

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.