COPING WITH BREAST CANCER AND MASTECTOMY:

A Prospective Study of the Process.

By

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ABSTRACT

Breast Cancer is one of the most common types of cancer in women. It is found among all races and has featured throughout history. An accepted form of treatment for this disease is to remove the entire breast, a procedure known as mastectomy. From a psychosocial perspective the implications are likely to have far reaching effects. But women respond to mastectomy in different ways, and use different strategies to cope.

Although unlikely that coping strategies are used in isolation, researchers disagree about how the different combinations may operate. To investigate the effects of disposition and situational factors on the coping process, thirty-two mastectomy patients were monitored from the eve of their surgery, for a period of three months. Almost all participants came from low socio-economic backgrounds and had limited formal education. A variety of quantitative and qualitative measures were used, with questionnaires and semi-structured interviews being administered on five occasions over the study period.

The research was based on a paradigm of positive psychology, and focused on the origins of strength in women dealing with mastectomy. The chief measure of disposition was Antonovsky's (1987) Sense of Coherence. Coping outcome was measured on the Satisfaction with Life scale (Diener et al. 1985), and the Mental Adjustment to Cancer (Watson et al., 1988) was used to assess coping styles. Other scale measures were the Acceptance of Illness, (Felton et al.1984) and Partridge & Johnston's (1989) Recovery Locus of Control.

Four related hypotheses were tested in this prospective, correlational study. To predict satisfaction with life after mastectomy, a simple coping model was conceptualised and tested with multiple regression analysis. As anticipated, findings indicated that coping with cancer and mastectomy is multi-dimentional.

Delineating the factors that differentiate good versus poor satisfaction with life post mastectomy, it was found that disposition, acceptance of illness, faith, religiosity, and coping style were all associated with adjustment. Women who coped well were older, had a high Sense of Coherence, found support in their faith and religious practices, and made more use of the Fighting Spirit style of coping. The less competent copers on the other hand, were characterised by younger years, lower Sense of Coherence, more severe treatment regimes, less support from religion, and more frequent use of the coping styles identified as Helpless/Hopeless and Anxious Preoccupation.

A strong positive correlation (0.63) was found between disposition, measured pre-operatively on the Sense of Coherence scale, and Satisfaction with Life assessed three months post-mastectomy. Results also indicate that in addition to a strong Sense of Coherence, the coping style Fighting Spirit and participants' age significantly predict successful adaptation to mastectomy. These findings support the main hypotheses and partially support the proposed coping model.

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INTRODUCTION

Although the world is full of suffering,
it is also full of the overcoming of it.

Helen Keller quoted in Strümpfer (1995).

A diagnosis of cancer is usually received with dismay and associated with pain. The fear of recurrence and the possibility of death are traumatic and highly stressful. But for women, breast cancer and mastectomy carry additional fears: disfigurement, loss of femininity, concerns about intimacy and sexual relationships. All of these can contribute to negative self-image and poor self-esteem. The disruptive demands of this type of life crisis present a serious challenge to patients' coping capabilities, and threaten quality of life and sense of well being.

This dissertation is concerned with how women deal with breast cancer and mastectomy. It explores different ways of coping, the origins of strength, and various factors that are thought to have an impact on the coping process.

There are nine chapters in all, the first six providing the background and review of literature. Chapter 1 talks about breasts from the symbolic and physiological perspectives. Chapter 2 deals with malignant breast disease: the incidence, staging and prognosis, risk factors, diagnostic procedures and treatment options. Chapter 3 describes the procedure of mastectomy, as well as adjuvant therapies, common psychosocial effects and issues concerning breast reconstruction. Chapter 4 gives a theoretical perspective on coping, and chapter 5 focuses specifically on coping with mastectomy. Chapter 6 presents a paradigm shift. Moving away from the familiar pathogenic perspective that is concerned with illness, disease and dysfunction, this chapter discusses the concepts of *salutogenesis* and *fortigenesis*, which trace the sources of health and strength in individuals. This section also introduces the construct s*ense of coherence*, as developed by Antonovsky (1979 & 1987).

Chapters 7 to 9 present the current research. The methodology is described in chapter 7 and chapter 8 reports on both quantitative and qualitative results. Chapter 9 discusses the findings and conclusions. It also points out the limitations of this study and suggests directions for future research. The dissertation concludes with a final comment by the author about what it has meant to be involved in research of this nature.

Chapter One

THE BREAST

Thy two breasts are like two young roes
that are twins, which feed among the lilies.

Song of Solomon.

1.1 Woman' s Symbol

From the beginning of human history the female breast has been a symbol of femininity, fertility and nurturing. Budding breasts are generally the earliest sign that a girl is entering the realm of womanhood. Tender and enlarged breasts invariably precede the monthly menstrual cycle. Pronounced fullness, hypersensitive nipples and mammary secretions are often the first signs that a woman is pregnant. And *"when the helpless state of the new-born infant is observed"*, the significance of a nurturing breast is obvious. The neonate's ability to suck, together with a mother's breast milk, is enough to sustain the infant for many months (Hales, 1986: p6).

Aside from their natural functions, breasts have always had strong connotations with feminine beauty and sexuality. The Babylonians represented their archetypal woman as a Mother Goddess, referring to her as the mother with the faithful breast (Kuny, 1984). In ancient art the significance of the female breast is emphasised by multiplicity. Diana of Ephesus is featured with up to 16 breasts, and the Mexican Goddess of the Agave is depicted with 400 (Lederer, 1968). In an ancient Minoan temple a mother Goddess depicted with her breasts exposed, bears the inscription: *"I have breasts, therefore I am"* (Ayalah & Weinstock, 1980). In animal species, breasts are obvious only in late pregnancy and during lactation. Woman's breasts on the other hand *"are remarkable for their permanent, full rounded contour"* (Hales. 1986: p7). Like fashions, the 'ideal breast' has varied through the ages. Cave art depicted man as a stick figure, but woman was shown with pendulous breasts and voluptuous curves. In Greek and Roman times the *"preferred breast was small and situated high on the female frame"*, but always prominent (Hales, 1984: p9).

More recently in the 1940s and 1950s big breasts, padded and uplifted, became the focus of fashion. Film stars with curves and cleavages like Diana Dors and Jayne Mansfield served to promote the 'voluptuous bosom' (Rafferty, 1995). And during this era, Margaret Mead expressed the opinion that *"We are confronted everywhere with pictures of partially dressed seductive women,....whose breasts, tailored for love, are explicitly not meant for the loving nourishment of children"* (Mead, 1949: p79).

Although efforts of feminists over the past thirty years have helped to de-emphasise breast size as an indicator of attractiveness, *"recent trends appear to reinstate the breast as an idealized part of woman's self image"* (Kuny, 1984: p4). In the Western world, the development and proliferation of cosmetic surgery attests to women's dissatisfaction with their body shape, and beliefs that their breasts do not measure up to society's standards (Rafferty, 1995).

Breasts are flaunted on the big and small screens, in magazines, and more recently on the Internet. Their fascination to men and to some extent women, is something that advertisers capitalise on. "*Breasts are exhibited to sell anything and everything from newspapers to night storage heaters, toffees to tractors. They are the basic stock-in-trade of the* *adman's art and the romantic novelist's pen"* (Faulder 1979, quoted in Hales, 1986:p8).

Breasts undeniably have strong associations with feminine sexuality and desirability. According to Rafferty, *"Men are socialised into regarding women's breasts as objects to view,"* and *"Women are socialised into sharing their breasts in a way in which men never have to share parts of their bodies"* (1995:p197). The significance of this part of the female anatomy extends well beyond it's functional role; the female breast is clearly much more than a mammary gland.

Historically it was the Amazons who were the rare exception to the 'mother-of-the-breast' archetypal woman. These formidable women, first described in early Greek history, devoted their energies to war rather than men and marriage. According to tradition, they were unnatural women who amputated their right breast to ensure that it did not interfere with their handling of a bow and lance (Lederer, 1968).

Modern woman has developed her capabilities way beyond traditional tasks, and her role of bearer and nurturer of proteges. She juggles home and career commitments, and is accomplished and successful in fields previously dominated by men. Women have become a force to be reckoned with in practically every walk of life: the boardroom, in government, in sporting arenas, and ventures into outer space. But according to Ehrenreich, the term 'female' still has a tendency *"to connote the oozing, bleeding, swelling, hot-flashing"* aspect of the species. This author contends that *"there are still staggering obstacles in the way of a body-proud, open-minded and biology-affirmative female consciousness"* (Ehrenreich, 1999:p52).

Rafferty contends that Western women living in the second half of the 20th Century experience a tension between expressing empowerment through their feminine bodies and denying differences from the masculine body, *"through reduction of the female form as a means of achieving equality with men, or a perceived sense of control and autonomy"* (1995: p197). This author believes that Western society in particular, puts great emphasis on physical attractiveness, especially concerning the shape, size and proportions of the breasts. As a result, many women feel pressured to match societal standards of attractiveness regarding their breasts, a situation that exacerbates body image problems if a woman is faced with disfiguring breast surgery. Ehrenreich agrees with these sentiments, and believes that girls find themselves under considerable pressure *"to conform to impossible notions of beauty"* (1999: p52).

But the perceptions and significance of the female breasts vary enormously from culture to culture. Moslem custom for example dictates that no part of a woman's breast may be revealed in public, so her dress is accordingly discrete. By contrast, it is traditional, normal and quite natural for the women of many African tribes to be seen bare-breasted and topless.

Hales (1986) believes that there are as many attitudes to breasts as there are women. She contends that women's attitudes are highly individual, depending in part on the attitudes of others who matter to her, as well as on her own personal experiences. From an individual point of view, the value attached to breasts also varies tremendously. As the chief source of nourishment for infants, healthy lactating breasts are an absolute necessity for impoverished women. For the movie star or model, whose trade depends upon a perfect pair, substantial insurance for these physical assets may be regarded as essential.

The true story of a woman in this study, who was encountered on the eve of surgery for a malignant breast tumour, provides yet another perspective. This woman's doctor had offered her a choice of surgical procedure, and she was wrestling with the decision. Her options were to have the whole breast removed (a mastectomy), in which case no further treatment would be necessary. Alternatively she could have just the lump cut out (lumpectomy), a procedure that would have to be followed with a 6-week course of radiotherapy. The patient eventually chose the mastectomy, basing her decision on the price of transport. She simply could not afford the bus fare to the hospital five-times a week for six weeks. She decided her breast was not worth that much to her.

1.2 Anatomy and Physiology

Although synonymous with womanhood, female sensuality and sexuality, from a medical perspective the breast is a modified sweat gland that secretes milk instead of sweat. Each breast is made up of about 18 lobules encased with fat to give it size and shape. Pantanowitz (1998) likens these lobules of glandular tissue to bunches of grapes. Each 'grape' is a secreting unit containing cells that produce milk via a duct system to the nipple. These ducts are positioned in a radial formation and each opens separately into the nipple. When milk is secreted, it flows out from the nipple like 18 fountains. The lobes of glandular breast tissue are supported by fibrous tissue called Cooper's ligaments, which run from the muscle underlying the breast to the skin to give the breast its structure. In addition to the breast's basic hemispherical shape, it has a tongue-like extension known as the tail of Spence. This tail leads into the armpit region, and is known as the axilla. Tumours can grow either in the breast itself or in this tail section.

As well as the ductal system, the breast contains blood vessels and lymph vessels. The lymph drainage follows the blood supply into the axilla and to the internal mammary chain. The lymph nodes, which are small bean-shaped organs, are found in clusters in the axilla. They are also found above the collarbone, in the chest, and in many other parts of the body. In the case of breast cancer, the prognosis is far worse if the lymph nodes are involved. Generally the more nodal involvement there is, the poorer the prognosis (Pantanowitz, 1998).

The functioning of the breast is dependent on the body's endocrine system and specifically on hormone production. These hormones are responsible for breast development at puberty, pre-menstrual enlargement of the breast, growth during pregnancy and also lactation. After the menopause the hormone levels fall and as a result, breast tissue begins to shrink and the ligaments become lax.

1.3 Breast Disorders

Breast diseases and disorders are numerous. Non-malignant disorders usually result from the cyclical hormonal changes that are found in all women before the menopause. These disorders range from normal state, through slight aberrations to benign diseases. Pantanowitz (1998) lists the most common ones as follows: -

- Fibroadenoma - mobile, round, smooth lumps found in young women.
- Cyclical mastalgia - severe painful nodularity, occurring in the period prior to menstruation.
- Lactating breast abscess.
- Galactocele - a milk retention cyst.
- Single or multiple breast cysts usually found in pre-menopausal women.
- Duct ectasia – a thick secretion that blocks the ducts. This usually occurs in the pre-menopausal period from age 35 to 50.
- Fat necrosis - a disorder that may look like breast cancer but is in fact caused by trauma to the breast.
- Intraduct papilloma - a benign growth or tumour which develops in a duct.

Benign tumours are not cancerous and can usually be removed without recurrence. The cells of these growths do not invade other tissue nor do they spread to other parts of the body. And most importantly, they are not life threatening.

Chapter Two

CANCER OF THE BREAST

Cancer is a cosmic slap in the face.
You either get discouraged or ennobled by it.

Richard Belzer, quoted in Tedeschi & Calhoun (1995).

2.1 Cancer Defined

Cancer is a very general term that is used to describe various kinds of malignant neoplasm or new tissue. The word itself derives from the Greek word 'karkinos' meaning a crab, and was named by Hyppocrates around 400 BC. This was because of the similarity Hyppocrates saw between crab's claws and the swollen veins that can surround cancerous tumours. Fallowfield & Clark describe cancer cells as *"greedy cuckoos, consuming an unfair share of the nutrients in the bloodstream"* (1991: p4).

Breast cancer is the uncontrolled growth of malignant tissue in the breast, and it covers a wide variety of disease patterns. At one extreme are women whose cancer goes no further than the breast, and at the other end of the spectrum are the women who never feel a lump in the breast, yet get ill with severe metastic disease in another part of the body (Pantanowitz, 1998). This author says that malignant neoplasm of the breast can be divided into two basic types : -

- Sarcomas which develop from connective tissue and muscle - a relatively rare occurrence in the breast.
- Carcinomas that arise from cell lining the glands, ducts or organ surfaces.

Duct carcinoma is the most common, and accounts for more than 80% of all breast cancers. In contrast to sarcomas, carcinomas are rare in women younger than 30, but the incidence increases with age. Carcinoma in situ is very early breast cancer that is confined to the lining of the ducts or glands. It only involves the tissue in which it began, and has not penetrated the basement membrane or metastasised. Invasive cancer on the other hand has infiltrated through this so-called basement membrane. It can also metastasise through the blood vessels to other parts of the body, breast cancer typically spreading to bones, lungs, liver and the brain. Carcinomas can also develop in the lobules of the breast and may invade the lymph nodes via the lymph channels. Involvement of lymph nodes is normally on the same side as the breast cancer but occasionally it may spread to the opposite axilla. (Pantanowitz, 1998.)

2.2 Demographics

Cancer of the breast is one of the most common forms of cancer in women, and according to Fallowfield & Clark (1991) its frequency is increasing throughout the western world. Breast cancer is diagnosed in approximately 12% of women worldwide and is the cause of death for approximately 3.5%. The risk varies considerably across different ethnic groups. Rice (1998) reports that white women are more likely to get the disease, but that African Americans are 2.2 times more likely to die from it. Rice suggests that the reason for this differential is because Black women tend to present at clinics much later than their white counterparts. Consequently, the tumours in these Black women are at a more advanced stage, treatment commences later and the prognosis is therefore poorer.

For South African women in general, breast cancer comes second to cervical cancer in terms of prevalence, but for Whites and Asians it ranks first. In South Africa the likelihood of developing cancer of the breast is estimated to be 1 in 68 for Black women, 1 in 33 for Coloured women, 1 in 20 for Asians and 1 in 15 for White women. In the USA the figure is 1 in 9, and in the UK it is 1 in 12 women. (Source: Cancer Association of South Africa.)

2.3 Clinical Classification of Breast Carcinoma

The tumour classification system that has been used in the present study is summarised below. This international system is described in Fallowfield & Clark (1991), who point out that these classifications are a subjective assessment and depend largely upon the examiner and the diagnostic tools available. Aside from primary tumours, the system also takes into account regional (armpit) nodes and metastases elsewhere in the body: -

To – no evidence of primary tumour.
T1 – tumours that are 2 cm or less in greatest dimension.
T2 – tumours between 2cm and 5 cm.
T3 - tumours over 5 cm.
T4 – tumours of any size that are fixed to the chest wall or skin.
Tx – primary tumour cannot be assessed.

No – no regional lymph node(s)
N1 – mobile axillary node(s)
N2 - axillary nodes fixed to one another or to other structures.
N3 – metastases to internal mammary lymph node(s)
Nx – regional lymph nodes that cannot be assessed.
Mo – no sign of distant metastases.
M1 – distant metastases present.
Mx – presence of distant metastases elsewhere in the body that cannot be assessed.

Clinical examination and pathology studies enable breast cancer to be divided into 4 stages. Stages I and II are potentially curable, stages III and IV are usually incurable. The following is a summary of the International Classification System as described by Fallowfield & Clark (1991) with the approximate prognosis for survival beyond 5 years shown in brackets : -

Stage I – mass confined to breast, not fixed – (about 90% survival).
Stage II – mass with mobile axillary nodes, no apical nodes (70%).
Stage III – large breast mass (fixed) or fixed axillary nodes or apical node involvement (30%).
Stage IV – cancer metastases beyond the breast and axilla (10%).

2.4 Risk Factors

This section on risk factors described below has been compiled from information supplied by the National Action Plan on Breast Cancer (NAPBC) in collaboration with the National Cancer Institute in the USA, as well as Pantanowitz (1998).

In most cases breast cancers are sporadic, with 90% occurring as a result of interplay between environmental factors and genes. This means that the environment affects the genes and causes them to mutate to cancer causing genes (oncogenes).

The most significant risk factors are **age and sex.** Eighty percent of breast cancer cases occur in women older than 50, and it is rare to find this disease in women under the age of 30. It is also extremely rare in males - the prevalence in females being 100 times that of males.

Heredity plays a role in some cases. For example, the risk is doubled if a pre-menopausal sister or mother has developed breast cancer. Having one or two close relatives with breast cancer will increase a woman's risk three to four times, and the closer the cluster the greater the effect will be (Fallowfield, 1991). Approximately 5 to 10 percent of women with breast cancer have a hereditary form of the disease and it is believed that inherited alterations or mutations in the BRCA1 and BRCA2 genes are involved in 30 to 70 percent of all inherited cases. Genetic testing for breast cancer is now becoming an option, so for women with a family history of breast and ovarian cancer, a genetic test may determine whether there is an increased risk for developing the disease.

Hormonal influences - Oestrogens stimulate the normal growth of breast tissue that is produced naturally by the body, and it is suspected that excess oestrogens contribute to breast cancer risk because of the way they promote breast cell growth. Thus early onset of menstruation and late menopause are believed to increase risk because both prolong oestrogen exposure. For the same reason, hormone replacement therapy (HRT) is considered to increase the risk. (But the many benefits of HRT, e.g. reducing coronary artery disease and osteoporosis, need to be weighed against the risk of developing breast cancer, before a woman rejects HRT). Some studies indicate that a woman who has taken birth control pills for more than 8 years, and began taking them at an early age or before her first pregnancy, has a small increase in her risk for breast cancer. It has also been found that late age of first pregnancy, or no pregnancy at all, increase a woman's risk because the oestrogen 'window period' is drawn out (Pantanowitz,1998).

Environmental factors - The disease is particularly common in Western countries, (USA - approximately 1 in 9 women and UK -1 in 12). Although breast cancer is uncommon in Japan, (about 1 in 50), studies have shown that within 2 generations, Japanese women who migrate to the USA assume the higher western rate (Pantanowitz,1998). This suggests that environmental factors, life style and diet do play a part in the onset of disease.

