bad luck. One patient each gave the following reasons: stopped using Tamoxifen; "medical reasons, without defining the reasons; insufficient treatment at diagnosis; nursing someone else with a chronic disease and financial problems.

**Table 10: Reasons patients gave for recurrence**

REASONS	
Can't think of any reason	17
Marital issues (separation, unfaithfulness)	4
The pill, change in hormones, menopause	3
Bad luck	2
An accident, a knock	2
Stopped Tamoxifen	1
Medical reasons	1
Insufficient treatment after 1st diagnosis	1
Nursing someone else with a chronic disease	1
Financial problems	1
Total	33

### 7.2.6 Expectations about recurrence

Table 11 shows that more than half of the patients had not expected their cancer to recur. Twenty seven per cent thought that it might and eighteen per cent thought that it would recur. A majority of 84 per cent experienced the recurrence as an emotional trauma.

**Table 11: Expectations about recurrence**

Expectations		Emotional shock	
		Yes	No
Yes	6 (18%)	4	2
Probably	9 (27%)	7	2
No	18 (54%)	17	1
Total	33	28	5

Of the six patients who did not experience the recurrence as an emotional shock, five had expected recurrence and only one did not expect it. This shows that it may lessen the blow if patients are aware of the possibility of recurrence. It does not, however, guarantee easier acceptance, because eleven (33%) who thought that it would, or probably would recur, still felt emotionally traumatised by the news and confirmed that it had been shattering. Anger and fright were common reactions. Some expressed less faith that they would be cured. One patient whose first breast lump was diagnosed very early, assumed that she had a very good prognosis. She was particularly shocked and angry at the news of recurrence.



### 7.2.7 The use of alternative treatments

The types of complementary treatments used by the respondents are shown in Table 12.

**Table 12: Complementary treatments used by breast cancer patients**

Type of treatment	Recurrence (N=33)	Comparison (N=63)
Special diet	4	3
Internal cleansing	1	1
Vitamins and minerals	4	7
Mental imagery	3	2
Faith healing	3	5
Acupuncture	1	0
Aromatherapy	2	1
Meditation	3	2
Relaxation	2	6
Visualisation	4	1
Herbal treatment	1	2
Reflexology	1	3
Massage	0	2
Art therapy	0	1
Music therapy	1	3
Total	30	39

The number of patients who made use of those treatments is shown in Table 13.

**Table 13: Number of patients who used complementary treatments**

Complementary treatments	Recurrence (N=33)	Comparison (N=63)
0	20	46
1	6	7
2	3	3
3	2	3
4	1	3
5	-	1
8	1	-

Not one of the 33 interviewees said that any of these complementary treatments would cure cancer. Most of the treatments were done on an ad hoc basis and were described as relaxing and enhancing their general health. The patients did not follow strict regimens, but would rather add more vegetables to their normal diets, listen to a tape instructing them on basic techniques of meditation and relaxation and would take a few

extra vitamins. The one patient who used eight different types of complementary treatments did not do so in a structured or disciplined way. She simply tried a few remedies friends had told her about or added Vitamin C to her diet after seeing a television program about its possible curative effects on cancer.

The most common form of complementary treatment mentioned was diet but no patient followed a strict “anti-cancer” diet. Eating more carrots and other yellow vegetables were mentioned. One patient drank fresh orange juice every day. Another said: *“I do try to eat more brightly coloured vegetables now, but do not follow a specific diet”*.

The use of vitamins and minerals was also on a very casual basis. One patient bought cod-liver oil and garlic capsules upon advice of a friend. One patient took Vitamin B but not in mega dosages. Another took extra vitamins C, E and cod-liver oil. One patient who used herbal remedies, did so a long time ago and could not remember exactly what it consisted of.

Eight patients tried faith healing. This sometimes involved the laying on of hands. One patient knew that a friend had given her name for a special healing meeting at her church but she decided not to attend the meeting. The friend told her afterwards that they prayed for her cure. Another patient was aware that her family went to pray for her, but she did not accompany them. Some of the patients who were religious did not ask for faith healing because their believe system did not allow for that.

The patient who used acupuncture for pain in her back did not think that it would have an effect on the cancer. Two of the patients went to the Canterbury hospital where complementary treatments such as aromatherapy were available to them. One patient said that she investigated the possibility, but could not find the time. Another said she found the treatment at the hospital very relaxing and had continued to take baths with

special salts at home.

Although it has been claimed that intensive meditation can reverse the cancer process, (Meares, 1981) the patients in this study group did not claim any such benefits, but said that it had a relaxing effect upon them. This was usually done with the help of tapes that gave instructions on how to relax and meditate. Four of the recurrence patients admitted that they had tried visualisation whereby they imagined with the help of instructions on these tapes, that their healthy white blood cells “attacked and destroyed” the malignant cells. Not one of them had specific training in relaxation or meditation.

The one patient who used reflexology described it as “*Relaxing, gave me peace of mind and helped me deal with it (the cancer) better*”.

The patient, who mentioned music therapy, found listening to music relaxing and felt that it had a soothing effect, which was beneficial to her general health.

#### 7.2.8 Correlation between health locus of control and the use of alternative treatments

There was no correlation between the use of alternative treatments and a high score on the IHLC. Only one patient in the study group turned to alternative treatment and went to Mexico. I was unable to arrange an interview with her because she was admitted to the psychiatric ward of the hospital upon her return and refused to speak to the breast care nurse. Sixty six out of the total patient population of 96 (69%) did not use any form of alternative treatment (Table 12) and those who did use other treatments did not see it as a cure for the cancer, but as complementary to conventional medicine.

## 7.3 Qualitative results

### 7.3.1 Introduction

Five patients with breast cancer were interviewed in an unstructured way. These interviews were analysed using the Swart and Wiehahn (1979) approach, as described in Chapter 6. The patients were at different stages of breast cancer but not one of them had a recurrence of breast cancer at that stage.

I interviewed patient number 2 at her home and patient number 4 in the ward at the hospital. The other three patients were interviewed in my office at the hospital. I received their names from the breast care nurse at the breast care clinic of the hospital and made initial contact by telephone. I explained the reason for the interview and all five patients whom I had approached agreed to take part in the study and all agreed to the publication obtained during the interviews.

The interactional analysis of each patient's interview, using the five-point analysis as proposed by Swart and Wiehahn (1979) follows. These points are:

- 1) *How does the patient talk to the therapist?*
- 2) *How does the patient talk about her problem?*
- 3) *What is the nature of the relationships of the patient?*
- 4) *What does the patient achieve with her behaviour and symptom?*
- 5) *In what context is the therapist in the relationship with the patient?*

The reader is referred to Chapter 6 for an explanation of the method of interpretation within a context of a terminal illness such as cancer.



