

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.