There appears to be some correlation between saturated fats and the incidence of breast cancer. Although early studies suggested a possible association between a high-fat diet and increased breast cancer risk, more recent studies have found that reduced dietary fat consumption did not decrease risk of breast cancer. It has also been posited that alcohol may indirectly increase oestrogen levels, and consequently the breast cancer risk. But as yet no biological mechanism for the relationship between alcohol and breast cancer risk has been established and studies have been inconsistent.

Exposure of the breast to ionising **radiation** is associated with an increased risk, especially when the exposure occurs at a young age. However evidence that examines the effects of occupational, environmental and chemical exposure on breast cancer risk is still very limited.

Research recently published by Hartman (in press, 1999) found that a **prophylactic double mastectomy** reduced the incidence of breast cancer in women who were at risk by 90%. Hartman of the Mayo Clinic in Minnesota USA, conducted this retrospective study with women who had a family history of breast cancer. The study traced 630 women aged between 18 and 79 years, who had had both of their breasts removed between 1960 and 1993. The research identified 214 women in the high-risk category and 425 who were at moderate risk for breast cancer. The incidence of breast cancer over an average follow-up period of 14 years was compared to that of their mothers and sisters who did not have this elective procedure. In the high risk group 38.7 cases of breast cancer were anticipated but only 3 were confirmed. This equates to a reduction of at least 90%. In the moderate risk group, 37.4 cases were expected but only four were found - a risk reduction of 89.5%.

2.5 Diagnostic Procedures

More than 90% of breast cancers initially present as a lump in the breast, and despite the fact that 4 out of 5 lumps seen in clinics are benign, most women *"realise their potential significance and are very frightened".* (Fallowfield & Clark, 1991: p5).

In some cases the presence of cancer can be diagnosed by clinical examination alone. The chief indications are dimpled or thickened breast skin and swollen glands in either the neck or armpit. Sometimes breast cancer presents with skin puckering or tethering, an appearance that resembles orange peel, or ulceration. Occasionally there is a blood stained nipple discharge, nipple retraction and breast distortion. A clinical examination involves a visual comparison of both the woman's breasts, palpation and an examination of the axillae for nodes. It may also include a systematic check for metastases in other parts of the body. Symptomology, menstrual history and family history of breast cancer can assist the diagnosis, which is often backed up by mammography (x-ray) and fine needle aspiration cytology.

An essential part of the diagnostic procedure is needle aspiration, a type of biopsy that uses cytology to examine the cell morphology. While this investigation can tell if a cell is cancerous or not, it cannot detect whether the cancer is invasive. For this the breast tissue specimen needs to be examined in its entirety, so a piece of the breast lump (a core biopsy) is necessary.

More than 70% of all cancers are detectable on x-ray before they can be palpitated, so the reason for mammography is early detection. The accuracy of this procedure increases with age because breast tissue becomes less dense with ageing. Routine screening is not normally recommended for women under 35 years, unless there is a strong family history of breast cancer. Controversy still exists around the merits of regular mammography for women between 40 and 50, but beyond 50 years it is a recommended procedure. Studies in the USA, UK, Europe and Canada have shown that morbidity and mortality can be reduced by about a third with regular screening (Pantanowitz, 1998).

2.6 Treatment Options

Once a diagnosis of breast cancer has been confirmed, the form of treatment needs to be assessed. From a medical perspective, the decision is complex, and the choices depend on a number of factors. The most important consideration is the tumour size and stage, but other factors such as the woman's age, menopausal status, general health and size of breast need to be taken into account.

It used to be routine procedure to prescribe a radical mastectomy to 'treat' breast cancer. This mutilating surgery involved cutting away the entire breast as well as the supporting muscle tissue. Current treatment usually involves some combination of (less radical) surgery, chemotherapy, radiotherapy and hormone therapy.

For women who are being treated conservatively, the surgical option is a lumpectomy. This procedure involves a wide excision of the lump from the breast, removing the least amount of tissue necessary. The second surgical option is a mastectomy, which involves removing the entire breast and (usually) the associated lymph nodes.

There are negative consequences associated with both surgical procedures. With lumpectomy there are fears that the cancer may return, as there is an almost 40% chance of a recurrence in the same breast after 5 years (Rice, 1998). In addition, the radiotherapy that commonly follows a lumpectomy has its own unpleasant side effects and tends to retard the recovery process. Mastectomy patients on the other hand tend to worry more about scaring, body image, appearance and personal relationships. Chapter 3 presents a more detailed picture of mastectomy, and discuses the procedure as well as the adjuvant therapies associated with it.

If the initial clinical assessment is a stage I tumour, where the mass is confined to the breast, the usual procedure is conservative surgery. But it sometimes happens that the pathology after excision indicates nodal involvement. In these cases the staging is changed to stage II, and further surgery is normally recommended to clear the cancerous areas that are involved. Mastectomy may also be indicated in a stage I breast cancer if the lump is large in relation to a particularly small breast. In a clinical stage II tumour, the usual approach is a mastectomy with ipsilateral auxiliary node clearance. If the nodes are found to be clear, the disease is then reclassified to a stage I tumour, which carries a better prognosis for survival. Generally the treatment for stages III and IV breast cancer is palliative, although radiotherapy, hormone therapy and chemotherapy may be used to shrink the tumour, and in some cases surgery is feasible after this (Plantanowitz,1998).

New approaches in the treatment of breast cancer are currently being investigated at the University of Texas M. D. Anderson Cancer Centre. Hortobagyi et al. (1998) describe the new treatments that include two different types of gene therapy, various drug combinations, a vaccine and bone marrow transplant. These therapies are at present being evaluated. At the same time scientists and physicians are collaborating to use the new information to find more effective techniques for detecting breast cancer at earlier stages when the cure rate is higher. The ultimate goal is prevention of this disease. The gene therapy studies, which are among the first for breast cancer patients in the USA, involve two concepts : a three-phase gene augmentation program known as chemoprotection and the injection of a "good" gene intended to reduce the proliferating effect of a cancer-causing gene associated with the metastasis of some cancer cells. Hortobagyi (1998), chairman of M. D. Anderson's Department of Breast Medical Oncology observed that we have never before had so many hopeful leads, which offer a much more optimistic outlook for breast cancer patients. Almost all patients today have multiple treatment options that can provide longer survival and a better quality of life.

Although it is becoming increasingly common for women to be involved in decisions about their treatment choice, many still prefer to leave the decision making to the medical experts. Beaver et al. (1996) report on a study in which 150 women, newly diagnosed with breast cancer were asked about their preferences to be involved in treatment decisions. The majority chose a passive role and left the decision making to their doctors. Fallowfield (1997) also found that fewer women than anticipated wished to play a significant role in the decision making process. Some research suggests that if women are given a choice they will choose breast-conserving surgery. However Fallowfield found that despite strong support for this hypothesis, a considerable number of women, did in fact opt for a mastectomy, when offered a choice.

A study by Levy et al. (1992) was concerned with surgical choice and psychosocial acceptance in breast cancer patients. The researchers assessed a group of 129 Stage I and Stage II breast cancer patients, 70% of whom chose conservative surgery (lumpectomy). When this group was compared to the group who chose mastectomy (30%), it was found that the lumpectomy patients were rated as more functional by observers, but they saw themselves as having less energy and receiving less emotional support than the mastectomy group. Levy suggests that breast-sparing surgery is not necessarily a psychosocial panacea - a view endorsed by a patient quoted in Fallowfield & Clark, (1991 : p56), who said: - *"I feel so guilty about feeling so lifeless and miserable. After all, it's not as though I had to have my breast cut off."*

Research by Jackisch et al.(1997) supports the opinion of Levy (1992). When patients in this study were assessed six years post-operatively, it was found that those who elected conservative breast treatment were generally not superior to the mastectomy patients. Jackisch reports that coping and post-operative quality of life were virtually the same within the two groups. Fallowfield (1997) says that hopes of conservative techniques reducing psychosocial morbidity have not materialised. She too reports few differences in the quality of life between women, whatever their surgical treatment. Moyer (1997) confirmed these findings. This author compared the results of 40 investigations and found the psychological sequelae of the conservative surgery were unexpectedly lacking in substantial benefits.

Chapter Three

MASTECTOMY

I was walking down the gangplank of a ferryboat with a lot of other women. At the bottom of the gangplank was a man, and he was checking each woman to see if she had her breasts. I was getting closer to the bottom when I woke up.

Bard & Sutherland quoted in Hales (1986).

3.1 The Procedure

From a surgical perspective, cutting into a woman's breast is no easy procedure, as *"the soft mobile tissues constantly challenge the spatial assumptions of the surgeon"* (Fallowfield & Clark, 1991: p9). Mastectomy involves taking away all the breast tissue, the nipple and an area of skin. The operation leaves a simple scar and a flattened chest wall. In the days before radiotherapy a more radical version of this procedure was used, and underlying chest muscle was also removed. This radical mastectomy left women considerably more mutilated than the modern approach and is seldom performed today. Auxiliary dissection commonly accompanies mastectomy and involves the removal of lymph tissue and glands, which may be diseased. A recent technique described by Pantanowitz (1998) is sentinel node biopsy. In this procedure a dye is injected around the tumour to indicate the relevant nodes that need to be removed. By identifying the diseased nodes ahead of surgery, the extent of auxiliary dissection is reduced along with potential complications.

3.2 Adjuvant Therapies

The term adjuvant refers to treatment given in addition to the primary treatment - mastectomy in this study. For patients who are 50 years old or less and pre-menopausal, the most common adjuvant therapy is 6 months of chemotherapy given intravenously. The specific combination or 'cocktail' of drugs varies along with individual patient regimes and cycles. Because chemotherapy is toxic to all bodily cells, many patients who have this form of treatment do experience unpleasant side effects, the most common of which are hair loss, nausea and vomiting. Although chemotherapy does have positive results in post-menopausal women, it is considered to be more effective for pre-menopausal patients (Pantanowitz, 1998).

In post-menopausal women, hormone therapy is the treatment of choice. The antioestrogens are considered to be the most effective method of endocrine inhibition for oestrogen sensitive tumours. Current studies suggest that antioestrogen therapy (specifically Tamoxifen) not only improves survival rates considerably, but also reduces cancer risk to the contralateral breast. Baum (1998) refers to response rates of up to 60% in advanced cancer when using this form of treatment. Unlike chemotherapy, the antioestrogens have few side effects and only about 5% of patients experience hot flushes, weight gain or vaginal dryness.

While it is standard procedure for patients undergoing lumpectomy to have radiotherapy to the remaining breast tissue, it is less common for mastectomy patients. According to Pantanowitz (1998), radiotherapy reduces the incidence of local recurrence but it does not seem to improve overall survival rate. Unpleasant side effects from radiotherapy include tiredness, nausea and red, sore skin. Occasionally there may be signs of radiation change to organs deeper in the chest cavity (Fallowfield & Clark, 1991). Some less fortunate patients do have to be subjected to the dreaded 'sandwich' treatment, which combines chemotherapy and radiotherapy. This regime usually means radiotherapy on a daily basis for six weeks, sandwiched between two six-month sessions of chemotherapy.

On a purely biological level, the effects of surgery and adjuvant therapies are a lot to contend with : - changes in body shape and functioning, pain levels, physical movement as well as sexual functioning. (Viljoen & Berard, 1994). In addition there are the psychosocial effects, which provide a host of problems of their own.

3.3 Psychosocial Effects

The notion that breast removal is an assault on woman's femininity is well researched. The literature suggests that the loss of a breast evokes a response similar to the grieving process described by Kubler-Ross (1982), and that shock and denial, anger, bargaining and depressed mood will invariably precede an acceptance of the new reality.

From a psychosocial perspective, a diagnosis of cancer and the prospect of mastectomy are catastrophic and can be expected to have far reaching effects on morbidity, body image and marital adaptation. According to Schlebusch (1998), adjustment disorders with anxiety, and mood disorders are the most frequent diagnoses in cancer patients. Research reviewed by Viljoen & Berard (1994) estimates that up to 30% of women who have their breast removed will need psychiatric support. And research also suggests than less than 5% ever receive it.

Dean (1987) estimated that the overall incidence of psychiatric morbidity following mastectomy was approximately three times that found in the general female population. Bloom, Kessler & Pee (1992) compared the psychosocial functioning of women after surgery for breast cancer to three non-cancer groups (one of which had no surgery at all). Initially the functioning of all surgical groups was significantly worse than the non-surgery group. One year later the mastectomy patients continued to have significantly poorer functioning, but all other groups were indistinguishable.

On the issue of body image, Margaret Mead (1949) had this to say : - *"the female breast has been so idealised in the United States that it has become the primary source of women's identification with the female role"* (Cited in Hales 1986: p 14). Fifty years later, women's magazines in many parts of the world tend to entrench this idealism. Examples of titles in a popular magazine that targets modern black women in South Africa, read: "Perfect breasts or bust", and "Breast Assets". While the story line proclaims that *"Most women, no matter how perfect their bodies are, are unhappy with the size and shape of their breasts"* (Myberg & Muthwa, 1999). It is suggested that such idealism may serve to increase body image problems for women after mastectomy, because *"it's very hard to be a woman with a scar instead of a breast in a society where everywhere you look there are pictures of idealised, beautiful, well-developed bodies"* (Rafferty1995: p196).

Much of the image we hold of our body is developed through our relationship with others and our perception of the way others see us. It is therefore not surprising that women project their own negative feelings about their body onto others. Burton et al, cite examples that illustrate this point : *"A man won't want to look at me now that I've had this done"*, said one woman (1995 : p14), while another patient who had been widowed, expressed gratitude that her husband would not have to see her body disfigured by the cancer.

Many studies have explored the impact that a mastectomy has on the sexual lives of women. Burton et al.(1995) cite Abt, Mc Gurran & Heintz (1978) who reported that 44% of mastectomy patients experienced a general decrease in sexual activity, 39% wore less revealing night-wear and 36% engaged in sexual activities with a bra or top on. Lee et al. (1992) compared mastectomy and breast conservation patients, and found that the women who had a mastectomy were more likely to stop sexual intercourse altogether.

However, Reaby, Hort & Vandervord (1994) conducted a study which challenges the assumption that mastectomy automatically leads to psychiatric morbidity as a result of an altered body image. This research (n=173) compared perceptions about body image, self-concept and self-esteem in three groups of women. In the first group, the women had mastectomies and wore external prostheses and in the second group the women had mastectomy followed by breast reconstruction. The control group had not experienced mastectomy. Reaby and her co-workers found no significant difference in self-concept between the three groups. Surprisingly, the body image and self-esteem mean scores showed that both mastectomy groups had more positive feelings towards their bodies than did the control group. Reaby et al. make the point that health professionals should not assume that all women will respond in the same way to mastectomy.

3.4 Breast Reconstruction

Breast reconstruction involves the replacement of tissue lost during surgery. It usually involves the creation of a breast 'form' with an implant placed beneath the chest skin or muscle. Various materials can be used as implants, the most common being silicone shells which are filled with either saline or silicone gel. An alternative is to use muscle and skin taken from the woman's own back or abdomen (Chambers, 1996).

In a study of 96 mastectomy patients (45 had breast reconstruction and 51 did not), Charavel, Bremond & Courtial (1997) attempted to define the kind of women that elected to have post-mastectomy reconstruction. Social, cultural and psychological variables were assessed, and analysis showed significant differences between the two groups regarding age, education, socio-economic status, leisure activities, sexual intercourse, information about breast reconstruction and fear of recurrence. Results suggested that social status was a deciding factor in a woman's access to information about reconstruction, and consequently whether or not she would have a breast reconstruction.

Fallowfield & Clark, (1991) suggest that as long as women choose reconstruction for themselves, and have realistic expectations of the surgical results, then the psychological outcome is likely to be good. They emphasise the point that all women need to be fully informed to be able to make their decision. Those with a strong sense of body image should always be offered the option of breast reconstruction, (provided it is technically feasible), and no woman should have her treatment determined on the basis of her age or marital status. The following quote from a 75-year-old spinster, who had never had a sexual partner, emphasises the need to consider the individuality of every woman. *"I know you think me a silly old thing, but quite honestly since the operation I just don't feel a woman anymore."* (Fallowfield and Clark, 1992 : p64).

Reaby (1998) reports that approximately 10% of Australian women choose to have breast reconstruction after mastectomy, and generally it is the younger women. The main reasons given were to get rid of the prosthesis, to wear all types of clothing, to regain femininity and feel whole again.

Although reconstruction is not necessarily of uppermost importance at the time of diagnosis or immediately post mastectomy, Goodare indicates that with time, many women will consider this options. One patient remarked: *"As the years passed and the possibility of a recurrence receded, I began to think that I didn't want to spend the rest of my life* *confined to certain styles of dress ....the idea of having an implant became attractive"* (Goodare, 1996 : p 110).

A study by Gross, Burnett & Borelli (1996) examined coping responses in women diagnosed with Stage I or Stage II breast cancer (n = 36). Using the Reaction to Diagnosis of Cancer Questionnaire (RDCQ), these authors found a significant change in the mean difference of the RDCQ scores in women who had immediate breast reconstruction when compared to those women who did not have reconstruction at all.

Kroll (1997) reviewed literature concerning the timing of breast reconstruction, and concluded that immediate breast reconstruction had many advantages to both patients and surgeons. Kroll reported that oncologically there was no reason not to perform immediate breast reconstruction, unless the prognosis was so poor that any breast reconstruction was unwarranted. From the patient's perspective, immediate reconstruction was more convenient and was psychologically easier to deal with. Spyrou et al. (1998) conducted a survey of general surgeons' attitudes towards breast reconstruction after mastectomy and concluded similarly that immediate breast reconstruction had psychological benefits when compared with delayed reconstruction.

Chapter Four

COPING

Illness is something to which we have to adjust. It is the success of such adjustment which is the measure of how well we cope with disease. If one person finds that adjustment easier to make than another, is it not logical to suppose that that person may find the actual disease less difficult to cope with?

Courtenay (1993).

4.1 Coping Defined

According to the Oxford dictionary, the verb cope means to *contend evenly, to grapple successfully with.* The modern computer thesaurus provides these synonyms for **cope**: - *manage, suffer, endure, accomplish, confront, face, encounter, contend with, survive, persevere.* It is evident from these equivalent terms that coping implies striving and adjustment, something that individuals do on a daily basis. We cope with life, and coping is a part of life.

Folkman and Lazarus (1980) describe coping as, "*all the cognitive and behavioral efforts to master, reduce or tolerate external or internal demands*" (Cited in Rice,1998:p 198). This definition of coping was a part of Folkman and Lazarus's cognitive-transactional theory of stress, which contends that internal demands are usually a reflection of the effect of emotional conflict or cognitive appraisals. These authors say that coping usually aims to either change the relationship between self and the environment (problem-focused coping), or it attempts to reduce emotional distress and pain (emotion-focused coping).

Although it was the intention of Folkman and Lazarus (1980) to produce an all-inclusive definition of coping, it is the opinion of Rice (1998) that the all-embracing attempt comes from Matheny et al. (1986). These authors incorporated both preventative and combative strategies in their description of coping. They say that when individuals engage in preventive coping, they "*try to prevent stressors from appearing through cognitive restructuring that alters the perception of demand, or through increasing resistance to the effects of stress*". Combative coping by contrast is essentially a reactive strategy. Matheny et al. contend that the stressor triggers "*a defensive counterstrike, in which we attempt to subdue or defeat the stressor in some fashion*" (Rice, 1998: p200).

Matheny et al. (1986) attempted to integrate the work of a number of stress theorists, and they define coping as "*any effort, healthy or unhealthy, conscious or unconscious, to prevent, eliminate or weaken stressors, or to tolerate their effects in the least hurtful manner*" (1986: p509). This suggests that coping strategies are not always healthy options, and that reality is sometimes distorted in an effort to deal with a situation. The authors also point out that coping can be an unconscious act and that it does not necessarily require stressors to be eliminated altogether.

A more recent definition of coping is described by Leventhal, Suls & Leventhal (1993), who say that coping is "*overt or covert behaviors that are intentionally adopted to manage a problem situation.*" (Cited in Suls & David (1996, p994). This definition emphasises management of the problem rather than emotions, and the phrase "*intentionally adopted*" suggests that coping does not happen unconsciously.