### 7.3.2 Interactional analysis of five patients

#### **Patient 1**

#### **Biographical information and breast cancer history**

Patient 1 was a 56 year old woman, married with two adult children.

She had a mastectomy of the right breast, which would have been followed up with chemotherapy, one month before the interview.

She delayed consulting a doctor but eventually she did tell a doctor about the lump, underwent a mastectomy and would have started with a course of chemotherapy soon after the interview. Her delay might have compromised her prognosis and she was aware of this. By following doctors' orders to the letter she probably tried to cope with guilt feelings about not confronting the issue when she felt the lump at first.

#### **Clinical impression**

She was a neatly dressed, friendly woman who appeared to be a little anxious upon meeting me. She seemed to become more relaxed as the interview progressed and willing to cooperate with the researcher but gave the impression of being guarded nonetheless. She seemed to share many of the Afrikaner values such as a strong belief in God and adhere to family values such as the protection of your children and the security of marriage.

#### **1) *How does the patient talk to the therapist?***

She spoke fluently and was able to express her thoughts logically and with clarity. She spoke willingly about both her emotions and thoughts, but her emotions seemed to be suppressed. Her tone of voice was in a slow and monotonous. At times she used

humour in her interactions. All in all, her way of communication seemed to be intellectual and factual, rather than emotional.

**2) *How does the patient talk about her problem?***

She tended to speak about her cancer and the feelings which cancer evoked in her in a distanced way. Yet, it seemed as if she was aware of her emotions, willing to work on her problem of having cancer. Nevertheless, she was very hesitant to express her emotions and stuck to the facts of her disease. When she spoke about emotions, her tone of voice was monotone and it gave the impression of an unwillingness to enter into cancer as a “problem”. However, in an intellectual way, she acknowledged that she was worried and shocked at having cancer. In similar fashion, she admitted that she was scared to undergo chemotherapy.

**3) *What is the nature of the relationships of the patient?***

Her relationship with her husband was described as stable, but that she was the one who had to take the major part in stabilizing the relationship with him since her diagnosis. She experienced that they both went through a difficult time since they had discovered that she had cancer. Again it appeared as though it was difficult for her to share her emotions with him; she allowed him to assist her in her physical care and managed to help him to deal with his emotions regarding her illness.

In spite of her intellectualization and distancing behaviour, it seemed as if she was in general, able to form good relationships, although possibly factually and intellectually defined. Her intellectualization gave the feeling of safety without the possibility of being vulnerable and in despair. She expressed a strong sense of responsibility towards her family. Her inability to confront her adult son who behaved irresponsibly and who took

advantage of her, was possibly because of her inability to redefine her relationship of a mother towards an adult (son).

She presented herself in a confident way and yet, at times she was hesitant in the relationship with the researcher, not willing to share emotionally. Intellectually she was able to express herself, but this had a rigid effect on the relationship, as if defining the relationship as fixed: one of researcher versus respondent.

She also came across as one who needed to work hard in the relationship, possibly to impress that she could cope well. But it appeared as if her efforts were a way of distracting her from her emotions, in that way again placing a barrier against any attempt – also for the researcher – to redefine the relationship.

#### **4) *What does the patient achieve with her behaviour and symptom?***

In her relationship with me as the researcher, her behaviour had the effect of me wanting to reach out and assist her in exploring and dealing with her emotions, yet at the same time leaving me disempowered. The covert message was: "Do not touch me (emotionally) I cannot deal with these negative emotions; I have to be strong and in control of myself for the sake of my husband and son". When she became hesitant, it seemed as if she was in need for emotional support, although too much was at stake – she had to be strong rather than vulnerable and in emotional pain. The fact that I was kept at a formal and professional distance frustrated me. A double message: "Help me, but don't come closer" at times also appeared to be part of her way of communication.

The hypothesis is that similar ways of dealing with her husband and son, may have left them irritable, frustrated and even guilty that they could not really assist this "strong woman" – that they could not reach her, because if they tried, she became hesitant and

stepped back.

**5) *In what context is the therapist in the relationship with the patient?***

The context was one of researcher and interviewee. Yet, there was a tendency towards a more therapeutic climate, which appeared to affect the interviewee to allow brief glimpses of her emotions. Yet, the context of research was dominant, possibly because of the researcher's attitude and the interviewee's reluctance to allow probing of her feelings.

The interview took place in a hospital setting where the researcher had an office. It was private and the context was defined.

**Patient 2**

**Biographical information and breast cancer history**

Patient 2 was a 73 year old woman who was retired at the time of the interview and who was living with her son and grandson because her husband, whom she was married to for forty five years had died.

She felt a lump in her breast while lying in bed. First investigations showed the lump to be benign. She never felt reassured and months later the lump became fixed and proved to be malignant. The cancer had spread to the other breast and both breasts had to be removed. She had the bilateral mastectomy approximately four months before the interview. Her disease was in remission at the time of the interview but she still had pain in both arms and could not be as active as she used to be.



## **Clinical impression**

She was well groomed and a proud lady who carried herself very well for her age. At the start of the interview she was reserved, but later on she talked readily about her emotions and how she experienced the diagnosis of breast cancer. She seemed to very courageous but vulnerable.

### **1) *How does the patient talk to the therapist?***

Her voice and facial expressions appeared to be congruent with her words. There was a constant sadness in her voice when she spoke about the cancer. At times she sounded brittle and depressed and her eyes filled with tears.

### **2) *How does the patient talk about her problem?***

She addressed the problem of cancer directly, weighed up the options and it seemed as if she chose to have the operation. Although she knew that her disease was in remission at that stage, she was scared at the same time that it might recur. She said that she was shocked at the time of diagnosis and also felt exposed because she realised the risk of getting ill again. Knowing that she may have little time left she had decided to live each day positively and with hope. When she spoke about this her voice sounded sad and she became emotional and cried.

She also dealt with the problem in a religious way. She expressed a deep sense of spirituality and said that she believed that she had a guardian angel that would protect her. She said that this belief helped her to feel calm and relaxed.

### **3) *What is the nature of the relationships of the patient?***

She seemed to have good interpersonal relationships because she had long standing

friends, was married for forty five years and had excellent relationships with her children. She realised that she needed support from her children and accepted it. She seemed to be in contact with her emotions and to be an emotionally warm and caring person. Sometimes during the interview she tried to hide her sadness and depression and explained that she also did this in her everyday life in order to save other people close to her of these hurtful emotions.