Whether reactive or proactive, combative or preventive, coping aims to reduce or prevent the harm that may arise from unmanaged stress. But the question that is pivotal to the current research, is whether individuals cope the way they do because of who they are, i.e. their personality, disposition and adaptive style, or whether coping is related to, or a function of, the life situations and circumstances that confront the individuals.

4.2 Disposition versus Situation

First generation coping researchers of the psychodynamic persuasion viewed coping and personality as one and the same. Coping was believed to be a function of individual personality characteristics, which were stable as well as enduring. Ego defences such as denial and repression were thought to be the mechanisms for adapting to stress.

However this psychodynamic approach failed to differentiate between personality and coping and was also unclear about the difference between antecedent behaviours and their effects. (Suls & Davids, 1996) As a result, this thinking gradually lost favour and was replaced in the 1970s and 1980s by a second generation of coping research which argued that coping was concerned with change, and that it was basically a normal adaptive response to the ongoing problems of life.

According to Watson & Hubbard (1996), researchers then turned their attention to situationally based approaches which apparently offered more flexibility in explaining how people coped with specific situations. (E.g. Carver, Scheier & Weintraub 1989, also Folkman & Lazarus, 1985.) Folkman & Lazarus argued that because of the structural nature of personality traits, they could not be regarded as adequate predictors of coping, for ... *"To be concerned with change is to be concerned with process as opposed to structure."* (1985: p150).

The concept of a coping style associated with personality-type was thought to be too inflexible to reflect changes in response to varying situations and circumstances. Coping was thus seen as a contextual process, shaped by a person's appraisal of specific demands and available resources. Folkman & Lazarus (1985) describe two types of coping : the first is directed towards the environment and the second towards the individual or self. Coping is seen as serving two functions, (a) - dealing with the problem that has caused the problem or stress (problem-focused coping) and (b) - managing or controlling the emotional aspects of the situation (emotion-focused coping).

Although the arguments of the situational approach to coping were persuasive and influential, Watson & Hubbard (1996) suggest that current thinking has changed again. This is partly because in 20 years of research, results have often been described as paradoxical, puzzling and disappointing. Watson & Hubbard say that the process-orientated paradigm of the 1970s and 1980s also has limitations, and this motivated researchers to investigate and develop more complex models of coping. It is suggested that both situational and dispositional influences play a role, and that individuals tend to show consistency as well as flexibility in their coping behaviours.

Suls and David (1996) note that current research seems to be moving to view coping and personality as overlapping, though not equivalent constructs. They point to strong evidence that broad personality dimensions are associated with preferred coping modes, and cite examples to suggest that dispositional and situational coping share a similar framework. These authors suggest that a third generation of coping research seems to be emerging; one which *"recognises and demonstrates that individual differences in personality play an important role in the coping process."* (1996, p993).

The work of Watson & Hubbard (1996) focuses on the role of personality traits, (specifically the five-factor model of personality), but these authors point out that they too endorse a more inclusive view of coping. This interactive approach recognises the significance of both dispositional and situational factors in the coping process, and puts personality and individual differences back into the equation, as important factors in the stress-coping process.

4.3 Coping and Trauma

The view that coping is a normal adaptive process and a response to the ongoing problems of life may apply to normal everyday stressors, but the question of coping with trauma raises very different issues. The word trauma suggests that the event is a shock, and according to McCann & Pearlman (1990), when events happen unexpectedly and suddenly they are particularly threatening to an individual's psychological well being. (In Tedeschi & Calhoun, 1995).

Characteristics that make events traumatic are: a perceived lack of control, the irreversibility of the event, the degree to which long-lasting problems are created, attachment of blame and the life stage of the individual when the trauma strikes. (Tedeschi & Calhoun, 1995). And if these are the parameters that define trauma, then a diagnosis of breast cancer and subsequent mastectomy would definitely qualify as a traumatic event.

The consequences of common stressors on physical and mental health are reported to be short-lived. According to Aldwin, Sutton & Lachman (1996) the effects of 'hassles' may last less than a day and more serious life events usually disappear within a year; thus justifying a homeostatic model of adjustment. The effects of trauma on the other hand may last for years, and these effects can generate positive or negative spirals. It is suggested that high levels of initial resources in individuals can lead to the development of additional resources and thereby increase resilience to further stress - a positive spiral. Negative spirals by contrast begin with low levels of coping resources, which contribute to a further depletion of resources, and in turn increase vulnerability to future stress. After trauma, thoughts, emotions and behaviour may all be affected in negative ways and it is common for individuals to experience psychological reactions such as depression, anxiety and confusion.

Historically psychologists and researchers have focused on pathology and the negative consequences of trauma, with considerably less attention being given to the positive consequences and growth experiences. But the past 10 to 15 years have seen a turn around in thinking, and this has resulted in a body of literature which suggests that many individuals do find some good even in the most traumatic events.

Tedeschi & Calhoun (1995) note that three broad categories of perceived benefits from trauma have been described: an altered philosophy of life, changes in self-perception and changes in inter-personal relationships. Although benefit finding has a prominent place in theories of coping with adversity, Affleck and Tennen (1996) say that a link to personality traits and disposition is only just beginning to be researched.

4.4 Personality and Successful Coping

Tedeschi & Calhoun believe that individuals assess negative traumatic events in characteristic ways and then employ particular strategies of behaviour to cope. They contend that a personality characterised by *"persistence, determination, confidence, an ability to make emotional connections with others, and acceptance of the limitations of circumstances when necessary"*, is essential for achieving positive outcomes from traumatic events and major life stressors. (1995: p 43). These authors suggest that a combination of tenacity and flexibility work well together; and more specifically, a personality that has elements of self-efficacy, an internal locus of control, optimism, resilience, hardiness, and a sense of coherence. Each of these personality traits is discussed briefly in the context of trauma, but sense of coherence, a core construct in the current research, will be discussed more fully in chapter 6.

Self-efficacy, according to Bandura (1977), is a person's expectation about the effectiveness of his/her own behaviour. Bandura, a prominent researcher in this field, regards self-efficacy as a crucial factor in all human functioning and believes that self-efficacy is what dictates whether or not a person will attempt to deal with a situation. Those with a perceived low self-efficacy are likely to become preoccupied with anxiety and fear of failure, and are likely to worry about things that may never happen. People with high self-efficacy on the other hand, who believe their efforts will be reasonably rewarded, are more likely to take on the challenge of a traumatic occurrence with confidence and appropriate action. (Tedeschi & Calhoun, 1995)

While self-efficacy has to do with expectation about effectiveness, the construct **locus of control** refers to the way people perceive their own efforts to be related to subsequent events. Individuals who have an internal locus of control see themselves as affecting the outcome of events, while those with an external locus of control, believe that event outcome is beyond their control. This construct shares similarities with Seligman's (1975) concept of learned helplessness. Tedeschi & Calhoun (1995) suggest that people with an internal locus of control and strong beliefs in their own capacity to control outcome, may have more difficulty coping with trauma than those individuals who have less extreme beliefs about their personal control.

Locus of control, self-efficacy and optimism all have overlapping characteristics, but **optimism** as described by Scheier & Carver (1985), focuses more directly on the outcome of events. Like people who have an internal locus of control and perceived self-efficacy, the optimist tends to adopt coping strategies that are active and problem focused. Scheier, Weintraub & Carver (1986) found that optimism was associated with acceptance or resignation only when events and circumstances were thought to be uncontrollable. Tedeschi & Calhoun (1995) suggest that optimism has benefits even in uncontrollable situations, because an optimist is more likely to accept isolated defeat while remaining optimistic about events in general.

The concept of the **'hardy personality'** is described by Kobasa (1979 & 1982.) Kobasa's hardiness is a global personality construct consisting of three components: -

- Commitment (vs. alienation) - a belief in the truth, value and importance of what one is and does,
- Control/personal responsibility (vs. powerlessness) - similar to internal-external locus of control
- Challenge (vs. threat) - the belief that change rather than stability is normal in life and presents opportunities for personal growth. (Strumpfer,1990)

Tedeschi & Calhoun (1995) suggest that in the context of trauma, hardiness may provide a buffer against stress and assist active coping, but point out that there are no studies which find direct links between hardiness and a perception of benefits from trauma.

Green (1986) explains **resilience** as the ability to accept one's weaknesses while setting out on achievable ventures. In much of the literature, the concept of resilience relates to children who start out in life at risk for failure, but who none-the-less manage to succeed. Tedeschi & Calhoun (1995) cite Rutter (1987) and Werner (1984), prominent researchers in the field of resilience. Rutter reports that both personality and environmental factors are associated with resilience in children. It is also suggested that individual's who deal successfully with environmentally stressful events, are to some extent 'inoculated' against future difficulties. Werner reports on four characteristics that resilient children have in common: -

- An active problem-solving approach,
- An ability to view even difficult experiences in a constructive light,
- A way of gaining other people's positive attention, and
- An ability to hold on to a sense of meaning in life through their faith.

She says that for some children, stress seems to have a *"steeling rather than a scaring effect."* (1984, p71)

Another 'positive' personality concept that was proposed by Siegel in 1986, embraces a number of the elements described in the constructs above. Cited in Fredette (1994), Siegel uses the term **exceptional patient** to describe those who exhibit the will to live in a 'potent form'. This type of survivor takes charge of life and strives to achieve peace of mind as well as health. Siegel talks of a 'survivor personality,' referring to people who are able to conquer crises through personal effort. He contends that to become exceptional, one needs to achieve specific personal goals. Siegal lists these as:- self respect, self-reliance, creativity, assertiveness and independence, positive outlook, a spiritual life/faith and forgiveness. One also needs honest expression of feelings, unconditional love for self and others, and an emotional support network. Siegel says these qualities are inherent in many, but they can also be developed in people. Once achieved, the qualities themselves *"can be translated into coping methods"* (Fredette, 1994:36).

4.5 Past Experiences and Coping

To explore the development of coping resources in adulthood, Aldwin, Sutton & Lachman (1996) examined the role of prior experience in the coping process. They produced evidence from three large community studies (N=1888) to suggest that the experience of past stressors does indeed form a context for future coping.

4.6 Coping and Religious Beliefs

Faith is an oasis in the heart which will
never be reached by the caravan of thinking.

Khil Gibran in Hayward (1985).

Many people turn to their religion to help them manage a crisis or traumatic event and Wallis (1996) suggests that some scientists are now beginning to look seriously at possible benefits that patients derive from spirituality. This author cites a study at the Dartmouth-Hitchcock Medical Centre in 1995, which found that one of the strongest predictors of survival after open-heart surgery was the degree to which patients drew strength and comfort from their religious beliefs. In this study (n = 232), the death rate of those who did not have religious faith was three times higher than those who did have strong faith. Wallis also points to the results of 30 years of research on blood pressure, which found that churchgoers had lower blood pressure than non-churchgoers did. When adjustment was made to account for smoking and other risk factors, the blood pressure of churchgoers was 5mm lower than those who did not go to church.

Aside from research into medical health and survival, Wallis (1996) also refers to studies which indicates that faith and religion have beneficial effects on mental wellbeing. A 1996 National Institute study on ageing (n=4000), found that elderly people who attended religious services were less depressed (and physically healthier) than those who did not attend regularly. Findings indicate that non-churchgoers have a suicide rate four-times greater than churchgoers, and many studies have found fewer anxiety-related illness and lower rates of depression *"among the religiously committed"* (Wallis, 1996:p46).

Explanations for such findings include healthier life-styles in churchgoers, for example less drinking, drug abuse and other excesses, but these factors were controlled in many of the studies concerned. The social support found in many religious communities is also believed to contribute positively to both mental and physical well being. The Dartmouth heart-surgery study found that *"those who were both religious and socially involved had a 14-fold advantage over those who were isolated or lacked faith."* (Wallis, 1996:p46)

Tedeschi & Calhoun (1995) say that people use religion in many different ways to help them cope. These authors suggest that a 'deferring' style tends to emphasise external support from God, and they believe that this style can block opportunities for learning from the experience. A 'collaborative' style on the other hand, places God in a relatively minor role and encourages individuals to actively explore their options and to develop coping skills. This collaborative style appears to be used more by people who have the confidence to confront their own problems. For them the situation is made more manageable (with God at their side) and these individuals' feel supported, while they help themselves to cope with the problem.

In the face of trauma and the chaos that accompanies it, religion also serves to maintain meaning in life. Berger (1967) describes it as an all-embracing order that shelters us from chaos: - a 'sacred canopy.' (Cited in Tedeschi & Calhoun, 1995). Because religion is concerned with universal truths and values, it can prevent traumatic events from shattering an individual's sense of purpose, and it can preserve the higher-order schemas of life.

Rothbaum, Weisz & Snyder (1982) say that a form of secondary control comes into effect when religious meaning is attached to a situation. For example, if a traumatic event is perceived to be a part of God's plan, the trauma is assigned meaning and it may be more easily accepted. And when meaning is preserved, the basis for coping is maintained. Spilka (1989) says that if meaning can be maintained (or new meaning found), it is likely that a person's self-esteem, positive outlook and control can also be preserved. (Cited in Tedeschi & Calhoun,1995)

Chapter Five

COPING WITH MASTECTOMY

Numerous descriptions in the scientific literature and lurid accounts in the popular press continue to chart the psychosocial havoc wreaked by the diagnosis of breast cancer and its treatment, especially if that treatment involves breast amputation.

Fallowfield & Clark (1991).

5.1 A Multitude of Variables

Rodrigue notes that studies investigating adjustment to cancer have in the past focused on patient variables, particularly on personality characteristics and associated emotions. The author says that while most research has found this disease was not necessarily a harbinger of psychological difficulties, *"many variables potentially mediate the relationship between cancer and psychological adjustment"* (1994: p205).

Not all women respond to the physical and the psychosocial distress of mastectomy in the same way. Reviewing research on the psychological processes in breast cancer, Royak-Schaler (1991) reports that there are 6 factors which are thought to be critical in the psychological response to mastectomy; she says these are : -

- The presence and perception of supportive relationships
- Variables in the life-stage when the cancer occurs
- Previous stability (emotional)
- Style of coping
- The time since surgery (mastectomy)
- The adjuvant therapies that are necessary.

Similar variables were described by Viljoen & Berard (1994). These authors suggest that the factors which have most influence on the severity of reaction are the patient's age when she has her mastectomy, the social tasks that are threatened or interrupted as a result of it, her personality and coping style prior to breast surgery and the emotional support systems that are available to her.

Jarrett, Ramirez, Richards & Weinman say that previous studies of coping with cancer *"have produced inconsistent and often contradictory findings"*. (1992: p 593). They note that conclusions from these studies have been restricted by problems in defining the concept of coping as well as the use of unreliable measures. Shapiro, Rodrigue, Boggs & Robinson (1994) observe that although numerous researchers have tried to understand how people cope with cancer, the studies tend to be isolated and fail to build on previous research.

The rest of this chapter summarises selected research that reports on factors which are thought to influence and impact on the way women cope with mastectomy.

5.2 Demographic Factors

Research suggests that of all demographic factors, patients' age has the most significant effect on coping with mastectomy. However the literature surveyed does not provide consistent findings on this issue.

In a study of 64 Egyptian mastectomy patients, Ali & Khalil (1991) found that coping effectiveness was positively and significantly correlated to age as well as time since mastectomy. These two variables accounted for 35% of the variance in coping effectiveness. Stanton & Snider (1993) also refer to studies indicating that younger women do not fare as well as older patients, as do Schlebusch & van Oers (1999).

Gross, Burnett & Borelli (1996) investigated coping in 36 mastectomy patients. They administered the Reaction to Diagnosis of Cancer Questionnaire (RDCQ) at 2 days and 30 days after mastectomy, and found that age and RDCQ scores had an inverse relationship. This finding contradicts the studies mentioned above. Gross et al. found that the variables marital status and educational level were not significantly related to adjustment, but their results did show that women who were employed had significantly lower RDCQ scores at 30 days post-mastectomy, which suggests less positive coping.

Schnoll, Harlow, Stolbach and Brandt (1998) used structural modelling to assess the relationship between age, disease stage, coping style and psychological adjustment in women with breast cancer. In this study, (n=100) it was found that younger women and those with early stage disease tended to use greater levels of the coping style known as 'fighting spirit. These women also showed better adjustment than older women.

5.3 The Effects of Adjuvant Therapy

The unpleasant physical symptoms of adjuvant therapies associated with mastectomy have been discussed in chapter 3. The most common side effects - nausea, fatigue, vomiting and hair loss vary in intensity from woman to woman, and sometimes just the thought of the treatment creates anxiety. Parsons, Webster & Dowd (1961) found that 75% of patients who were given sham radiotherapy complained of fatigue and nausea. (In Fallowfield and Clark, 1991).

The way that women cope with the symptoms and side effects of treatment also varies considerably, as extracts from cases described by Fallowfield and Clark (1991) illustrate. One woman, fearing the very worst, had this to say; *"It got so bad that I started to shake days before I* *knew I was due to go in. I was sick - I couldn't keep anything down,"* (1991: p63). Another more positive patient *"just used to lie there thinking of the X-rays tracking down and blasting the cancer cells .... I felt very certain that every bit of the cancer was being killed and that helped me through".* (p 60). One terrified woman claimed that *"it felt like waiting to be executed"* and had nightmares about it", while another said she *"quite enjoyed the camaraderie; it was like being in the war."* (1991:p59- 60).

When attempting to isolate the psychological effects of ongoing treatment for breast cancer (as opposed to just surgery), researchers have observed that *"both radiotherapy and chemotherapy intensify behavioral disruption and emotional distress, interrupting the gradual recovery that occurs without adjuvant treatment".* (Royak-Schaler, 1991: p74).

Fallowfield and Clark (1991) cite research by Lucas, Maguire & Reason (1987) who reported significantly high correlations between the amount of radiotherapy given, adverse reactions and (subsequent) psychiatric morbidity. Rodrigue, Behen & Tumlin (1994) also report on studies that suggest significant distress is more common among individuals actively receiving radiotherapy or chemotherapy.

Royak-Schaler (1991) notes that although the literature does point to reactive depression and anxiety disorders in 18% to 39% of mastectomy patients, the condition seems to be temporary for approximately 84% of women.

5.4 Personality and Dispositional Factors

In her review of the literature, Royak-Schaler (1991) found that one of the best predictors of successful adjustment to mastectomy was a woman's psychological state before cancer. This author identified three factors that appeared to predict psychological adaptation: the perceived causes for developing cancer, the coping skills and style that are used to manage the demands of breast cancer and perceived control over general health as well as the disease.

Carlsson & Hamrin (1994) reviewed psychosocial aspects of breast cancer over the period 1989 to 1992 and produced similar findings to Royak-Schaler (1991). Carlsson & Hamrin reported that coping prior to the cancer diagnosis was a good predictor of subsequent coping, and despite methodological problems in the studies reviewed, they do suggest that disposition and previous life experiences play a major role in coping.

Rice (1998) reports on a study conducted by Calver, Scheier & Pozo in 1992, in which women diagnosed with breast cancer were measured for optimism immediately prior to surgery and again 3 months post surgery. The coping strategies used by the patients with higher levels of optimism concerned accepting the reality of the situation, seeing it in a positive a light, actively doing what had to be done and sometimes using humour as a tension breaker. At the three-month follow up, the study found that optimism was still linked to acceptance of the situation, while the pessimistic patients tended to give up and use denial as a way of coping.

Carver et al (1994) also examined the personality trait optimism versus pessimism, as a predictor of adjustment during the first year after surgery for breast cancer (n = 70). Optimism and pessimism were measured at diagnosis. Subjective well being (satisfaction with life and mood states) was measured the day before surgery, then again at 3-months, 6-months and 12-months post surgery. Results showed that the pessimistic women showed worse adjustment at every measurement point during the study.