As an old person she was worried about being totally dependent on others and this made her very vulnerable. She had the ability to describe her emotions because she seemed to be in touch with them and acknowledged her sadness about losing both her breasts.

In spite of being assertive and brave she also came across as very vulnerable in her relationship with the researcher. There was helplessness in her voice when she said things such as *"this is something that I just have to go through"*. She presented herself as a person who was proud and vulnerable at the same time. The influence on me was that I had respect for her dignity but at the same time empathized with her vulnerability.

#### **4) *What does the patient achieve with her behaviour and symptom?***

She seemed to be an action oriented person because she confronted the problem immediately when she felt the lump in her breast by arranging an appointment with a doctor. Since the diagnosis had been made she went had an operation and followed up on her appointments. She also followed to the letter the instructions, such as exercises prescribed by the physiotherapist. Within her physical limits, she stayed active in order to avoid depression. Because of her action-oriented behaviour, other people such as doctors and her family assisted her as far as they possibly could. Her attitude towards her disease and her openness about her feelings also had a positive effect on the

therapist. She succeeded in creating an emotionally warm climate during the interview that made it easy to have an emotional relationship with her.

**5) *In what context is the therapist in the relationship with the patient?***

Her honesty about her feelings created an empathy and understanding for her situation and a wish to be able to help more. Her style of interacting changed the interview into an experience where the researcher felt privileged and enriched to share her experience of having cancer.

This interview took place at the patient's flat that she shared with her son and grandson. This may have created a stronger sense of security during which she felt more comfortable to share her feelings with me than might have been possible for her in a hospital environment.

**Patient 3**

**Biographical information and breast cancer history**

Patient three was a fifty three year old woman who had a radical mastectomy about four months before the interview. She was a nurse for more than thirty years and became matron before she retired.

She knew that she had a genetic risk of developing breast cancer because her mother died of it. This caused her to be very cautious and in spite of regular self examinations and doctors' appointments, the cancer was diagnosed after it had already spread to her lymph nodes. This meant that a radical mastectomy was required. Her perception of the experience of breast cancer was influenced by her impressions of her mother's illness

when she was young.

She underwent chemotherapy and followed doctors' instructions to the letter. Her follow-up treatment consisted of Tamoxifen tablets that she took as a prophylactic measure. She planned to have surgery after the mastectomy to reconstruct the one breast but also to have breast tissue removed from the other breast. This would also be a prophylactic measure to prevent cancer in the other breast.

### **Clinical impression**

She was a well dressed and well spoken woman who gave the impression of taking control of most situations. She let me know immediately that she was in a senior position at a hospital where she had numerous responsibilities and one of those was the training of junior staff. She seemed to have all the facts of breast cancer and other cancers at hand and was willing to share her thoughts with me. However, I got the impression that she needed to be in command of the situation.

#### **1) *How does the patient talk to the therapist?***

She spoke very clinically, logically and non-stop about the historical facts of the development and treatment of her cancer. This probably had to do with the fact that she was a nurse for years but also because she distanced herself emotionally from her situation. Yet, when relating the course of events about the diagnosis and treatment of her cancer, there was sometimes a slight indication of sadness and loneliness in her voice. At these times, her tone of voice became lower and she spoke more slowly. She laughed when she spoke about sad situations and this gave the impression that she tended to be incongruent and that she did not acknowledge sadness. Sometimes there would be anger in her voice; for example when she spoke about nurses telling her that a



procedure would not hurt. She said that they did not have an idea of what it felt like. At these times her tone of voice would become louder and adamant.

## **2) *How does the patient talk about her problem?***

She spoke about the problem as though it was not happening to her but rather to a patient. This gave the impression that she was dissociating from hurtful feelings. However, there were brief moments of emotionality in her voice that she controlled immediately again by explaining how she took action to cope with her problems.

She tended to be very analytical about the facts of the situation, knowing what her chances of survival were and by planning for the future. Part of her plans for the future was to have a reconstruction. Again, she took action to confront the problem. Those things that she could not change she said she accepted as God's will and said that she faced one day at a time. She often tended to use humour to deal with painful or embarrassing moments such as laughing about the problems she had with her prosthesis.

## **3) *What is the nature of the relationships of the patient?***

She appeared to be used to be in control of most situations, as confirmed by the fact that she used to be a matron and lecturer at a hospital. She gave the impression of carrying this "leader role" into her other relationships. She would, for example relate how she instructed nurses who took care of her during her own illness, to be more sympathetic and told them that they could not possibly understand what the patient went through unless they went through the same thing themselves. Her relationship towards the researcher seemed to be the same. She tended to be overbearing, often patronising and she interrupted me constantly. She was friendly, but stayed distant during most of the

first interview.

**4) *What does the patient achieve with her behaviour and symptom?***

She presented as an assertive person who was able to take control of most situations, also of her emotions. She was determined and followed through on her plans. This included planning to minimise the chances of cancer recurring.

By shying away from hurtful emotions, she managed to distance herself from other people and her domineering interpersonal style, separated her further. She managed this domineering style by constant talking, which caused a sense of boredom and apathy in the listener.

**5) *In what context is the therapist in the relationship with the patient?***

Her domineering style succeeded in putting the researcher in a subservient style. The constant monologue frustrated the listener and the therapist stopped paying full attention.

She succeeded in avoiding hurtful emotions by talking all the time and by trying to impress the researcher by being in control. As soon as emotions were mentioned, she would defend by saying, for example, that it would not help to lie and cry and that she preferred to do something. The therapist got a clear message that she was not willing to change a thirty-year pattern of being action orientated and of being in control within an hour-long first interview. She was able to talk about emotion, but extremely careful not to be vulnerable or weak.

## **Patient 4**

### **Biographical information and breast cancer history.**

Patient 4 was a 36 year old married woman with two children aged eleven and fourteen.

She was an attractive woman who was used to be admired for her good looks.

She felt lumps in both her breasts and expected that it might be cancer because her grandmother died from it. She consulted a doctor who referred her to the breast cancer clinic at the hospital. She first underwent a hysterectomy and then a bilateral mastectomy.

She underwent the bilateral mastectomy four days before the interview took place and had not received the pathologist's results on the amount of node involvement at the time of the interview. She would probably have to undergo chemotherapy after being discharged from hospital.