In a mixed group of cancer patients (breast comprised 43%), Merluzzi & Martinez Sanchez (1997) found that psychosocial adjustment was strongly correlated with most factors of the Cancer Behavior Inventory, which was devised as a measure of self-efficacy for coping with cancer. As anticipated, the results indicated a strong relationship between efficacy and adjustment to cancer. Efficacy expectations were also significantly correlated with optimism in this study.

5.5 Social Support

Although social support is presumed to buffer the effects of stress for cancer patients, Rice (1998) describes research by Revenson, Wollman & Felton (1983) which contradicts this hypothesis. The study found that patients who received more social support showed worse adjustment and more negative affect than those receiving less social support. Rice suggests that the ongoing presence and support of the extended family may in fact serve as constant reminders of the disease and continue to stir up negative emotions over longer periods.

Contrary to these findings, Lichman, Taylor & Wood (1988) found that breast cancer patients who did have positive and supportive family members showed more positive adjustment. In the five studies reviewed by Carlsson and Hamrin (1994), most came to the conclusion that social support contributes significantly to the psychosocial adjustment of women with breast cancer.

Attempting to isolate factors that differentiated between good and poor psychological adjustment to cancer, Rodrigue et al. (1994) found that intrapersonal, family and socio-ecological variables accounted for 27-41% of the variance in adjustment when demographic and illness-related variables were controlled. It was found that size and satisfaction with support systems were linked to negative affect. In other words, the less support the patient received, and the lower the satisfaction with that support, the more distress was reported.

Research by Levy et al. (1992) suggests that it is the patients' perception of emotional support that is important. This endorses findings by Bloom (1982) who contends that it is the perception of support, measured by the frequency of contact and family cohesiveness that is *"the strongest predictor of healthy coping responses to mastectomy"* (Cited in Royak-Schaler,1991: p81).

Reviewing the literature on social support for breast cancer patients, Royak-Schaler (1991) identified three major sources of support; family, the doctors and medical personnel, and other patients. This author describes the 1960s as a period of neglect for breast cancer patients, many of whom were not even told their diagnosis. During the 1970s, more research was done and health care professionals gave patients much more support. The 1980s saw advances in teaching patients about coping with the psychosocial problems associated with cancer. And the challenge for the 1990s, says Royak-Schaler, *"is to understand various coping styles and their immunological correlates and to develop intervention to promote healthy outcomes"* (Royak-Schaler,1991: p85).

5.6 Coping Styles

The notion of the cancer-prone personality was the focus of much research in the 1950s and 1960s. This personality type was characterised by: *"ineffective expression of anger, unresolved dependency issues, including emotional distance from parents and sexual disturbance"* (Royak-Schaler, 1991: p73). Although some of this work has since been challenged, many studies have found that the suppression of anger and the stoic, passive styles are associated with poorer disease outcome.

One of the best known studies concerning coping styles and women's adaptation to breast cancer, was conducted at the Faith Courtauld

Research Unit in London. This developmental work of Greer, Morris & Pettingale in 1979 identified four mutually exclusive coping categories; fighting spirit, denial, helpless/hopeless and stoic acceptance. After five years this study found that recurrence-free survival was more prevalent (75%) among women who reacted with either fighting spirit or denial. Those who favoured the stoic acceptance or helpless/hopeless styles fared less well (Royak-Schaler,1992).

In a later study at the Faith Courtauld Centre, researchers Burgess, Morris, & Pettingale (1988) were unable to replicate the specific responses of the earlier 1979 study. They found that cancer patients used a variety of behavioural and cognitive responses, and sometimes a combination of all four styles in a single interview. These authors identified four broad coping styles: - anxious/depressed, denial, confrontational coping and fatalistic outlook (Jarrett et al.1992).

Rodrigue et al. (1994) found that individuals who adjusted well to cancer used fewer non-confrontational coping styles such as avoidance and acceptance-resignation. The authors note that this is consistent with their previous findings, and those of others such as Burgess et al.(1988).

Ferrero, Barreto & Toledo (1994) also found that the styles Fighting Spirit and Denial correlated with better present and future quality of life. They report that Helpless/Hopeless, Anxious Preoccupation and Fatalistic styles were negatively associated with well-being.

In the Courtauld studies, breast cancer patients seemed to use a combination of emotion and problem-focused coping, as described by Lazarus & Folkman (1984). Those who believed in their own ability to manage their health (i.e. who had an internal locus of control) tended to use cognitive, problem-focused responses, while the more fatalistic employed emotion-focused strategies (Royak-Schaler,1991).

In a retrospective study of 244 Australian women with breast cancer, Lavery & Clarke (1996) found that both problem and emotion-focused coping strategies were positively associated with adjustment. Women who rated their own adjustment as excellent showed lower levels of helplessness, made fewer changes to their lives, sought more information about their illness and actively looked for alternative therapies. Because the study was retrospective it depended on recall of events. The study was further limited because the sample was self-selected.

Jarrett et al.(1992) measured coping in breast cancer patients and found that most patients used a wide range of coping responses, a finding that challenged the notion of mutually exclusive coping styles. Research on coping with cancer has, according to Jarrett, seen a move away from the *"search for enduring coping styles towards the study of situation-specific responses outlined by Lazarus and Folkman"* (1992:p 594).

Shapiro et al. (1994) used cluster analysis to test for coping categories and found that subjects fell into one of three groupings: confrontive, resigned avoidant, or a combination of non-dominant styles. However these authors concur with other researchers that people with cancer are likely to have *"numerous coping strategies in their cognitive or behavioral repertoire"* ... and *"The use of particular coping strategies likely depends on numerous intrapersonal and situational factors"* (1994 ; p157).

5.7 A Multi-dimensional Approach.

Research by Rodrigue et al. (1994) explored multidimensional determinants of psychological adjustment to cancer in general - (29% of the sample were breast cancer patients). This study examined *simultaneously the collective contribution of key psychosocial variables"* - (demographic, family, intrapersonal and socio-ecological), and results suggest that *"adjustment to cancer may best be understood within a multi-systemic model"* (1994:p212).

Based on literature reviewed, Royak-Schaler concludes that *"breast cancer is an ever changing process that requires women to make difficult adjustments along the way...... Therefore, identifying an enduring coping style may be difficult"* (1991: pp 79-80). However, there are not many studies that have investigated the long-term psychosocial aspects of breast cancer, and prospective studies are even less common.

Heim, Augustiny, Schaffner & Valach (1993) conducted one of the few prospective, longitudinal studies. Believing that demands on individuals vary within a particular illness, and from time to time, these authors set out to examine the stability and variability of coping in breast cancer patients. Their research focused on coping with cancer over both time and situation, and monitored 74 breast cancer patients for 3-5 years at 3-6 monthly intervals. Using the Bernese Coping Modes scale Heim et al. measured 26 coping modes. Results confirmed the arguments in favour of stability and variability in coping activity over both time and situation. In support of stability, it was found that there was consistent distribution of coping modes over time. There was also evidence for variability, with a great range of coping modes being used by participants at different times and in situations. The researchers also observed an average of ten coping modes per patient at each interview. In subsequent work by Heim, Valach & Schaffner (1997), the authors concluded that in long-term studies on coping and adaptation to illness, stage-related measures are preferable to time measures alone.

The findings of Heim et al.(1993) add to the long-standing debate around disposition versus situation, and trait versus state. While there are those who favour the trait approach and others who advocate situational stability, Heim and colleagues contend that the issue is not about the existence of these phenomena in the coping process. Instead it is, *"how* *to assess their significance and how to interpret the presence of both consistent and varying patterns."* Referring to the biopsychosocial model of illness and its multivariate basis, Heim describes Antonovsky's (1979) salutogenic model, as a *"promising interactionist point of view."* (1993:p 540).

Chapter six

A SALUTOGENIC PARADIGM

When you are told that you have some kind of physical affliction, you can prepare either to suffer or to heal.

Unknown source, in Friedberger (1996).

6.1 The Origins of Health and Strength

As Seligman (1998) points out, psychology is not just the study of weakness and damage. It should also be concerned with the study of strength. He contends that after fifty years of working in the medical model, which focuses on personal weakness, the (psychology) profession needs massive research on human strength and virtue. Strümpfer (1990) notes that other social sciences as well as psychology also tend to function mainly in this paradigm of pathogenic thinking, which is orientated towards the causes and correlates of disease and why people become physically and psychologically ill.

An alternative approach is to look for the causes and origins of health, a way of thinking that is conceptualised in what Antonovsky (1979) calls a salutogenic paradigm. The word 'salutogenesis' derives from the Latin: *'salus'* meaning health, and the Greek: *'genesis'*, which means origins. Antonovsky (1979 & 1987) developed a theoretical model in this salutogenic framework, which had as its core construct the Sense of Coherence.

Strümpfer (1990) refers to similar salutogenic constructs that fall within this relatively new paradigm. These are Kobasa's (1982) 'hardiness', Ben-Sira's (1985) 'potency', Rosenbaum's (1988) 'learned resourcefulness' and Colerick's, (1985) 'stamina'. Others concepts which have partial connections with salutogenesis are self-efficacy, (Bandura, 1977), internal-external locus of control, (Rutter, 1966) and resilience (Werner, 1984).

Strümpfer (1990) describes three implications of Antonovsky's (1987) salutogenic thinking :

- The first does away with the dichotomy that people are either healthy or diseased, and proposes a *'health ease/dis-ease continuum"* (Antonovsky, 1987, p3). It suggests that all people fit somewhere between the two theoretical extremes of total well being and terminal illness.
- Secondly, salutogenic thinking proposes the possibility that stressors may have 'healthy' consequences and rejects the more common notion that stressors are inherently bad.
- The third point is that 'deviant cases' are important to study. The deviants are those who make it against all odds, for example the patient who continues to enjoy life while struggling against a life-threatening illness. The salutogenic approach poses the question: - what makes this type of individual special and able to cope successfully?

6.2 Sense of Coherence

Attempting to unravel the 'mystery of health' and to explain how some people cope with stress and stay well, Antonovsky (1979 & 1987) introduced the concept Sense of Coherence (henceforth SOC). This author describes SOC as a global, dispositional orientation to life, rather than a state or trait. SOC does not refer to a particular kind of coping strategy but to factors that provide the foundations for successful coping in all cultures. It is an underlying construct that facilitates the development of coping strategies rather than a specific style of coping (Bowman,1997).

Antonovsky's formal definition of SOC was redefined in 1987 as follows :
" The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement." (1987, p10).

An individual's SOC relates partly to personality, but it is also developed by life experiences through what Antonovsky calls generalised resistance resources (GRRs). Antonovsky contends that GRRs facilitate the effective management of tension in any demanding situation and help individuals to make sense of the life stressors that they constantly encounter. He set out to understand why GRRs such as ego strength, cultural stability, wealth and social support appeared to promote health, and what it was that these resources had in common. Antonovsky concluded that the answer was SOC. He says, *"The evidence is clear that the SOC is directly related to health status, both correlatively and predictively."* (1990: p 166)

It is suggested that we find our given place on the SOC continuum by the end of our first decade of adulthood *"... having sorted out or accepted the inconsistencies in the different areas of life"* (Antonovsky, 1987 p 119). Once formed, it is unlikely that one's SOC will change in any radical way. Although the level may shift temporarily in either direction, the tendency is to revert to the individual's norm.

The SOC construct has three components: comprehensibility, manageability and meaningfulness. People who have a strong SOC are high on these components compared to those with a weak SOC. The first component, comprehensibility, refers to the way people make cognitive sense of their internal and external environment. Manageability relates to the belief that one has about the adequacy of resources available to meet the demands of stressors. Antonovsky (1987) makes the point that available resources can be under an individual's own control or controlled by legitimate, trustworthy others, e.g. a spouse, God, doctor. Meaningfulness has a motivational element, and refers to perceptions about the demands as challenges deserving of personal investment.

6.3 Sense of Coherence and Personal Growth

By way of explaining how personal growth happens, Tedeschi & Calhoun (1995) developed a model for coping with trauma. These authors are of the opinion that the tasks which provide the foundation for positive change and successful coping, fall into those same three interrelated categories that are described by Antonovsky's (1987) sense of coherence, namely : manageability, comprehensibility, and meaningfulness.

When facing-up to a traumatic event, it is suggested that the individual initially goes through a stage of denial, after which the manageability of the event is assessed. Attempts at primary control of the situation, may give way to secondary control, as the person adjusts to the uncontrollable event and their expectations are modified. This can manifest in an acceptance of the situation. According to Tedeschi & Calhoun (1995), when attempts at primary control are unsuccessful some people find the situation intolerable. This is particularly true for those who have shown high levels of self-efficacy, hardiness, resilience or optimism in the past.

People make sense of their world, or find it comprehensible, because of the assumptions or higher order schemas that they hold. Tedeschi & Calhoun (1995) say that an individual's world is based quite literally upon these schemas, and that traumatic events will challenge the belief system and call into question basic assumptions about the world. Comprehensible is initially threatened by trauma, and this then requires a substantial reorganisation of existing schemas. Like Antonovsky (1987), these authors believe that meaning in life goes beyond manageability and comprehensibility. They say that meaning instils value and purpose in life, and that meaningfulness refers to the extent to which life makes emotional sense, and is worthy of commitment and an investment of energy.

This coping model proposed by Tedeschi & Calhoun (1995) holds that personality factors are involved in both early and subsequent responses to trauma. People who are have an internal locus of control, high level of self-efficacy, are optimistic and hardy, may initially have a sense that they will be able to cope successfully through their primary (normal) coping strategies. But because trauma challenges one's normal ways of coping and one's existing schemas, the situation *"is deemed to be unmanageable, incomprehensible or unmeaningful"* (1995, p90). The model suggests that a secondary coping response is then set in motion. This stage is characterised by rumination, which leads to schema revision and an attempt to relieve distress via emotion-focused coping. At this point, support from significant others may influence the traumatised person in making sense of the situation and in helping to find ways of managing it.

Schema revision, personality characteristics and assistance from others may all influence the way the individual accepts the unchangeable aspects of the situation and develops a new understanding of what has occurred. When this happens and goals are realistically revised, emotional distress is reduced and coping can be described as successful.

Tedeschi & Calhoun believe that *"The meaningfulness of life is deepened when the preciousness of what remains is enhanced by the losses"* (1995, p91).

6.4 Quality of Life & Life Satisfaction

Quality of life has become an important focus, as well as a catch phrase in cancer medicine. Like happiness, it is a familiar term, and one that is generally understood, but it is reputedly difficult to define and hard to measure (Slevin, 1992). Hales says that quality of life is an ambiguous construct since a specific situation or set of circumstances may make one individual extremely happy while frustrating another (1986).

According to Wellisch (1984) the assessment of quality of life occupies a place somewhere between science and philosophy, and presents considerable measurement difficulty. The author believes that for a cancer patient the concept quality of life is *"far more involved than the person's well being or status at any one point ..... Quality of life should be viewed as a process or response to a flow of events"* (1984, p2290).

A review of studies that concern quality of life points to a variety of instruments and many different approaches to measurement. This suggests that there are many different theoretical backgrounds to the concept. (E.g. Fallowfield, 1990; Carlsson & Hamrin, 1994; Stefanek, 1995).

Gill & Feinstein (1994) note the lack of clarity and consistency in both definition and the measurement of quality of life. Reviewing 75 articles, these authors contend that many published quality of life measures are clinically inappropriate because of poor face validity. They say that many researchers do not adequately define their concept of quality of life, and fail to identify their specific domains of measurement. Gill & Feinstein point out that quality of life is a very personal perception, indicating the way individuals feel about their health, and non-medical aspects of their lives. They conclude that the majority of quality of life measures in the medical literature "*seem to aim at the wrong target*" (1994, p619).

Ganz (1994) is somewhat more positive about the measurability of this construct, saying that there is growing consensus about quality of life dimensions, and that many more appropriate measuring tools are now available. This author also notes that quality of life is being used more and more as an outcome measure in research.

Fallowfield, a prominent researcher in the field of breast cancer, believes that appropriate monitoring of quality of life parameters should be a mandatory part of the follow-up when determining the outcome of various treatments for breast cancer. Fallowfield (1990) includes four primary fields of functioning in her explanation of the concept quality of life: psychological, social, occupational and physical. She lists depression, anxiety and adjustment to illness as typical items in the psychological domain.

Diener, Emmons, Larson & Griffin (1985) reports that in addition to the recent appeal in measuring quality of life and health status, there is also a growing interest in the concept of subjective well being. According to Diener et al., well being is thought to comprise two components: the affective, emotional component and the cognitive-judgemental aspect. The latter has been conceptualised as life satisfaction. This author says that although many scales have been developed to measure affect, very few have been developed to measure general life satisfaction.

Reviewing the literature concerning quality of life, life satisfaction and well being, it would seem that there is considerable overlap between these somewhat inexact constructs. (E.g. Tate, Riley, Perna & Roller, 1997 and Riley et al. 1998). Gill & Feinstein (1994) believe that quality of life can only be suitably measured by finding out the opinions of patients, and replacing or supplementing instruments developed by 'experts'.

6.5 The Fortigenic Concept

When Antonovsky (1979, 1987) coined the phrase salutogenesis, he was primarily concerned with the study of physical health and disease. But Strümpfer (1995) contends that Antonovsky was in fact dealing with far more than the determinants of physical health. He suggests that Antonovsky's focus also included sources of strength in general. On the basis of Antonovsky's writings, and to indicate this broader focus, Strümpfer then *"proposed a more embracing construct fortigenesis, which means the origins of strength"* (Wissing & van Eeden (1997: p5).

Writing in 1994, Antonovsky said, *"I have no illusions. A salutogenic orientation is not likely to take over. Pathogenesis is too deeply entrenched in our thinking"* (1994, p6). But Martin Seligman, world renowned for his theory of learned helplessness, is currently an enthusiastic promoter of what he calls the study of positive psychology. While acknowledging that huge strides have been made in understanding and treating mental illness, he points out that *"Treatment is not just fixing what is broken, it is nurturing what is best within ourselves."* Seligman also suggests that there is a *"set of human strengths that are most likely buffers against mental illness"* (1998:pp 1-2).

6.6 Focus and Hypotheses of the Thesis

The present research is based on a paradigm of positive psychology, and conducted from a salutogenic (Antonovsky 1979, 1987) and fortigenic perspective (Strümpfer, 1995). By exploring women's experience of breast cancer and mastectomy, the study aims to distinguish successful coping from poor coping, and to identify sources of psychological health and strength. If this can be achieved, there may be positive implications for the less successful copers. For by identifying the women who are at high risk for psychological distress, *"they may be timeously targeted for psychological intervention".* (Schlebusch & van Oers, 1999: 31).

From the literature reviewed, findings are inconclusive. Researchers disagree about the role and significance of dispositional and situational factors in the coping process. The research challenge was to explore the interaction of these variables, their impact on the coping process, and their significance as predictors of successful coping.

It is hypothesised that after a diagnosis of breast cancer and subsequent mastectomy :

1. Successful coping involves a combination of stable traits, variable adaptive behaviours and previous life experiences.

2. Women's disposition before mastectomy is one of the best predictors of successful, adaptive coping.

3. Women with a strong *sense of coherence* (SOC) (Antonovsky, 1987) cope more successfully than those with a weak SOC.

4. There is a positive correlation between *sense of coherence* (SOC) measured before mastectomy, and *satisfaction with life* (SWL) (Diener et al, 1985) assessed three months after surgery.

It is hoped that this study will contribute to the body of 'salutogenic' research, which aims to learn more about adaptive coping, the origins of psychological health, and why some people are *"located towards the positive end of the health ease/disease continuum"* (Antonovsky, 1987, pxii).

Chapter Seven

METHODOLOGY

7.1 Design

This study took the form of a prospective, correlational field survey. It combined quantitative and qualitative methodology to analyse data gathered from a combination of questionnaires and interviews.

7.2 Preparation & Pilot Study

Preliminary enquiries were made to the Department of Radiation Oncology about the feasibility of conducting psychological research at Groote Schuur Hospital. A formal application was then made to the Research Ethics Committee, at the Faculty of Medicine, University of Cape Town. Once approval was received by this committee (Appendix A) and by the Heads of Department in Radiation Oncology and Surgery the practical preparation began.