### **Clinical impression**

She was a very attractive woman who was clearly proud of her appearance and she took great care to look her best even a few days after her operation. She spoke easily about her feelings and allowed me to see her pain very soon after meeting me. She gave the impression of someone who copes well and even in these difficult circumstances she was in touch with her feelings and saw the light at the other side of the tunnel, in spite of being extremely worried about her illness.

#### **1) *How does the patient talk to the therapist?***

She spoke in an emotional way and her voice changed rapidly to express various

emotions such as sadness, anger and happiness at being alive after two major operations. At times she spoke haltingly, looking for words to express her emotions, at other times she just kept quiet while the tears ran down her face without any attempt at stopping them. During these times she sounded helpless, exposed and vulnerable. At other times she sometimes managed to smile through her tears and looked happy.

## **2) How does the patient talk about her problem?**

She spoke directly about the operation and her feelings about losing her breasts. She sounded broken and angry that this had happened to her. Her feelings were still very much in the foreground as she spoke about the problem. She said: "*I put my hands everywhere, except on my chest. I don't want to feel it*". She wanted to postpone the reality of a flat chest and said that she did not want to think about it because it scared her. She said her husband enjoyed touching her but after the operation: "*There was just nothing*".

She was a very attractive and friendly woman who seemed to feel the loss of both her breasts acutely. For someone who was so proud of her appearance the cosmetic results of the operation were probably devastating. She was extremely sad about this loss and went rapidly through feelings of desperation, anger and loneliness. Within this mixture of feelings she still retained a sense of humour. She used different coping mechanisms such as repressing her fear of seeing her breasts and postponed looking at her chest.

The way she spoke varied all the time with her having an optimistic view of the future one moment and falling apart the next. Then she could not see her way open in dealing with her family and work. She said that she tried to prepare herself for what would happen, but the reality of the loss of her breasts was much harsher than she had expected. She also felt that she had no choice in this, the disease just happened. She



said that she knew that she was in the situation alone and other people could not really give advice or help her. In the end, she was the one who would have to face the world.

At the stage of the interview her feelings were still very confused about her experience of having breast cancer but she was brave enough not to attempt to shy away from her anger, sadness and fear.

### **3) *What is the nature of the relationships of the patient?***

She seemed to have a good relationship with her husband whom she trusted enough to discuss her feelings. She had two children aged eleven and fourteen and she told them directly what was going to happen to her before the operation. They were allowed to ask direct questions, for example, her son said: "*Are you going to lose all your hair*"? She answered that if she would lose it, they would go and buy a wig for her. They visited her in hospital and seemed to cope as well as one would expect in such a difficult situation. She seemed warm and able to keep very close relationships with those near her.

She also felt anger towards people who never used to give any attention to her but who then suddenly phoned her or who wanted to visit her. She felt that they would abandon her again as soon as her situation had no gossiping value anymore. This gave me the impression that she worked hard at relationships with those close to her, but she was also an assertive person who would not be overwhelmed by insincere attention.

Her relationship with the researcher was very open and she was willing to share her emotions. This made me feel privileged to be in that hospital room with her and I knew that it was not a place for pretense of any sort.

**4) *What does the patient achieve with her behaviour and symptom?***

She was such an emotionally warm person within a very vulnerable situation that she achieved a very close relationship almost instantaneously. It was as if she left no room for superficialities, because it simply did not suit her situation she was in. She needed to let her emotions flow freely which allowed her to move between extremes and she took the therapist with her. It would have been impossible not to be touched by her pain and feelings of helplessness and not to be impressed with her will to live in spite of everything. The way she dealt with the situation achieved a warm emotional climate wherein most people would probably reach out towards her to help ease her load.

**5) *In what context is the therapist in the relationship with the patient?***

When I walked into her room and realised that she was under forty years of age and had just undergone a bilateral mastectomy, I felt overwhelmed and inadequate to deal with her hurt. She created a context of openness in that hospital room that helped me to deal directly with my own and her feelings and this in turn gave her the opportunity to deal with the situation better.

With her lying in her hospital bed and the interview taking place so soon after her operation, this conversation was placed in an immediate emotionally laden context. She was still emotionally raw and unsure about the pathological results. She had not looked at her chest yet and was extremely vulnerable. Within this situation she presented as a person who was in touch with her feelings and who was able to express them congruently and often with humour. She would, for example, say that she would be able to lie on her stomach easier without breasts. She was able to talk directly and openly about the problem and was extremely vulnerable at that stage. She said that there was a difference between the therapist who just allowed her to talk and work out her feelings

for herself and other people who wanted her to “look on the bright side of things”. They said, for example, that she could now have larger breasts when she had reconstruction. She appreciated that she did not have to keep a brave face with the therapist. She said that she felt better after talking to me and I walked out of her room feeling enriched and in awe of her ability to survive the ordeal that she had just been through.

## **Patient 5**

### **Biographical information and breast cancer history.**

The patient was 50 years old at the time of the interview. She was married and had two adult sons.

She felt a huge lump in her breast after using hormone replacement therapy for a few weeks. She did not expect it to be cancer but went to see a gynecologist immediately. Results of the biopsy showed that the lump was malignant. She had two mastectomies a few months apart. She had the second mastectomy as a prophylactic measure because she was scared that the cancer might recur in the other breast. Both scars healed to such an extent that she decided to have reconstruction done to both breasts.

At the time of the interview, she was undergoing breast reconstruction. It is a process that takes place over several stages. She had inflammation in both breasts and it caused pain. She was confused about whether she should go on with the reconstruction or remain as she was.

### **Clinical impression**

She was well dressed, and an attractive woman who made superficial contact with the

therapist with comfort and ease, but she gave the impression that she found it difficult to move to deeper emotional contact. She made good eye contact and spoke fluently although in a monotone. She seemed willing and almost eager to take part in the research project, but at the same time she was guarded about what she said.

**1) How does the patient talk to the therapist?**

She spoke easily and fluently about the facts of her illness – for example how she lost her hair during chemotherapy. She spoke very fast and in a flat monotone. She seemed to not allow any sad emotions into her voice. To avoid sadness she would laugh easily, particularly at awkward situations, for example, about the difficulties of wearing a prosthesis or by being nauseated when she walked into the treatment room even before having chemotherapy. This gave me the impression that she was probably worried about either the breast reconstruction or the cancer, because she sounded anxious and depressed in spite of her fluency.

**2) How does the patient talk about her problem?**

She spoke realistically and factually about her disease and knew that the cancer might recur. She said that she lived with the thought on a daily basis. She explained the facts of the problem, but not the emotional impact it had on her – for example, she explained the costs of a swimming costume with built-in prosthesis, but not how it made her feel to be without breasts.

She explained that was not possible for her to “*lie down in a little heap*” and that she had to be strong because she did not have another choice. She would admit, though, that: “*there is a little voice telling me it is coming back*”. She seemed to see the cancer as something that she had to live with and the best way to do this was to carry on bravely



with her life and not to allow other people to see how scared she was. She said the person next to her had to see a psychologist regularly but they did not arrange for her to see one "*because she managed so well it looked as though she only had the flu*". She seemed to repress any negative emotion that she experienced and I got the impression that she was so scared and vulnerable that she found it necessary to deal with the problem by keeping a brave face in front of everyone else.

### **3) *What is the nature of the relationships of the patient?***

She probably carried these behaviour patterns over to the rest of her life because she related how she organised her life and her family and how she supported other people, probably forgetting herself in the process. For example, she told me how she supported the other patient with breast cancer with whom she shared a room in hospital. She appeared to have a style of denying her own fears by focussing onto someone else's. She lived a life of being positive, brave and carrying on in spite of her illness. She told me that she knew many people but did not have any close friends. She said that she had a good relationship with her husband and sons, but that she cried alone in the bathroom with the taps running.

She seemed to put up a front when with others, but I sensed that there seemed to be a feeling of worry, sadness and of being isolated. However, she had been so used to putting up a positive front that I got the impression that it would be very difficult for her to speak about her feelings. She appeared to deny sad emotions and when she did experience them, she would do it where no one was there to witness it. She dealt with me in the same way as with others – superficially, leaving one with a feeling that there is vulnerability, sadness and pain behind the mask of strength.

She was used to support others emotionally and she probably found the therapist's

behaviour of not being willing to be supported and taken care of, as uncomfortable and disturbing. She gave indications of this by laughing uncomfortably every time the possibility of sadness was mentioned. This behaviour kept the relationship on a superficial level.

By staying clear of hurtful emotions but at the same time telling me that she cried alone in the bathroom, she managed to keep emotional distance between her and the researcher. This double message of “I am fine because I did not need a psychologist – but I cry alone”, made me feel helpless and inadequate in my attempts to find out about her emotions and how she experienced her disease emotionally. This was probably the influence she would have on other people in her life, because neither the nurses nor her husband and sons knew that she was crying just as any other patient with breast cancer.

#### **4) *What does the patient achieve with her behaviour and symptom?***

She managed to keep her emotional distance by relating facts about her illness. It probably helped her to defend against painful feelings such as the insecurity of not knowing when the cancer might recur or the awkwardness of being without breasts. She managed so well with this front of being fine that the nurses did not arrange for her to see a psychologist. It was normal procedure in this hospital to refer all patients who underwent a mastectomy.

Using humour probably served the same purpose of shying away from hurtful feelings and embarrassment. She was, however, a person who was willing to take responsibility for her illness and who would find practical ways of dealing with the implications thereof. She would for example spend time, effort and money to find a costume with prostheses so that she could go on swimming. She also opted for breast reconstruction, in order to improve her body image.

She gave the impression of dealing with the problem in an active way. She was not only a victim of cancer; she was in control in spite of it.

**5) *In what context is the therapist in the relationship with the patient?***

She impressed the therapist as a well spoken person who thought her actions through before acting. She saw me at my office in the hospital and the interview remained within a context of a research interview throughout. She talked easily to me but I had the impression that she was sharing facts, but very scared to talk about her concerns that the cancer may return or her feelings about losing her breasts.

The patient dictated the shape of the interview into that of an intellectual conversation about the facts of her disease. She preferred to sketch these facts and to explain the rational choices she made based upon these facts. Every time a maneuver was made towards moving the interview towards a more emotional level, she reacted by giving more facts or by using humour. She also attempted to steer the conversation away from herself, by asking the therapist personal questions.

**7.3.3 Qualitative investigation - results**

Each patient presented with her own unique style in converting her own feelings and thoughts about her experience of having breast cancer. Once again, the researcher realised that the experience of having breast cancer cannot be interpreted on its own. The person as a whole, a gestalt is involved and the time since the cancer had been diagnosed also had to be taken into account. For example, Patient 1 was more worried about her son who would not take responsibility for his own life than her cancer. Patient 4, who underwent a bilateral mastectomy only a few days before the interview, was still overwrought with feelings of loss and fear of looking at her chest. In spite of these individual differences, the following common themes emerged that need mentioning.



- (i) All five these patients to some extent used distancing from the illness to help them cope with the pain of having breast cancer. Even the patient who had her operation a few days before the interview, distanced herself from it at stages during the interview. This defense mechanism appeared to become more in place as time went by, as can be seen from the interviews with those women who had their operations months before, such as Patients 3 and 5. They all seemed to suppress their emotions to some extent, particularly those of anger and sadness. This may be due to the fact that they do not want to give the impression of just collapsing in a heap and feeling sorry for themselves, as expressed by Patient 3. They kept themselves busy, such as Patient 1 who wanted to start baking for a home industry as soon as possible.
- (ii) Humour appeared to be another way of coping with breast cancer. Some patients made fun of having just one breast and feeling unbalanced, a prosthesis that fall out (Patient 5) or finding it much easier to sleep on their stomachs because there were no breasts in the way (Patient 4).
- (iii) There was a very strong undertone of sadness and a sense of the inevitability of their fate. Together with this sadness, all of them described a feeling that they had no choice, they had to go through with the treatment. Patient 2 said directly *"This is just something I have to go through"*.
- (iv) All the patients said that they had to keep up a brave appearance in front of family and friends and found it a welcome change to be able to speak openly and frankly about their feelings of fear and sadness. Even though they would, for example, allow their husbands to help with the wound, such as was the case with



Patient 1, she still found that she could not talk to him openly because of his worries about her health. Patient 2 said her children already took care of her she did not want to worry them more. Right at the end of all the interviews, they would thank me and said that talking helped them in some way.

- (v) They took responsibility for the feelings of those close to them and tried to make things easier for them. For example, Patient 1 was more worried about her son who was depressed and felt partly responsible. Patient 4 spent extra time to explain to her children what was happening to her and answered their questions as well as she could. Patient 5 said she functioned so well that someone commented that it seemed as though she only had the flu.
- (vi) All of them could relate what happened to them in a coherent, factual way and this seemed to be a way of making sense of what happened to them. They could all relate their medical histories very well.
- (vii) Some of them used religion as an emotional crutch to help them through the difficult forms of treatment and the worries they had about their cancer. For example, Patient 2 said she had a guardian angel that protected her. Patient 3 said what happened was God's will and that she took one day at a time.
- (viii) All five patients used conventional treatment and although they were scared of the side effects of chemotherapy, as was the case with Patients 1, 4 and 5, not one of them gave me the impression that they wanted to stop treatment.