Over a period of three months, the author observed and became familiar with routines, procedures and protocol at Groote Schuur Hospital. Thanks to the interest and co-operation afforded by the professional medical team, it was possible to sit-in on consultations at various out-patient clinics, accompany patients to the mammogram unit, observe examinations and biopsies, and also to watch a mastectomy being performed. The multi-disciplinary team also welcomed my attendance at case discussions and meetings at which pathologists and radiologists described their findings.

Apart from the acquisition of knowledge and information about breast disease, these months of preparation provided a glimpse into the patient's experience of breast cancer; from their initial fears, through all the diagnostic procedures to the surgery itself. It was also vital for the planning and appropriate timing of the various data gathering stages.

A small pilot study was undertaken over a reduced time frame and as a result some planned procedures were slightly modified. It was found that some patients had difficulty with the questionnaires because of their limited reading ability. So in the main study, all questionnaires were administered in an interview-format to ensure that the questions were clearly understood. Also recording interviews in a busy general ward or out-patient clinic proved extremely unproductive, so this method was abandoned.

The use of case study material was considered to provide another measure of coping outcome. To test the feasibility of this approach, seven case studies were compiled from interview and demographic data. The cases were given to a 3rd party (clinical psychologist) who was asked to rate the way these patients were coping with their illness. The assessor was asked to score participants out of a maximum of 10 points. In this mini-sample, the scores ranged from 1/10 to 9/10, but the assessor felt that scores related more to general mental health, rather than the way participants were coping with their current medical condition. For this reason it was decided not to pursue the case-study approach. As a point of interest, it was found that the correlation between coping, as assessed by the 3rd party, and Satisfaction with Life (SWL scale) was 0.66. However as this sample was unacceptably small, (n=7) it was not possible to draw any meaningful conclusions.

7.3 Subjects

Thirty-two mastectomy patients took part in the study. The mean age of participants on entry to the study was 54.9 years, and the range was 33 to 76 years. Other demographic information is presented in chapter 8. Potential participants were women who attended the breast clinic at Groote Schuur Hospital in Cape Town. Criteria for inclusion in the study were a diagnosis of breast cancer (irrespective of the stage), and a scheduled mastectomy. Patients were to be excluded if they had a concurrent serious psychiatric disorder or secondary cancer, but no such case presented. The study also required that participants be able to speak and understand English; two likely subjects were excluded on the basis of these criteria.

Between March and July 1998, thirty-four mastectomy patients were approached and invited to take part in the study. Thirty-two agreed, one declined, and another's husband would not permit her to be interviewed. There was no attrition; all thirty-two participant completed the five requisite questionnaires plus all scheduled interviews.

7.4 Procedure.

It took 4 months to recruit the 32 participants. During this time, all patients scheduled for a mastectomy were visited in the hospital ward the day before their planned surgery. They were introduced to the study, invited to take part and asked for their informed consent. (Appendix C). On this occasion, demographic information (Appendix B) was collected and the first measure of disposition, the Orientation to Life Questionnaire was administered. (Appendix D). This part of the procedure proved much easier than anticipated as potential participants were generally enthusiastic about the study and co-operated willingly.

During the planning stages of this research, the author observed patients at the breast cancer clinics, where the shock and distress of their cancer diagnosis was painfully evident. By contrast, the atmosphere in the wards on the eve of surgery was remarkably peaceful. Most of the mastectomy patients were calm and quite happy to be interviewed. One possible explanation for this unexpected response, was that most of the women had checked into the hospital in the morning, and by the time they were interviewed late afternoon, they were bored and quite pleased to have someone to talk to. Also for many of the participants it was an unusual 'luxury' to sit in bed, have meals brought on a tray and to be paid attention. A number of participants remarked that they felt proud and important to be involved in the study.

Two days after surgery, participants were seen in hospital again. The Recovery Locus of Control questionnaire (Appendix E) was administered together with a brief semi-structured interview to assess previous ways of coping. (Appendix I)

At monthly intervals after surgery, participants were followed up with a telephone interview to monitor their physical and emotional status. This type of interview was generally fruitful, and most women were keen to elaborate on their experiences of mastectomy. But when contact had to be made at their place of work or via a neighbour's telephone, participants were generally less forthcoming and tended to answer in monosyllables. However, these calls still served the purpose of maintaining relationships with participants. This was important because the final interview and questionnaire session was lengthy, and required the respondents' full co-operation. It was also found that the telephone interview had a slight advantage over the face-to-face session, in that it was easier to record answers without the concern of losing eye contact. (See Appendices I to O for interview questions and examples of completed forms.)

Three months after mastectomy, or as close to this date as possible, participants had a final interview and completed three more questionnaires : - The Mental Adjustment to Cancer, Satisfaction with Life Scales and Acceptance of Illness (Appendices F, G & H). Most of the final interviews took place at the outpatients department of the hospital, but occasionally it happened that a patient's treatment had been completed or terminated, so the interview took place at their home.

7.5 Measures and Instruments

7.5.1 Orientation to Life Questionnaire

The Sense of Coherence (Antonovsky, 1987) was used as the chief measure of disposition. Antonovsky operationalised this construct into a format called the Orientation to Life Questionnaire (Appendix D), a 29-item tool designed to measure an individual's orientation to life, or way of experiencing the world. Subjects indicate agreement/disagreement on a 7-point Likert-type scale. The minimum score is 29, maximum 203. Sense of Coherence (SOC) has three components : comprehensibility (11 items), manageability (8 items) and meaningfulness (10 items), which are measured on sub-scales.

The SOC /Orientation to Life scale has been used in many studies in the area of health and it correlates positively with general well-being, life satisfaction, quality of life and hardiness. Research from twenty-six different studies substantiates the scale's reliability, validity and feasibility. Antonovsky (1993) reviewed the instrument's criterion validity in four domains: generalised perceptions of self and environment, perceived stressors, health and well-being, attitudes and behaviour, and found that most correlations were statistically significant.

Published studies report Cronbach alpha measures that range from 0.82 to 0.95, and in the present study the Cronbach's alpha was 0.81. Only one study was found that used this scale with cancer patients, (Krivolahvy, 1990 cited in Antonovsky,1993) and literature searches to-date have not identified any studies which use the SOC with mastectomy patients.

7.5.2 Recovery Locus of Control Scale

Partridge & Johnston (1989) designed this 9-item questionnaire to measures internal/external perceptions of control over recovery. (Appendix E). Five of the items are designed to reflect internal beliefs and four items reflect external beliefs. Questions are answered on a five-point Likert scale from *strongly agree* to *strongly disagree*. The total score measures the strength of an individual's internal recovery locus of control belief. A high score (maximum 45) is indicative of a strong internal locus of control, while a low score (minimum 9) indicates a strong external locus of control. The authors developed the scale from a content analysis of statements made by wrist fracture and stroke patients, and say there do not appear to be any similar scales. They report an internal consistency range of 0.49 to 0.80. The current study's Cronbach's alpha was 0.68.

7.5.3 Mental Adjustment to Cancer Scale (MAC)

This 40-item scale was developed by Watson et al. (1988) to assess adjustment to a cancer diagnosis. (Appendix F). It is used to measure the coping styles of people with cancer. Participants complete a 4-point Likert-type scale with responses ranging from *definitely applies to me* to *definitely does not apply to me*. The MAC incorporates five sub-scales which are shown below, followed by a brief description of each style. (Jarrett, Ramirez, Richards & Weinman,1992).

Sub-scale	**Number of items**	**Range of scores**
Fighting spirit	16	16 - 64
Helpless/Hopeless	6	6 - 24
Anxious Preoccupation	9	9 - 36
Fatalistic	8	8 - 32
Avoidance.	1	1 - 4

Fighting Spirit - the diagnosis is seen as a challenge. The patient has an optimistic view and believes it possible to have some control over the cancer. The coping response is confrontational.

Helpless/Hopeless - Cancer is perceived as a loss, and the patient believes the prognosis is an inevitable, negative outcome. No active coping strategies are present and the patient feels it is impossible to exert control over the illness.

Anxious Preoccupation - The diagnosis is perceived as a major threat. There is uncertainty about the prognosis and control over the cancer. Coping responses include searching compulsively for reassurance.

Fatalistic - The diagnosis is seen as a minor threat - outcome is accepted with equanimity. The patient does not believe it possible to exert control over the disease. An attitude of passive acceptance is shown, with no confrontational strategies.

Avoidance (denial) - The diagnosis is seen as a minimum threat. The issue of control is irrelevant and the patient has a very positive view of the prognosis.

Each of the MAC sub-scales has a separate score, which can be converted to a T-score for comparative purposes. Waton et al. (1988) amalgamated the sub-scales fighting spirit and helpless/hopeless, naming it FSH, because analysis revealed that these styles formed a bipolar scale. The scale Avoidance has only one item, so it is not included for scoring purposes.

The authors, report acceptable internal consistencies for all the sub-scales. Cronbach's alpha values are as follows, with the present study values shown in brackets. Fighting spirit, 0.84 (0.85); helpless/hopeless, 0.79 (0.67); anxious preoccupation, 0.65 (0.30); fatalistic, 0.65 (0.28). The big discrepancies in the last two sub-scales are discussed in Chapter nine.

7.5.4 Satisfaction with Life Scale (SWL)

This 5-item scale (Diener, Emmons, Larson & Griffin, 1985) was used as the main measure of coping outcome. SWL is a subjective measure of life satisfaction, assessed according to a person's own criteria of quality of life and is rated on a 7-point scale, from *strongly agree* to *strongly disagree*. (Appendix G). The possible range of scores is 5 - 35. Diener et al.(1985) report an alpha reliability index of 0.87, which is exactly the same as that found in the present study.

7.5.5 Acceptance of Illness Scale (AOI)

This questionnaire developed by Felton et al. (1984) focuses directly on the way patients are able to accept their illness without experiencing negative emotions and feelings. The scale has 8-items with responses on a 5-point Likert-type scale. (Appendix H). Responses range from *strongly agree* to *strongly disagree*, and the possible score range is 8 - 40. The authors report a high internal consistency (Cronbach's alpha = 0.81 to 0.83) which was matched by this study's alpha of 0.82. Acceptance of Illness scores were examined as a second potential measure of coping/outcome.

7.5.6 Qualitative Measures

Coyne & Gottlieb contend that the study of coping *"has become too narrowly method-bound, defined by the uncritical application of standardised checklists to diverse populations and situations".* (1996: p961). These authors suggest that the currently popular checklists present an incomplete and distorted picture of coping, and recommend that researchers use a wider range of methods. To guard against this potential problem, interviews were used as well as the scales that are described above. Over a period of three months every participant had four semi-structured interviews. There were between 8 and 12 questions in each, most of which were open-ended. The first and the last interviews were face-to-face, and the other two were conducted by telephone. The interviews were specifically designed for this study.

The first interview (Appendix I) was developed primarily to uncover previous coping styles, and was based on questions designed by Aldwin, Sutton & Lachman (1996). Participants were asked to recall a low point or difficult situation in their lives and to describe how they had coped, what resources they had drawn on and what they had learned from the experience. This data was used to compare previous and present coping styles as well as resources. Appendix J is an example of a completed interview form.

The telephone interviews (Appendix K) were used to follow-up and monitor participants' physical and emotional status, and were administered one and two-months post mastectomy. Questions were specifically developed to elicit styles of coping, (for comparison with the MAC scales), resources and support systems. Examples of completed interviews are provided in Appendices L and M.

The final face-to-face interview (Appendix N) focused on psychosocial issues: specifically body image, breast reconstruction, sexuality, negative emotions and loss. An example is given in Appendix O.

7.6 Analysis

There were three sources of data; questionnaires/scales, interview material and the patients' files, from which the demographic and medical data was extracted. As the qualitative data consisted mainly of short answers to semi-structured interview questions, much of this material was able to be transformed to quantitative data and entered into Excel spread-sheets along with the demographic, scale and medical data. Statistica (StatSoft, Inc.,1995) was used for the analysis.

Analysis of the interview data involved a careful scrutiny of participant's responses, to identify words and phrases that were indicative of ways of coping and resources used. Words were highlighted in different colours to represent different coping styles. If no particular style stood out, then *combination* was recorded. Resources were similarly coded and grouped into four categories: faith, family, friends and self.

A measure of religiosity was obtained from responses to the open-ended questions in all four of the interviews. Every unsolicited references to God, Lord, prayer, church and faith was counted as a recording unit, and these were totalled to give a *religiosity* score. Faith was judged subjectively by the interviewer. This assessment was based on the intensity and perceived sincerity with which participants talked about their faith and relationship with God. Participants' faith was recorded as none, some or strong. In the same way that religiosity was scored, every reference to support from family, friends or self was counted as a recording unit and added-up to give a measure of that resource. The resource with the highest score was described as the *main resource.*

Illness-related information gathered from participants' files, was converted to quantitative data. Tumours were coded according to the international system described in chapter 2 (T1-T4, plus nodal involvement). Treatments were coded in order of severity, as follows :

1. Hormone therapy only.
2. Chemotherapy only.
3. Chemotherapy + Hormone therapy.
4. Radiotherapy only.
5. Chemotherapy + Radiotherapy.
6. Hormone + Chemotherapy + Radiotherapy.

The data on tumour size/stage was collected from the participants' files after all questionnaires and interviews had been completed. As tumour size is related to prognosis, it was felt that prior knowledge of this nature could be responsible for interviewer bias. It was apparent from the interviews, that participants were generally unaware of the staging of their cancer. The exceptions were the two T4-patients, who required radio- therapy to shrink their tumours prior to surgery. The effects of treatments on hair loss, were coded as, no loss, thin or loss. (1 - 3). And based on participants' descriptions of the generally unpleasant side-effects resulting from treatment, the effects were recorded as none, some or bad (1 - 3).

Cronbach's alpha values were determined for all scales and sub-scales and descriptive statistics were extracted. A correlation matrix (Pearson Product-Moment correlation coefficient) was set up to compute the coefficients and examine associations between all variables. The matrix was subsequently reduced and tabulated in groups and categories.

In view of the large number of variables and relatively small sample size, the use of multivariate techniques of analysis was limited. A simple predictive coping model was conceptualised, which was based on findings in the literature reviewed, this study's correlation analysis, interview data, and observations of participants. It was proposed that the combination of Sense of Coherence, Fighting Spirit style, age and religiosity, would significantly predict Satisfaction with Life after mastectomy. Multiple regression analysis was used to test this model.

Chapter Eight

RESULTS

8.1 QUANTITATIVE ANALYSIS

When you can measure what you are speaking of and express it in terms of numbers, you know something about it. When you cannot express it in terms of numbers, your knowledge of it is of a meagre kind.

Lord Kelvin, 19th century philosopher, in Fallowfield (1990).

Table 1.

Abbreviations Used

Scales		
Sense of Coherence	-	SOC
Recovery Locus of Control	-	RLOC
Mental Adjustment to Cancer	-	MAC
Acceptance of Illness	-	AOI
Satisfaction with Life	-	SWL
Coping styles (MAC scale)		
Fighting Spirit	-	FS
Helpless/hopeless	-	H/H
Fighting Spirit - Helpless/hopeless	-	FSH
Anxious Preoccupation	-	AP
Fatalistic	-	F
Avoidance	-	A
Religiosity	-	REL

8.1.1 Demographics

The key characteristics of the sample are presented in Table 2. In essence:

- The sample (n = 32) had a mean age of 54.9 years (SD = 10.41) and the range was 33 to 76 years.
- The majority (75%) belonged to the so-called coloured population group, 19% were white and 6% black (n = 2).
- English was the home language of 50%, Afrikaans 44%, and 6% spoke Xhosa (n =2).
- A little over half (53%) of participants were married, 25% widowed, 13% had never married and 9% were divorced.
- 22% were childless and 78% had at least one living child.
- Education level was modest; 9 % matriculated, just over half (53%) attended high school (attaining standard nine or lower), and 38% had a primary school education.
- Most subjects were not employed outside home (40%), 13% worked part-time and 19% were employed full-time. 28% were pensioners.
- Almost all came from a low socio-economic background; 44% had a gross family income of less than R1000 per month, 53% received between R1000 and R5000 per month, and 3% earned more than R5000 per month.
- The majority were Christian (88%), 9 % Moslem, 3% other (n =1).

Table 2 below shows the sample characteristics in relation to the two main scale measures: - SOC (disposition) and SWL (coping outcome). Of note, is the strong relationship between age and the scale measurements, marked *. Percentages marked # also require comment. Firstly, the high mean SOC associated with Black and Xhosa speaking subjects, cannot be considered meaningful because this sample sub-group is so small (n = 2). Secondly, the inverse relationship between income and SOC (group means), which looks significant, was reflected as a negative but insignificant correlation of -0.23 in the correlation matrix.

Table 2. Sample Characteristics

	N	Percent	Mean SOC	Mean SWL
Age Group.				
31 - 40	2	6%	134	14
41 - 50	10	31%	134	24
51 - 60	11	34%	137	24
61 - 70	6	19%	161*	31*
70 +	3	9%	166*	33*
Ethnic Group				
Coloured	24	75%	142	26
White	6	19%	141	24
Black	2	6%	164 #	20
Home Lang.				
Afrikaans	14	44%	139	25
English	16	50%	144	26
Xhosa	2	6%	164 #	20
Marital Status				
Married	17	53%	143	26
Not married	15	47%	145	25
Education				
Primary	12	38%	139	25
Secondary	17	53%	147	25
Matric	3	9%	136	25
Employment				
Not employed	13	41%	137	24
Employed	10	31%	137	23
Pensioner	9	28%	159*	31*
Income				
<R1000pm	14	44%	149 #	26
>R1000pm	18	56%	139 #	25
Religion				
Christian	28	88%	143	26
Moslem	3	9%	142	22
Other	1	3%	143	23

Correlation coefficients also revealed that age was the only demographic factor significantly associated with SWL (.61). Table 3 below shows that age correlated positively with the secondary outcome measure AOI (.55), the coping style FS (.39) and SOC (.46). Significant negative relationships were found between age and the coping styles H/H (-.65) and AP (-.41). No other demographic variables were significantly associated with the scale measurements, and are therefore not presented here.

Table 3. Correlation Matrix : Age & Scale Measures

Scale	SWL	SOC	RLOC	AOI	FS	HH	AP	F
AGE	**.61**	**.46**	.28	**.55**	.39	**-.65**	**-.41**	.02

(N=32) Highlighted correlations are significant at p < .05000

8.1.2 Illness and Treatment Variables.

Table 4. Summary of Tumour stage & Treatment Regime.