#### 7.3.4 Themes emerging from the quantitative analysis of the questionnaire data

Two of the main themes emerging from by the quantitative analysis of the questionnaire data and the structured interview was confirmed by the information obtained from

therapeutic research interviews.

(i) Most women who have breast cancer fear that it may start again.

During the interviews, it emerged that they feared that not all of it had been removed and they would eventually die from it. Patient 2 said directly that she feared that it may recur; Patient 3 took both Tamoxifen and planned to have a prophylactic mastectomy in an attempt to prevent a recurrence; Patient 5 spoke of a little voice telling her that the cancer might start again. This fear was intensified by knowledge of friends or family members, who had died of cancer, as was the case with Patients 3 and 4.

(ii) Not one of the patients who took part in the interviews made use of alternative forms of medicine.

This confirmed the previous conclusion emerging from the quantitative research process that most patients will undergo conventional treatment in spite of the side effects.

As expected, the qualitative analysis of the research interviews supplied more individual information on how patients experience having breast cancer. Working with each patient, gave a strong impression that this experience is complex and although there may be themes such as those discussed above, it would be an oversimplification to describe it only quantitatively.

In the last chapter, the knowledge gained from the literature review, the quantitative analysis and the qualitative analysis is integrated.

## CHAPTER 8

### DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

#### 8.1 Introduction

Upon completion of this study, I realised that it had evolved in parallel with my own growth both as a scientist and as a therapist. I started the study in England in 1993 where the research climate in medical psychology was mainly quantitative and evidence was based on comparisons between large groups of patients. These studies were often done by psychologists working in collaboration with medical practitioners and statisticians, with the doctors and statisticians often dictating how the research should be conducted. This meant that the model and the terms used during these projects suited the positivistic and medical paradigm. Such collaboration in huge breast cancer studies brought new insights to the fore regarding, for example, patients' views on different treatment regimens. These brought the concept that the patient should play an important role in treatment decisions.

As a researcher in that environment, I got the impression that qualitative information on aspects such as the emotional experience of having breast cancer, were lost because the methods were not geared to describe such a private and emotionally variable phenomenon. Quantitative studies employing questionnaires may result in psychology studying a decontextualized self which may result in superficial understandings of the complexities of human experience (Hoskins, 2000).

Upon my return to South Africa and as a student in clinical psychology, I became more adept at the use of qualitative research approaches to human behaviour. I realized that

these orientations might provide a wider perspective on a person's experience and in the case of cancer, of having a life threatening disease. The knowledge gained from my studies equipped me to interact more effectively with patients with breast cancer during therapy and I became aware of other ways of conducting research.

In Chapter 1 I elaborated how my own development had an influence on my view of the study. During the first quantitative phase of the study, I was acutely aware of the distance between myself as the researcher and the patient. The questionnaires required very little interaction between patient and researcher. Part of the quantitative research was to use semi-structured interviews. These required that questions should be asked in a structured way. I had to be in the role of the objective inquirer/researcher. However, I found often after terminating the interview, when the tape recorder was switched off, patients talked more freely, which allowed them to say what was on their minds. However, there was no structure in the research design to capture these valuable data. This made me aware that quantitative methods would not provide a fully comprehensive view on the emotional experience of breast cancer. It became necessary to employ qualitative methods by conducting therapeutic research interviews.

During the therapeutic interview phase of the research, the patients who participated were allowed to speak about aspects that seemed to be important to them. By applying the interactive analysis to describe these interviews, the qualitative data could be recorded. During the interviews, the researcher became interactive in the process and it clarified what the patients wanted to convey about their experience of having cancer. Producing the descriptions of the interviews I realized that although the focus of the interviews was on the patients' experience, the researcher's own subjectivity entered into the descriptions of their experience of having breast cancer (Hoskins, 2000). This approach towards research can thus be described as an intersubjective interpretation of



the discourse that took place.

Upon completion of this study, there is no doubt in my mind that the qualitative interviews provided much needed knowledge for health care workers supporting cancer patients. However, coming to that conclusion was also a process. It was as though the research and the researcher had to go full circle to gain understanding of how to proceed. As discussed in Chapter 1, it was as though I had to undergo a “cure” from my own rigidity of mind to be able to conduct this research.

The conclusions drawn from this study in terms of both the quantitative and qualitative analysis will follow.

## **8.2 Quantitative analysis**

The following hypothesis 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 do.

### **8.3 Discussion of the results of the quantitative analysis**

The results of the quantitative analysis of the data showed that women who had experienced a recurrence of their cancer was a group who had lower perceptions of their general health and suffered from more emotional morbidity than other women whose disease was in remission. These results are in accordance with the studies mentioned in the literature review. It is clear that a high percentage of breast cancer patients suffer from emotional disorder.

This study confirmed that the news of recurrence caused emotional trauma. The devastating effect of such news was also reflected in the depression scores of the recurrence patients who were significantly more depressed than the comparison group. We found that 82 per cent of patients experienced the news of recurrence as an emotional trauma. During the interviews, patients described how distressed they were at the time. The overall majority expressed emotional distress upon hearing that their cancer had started again. It is clearly a stage when emotional support should be available.

The majority of patients could not think of anything that caused the recurrence of their breast cancer and one can only speculate about the reason. It is possible that they thought it was purely a matter of chance, if it happened to them once it could happen again, or they were not interested in causes but in getting on with the treatment. In contrast with results reported by Fallowfield and Clark (1991) where knocks, bumps or strains were seen as the most common causal factors blamed for the development of breast cancer, only one patient thought that a knock could have caused the recurrence. It is possible that the recurrence patients in this study had acquired more knowledge of the disease since development of their initial cancer and realised that a knock on the breast could not cause breast cancer. Another possible reason could be that they were too shocked or depressed to think about possible causes and this led to disinterest or to a diminished ability to think or concentrate similar to patients with trauma (Kaplan, Sadock & Crebb, 1994).

Patients who expected a good prognosis after their first diagnosis of breast cancer are more surprised and shocked by the news of recurrence. This finding confirmed those of Weismann et al. (1986) and Cella (1990). Although expectation may soften the emotional impact of such news we found that 33 per cent of those who expected it might recur or would recur, still found the news an emotional shock. We found that 82 per cent experienced the news of recurrence as an emotional trauma.

The devastating effect of the news of recurrence was also reflected in the depression scores of the recurrence patients who were significantly more depressed than the comparison group. These results confirmed those of a prospective study done by Hall et al. (1995) who found a significant difference, with the recurrence patients suffering more from psychiatric morbidity than women with breast cancer who were disease free at that stage. They found that half of the 38 patients with recurrent breast cancer that they

interviewed were either clinically anxious and/or depressed. They concluded that the psychiatric distress appeared to be a direct reaction to the diagnosis of recurrence because the difference between the groups was not present before.

The patients whose cancer recurred also suffered from poorer general health than the comparison group at first assessment, but there was not a significant difference after one year. This may be explained by the fact that only one of those patients who survived for one year had visceral metastases, which implied a bad prognosis. The majority of the survivors may well have enjoyed better general health and had better prognosis than those patients who did not take part in the twelve month assessments. However, at the 12 month assessment, 4 of the 16 recurrence patients who were well enough to fill in the forms, again suffered from psychological morbidity. Three of those were “new” cases that indicate that psychological morbidity in recurrence patients may also develop later and is probably linked to physical health.

There was not a statistically significant relationship between any of the locus of control dimensions and the use of complementary medicine. The hypothesis that those patients with a high internal locus of control will be more inclined to use complementary treatments, particularly after the experience of recurrence, was not confirmed. Although a small number of them used complementary medicine, they did not believe that this would cure their cancer and stated that it was used more for relaxation and general health. These patients still believed in the ability of their doctors to control or cure their cancer, also in the case of those patients whose cancer had recurred. It seemed as though these patients did not exhibit a preferred mode of locus of control as described in the literature (Rotter, 1966; Wallston, 1989). Although they would, for example, say that they trusted the doctors, this trust did not seem to be unrealistic to a point of not assuming own responsibility.



There were no differences in general health or anxiety and depression between husbands of the patients whose cancer recurred and husbands of the comparison patients. This may be due to the general nature of the questionnaires, which were possibly not sensitive to distress caused by specific problems such as illness of the wife. Although this study dealt mainly with the emotional impact of the news of recurrent cancer on patients, it might have been more informative to interview the husbands as well to get a broader perspective on the impact of recurrent cancer on partner relationships.

When one does research with patients who had a recurrence of their cancer it is important to take into account that many of them would have died or would be too ill to take part in the assessment one year after recurrence. It is important to start with great numbers to be able to do follow-up assessments.

#### **8.4 Confirmation of themes from the quantitative analysis**

As shown in Chapter 7, much of the knowledge gained by the quantitative analysis of the questionnaire data and the structured interviews, was confirmed by the information obtained from the therapeutic research interviews.

The therapeutic interviews also showed that most women who have breast cancer fear that it may start again. This is an issue that will have to be dealt with as soon as a woman has been diagnosed with a first breast cancer.

The use of alternative medicine is not in place of traditional medicine but rather as an add-on to conventional medicine. All the women who were interviewed kept their faith in their doctors and would only use complementary treatments for relaxation or general health. The therapist should possibly make patients aware of the fact that the use of any

complementary treatment should be discussed with the treating oncologist.

## **8.5 Discussion of the results of the qualitative analysis**

Five patients were interviewed and the interactive analysis provided insightful additional information on the emotional experience of breast cancer. Each patient presented with her own unique style in converting her own feelings and thoughts about her experience of having breast cancer. Once again the researcher realised that the experience of having breast cancer cannot be interpreted as a factor on its own, but that the total background of the person should be involved.

Additional information provided by these therapeutic interviews showed that most patients use distancing as a defense mechanism to help them cope with the pain of having breast cancer. They appeared to suppress their feelings of anger and loss and it is not clear whether this had been their style of dealing with strong feelings pre-morbidly. There is the possibility that this mechanism may actually be a contributing factor towards developing cancer (Eysenck, 1988; Cooper & Watson, 1991; Derogatis, Abeloff & Melisaratos, 1979). It has also been proven that therapy aimed at allowing women to express their feelings may prolong survival in cancer patients (Spiegel & Bloom, 1989; Spiegel, 1993).

The important role that humour (often a crude sense of humour), plays in coping has been shown in these therapeutic interviews. It provided an outlet for expressing the feelings of desperation and helplessness and the ability to laugh eased the desperateness of their situations and provided emotional relief.

The patients' feelings changed rapidly and in spite of the humour there was always an undertone of sadness and a desperate feeling that they had to comply with the treatment

and cope with the side effects. Most patients said that they tried to keep up a brave appearance in front of family and friends. Although humour is a good defense mechanism for relieving emotional pain temporarily and thus has a definite place in coping with a chronic illness, it is also a way of distancing from hurtful feelings. If used constantly, such behaviour may become fixed and incongruent and there may be the risk that hurtful emotions will not be expressed. Once again, this may lead to suppression of feelings that may have an effect on the development or recurrence of breast cancer.

There is a strong sense of underlying sadness with these patients with breast cancer and almost a resigned sense of having to go through with the treatment.

These therapeutic interviews revealed that most patients needed therapy to help them deal with their feelings more congruently. Most of the patients would also benefit from sessions with their partners or family members. Once the therapy succeeded in opening up feelings and addressing these feelings in an open trusting relationship, most of the "brave face and keeping a strong appearance" would not be necessary. This would also reduce dependence on a therapist, because the partner or family would be able to take on the role of the therapist, or to assist in the process of therapy.

## **8.6 Reflections on the different research approaches**

There are definitive advantages to the examination of research questions according to a variety of theories and by the application of different research methods. During the course of the study themes or a pattern may emerge. This will provide conclusions that may be assumed, fairly confidently, to be reliable. For example, the finding that most patients with breast cancer fear that it may start again, was mentioned in the literature and was shown in both the quantitative and qualitative results. Suppression of emotion



was found in both the interviews and mentioned in the literature (where it was described as Type C personality). The advantage of the interviews was that it also showed how this suppression is achieved by a variety of coping methods such as by using humour; by being domineering; or by keeping a brave face in front of family and friends. Each person's own style of coping was shown and therapy could be directed with definite aims in mind.