Tumour stage		**n = 32**	
T1 – tumour < 2 cm.	-	12	(38%)
T2 – tumour 2cm - 5 cm.	-	16	(50%)
T3 - tumour > 5 cm.	-	1	(3%)
T4 – tumour fixed to the chest wall or skin.	-	2	(6%)
Tx – tumour cannot be assessed.	-	1	(3%)

Treatment regime		**n = 32**	
None	-	1	(3%)
Hormone therapy only	-	5	(16%)
Chemotherapy only	-	18	(56%)
Chemotherapy + Hormone therapy	-	1	(3%)
Radiotherapy only	-	1	(3%)
Chemotherapy + Radiotherapy	-	4	(13%)
Hormone + Chemotherapy + Radiotherapy	-	2	(6%)

Table 5. Correlations Matrix :

Illness / Treatment & Scale Measures

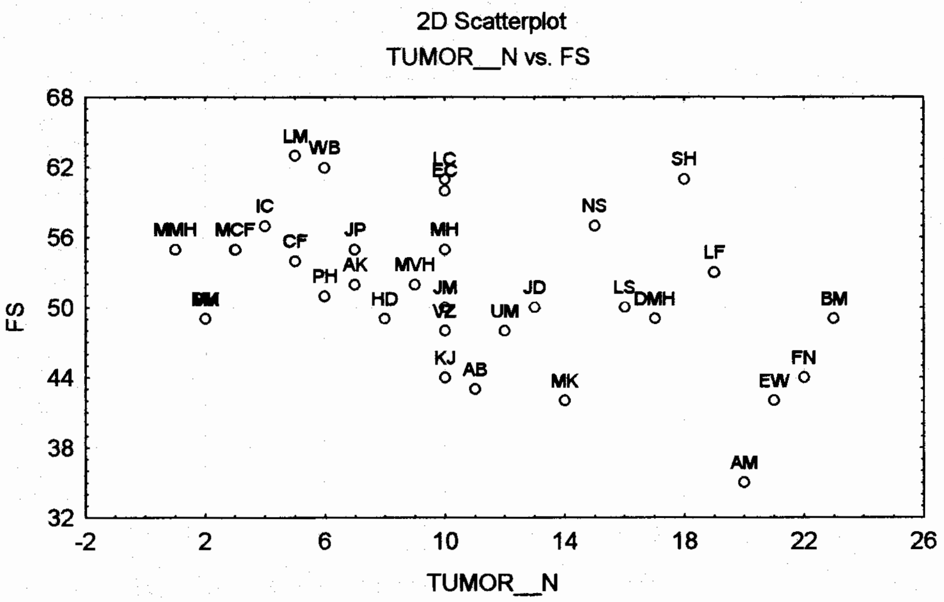
	TUMOUR	**TREATMENT**	**HAIR / LOSS**	**S. EFFECTS**
TUMOUR	1.00	**.45***	.28	.20
TREATMENT	**.45***	1.00	**.44***	.07
HAIR/LOSS	.28	**.44***	1.00	-.05
S. EFFECTS	.20	.07	-.05	1.00
SOC	-.05	-.23	-.18	.06
RLOC	-.13	-.11	.03	-.05
AOI	-.24	-.28	-.25	-.11
SWL	-.31	**-.38***	-.16	-.20
FS	**-.39***	**-.38***	-.06	-.04
H/H	.20	.29	.21	.25
AP	.22	.24	.25	.36
F	-.06	-.17	-.05	.26

(N=32). Highlighted * correlations are significant at $p < .05000$.

As could be expected, tumour stage was positively related to treatment regime, which in turn was associated with hair loss. Severity of treatment was not related to other negative (self-report) side effects. Apart from the associations with FS and SWL no other correlations were significant. See Table 5 above.

A moderate negative correlation was found between tumour size and the coping style, FS (-.39). A scatter plot was then produced to investigate this relationship further, and Figure 1 below shows that the main outliers are the participants with largest tumours and greatest nodal involvement, (poorest prognosis). Removing three cases from the analysis (BM & FN = T4, EW = T3), the correlation between tumour size and FS became insignificant at -.17. Severity of treatment was also correlated negatively with Fighting Spirit (-.38) and SWL (-.38). With the outliers removed, these correlation coefficients also dropped. (FS to -.27, and SWL to -.26).

Figure 1. **Tumour size & Nodal Involvement versus Fighting Spirit Coping Style**



8.1.3 Dispositional Influences

Table 6. **Descriptive Statistics : Disposition & Outcome Measures**

Scale	**Valid N**	**Mean**	**Min**	**Max**	**S. Dev.**	**C' alpha**
SOC	32	143.15	101	188	23.25	0.81
RLOC	32	34.90	28	42	3.43	0.68
AOI	32	31.12	20	40	5.58	0.82
SWL	32	25.34	7	35	6.75	0.87

Table 7. **Correlation Matrix :**
Disposition, Outcome & Religiosity

	SOC	RLOC	AOI	SWL	REL
SOC	1.00	**.43***	**.39***	**.63***	.42*
RLOC	**.43***	1.00	**.46***	.27	.26
AOI	**.39***	**.46***	1.00	**.67***	**.48***
SWL	**.63***	.27	**.67***	1.00	**.61***
REL	**.42***	.26	**.48***	**.61***	1.00

Highlighted * correlations are significant at p < .05000. N=32

The results presented in Table 7 above, show that consistent with expectations, SOC is significantly correlated with SWL (.63). A moderate positive relationship (.39) was found between SOC and AOI. The second measure of disposition, RLOC, was positively associated with AOL (.46) but there was no significant relationship with SWL. Religiosity showed a strong positive association with SWL, and was moderately associated with both SOC and AOI. Faith and religiosity are dealt with in more detail in the qualitative analysis.

8.1.4 Coping Styles

Table 8. **Descriptive Statistics : Coping Styles**

Scale	**Valid N**	**Mean**	**Min.**	**Max.**	**S.Dev.**	**C' Alpha**
FS	32	51.37	35	63	6.51	0.85
HH	32	10.53	6	16	2.60	0.67
AP	32	21.71	15	27	3.22	0.30 *
F	32	22.37	18	27	2.32	0.28 *

* Possible explanations for these low coefficients are discussed in Chapter 9.

Table 9. Correlation Matrix :

Coping styles, Disposition, Outcome & Religiosity.

	F S	H/H	FSH	AP	F
SOC	.33	**-.38***	**.37***	-.23	-.33
RLOC	.26	**-.44***	.33	-.14	-.07
AOI	**.55***	**-.66***	**.63***	**-.55***	.11
SWL	**.64***	**-.63***	**.69***	**-.43***	-.12
REL	**.57***	**-.54***	**.61***	**-.35***	.04

N=32. Marked correlations are significant at p < .05000.

The coping style FS was positively correlated with SWL and also with AOI. Conversely, the H/H style was negatively associated with these outcome measures. These relationships are reflected by the strong positive correlations on the bipolar scale FSH, which correlates positively with SWL (.69) and AOI (.63). FSH was also positively associated with the SOC scale (.37). The AP-style was negatively associated with SWL (-.43) and AOI (-0.55), but was not significantly related to the measures of disposition. The F-style of coping showed no significant relationships with any of the scale measures. Religiosity correlated positively with FSH (.61) and negatively with AP (.35). Results are presented in Table 9 above.

8.1.5 Multiple Regression Analysis

Independent variables SOC, FS, AGE and REL were entered into the multiple regression analysis (MRA) to test a model that proposed SOC (disposition), FS (coping style), age and religiosity, as a good combination of factors to predict SWL. Table 10 below summarises the results of the first MRA, which shows that SOC and FS are both significant predictors in this combination of variables.

Religiosity was dropped from the next MRA, and it was then found that FS, SOC and AGE accounted for 63% of the variance in SWL. The results are presented in Table 11 below.

Table 10. Regression Summary One for Dependent Variable : Satisfaction with Life (SWL)

	BETA	St.Err.of BETA	B	St.Err.of B	t(26)	p-level
SOC	.34	.13	.10	.04	2.64	.014
FS	.34	.13	.35	.14	2.49	.019
AGE	.25	.13	.15	.08	1.89	.070
REL	.17	.14	.38	.31	1.22	.234

R= .82562339 R^2= .68165398 Adjusted R^2= .63449161. df = 4.27
F (4,27)=14.453 p<.00000 Std. Error of estimate: 4.0820

Table 11. Regression Summary Two for Dependent Variable : Satisfaction with Life (SWL)

	BETA	St.Err.of BETA	B	St.Err.of B	t(26)	p-level
FS	.41	.12	.43	.13	3.38	.002
SOC	.37	.13	.11	.04	2.96	.006
AGE	.28	.13	.17	.08	2.15	.040

R= .81497543 R^2= .66418494 Adjusted R^2= .62820476. df = 3.28
F (3,28)=18.460 p<.00000 Std. Error of estimate: 4.1170

Multiple regression was also performed using the same independent variables (SOC, FS, AGE and REL) to predict acceptance of illness (AOI). In this analysis the interactions were not significant. When religiosity was dropped from the next regression analysis, FS and AGE became significant predictors, accounting for 38% of the variance in AOI. These results are presented in Table 12 below.

Table 12. Regression Summary for Dependent Variable : Acceptance of Illness (AOI)

	BETA	St.Err.of BETA	B	St.Err.of B	t(26)	p-level
AGE	.36	.17	.18	.08	2.15	.040
SOC	.11	.16	.03	.04	.70	.492
FS	.35	.16	.30	.14	2.20	.036

R= .66477998 R^2= .44193243 Adjusted R^2= .37992492. df = 3.27
F (3,27)=7.1271 p<.00112 Std. Error of estimate: 4.4312

8.2 QUALITATIVE ANALYSIS.

> ***Grown-ups love figures. When you tell them you have made a new friend, they never ask you questions about essential matters. They never say to you, 'What does his voice sound like? What games does he love best. Does he collect butterflies? Instead they demand: "How old is he? How many brothers has he? How much does he weigh? How much does his father make? Only from these figures do they think they have learned anything about him.***
>
> De Saint-Exupery (1943)

8.2.1 Coping Styles

From the interview data, six clearly identifiable styles of coping were evident. In addition to the five described by the MAC scale, (fighting spirit, helpless/hopeless, anxious preoccupation, fatalistic and avoidance), another style identified as **Stoic Acceptance** was also apparent. This style (henceforth SA), was particularly evident when participants described the ways they had coped with previous low points in their lives. The SA-style was identified by phrases such as :

- "I accepted it but felt lousy".
- "It was difficult but I just had to deal with it".

Although this style of coping was not as prevalent in the three-month period post mastectomy, it was the dominant style for 6 participants (19%) during the month one, and for 5 (16%) in the second month. However the SA-style was often found mixed or overlapped with the Fatalistic (F) style. The overlap is illustrated in this participant's response:

- "I believe in prayer and I just accept. All my people died of cancer and I am very accepting"

A month after mastectomy the most commonly used coping style was Fighting Spirit (FS). In the first telephone interview this style was evident in 12 participants (37%), and it was the dominant style of 9 (28%), during the second and third months. By way of example, the following responses were identified as the FS style.

- "I try not to worry.... and to be strong... I'm not helpless, I just get on with things."
- "I go out, ...don't let it get me down, ... I feel positive about life."

During the second month 5 participants (16%) displayed the Anxious Pre-occupation coping style (AP), compared with 3 (9%) in the previous month. These two comments illustrate this style :

- "I just wish my hair would just grow ...I don't got to parties and functions any more because of my hair."
- "I keep on praying to God to take away my pain... I'm up and down, I never thought it would be so bad"

Analysis of styles used over the whole 3-month study period revealed that 14 of the 32 participants (44%) exhibited mixed or combinations of styles. This was sometimes evident in one fairly brief interview, as the following exert illustrates :

Interviewer:	How would you describe the last month?
Participant:	It was terrible like I was dying .... A bit lonely .... feel very much alone. (Helpless/Hopeless style).
Interviewer:	Have there been any positives for you?
Participant:	A little ... but if its God's will then that's ok. I've had 53 good years. (Fatalistic style)
Interviewer:	How do your friends and family think you are coping?

Participant: They don't really think there's anything different - expect me to do everything as usual ... so I do it. (Stoic Acceptance)

Interviewer: How do you feel that you are coping?

Participant: I am a strong person, I cope on my own.... I fight against my negative feelings. (Fighting Spirit)

8.2.2 Influences of the Past.

No obvious relationships between previous ways of coping and the present coping styles were identified. Of the 32 participants, 7 (22%) showed some consistency of style during the study period which matched their previous coping style. The style that was most commonly used in previous coping was stoic acceptance. It was identified in 9 of the 32 respondents (28%). Describing how they had coped with a previous low-point in their lives, typical examples of the stoic-type responses were :

- "I just had to accept it. I felt very alone but made the best of it"
- "I resisted it ... and just suffered it".
- "Struggled on - just got on with it".

The helpless/hopeless (H/H) style was evident in 8 (25%) of the women when they described their previous low-point. For example :

- "I was devastated - went on anti-depressants, ... haven't really started again". (Patient 1.)
- "I almost smoked myself to death ....I haven't really got over it ... I'm still crying. (Patient 2.)
- "I cried day and night, prayed and cried day and night, still struggle" (Patient 3.)

Two participants (6%) continued to use the H/H style to cope with the mastectomy, and both perceived the long-term effects of their previous low-point as totally negative.

- "I learned to expect the worst" ..... "I just cry". (Patient 2 above)
- "A lot of sadness ... don't want to go out ....I stay home the whole day ... no nothing is positive. (Patient 3 above)

Four participants who had previously exhibited the H/H-style, adopted various style combinations during the three-months after mastectomy. However, two changed radically from a previous H/H style to the FS style which was evident throughout the study period. The following exerts are illustrative.

- "I've had no problems - I don't mope. ... I cope with everything fine. I'm pleased with myself... not depressed or frustrated... It feels like it was 3 or 4 years ago - not 3 months".
- "I've found strength that I didn't have before ....absolutely no problems at all... I even had my hair tinted. (I'm) much stronger emotionally and spiritually ... they say I sound so positive".

Reporting on the long-term effects of previous low-points, 14 participants (44%) said that there had been positive effects or benefits, 12 (38%) described mixed effects, and 6 (18%) reported only negative effects. Most participants, who had previously used the helpless/hopeless style, said that the long-term effects of their low-point were mixed. For example, one participant believed she had learned "a lot" from the experience and said "it helped me to deal with my own cancer".

Reflecting on the main source of strength that had helped them cope with a previous low point; 16 (50%) said it was their faith or God, 8 (25%) reportedly drew on their own inner strength, 5 (16%) turned to friends, while 3 (9%) reported that their families had been their main resource.

8.2.3 Resources

To compare current and past sources of strength, the resource units derived from the four semi-structured interviews were combined. Resources were initially grouped into four categories: faith (incorporating religiosity), family, friends and self. Adding the recording units, faith/religiosity accounted for 48% of the total. Family support scored 27%, friends 18%, and self accounted for 7%. Although imprecisely measured, it is apparent that faith and religiosity are important sources of strength. Correlating resource units with coping outcome, the only significant relationship was between Faith/religiosity and SWL.

Quantifying the interview data, a strong association was found between faith and religiosity. For this exercise faith was coded: none = 0, some = 1, strong = 2. The measure of religiosity ranged from 0 to 10 with a mean of 3.6. These measures of faith and religiosity were then correlated with the scale measures and the results are presented in Table 13 below.

Table 13. **Correlation Matrix :**
Faith, Religiosity & Scale Measures.

	FAITH	REL.
FAITH	1.00	**.75**
REL.	**.75**	1.00
SOC	**.53**	**.42**
RLOC	.20	.26
AOI	**.50**	**.48**
SWL	**.65**	**.61**
FS	.33	**.57**
H/H	**-.49**	**-.54**
AP	-.25	**-.35**
F	-.17	.04

Highlighted * correlations are significant at $p < .05000$. N=32

Positive relationships were found between the scales satisfaction with life (SWL), acceptance of illness (AOI), sense of coherence (SOC) and the measures of religiosity (REL) and faith. The coping style fighting spirit (FS) was positively associated with religiosity, and the helpless/hopeless (H/H) style was negatively associated with both faith and religiosity. Surprisingly there was no significant correlation between faith or religiosity and the coping style fatalistic.

8.2.4 Body Image

Body did not appear to be of prime importance to the participants in this study. After 3 months, it was found that :

- Of the 32 women 20 (63%), felt comfortable with their bodies, 4 (13%) had mixed feelings and 8 (25%) were not happy with their changed body image.
- Only 1 participant (3%) was definitely considering breast reconstruction, and a further 4 (13%) said maybe.
- A large majority of 27 (84%) said they were quite comfortable talking to others about their experience, and only 3 (9%) reported feeling 'separate' or in some way different to other women.
- Similarly, 26 (81%) said they felt no sense of loss, while 6 (19%) were experiencing some feelings of loss.
- Asked about negative emotions such as anger, depression, guilt or fear; 18 participants (56%) said *yes*, they did have some such feelings, while 14 (44%) responded *no*.

Chapter Nine

DISCUSSION

9.1 Support for Hypotheses and Coping Model

Results support the main hypotheses of this thesis. The findings indicate that after a diagnosis of breast cancer and subsequent mastectomy :

- ✓ Successful coping involves a combination of stable traits, variable adaptive behaviours and previous life experiences.
- ✓ Women's disposition before mastectomy is one of the best predictors of successful, adaptive coping.
- ✓ Women with a strong *sense of coherence* (SOC) (Antonovsky, 1987) cope more successfully than those with a weak SOC.
- ✓ There is a positive correlation between *sense of coherence* (SOC) measured before mastectomy, and *satisfaction with life* (SWL) (Diener et al, 1985) assessed three months after surgery.

Coping theorists and researchers have long debated the question of disposition versus situation, and trait versus state. Researchers such as Heim et al. (1993) believe that the real issue is about interpreting the presence of both disposition and situation, and assessing their relative importance. This was the research challenge that subsequently led to the testing of a coping model. Results partially support the model proposed in chapter seven, which slightly modified, was able to explain almost two thirds of the variance in adaptive coping measured on the satisfaction with life scale (SWL). The combination of variables sense of coherence (SOC), Fighting Spirit (FS) and age, significantly predicted satisfaction with life after mastectomy. Religiosity was included in the original model, but in the regression analysis its contribution was not found to be significant. The discussion that follows draws together quantitative and qualitative results and highlights the important research findings.

9.2 Important Findings.

9.2.1 Overview

Delineating the factors that differentiate good versus poor satisfaction with life after mastectomy, it was found that disposition, acceptance of illness, faith, religiosity, and coping style were all associated with adjustment. Women who coped well were older, had a high SOC, found support in their faith and religious practices, and made more use of the Fighting Spirit style of coping. The less competent copers on the other hand, were characterised by younger years, lower SOC, more severe treatment regimes, less support from religion, and more frequent use of the coping styles identified as Helpless/Hopeless and Anxious Preoccupation.

As anticipated, the results indicated that coping with cancer and mastectomy is multidimentional. This supports the earlier work of Rodrigue, Behen & Tumlin (1994). It also agrees with the findings of Heim, Augustiny, Schaffner & Valach (1993), who argued in favour of stability and variability in coping activity over both time and situation. Proponents of the interactionist approach, Heim et al. describe Antonovsky's (1979 & 1987) salutogenic model, as a *"promising interactionist point of view."* (1993:p 540)

9.2.2 Sense of Coherence - A Key Element.

Results support Antonovsky's (1987) theory that SOC is important in coping with stressful situations. Findings also agree with the work of Bowman (1997), Wissing & van Eden (1997) and Antonovsky (1993), who found SOC to be applicable and valid across culture, age and socio-economic differences. Though SOC may develop along varying cultural routes, there is support for Antonovsky's (1987) suggestion that SOC is a global orientation that goes beyond cultural bounds. Furthermore, the SOC can be used as a quick gauge of coping, as it is a relatively short scale, and simple to administer.

In the present study the SOC scale had an acceptable internal reliability of .81 and a mean score of 143.15. This is surprisingly high when compared with normative data from other published research. Antonovsky (1993) reports on 21 studies in which the means range from 117 to 152.6. In these published studies, the lowest reported scores were Czech cancer patients, Israelis with cerebral palsy and US undergraduate females. Scoring high were Kibbutz members, Israeli retirees and medical students. Based on correlation and multiple regression analyses, this high mean suggests that the sample population will, on average cope well with mastectomy. This was corroborated by the mean SWL score of 25.3, which compares well with the range of scores (23.3 to 25.8) reported by the authors of SWL, Diener et al. (1985).

A caveat, and possible explanation for these high means (both SOC and SWL), centres on the way the questionnaires were implemented. Because many participants were limited in their comprehension and reading abilities, all questionnaires were administered orally. Thus participants' privacy and the option to remain anonymous was compromised. Under these circumstances, is possible that participants may have wanted to "look good" in the eyes of the interviewer, and responded accordingly.

9.2.3 Age - The Only Significant Demographic Factor

This study found that participants' age was significantly related to adaptive coping; older women scoring higher on the SWL and Acceptance of Illness scales. Age was also a significant predictor of SWL in the multiple regression analysis. These results support the findings of Ali & Khalil (1991), Stanton & Snider (1993), and Viljoen & Berard (1994).

However, the literature reviewed was not consistent on this issue. Research by Gross, Burnett & Borelli (1996) found that younger women coped better. And a more recent study by Schnoll et al. (1998) suggests that the conflicting results regarding age and psychological adjustment to breast cancer, may be explained by the mediating role of coping strategies. These authors found that the style Fighting Spirit was more prevalent in younger women who also showed better adjustment to mastectomy.

9.2.4 Coping Styles - Providing Another Perspective

The interview material added an important new dimension to the scale data. The Mental Adjustment to Cancer questionnaire (MAC), which was administered at a specific time in the recovery period (3-months post mastectomy), provided a 'snap-shot' of the styles used at that point. The interview data on the other hand showed the 'movie', revealing variability in style, and demonstrating that participants used different styles at different stages in their recovery period.

The quantitative analysis indicated that the Fighting Spirit style was linked to better outcome after mastectomy, while the Helpless/Hopeless style fared less well. This finding supports the early developmental work of Greer, Morris & Pettingale (1979), as well as later research by Ferrero, Barreto & Toledo (1994).

From the quantitative and qualitative analyses, it was clear that there was some overlap in styles, particularly between Anxious Preoccupation, Helpless/Hopeless, Fatalistic and Stoic Acceptance. Watson et al, (1988), authors of the mental adjustment to cancer scale (MAC) also found a small to moderate degree of overlap between the same sub-scales - with the exception of Stoic Acceptance, which is not a part of MAC. These overlaps may partly explain the low measures of internal consistency found in two of the MAC sub-scales. The Cronbach's alpha for Anxious Preoccupation was .30, and for Fatalistic it was .28. (Watson et al.1988 reported moderate coefficients of .65 for both of these sub-scales).

It should also be mentioned that subtle differences in some of the MAC items could be misunderstood by respondents who have a poor command of English. For example : Item 2. - *I feel I can't do anything to cheer myself up.* (Helpless/Hopeless), could be taken to mean much the same as item 7. - *I feel that nothing I can do will make a difference.* (Fatalistic). Examples of other items, open to misinterpretation are: Item 32. - *I keep quite busy, so I don't have time to think about it* (Fighting Spirit). This could be construed as avoidance. Also item 10. - *I have been doing things that I believe will improve my health e.g. exercising.* (Anxious Preoccupation). It could be argued that this positive statement indicates a fighting spirit.

Data from the interviews showed that almost half of the participants used various style combinations. This finding backs up other research which challenges the notion of mutually exclusive coping styles. There appears to be considerable support for the view that most breast cancer patients use a wide range of coping responses, and are likely to have numerous strategies in their coping repertoire. (E.g. Burgess, Morris, & Pettingale (1988), Jarrett et al. (1992), Shapiro et al. (1994) and Burton et al (1995). Interestingly, Heim et al. (1993) observed an average of ten coping modes per patient at each interview!

A striking finding in this study was the prevalence of Fighting Spirit style in the first month after surgery. This was evident from the interview data in more than a third of the sample. Closer inspection of responses indicated that this positive (sometimes euphoric) style was linked to getting over the initial 'hurdle'. Many participants expressed relief and gratitude that 'it' was over, which is one possible explanation why Fighting Spirit dominated in the early stages of recovery. Surviving the first 'bout' against cancer, appeared to be reinforced by friends and families. Comments such as, *"they say I look so well, and don't look sick"*, were frequently found in the interview material.

A second point of note was the increase in Anxious Preoccupation style observed in the second month. This appears to be related to hair loss and other unpleasant side effects of treatment. At the time of the first post-operative interview, many participants had not started their adjuvant therapies, so side effects were not commonly reported. But by month two, most were receiving some type of treatment. At this stage, Anxious Preoccupation was recorded as the dominant style in 16% of the sample. In fact, the majority of subjects did refer to unpleasant effects and showed signs of Anxious Preoccupation, but this style tended to be intermingled with others. The variability of styles found in the first three months after breast surgery, agrees with the findings of Royak-Schaler (1991), Carter (1993) and Heim et al.(1993).

Although the MAC scale involves considerably less work on the part of researchers, the qualitative approach is important because it provides a different perspective on coping styles and permits a more comprehensive understanding of the recovery process. By monitoring participants' styles over a period, changes and variations can be investigated and explained. This in turn has implications for the planning and provision of appropriate patient support during recovery from mastectomy.

9.3 Other Findings

9.3.1 Faith and Religiosity

Kallenberg posed the question *"Do people with a religious faith find it easier to go through a crisis compared to others?"* (1991: p1). In a long-term study to understand grieving, this author described the construct, *view-of-life*, a concept that incorporates religious and philosophical ideology, but is considerably broader than religion. Kallenberg found many similarities between this view-of-life concept and Antonovsky's (1987) Sense of Coherence (SOC). In Kallenberg's follow-up study, the three SOC components (comprehensibility, manageability and meaningfulness) were successfully used as instruments to interpret participants' view-of-life.

Results of the present study suggest support for the opinion that SOC contains elements of religious faith that are related to resources within the individual's disposition. Although the measures of faith and religiosity were assessed qualitatively, it was clear that both these variables are important sources of strength, and warrant further investigation

9.3.2 Illness Related Variables

Adjuvant therapies were negatively associated with adaptive coping, which substantiates many other studies. E.g. Fallowfield & Clark (1991), Royak-Schaler (1992), Baum (1998) and Pantanowitz (1998). However it is perhaps surprising that the correlation was not stronger than -.38, and that treatment severity was related only to hair loss, and not to any other regularly reported side effects.

One explanation, is the considerable variation in chemotherapy 'cocktails' and regimes, which the research did not take into account.

Individual tolerance for treatments also varies considerably. Another possible reason is that side effects such as nausea and vomiting are more transient in nature, less obvious to others and therefore less embarrassing than hair loss. So if an interview coincided with a between-treatment phase (generally free from side-effects), respondents were less likely to dwell on the nausea that they may have experienced two weeks previously.

The only scale measurement that was significantly linked to tumour size and treatment was the coping style Fighting Spirit - a moderate negative correlation. The reason was found in three outliers, which represented the participants with the largest tumours and greatest nodal involvement. To shrink the tumours, two of these patients had undergone radiotherapy prior to surgery, so unlike other participants, they were aware of the severity of their disease and the relatively poor prognosis that it carried. This may account for their lack of fighting spirit.

9.3.3 Recovery Locus of Control

Recovery Locus of Control (RLOC) was found to relate positively to Acceptance of Illness (AOI), a scale that focuses directly on the extent to which respondents adjust to their illness without negative responses or feelings. Both RLOC and AOI correlated negatively with the Helpless/Hopeless style of coping, which agrees with the view that an external locus of control relates to Seligman's (1975) concept of learned helplessness. According to Seligman's theory, learned helpless occurs when individuals see no connection between their own behaviour and a negative event, and so believe there no way out of the situation.

No significant association was found between RLOC and adaptive coping as measured on the Satisfaction with Life scale. This finding supports the opinion described in Tedeschi & Calhoun (1995) that individuals with an internal locus of control, who believe in their own capacity to control outcome, may have more difficulty coping with trauma than those who have less extreme beliefs about their personal control. Such an explanation may well apply in this study. Mastectomy patients (and other cancer patients) with an internal locus of control, face an ambiguous situation regarding their personal control over an often unpredictable disease such as cancer.

Another point to consider, is whether or not the RLOC instrument is reliable in this context, because it was not developed specifically for cancer patients. When authors, Partridge & Johnston (1989) evaluated the scale's internal consistency, they produced an alpha range of 0.49 to 0.80. The current study's Cronbach's alpha is 0.68, which is not particularly high. Furthermore, the instrument was administered just two days after mastectomy, a time of considerable uncertainty for patients with breast cancer. The reason being that pathology has not confirmed the histology or nodal involvement, so prognosis and treatment regimes are unknown at this stage. Clearly, a statement such as *"I have little or no control over my progress from now on"*, will raise issues of confusion when the patient's future is uncertain. Many participants did have difficulty responding to this item, and other similar statements on the RLOC.

9.3.4 Body Image Issues

Not surprisingly, body image and breast reconstruction was found to be more important for younger, rather than older women. But on the whole, participants were relatively well adjusted to their mutilated bodies. Two possible explanations are offered for this finding. The first concerns the time period. In the first three months after mastectomy, women are more concerned about surviving cancer and the post-mastectomy treatment, and less worried about their appearances, as the following extracts suggest:

- *It's too soon (for reconstruction) - I'm still in a state of shock.*
- *I worry about the results of the scan ... if there's still cancer.*
- *Bit of a shock to have the 'sandwich' treatment ... more a dread of what's to come.*

Secondly, the interviews took place between March and October, which is a cold time of year in Cape Town. In the summer months, lighter clothing may contribute to feelings of self-consciousness about body image. As one participant commented, "*maybe in summer I won't be able to wear anything nice*".

9.3.5 Social Support

Social support is presumed to buffer the effects of stress for cancer patients, but in this study participants reported that religious support was considerably more important to them than the social support of family and friends. While religiosity and faith were significantly related to coping /SWL, no relationship could be found between SWL and family or friends. This differs from Royak-Schaler's (1991) review of the literature, which identified family, medical personnel, and other patients as the three major sources of support.

Although results cannot be fairly compared with other research reviewed because of their different methodological approaches, they do appear to be at odds. Studies by Lichman, Taylor & Wood (1988) and Carlsson and Hamrin (1994) concluded that social support contributes significantly to the psychosocial adjustment of women with breast cancer. Bloom (1982) and later work by Levy et al. (1992) suggest that it is the patients' perception of emotional support that is important. In this study, perceived emotional support came mostly from participants' faith in God.

9.3.6 The Role of Past Experience

Although there were no obvious relationships between present and past ways of coping, it cannot be concluded that they did not exist. Previous coping was recalled from memory, and in some cases the event in question had happened many years before. Also, as no statistical measures were used to assess past coping styles, meaningful comparisons could not be made.

Reviewing the literature, only one study could be found that compared past and present coping. This was the work of Aldwin, Sutton & Lachman (1996), who found evidence to indicate that the experience of past stressors forms a context for future coping, and that general coping skills are developed from prior experiences.

This finding can be linked to the construct that is central to the present research, namely the Sense of Coherence or SOC (Antonovsky.1987) Antonovsky contends that an individual's SOC relates partly to personality but is also developed by life experiences. The connection is through what he calls generalised resistance resources or GRRs, a construct very similar to the general coping skills described by Aldwin, Sutton & Lachman (1996).

9.4 Conclusions

The study investigated potential predictors of coping, and explored different resources and sources of strength. Results indicate that in addition to disposition, coping style and participants' age are significant elements in the coping process.

Sense of coherence (SOC) the principal measure of disposition developed by Antonovsky (1979 &1987) was strongly linked to adaptive coping (SWL) in mastectomy patients. Though SOC is a broader concept than personality, these findings do lend support to the opinion of Suls and David (1996), that current research is moving to view coping and personality as overlapping though not equivalent constructs.

It was also clear that the constructs faith and religiosity were both important sources of strength. The positive relationships between faith, religiosity and SOC, support to the view that SOC contains elements of faith, that are related to resources within the individual's disposition.

Antonovsky (1994) says the SOC is most definitely not a coping style, nor is it a substantive resource. Because individuals' deal with such a variety of problems, no specific resource or style can be appropriate at all times. The individual with a strong SOC is likely to select the most appropriate tool for the task at that particular time. The SOC extracts the essence of specific coping resources, which might be a belief in God, social support, or financial means. It then expresses what they have in common.

If Antonovsky's (1994) theory is correct, then perhaps it is not necessary to seek out specific sources of strength, styles and strategies that predict effective coping. As this study has indicated, SOC can stand alone as an important measure and determinant of coping.

9.5 Limitations of the study

9.5.1 Sample Size and Characteristics

The sample was not particularly representative of the female population in the Western Cape region. Characteristics were very similar regarding cultural background, education, socio-economic status and religion. Although the incidence of breast cancer is known to be much lower in black women than in whites, it was somewhat surprising that there were so few black women in the sample, (n = 2, or 6%). This was unfortunate because there is a lack of research and information about black women's experience of breast cancer. (Schlebusch & van Oers,1999).

The oncologist at Groote Schuur Hospital where the study was conducted, indicated that black women tend to present at oncology clinics much later than white women; often with a stage III or IV disease when mastectomy is not always an option. Rice (1998) also reported this phenomenon in African American women. And it was noted that Hales reported a similar sample profile at the same breast clinic in 1986.

9.5.2 Statistical Limitations.

The large number of variables and relatively small sample (n = 32), restricted the use of multivariate techniques of analyses. And unfortunately the sample is not large enough to assume that the results of the multiple regression analysis (MRA) are stable. In addition, an important consideration in MRA, is the extent of correlation between the predictors themselves. When there is a high degree of multi-collinearity between the independent variables, the regression equation becomes unstable between data samples (Howell, 1989). In this study, the predictors SOC, REL, FS coping style and age were shown to be significantly interrelated.

9.5.3 Measures

The measures used to assess faith and religiosity were somewhat imprecise, and in retrospect these constructs should have been defined more clearly, e.g. Kallenberg (1991).

While the SWL scale is a very concise way of evaluating life satisfaction, it is questionable whether this is an adequate method to assess coping. Other dependent measures should also be considered, e.g. Burton &

Conneely (1986, unpublished manuscript) discussed in Burton et al. (1994)

The instrument used to measure coping styles (MAC) does not accommodate the Stoic Acceptance style, which was clearly evident in the interview data. Stoic acceptance was identified in the renowned work of Greer, Morris & Pettingale (1979), and was also included in the more recent studies by Burton and colleagues (1995).

Participants' satisfaction with their body image was assessed qualitatively from the interview data. An instrument such as the Situational Inventory of Body Image Dysphoria (Cash, 1994), used in Schlebusch & Oers (1999) should be considered if this topic is to be explored fully.

9.5.4 Lack of Controls

It was not feasible to have a control group in this study, and therefore not possible to assess whether results were contaminated in any way. A specific concern is that participants' may have felt supported, simply by being in the study. This phenomenon was apparent in a study by Burton et al. (1995), who investigated the benefits of preoperative psychological preparation for mastectomy patients. Conducting a randomised trial, they found that one of their controls, the 'chat' group, compared very favourably to the psychotherapeutic intervention group, and on most outcome measures these two groups were indistinguishable. (This particular control group had a 30-minute preoperative chat session with a surgeon trained in Rogerian counselling techniques, while the intervention group had psychotherapy with a clinical psychologist.)

Such findings do raise concerns about the present study, in which it was noted that a considerable number of participants said, *"it helped a lot to talk"*. And as has been mentioned previously, some subjects commented that they felt proud and important to be involved in the study and they may have tried to impress the interviewer.

9.6 Directions for future research

Based on the findings and shortcomings of the present research, it is recommended that future researchers in this field consider the following suggestions :

- Conduct the study with different populations. Include participants from different socio-economic groups and those with higher education to investigate the influence of these variables on coping. Also increase the follow-up period, monitoring the group at three-monthly intervals for at least one year.

- Examine the construct *faith* more thoroughly, using more precise measures, or alternatively use in-depth interview techniques. The question of religiosity versus spirituality also warrants further exploration.

- Investigate the full impact of mastectomy on marital relationships. This study looked at the question of body image on a rather superficial level because it was not the crux of the thesis. Nor was it the intention to have input from husbands or partners. However, a number of husbands did attempt to engage the researcher in conversation, and anecdotal evidence suggests that husbands were keen to talk about their own fears and concerns.

9.7 Personal comment

In conclusion, a brief comment on what this study has meant to me, a researcher in the field of breast cancer.

I have been impressed and at the same time humbled, by the hardiness and resilience of participants in this study. They are a source of inspiration, and prompt me to question my own ways of coping. Towards the end of the interviewing and data gathering stage of the study, a personal health problem arose. Alongside the negatives, there were benefits to be found, as many participants in the study had pointed out. For me it was a glimpse into the world of uncertainty, a view that must confront every person who has to deal with cancer.

On a personal level I have been enriched. New understandings have extended well beyond mastery of research techniques. Involvement in a study of this nature has hopefully increased my ability to empathise, and will influence my capacity for counselling and research practice.

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APPENDIX A

UNIVERSITY OF CAPE TOWN

Faculty of Medicine

Observatory 7925
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Fax No: (021) 47-8955
E-Mail address: MEDFAC@MEDICINE.UCT.AC.ZA

01 December 1997

ERC REF NO: 195/97

Ms J Hudson
Psycology

Dear Ms Hudson

RE: COPING WITH MASTECTOMY: A PROSPECTIVE EXPLORATION OF THE PROCESS.

I have pleasure in informing you that the above study has been **formally** approved by the Research Ethics Committee on the 28 November 1997.

Including is a list of Research Ethics Committee Members who have formally approved your protocol.

Please quote the above Reference number in all correspondence.

Yours sincerely,

PROFESSOR FOLB
CHAIR: RESEARCH ETHICS COMMITTEE

Queries: Miss Miriam Razak
Research Ethics Committee
Room 212 Werner and Beit
UCT Medical School
Anzio Road, Observatory, 7925
Tel: (021) 406-6492 Fax: (021) 406-6390
E-Mail: Miriam@medicine.uct.ac.za

APPENDIX B

DEMOGRAPHIC DATA

Date____________ Patient's initials ___________ Participant No. __________

DOB____________ Hospital / Dr.______________________________________

1.AGE

Under 30 ☐
31 - 40 ☐
41 - 50 ☐
51 - 60 ☐
61 - 70 ☐
71 plus. ☐

2.HOME LANGUAGE

Afrikaans ☐
English ☐
Xhosa ☐
Other ☐

3.HIGHEST EDUCATION

Primary school ☐
Secondary school (no Matric) ☐
Matric ☐
Tertiary (university/college) ☐

4.INCOME (family, gross monthly)

Less than R1000 ☐
R1000 - R5000 ☐
R5000 - R10000 ☐
More than R10000 ☐

5.MARITAL STATUS

Married ☐
Common law partner ☐
Divorced ☐
Widowed ☐
Never married ☐

6.ETHNIC GROUP

Asian ☐
Black ☐
Coloured ☐
White ☐

7.EMPLOYMENT STATUS

(Outside home)
Full time ☐
Part time ☐
Not employed ☐

8.RELIGIOUS AFFILIATION

Christian ☐
Jewish ☐
Moslem ☐
Other (specify) ☐
None ☐

APPENDIX C

UNIVERSITY OF CAPE TOWN

Department of Psychology

University of Cape Town · Rondebosch 7700 · South Africa
Telephone: (021) 650-9111
Fax No. (021) 689-7572

Dear Patient,

I am a Psychology Masters student at the University of Cape Town, undertaking research in the field of health psychology. My study concerns the way women experience mastectomy and how it effects their lives. I believe that the findings will be of benefit to those who are affected by and concerned with breast cancer and mastectomy.

If you agree to take part in the study, you will be involved for a period of three months from the time of your diagnosis. You will complete various questionnaires and have interviews with me, all of which will be sensitive to your condition at the time and should not be taxing to you. After you have been discharged from hospital, I will telephone you once a month to monitor your progress.

The results of the study will be written up in my thesis and may be published in a research journal, but your identity and personal information will be kept confidential. Your participation in the study is voluntary and you may withdraw your participation and data/information at any time. If you have questions about this research you may contact my supervisor, Dr. Helgo Schomer at the University of Cape Town, 650-3435 or at 438-5308.

Please indicate your consent by signing a copy of this letter and returning it to me. The other copy is yours to keep. Your contribution will be greatly valued and appreciated.

Yours sincerely,

Signed by candidate

Jane Hudson.

……

I have read this letter and consent to participate.

Signature: ______________________________ **Date:** ______________________________

FOR OFFICE USE

Patient's initials______ **Telephone no.**________________ **Participant number** ______________

APPENDIX D

ORIENTATION TO LIFE QUESTIONNAIRE

Date__________ Patient's initials __________ Participant No. __________

Below is a series of questions relating to various aspects of our lives. Each question has seven possible answers. Please mark the number which expresses your answer, with numbers 1 and 7 being the extreme answers. If the words under 1 are right for you, circle 1; if the words under 7 are right for you, circle 7. If you feel differently, circle the number which best expresses your feeling. You can choose any number between 1 and 7. Please give only one answer to each question.