The different methods possibly evoked contrasting emotional reactions from the participants. All the patients who were interviewed said that they "*felt better after discussing their experiences with someone who is an outsider*". With the interviews the patients were allowed to discuss aspects of their experience that they deemed important. The structure of the questionnaires employed in the quantitative analysis were of such a nature that patients chose between alternatives provided by the questionnaires. This has the advantage of standardization, but lost the individuality of a person's experience.

Therapeutic interviews, done by a qualified person should have a therapeutic effect. The patients, who said that they felt better after being able to talk to someone, confirmed this.

Researchers should be aware that the "objective" relationship of the quantitative approach to research and the intersubjective stance and relationship of the qualitative approach, would bring two different sets of valuable data to the fore. Both need to be taken into account. However, in research designs where there are indications, even possible clues of trauma or shock, it is advisable that unstructured therapeutic interviews should be implemented as a research tool. Beyers (Personal communication, 2000) is of the opinion that in cases of severe shock and trauma, the use of questionnaires border on unethical behaviour. He is of opinion that the rigidity of the quantitative



researcher does not allow the person in trauma to present him or herself as he or she is at that moment in time. Furthermore, such an objective stance then biases the results.

A finding of the quantitative approach that was confirmed by the qualitative approaches was that breast cancer patients need to be emotionally supported. One can also interpret the suppression of emotions and the use of defense mechanisms as ways of coping with stress and trauma. These are indications for psychological support, even therapeutic interventions to “be with” the cancer patient, especially the women who possibly mourns the loss of a body part which may be her symbol of womanhood and sexuality.

The qualitative interviews provided information that was not contained in the quantitative research. For example, the role of religion was mentioned by some of the patients. This will be an aspect that would not easily be addressed in a big international study because of the diversity of religion all over the world. However, in qualitative research, the possibilities of dealing with issues such as religion and illness are endless. One finds that patients often use their religion as an emotional crutch that helps them to deal with their emotions. Because of the unstructuredness of qualitative research, one has no fixed ideas of what the meaning of religion to these patients is. One may find then that some start asking questions of the fairness of their God; or they explore the meaning of religion to them and how they find comfort in believing that God will be with them when they die. This style of interviewing allows one to understand how the same phenomenon, such as patients' belief or sometimes, anger at God, may help or hinder them in their adjustment to cancer.

There is also the possibility that the items in the questionnaires may trigger some feelings of apprehension or fear that were not present before. For example, the locus of

control questionnaire may enhance the feeling that the patient does not have control over what is happening to her. This may be a fearful thought in itself and may cause stress. Questions from the General Health Questionnaire used in this study such as: “been feeling unhappy or depressed” or “been thinking of yourself as a worthless person” may trigger negative self-depreciating thoughts. Although it is accepted that many patients with breast cancer may experience these feelings, some may not and these questions may create unnecessary confusion and worry.

International studies, where thousands of people participate and where different health practitioners collaborate, need a common language. For such studies, quantitative research is the most practical. Terms such as sample size – the bigger the better or “well standardized questionnaire” form part of the scientific lingo. The shorter the questionnaire the better, because that would mean that it is easy to administer to thousands of patients all over the world. The more people in one group who agree with a statement as compared with another group who disagree, the bigger the level of significance, and that would mean an important result in the research community.

As could be expected this does not happen too often in psychological studies, possibly because quantitative methods are not always the “right tool for the job”. Adequate qualitative research will possibly provide more insightful information that will be of more practical use to health practitioners in providing a better service to their patients. Both approaches towards research in the field of psycho-oncology are important and fulfill a specific role.

## **8.7 Integration of the theories, the literature review and the results of this study**

Most of the theories chosen as framework for this study share a common principle of being relational. For example, the coping theory of Lazarus (Lazarus, 1966; Lazarus & Folkman, 1984; Lazarus, 1991) emphasised the relationship between the individual and herself; the individual and others around her; the individual and the disease. It showed that coping is not an event with linear movement, but rather a process that is circular and ongoing. The multi-dimensional health locus of control theory of Levenson (1974) also operates from a relational perspective, namely the person's relation towards the self (internal) relation towards others (powerful others) and towards the world or God (chance). The paradigm used for the qualitative research in this project also used interactional psychology as theoretical framework. As discussed in Chapter 5, this theory evolved from a long history of other relational theories.

The quantitative part of this study was also an attempt to stay within the framework that coping with breast cancer is an ongoing process, because the measurement was not just a one-off affair. The questionnaires were administered three times to the group of patients who experienced a recurrence of their breast cancer. This was to accommodate the possibility that coping changes over time and that this may be reflected in the results.

The stage of the research where the relational character of the study was accentuated, was during the research interviews. During these interviews the relation between the researcher and the patients was used to describe the findings. The true intersubjective nature of psychological research was illustrated in this process.



## 8.8 Conclusions and recommendations

There is no medical cure for all cancer patients and it seems as if the psychological treatment of these patients is far from adequate. This study attempted to show how multifactorial and complicated the effects of the disease are to the human psyche and hopefully to provide an understanding of how to deal with these patients during therapy. Although the study provided certain specifics regarding the interactional dynamics of patients with breast cancer, it should not be seen as exhaustive. It is hoped that the indicators will enhance health practitioners' knowledge of the complexities involved in the psychological experience of the recurrence of breast cancer, if not to all patients living with a life-threatening disease.

Both the quantitative analysis and the qualitative research showed that support, such as therapy, for these patients should be a standard procedure. Therapy should be individualized towards the specific needs of each patient, but there emerged general guidelines that may be followed. Most patients find it difficult to express their feelings of anger, loss and sadness. Therapy should be aimed at assisting them to express these. There could be a possibility that the inability to express their feelings may have been a contributing factor towards developing cancer or the recurrence thereof. It is possible that therapy may help break the vicious circle where the suppression of feelings may be a contributing factor.

Not this study, nor my previous study (Falkson, 1999) provided all the answers to the question of how people experience cancer. I received a telephone call from one of my patients who was dying, who said: *"I know why God made lovely things such as flowers, but Annette, can you tell me why I must have so much pain? Why did He do that?"* I suppose I will reach the end of my own life journey without being able to answer



questions such as these, regardless of all my research projects.

## 8.9 Closing remark

Irrate (1976) said: “*Science, reduced by nineteenth century positivism to mere sciences of facts, has become alienated from the problems that are truly decisive in man’s life*”. It is the responsibility of the human sciences and particularly psychology, to provide non intrusive methods that will provide valuable information that can be used to enhance the quality of life of patients; to understand the complexities of the lives of people; to possibly prevent illness and to prolong the lives of those who wish to do so, regardless of pain and illness.

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