1. When you talk to people, do you have the feeling that they don't understand you?

1	2	3	4	5	6	7
never have this feeling						always have this feeling

2. In the past, when you had to do something which depended upon co-operation with others, did you have the feeling that it:

1	2	3	4	5	6	7
surely wouldn't get done						surely would get done.

3. Think of people with whom you come into contact daily, aside from the ones to whom you feel closest. How well do you know most of them?

1	2	3	4	5	6	7
you feel that they're strangers						you know them very well

4. Do you have the feeling that you don't really care what goes on around you?

1	2	3	4	5	6	7
Very seldom or never						very often

5. Has it happened in the past that you were surprised by the behaviour of people whom you thought you knew well?

1	2	3	4	5	6	7
never happened						always happened

6. Has it happened that people whom you counted on disappointed you?

1	2	3	4	5	6	7
never happened						always happened

7. Life is:

1	2	3	4	5	6	7
full of interest						completely routine

8. Until now your life has had:

1	2	3	4	5	6	7
no clear goals or purpose at all						very clear goals and purpose

9. Do you have the feeling that you are being treated unfairly?

1	2	3	4	5	6	7
very often						very seldom

10. In the past ten years your life has been:

1	2	3	4	5	6	7
full of changes without your knowing what will happen next						completely consistent and clear

11. Most of the things you do in the future will probably be:

1	2	3	4	5	6	7
completely fascinating						deadly boring

12. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?

1	2	3	4	5	6	7
very often						very seldom or never

13. What best describes how you see life?

1	2	3	4	5	6	7
one can always find a solution to painful things in life						there is no solution to painful things in life

14. When you think about your life, you very often:

1	2	3	4	5	6	7
feel how good it is to be alive						ask yourself why you exist at all

15. When you face a difficult problem, the choice of a solution is:

1	2	3	4	5	6	7
always confusing and hard to find						always completely clear

16. Doing the things you do every day is:

1	2	3	4	5	6	7
a source of deep pleasure and satisfaction						a source of pain and boredom

17. Your life in future will probably be:

1	2	3	4	5	6	7
full of changes without your knowing what will happen next						completely consistent and clear

18. When something unpleasant happened in the past, your tendency was:

1	2	3	4	5	6	7
"to eat yourself up" about it (be very upset)						to say "ok that's that, I have to live with it," and go on

19. Do you have very mixed-up feelings and ideas?

1	2	3	4	5	6	7
very often						very seldom or never

20. When you do something that gives you a good feeling:

1	2	3	4	5	6	7
it's certain that you'll go on feeling good						it's certain that something will happen to spoil that feeling

21. Does it happen that you have feelings inside that you would rather not feel:

1	2	3	4	5	6	7
very often						very seldom or never

22. You anticipate that your personal life in the future will be:

1	2	3	4	5	6	7
totally without meaning and purpose						full of meaning and purpose

23. Do you think there will *always* be people whom you'll be able to count on in the future?

1	2	3	4	5	6	7
you're certain there will be						you doubt there will be

24. Does it happen that you have the feeling that you don't know exactly what's about to happen?

1	2	3	4	5	6	7
very often						very seldom or never

25. Many people - even those with a strong character - sometimes feel like sad sacks (losers or blunderers) in certain situations. How often have you felt this way in the past?

1	2	3	4	5	6	7
never						very often

26. When something happened, have you generally found that:

1	2	3	4	5	6	7
you over-estimated or underestimated it's importance						you saw things in the right perspective

27. When you think of difficulties you are likely to face in important aspects of your life, do you have the feeling that:

1	2	3	4	5	6	7
you will always succeed in overcoming the difficulties						you won't succeed in overcoming the difficulties

28. How often do you have the feeling that there's little meaning in the things you do in your daily life?

1	2	3	4	5	6	7
very often						very seldom or never

29. How often do you have feelings that you're not sure you can keep under control?

1	2	3	4	5	6	7
very often						very seldom or never

APPENDIX D

Scoring

Source: Antonovsky, 1987, pp. 189-194. Added to instructions: "You can choose any number between 1 and 7", following Antonovsky, 1992, p. 6.

Scoring: Check, for each person, whether 5+ items were unanswered; if so don't use? If 1-4 items unanswered, calculate mean of the person's answers an substitute that for missing responses. (Antonovsky, 1992, p.6.)
Reverse scoring on Items 1, 4, 5, 6, 7, 11, 13, 14, 16, 20, 23, 25, 27 (1→7, 7→1). Then sum all responses to Items 1-29.

SOC-13: Retaining the appropriate reversals, sum responses to Items 4, 5, 6, 8, 9, 12, 16, 19, 21, 25, 26, 28, 29.

References

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Appendix: The Sense of Coherence Questionnaire

The notation to the left of each item represents the profile structure of the item, derived from the mapping sentence used in questionnaire construction (see p. 77). C = comprehensibility, MA = manageability, ME = meaningfulness. The four numerals represent the elements in facets A, B, C, and D, respectively.

A high score represents a strong SOC. Before calculating the total score, the thirteen items marked R should be reversed.

For those interested in using a short form of the SOC, the thirteen items marked * are recommended.

These notations, obviously, are to be omitted when the questionnaire is used.

RECOVERY LOCUS OF CONTROL SCALE

Date_______________ Patient's initials _____________ Participant No. ______________

These are statements that other people have made about their recovery. Please will you indicate the extent to which you agree or disagree with them . Tick the appropriate box.

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
1. How I manage in the future depends on me, not on what other people can do for me.					
2. It is often best just to wait and see what happens.					
3. It's what I do to help myself that's really going to make all the difference.					
4. My own efforts are not very important, my recovery really depends on others.					
5. It's up to me to make sure that I make the best recovery possible under the circumstances.					
6. My own contribution to my recovery doesn't amount to much.					
7. Getting better now is a matter of my own determination rather than anything else.					
8. I have little or no control over my progress from now on.					
9. It doesn't matter how much help you get, in the end it's your own efforts that count.					

This measure is part of *Measures in Health Psychology: A User's portfolio,* written and compiled by Professor John Weinman, Dr. Stephen Wright and Professor Marie Johnston.

APPENDIX F

MENTAL ADJUSTMENT TO CANCER SCALE (MAC)

Date__________ Patient's initials__________ Participant No. ____________

INSTRUCTIONS: A number of statements are given below which describe people's reactions to having cancer. Please circle the appropriate number to the right of each statement, indicating how far it applies to you at present. For example, if the statement definitely does **not** apply to you, then you should circle 1 in the first column.

	Definitely does not apply to me	*Does not apply to me*	*Applies to me*	*Definitely applies to me*
1. I have been doing things that I believe will improve my health e.g. changed my diet.	1	2	3	4
2. I feel I can't do anything to cheer myself up.	1	2	3	4
3. I feel that problems with my health prevent me from planning ahead.	1	2	3	4
4. I believe that my positive attitude will benefit my health.	1	2	3	4
5. I don't dwell on my illness.	1	2	3	4
6. I firmly believe that I will get better.	1	2	3	4
7. I feel that nothing I can do will make a difference.	1	2	3	4
8. I've left it all to my doctors.	1	2	3	4
9. I feel that life is hopeless.	1	2	3	4
10. I have been doing things that I believe will improve my health e.g. exercising.	1	2	3	4
11. Since my cancer diagnosis, I now realize how precious life is and I'm making the most of it.	1	2	3	4
12. I've put myself in the hands of God.	1	2	3	4
13. I have plans for the future e.g. holiday, jobs, housing.	1	2	3	4
14. I worry about the cancer returning or getting worse.	1	2	3	4
15. I've had a good life; what's left is a bonus.	1	2	3	4
16. I think my state of mind can make a lot of difference to my health.	1	2	3	4
17. I feel that there is nothing I can do to help myself.	1	2	3	4

	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
18. I try to carry on my life as I've always done.	1	2	3	4
19. I would like to make a contact with others in the same boat.	1	2	3	4
20. I am determined to put it all behind me.	1	2	3	4
21. I have difficulty in believing that this happened to me.	1	2	3	4
22. I suffer great anxiety about it.	1	2	3	4
23. I am not very hopeful about the future.	1	2	3	4
24. At the moment I take one day at a time.	1	2	3	4
25. I feel like giving up.	1	2	3	4
26. I try to keep a sense of humour about it.	1	2	3	4
27. Other people worry about me more than I do.	1	2	3	4
28. I think of other people who are worse off.	1	2	3	4
29. I am trying to get as much information as I can about cancer.	1	2	3	4
30. I feel that I can't control what is happening.	1	2	3	4
31. I try to keep a very positive attitude.	1	2	3	4
32. I keep quite busy, so I don't have time to think about it.	1	2	3	4
33. I avoid finding out more about it.	1	2	3	4
34. I see my illness as a challenge.	1	2	3	4
35. I feel fatalistic about it.	1	2	3	4
36. I feel completely at a loss about what to do.	1	2	3	4
37. I feel very angry about what has happened to me.	1	2	3	4
38. I don't really believe I had cancer.	1	2	3	4
39. I count my blessings.	1	2	3	4
40. I try to fight the illness.	1	2	3	4

Thank you for taking the trouble to complete this scale!

This measure is part of *Measures in Health Psychology: A User's portfolio,* written and compiled by Professor John Weinman, Dr. Stephen Wright and Professor Marie Johnston.

SATISFACTION WITH LIFE SCALE

Date______________ Patient's initials ______________ Participant No. ____________

Below are five statements with which you may agree or disagree. Using a 1 to 7 scale, indicate your agreement with each item by placing the appropriate number in the box next to that item. Please be open and honest in your responses. The 7-point scale is :

1 = strongly disagree
2 = disagree
3 = slightly disagree
4 = neither agree nor disagree
5 = slightly agree
6 = agree
7 = strongly agree

☐ In most ways my life is close to ideal.

☐ The conditions of my life are excellent.

☐ I am satisfied with my life.

☐ So far I have got the important things I want in life.

☐ If I could live my life again, I would change almost nothing.

This measure is part of *Measures in Health Psychology: A User's portfolio,* written and compiled by Professor John Weinman, Dr. Stephen Wright and Professor Marie Johnston.

APPENDIX H

ACCEPTANCE OF ILLNESS SCALE

Date ____________ Patient's initials __________ Participant No. _______________

INSTRUCTIONS: Please respond to each of the following items by choosing a number from 1 to 5 on the scale adjacent to the item which you feel best describes you. Then **circle** the number you have chosen. There are no right answers to any of the questions.

1. **I have a hard time adjusting to the limitations of my illness.**

Strongly agree 1 2 3 4 5 Strongly disagree

2. **Because of my health, I miss the things I like to do most.**

Strongly agree 1 2 3 4 5 Strongly disagree

3. **My illness makes me feel useless at times.**

Strongly agree 1 2 3 4 5 Strongly disagree

4. **Health problems make me more dependent on others than I want to be.**

Strongly agree 1 2 3 4 5 Strongly disagree

5. **My illness makes me a burden on my family and friends.**

Strongly agree 1 2 3 4 5 Strongly disagree

6. **My health does <u>not</u> make me feel inadequate.**

Strongly agree 1 2 3 4 5 Strongly disagree

7. **I will never be self-sufficient enough to make me happy.**

Strongly agree 1 2 3 4 5 Strongly disagree

8. **I think people are often uncomfortable being around me because of my illness.**

Strongly agree 1 2 3 4 5 Strongly disagree

This measure is part of *Measures in Health Psychology: A User's portfolio*, written and compiled by Professor John Weinman. Dr. Stephen Wright and Professor Marie Johnston.

APPENDIX I

FIRST SEMI-STRUCTURED INTERVIEW

Date…………….Patient's initials…………….. Participant no. ……………….

AIM : - To uncover previous coping styles.

FORMAT & QUESTIONS : -

I would like you to reflect on your life and to recall a specific low point that really stands out for you. It may be an event or particularly difficult situation that you had to deal with.

1. What was that low point?……………………………………………………………………

………………………………………………………………………………………………

2. How long ago was it?…………………………………………………………………
3. How did you cope with it?…………………………………………………………………

………………………………………………………………………………………

………………………………………………………………………………………

4. What resources did you draw on? (your own inner resources or others?)

………………………………………………………………………………………………

5. How long did it take to get over it ... or to come to terms with it? ……………

………………………………………………………………………………………………

6. What have you learned from this experience? ……………………………………..

………………………………………………………………………………………………

7. Have there been any long term effects?……………………………………………..
8. Are these positive, negative or mixed? ……………………………………………..

ANALYSIS : -

a) Type of problem - Marital, work, bereavement, divorce, assault, family, other

b) Previous coping style – Denial, fighting spirit, stoic acceptance, fatalistic,logic

c) Resources – INNER / faith, OUTER / God, husband, family, friends

d) Time needed to adjust - <1yr 2yrs 5yrs ……….. ……….

e) Perceived long term effects – predominantly …. positive, negative or mixed.

FIRST SEMI-STRUCTURED INTERVIEW

Date 22.6.98 **Patient's initials** V.Z. **Participant no.** 28

AIM : - To uncover previous coping styles.

FORMAT & QUESTIONS : -

I would like you to reflect on your life and to recall a specific low point that really stands out for you. It may be an event or particularly difficult situation that you had to deal with.

1. What was that low point? My husband died suddenly of a heart attack – from stress.
2. How long ago was it? 4 years. ? H|H
3. How did you cope with it? My world fell apart – but then I got on with it. Also my mother gave me up when I was 6 – so I learned to get on on my own. FS FS
4. What resources did you draw on? (your own inner resources or others?) Mysey and [✓ God.]
5. How long did it take to get over it ... or to come to terms with it? About 1 or 2 years
6. What have you learned from this experience? To be tough ← FS
7. Have there been any long term effects? Yes, I'm stronger.
8. Are these positive, negative or mixed? Mixed.

ANALYSIS : -

a) Type of problem - Marital, work, [✓ bereavement,] divorce, assault, family, other

b) Previous coping style – Denial, [✓ fighting spirit,] stoic acceptance, fatalistic, logic

c) Resources [✓ INNER] / faith, + OUTER / [✓ God,] husband, family, friends

d) Time needed to adjust - <1yr [✓ 2yrs] 5yrs ....

e) Perceived long term effects – predominantly .... positive, negative or [✓ mixed.]

APPENDIX K

TELEPHONE INTERVIEW

Patient's initial________________ Participant number________________________

Date_____________ Call number ______________ Mx date ___________________

1. In a word, how would you describe the last month? ___________________________
2. How have you been physically? ________________________________
3. What kind of feelings and emotions have dominated this period?
4. How have you coped with these feelings?__________________________________
5. What or who has been your greatest source of strength? ________________
6. What (if anything) has changed for you in the past month?
7. Have there been any 'positives' for you? ___________________________________
8. What kind of things are these?_________________________________
9. Do your family and friends think you are coping well? ________________________
10. Why? ____
11. How well do <u>you</u> think you are coping? __________________________________
12. Why do you say this? ____________________________________

APPENDIX L

TELEPHONE INTERVIEW

Patient's initial A K. Participant number 6.

Date 7/5/98. Call number 1 Mx date 7/4/98

1. In a word, how would you describe the last month? It's been FINE.
2. How have you been physically? Fine, not much pain - but I was discharged too early + had to see my own doctor.
3. What kind of feelings and emotions have dominated this period? Quite normal - I've been calm most of the time. Sometimes a bit sad.
4. How have you coped with these feelings? I've had prayer meetings - that's very uplifting.
5. What or who has been your greatest source of strength? When I pray. And also my husband and daughter - but mainly the Lord.
6. What (if anything) has changed for you in the past month? It's like a waiting time - uncertain. I have a problem with my liver and had to have more tests. (F)
7. Have there been any 'positives' for you? Oh yes.
8. What kind of things are these? I feel more positive since the operation. (FS)
9. Do your family and friends think you are coping well? Oh yes!
10. Why? They didn't expect me to be so good. Say I look different (nice.)
11. How well do you think you are coping? Very well. There are tearful times but not many. (FS ?)
12. Why do you say this? It's not so bad as I expected.

Resources - Faith × 3
Family × 2.

Style. Mainly (FS)
Some Fatalistic

TELEPHONE INTERVIEW

Patient's initial J M. **Participant number** 10.

Date 16/7/98 **Call number** 2. **Mx date** 12/5/98.

1. **In a word, how would you describe the last month?** OK.
2. **How have you been physically?** Been for physio - the Chemo really knocked me - hair fell out - got a wig.
3. **What kind of feelings and emotions have dominated this period?** I felt a bit traumatised when the hair fell out. It was really terrible + I wasn't prepared for it. AP ?
4. **How have you coped with these feelings?** I hid in a corner initially ← H/H - didn't expect it to affect me so badly. Felt like screaming. Then gradually I tried going out - + friends all said I looked so good. AP ?
5. **What or who has been your greatest source of strength?** Family + especially friends have been very supportive. I've pushed myself (physically) and felt so much better. ← FS - But I can't walk much because of the M.S. (Multiple Sclerosis.)
6. **What (if anything) has changed for you in the past month?** No - I don't think so - but my tastes have changed - foods also!
7. **Have there been any 'positives' for you?** Not really. - but
8. **What kind of things are these?** I never knew there were so many kind people in the world - even complete strangers. I met someone else who had the op. and it was good to share.
9. **Do your family and friends think you are coping well?** - Oh yes!
10. **Why?** Because I look so well - say "wow, you ~~&~~ are looking great!"
11. **How well do you think you are coping?** Quite well.
12. **Why do you say this?** I feel so well except for the Chemo times. I had a bit of a death wish before the op. + didn't want to plan anything. Now I have my keenness to live back! ← FS

In Fnch x 2. <thio. Comb-

APPENDIX N

FINAL INTERVIEW

Date …………… Mx date …………………… Initials ……………. Participant no…………

1. How do you feel about your physical appearance? ………………………………………………

……

…………………………………………………………………(Check which breast?) …………

2. Have you considered reconstruction? ……………………………………………………………

3. Can you talk openly about it to your family? … and friends? (i.e. feelings, concerns fears)

……

……

4. Do you feel in any way separate / different from others who do not have cancer?…………

……

5. How comfortable is your husband with the new you? …. (The single breast and the cancer.)

……

……

6. Have you been able to resume your normal intimate / sex life?…………………………………

7. Do you feel any sense of loss?……………………………………………………………………

……

8. Any feelings of fear? ………….or guilt …….depression? ……..other negative emotions? ….

……

8. In the last two years, did anything particularly stressful happen to you?………………..

9. T and N stage? ……………………………………………………………………………………

10. Is there anything else that you would like to mention / talk about? …………………………

……

……

……

Style : Mostly Avoidance / Denial.

Resources : No ref. to help/support from anyone

APPENDIX O

FINAL INTERVIEW

Date 28/8/98 **Mx date** 2/6/98 **Initials** MCF **Participant no** 22

1. How do you feel about your physical appearance? Still can't get used to it. I try not to look. ← Avoidance

(Check which breast?) R

2. Have you considered reconstruction? No.

3. Can you talk openly about it to your family? ... and friends? (i.e. feelings, concerns fears) Ⓐ

Not really. I don't want them to ask. Want to pretend it hasn't happened. Denial

4. Do you feel in any way separate / different from others who do not have cancer?

Never think about it. ← Ⓐ

5. How comfortable is your husband with the new you? .... (The single breast and the cancer.)

Doesn't bother him – but no touching!

6. Have you been able to resume your normal intimate / sex life? No – but I don't want my husband anyway – he drinks.

7. Do you feel any sense of loss?

No.

8. Any feelings of fear? ....or guilt ....depression? ....other negative emotions? ....

A bit down sometimes.

8. In the last two years, did anything particularly stressful happen to you? No.

9. T and N stage? T1 N 0/17

10. Is there anything else that you would like to mention / talk about? (FS)

I want to fight to see my son grow up.

Note MCF has not been back to the hospital for her check up (not since op.) Not on any treatment but has pain in her side + wonders if she should go back. Denial?