

1.15 SOCIAL RELATIONSHIPS

Social support appears to be an important resource for those suffering from chronic disease. It may lower the likelihood of illness initially. Social support does reliably speed recovery from illness and it reduces risk of mortality. Self-reports of good social relationships and positive adjustment to chronic disease are consistently found in the literature for cancer (Taylor 1990).

Social support may also reduce the distress that accompanies chronic illness. Fewer illness-related problems among chronically ill populations have been documented for those with high levels of social support. Social support also appears to affect health habits and in particular promotes adherence to medical regimens (Taylor 1990).

Chronic disease can itself adversely affect potential social support resources. For example, the stressful event of cancer creates fear and aversion in family and friends, but also creates a simultaneous awareness of the need to provide support. These tensions may produce a variety of adverse outcomes, such as physically avoiding the patient, avoiding open communication about the disease, minimising its impact or demonstrating forced cheerfulness. Under such conditions, the availability of effective social support may be reduced (Taylor 1990).

Distant relationships with friends and acquaintances appear to be more adversely affected in these ways than intimate relationships. However, intimate others, may themselves be highly distressed by the loved one's condition and be ineffective in providing support because their own support needs are unmet (Taylor 1990).

1.15.1 THE SOCIAL DOMAIN

A decline in social activities takes place after the diagnosis of breast cancer. Patients sometimes isolate themselves because of shyness, fear of rejection, or because their body and self-image has been negatively affected. However, it does appear that the reaction is limited and of a short duration for most patients. The first three months post mastectomy seem to be the most critical and psychological healing has taken place for most patients by this time.

In many circumstances the woman's own family and friends play a key role in helping her adjust to her mastectomy and to her illness. The relationship that we have with others meets a number of our general psychological needs. They provide a sense of identity, acceptance, and emotional security; they increase our feelings of self-worth and self-esteem; and, in time of stress, they can be a source of information, practical advice and general emotional support. Studies of people's reaction to various kinds of crises have consistently shown that they are better able to withstand these where they have attachments with others and an absence of this social support can make them more vulnerable to life stress at both physical and psychological levels. Social contacts per se can be a mixed blessing in the context of illness. It is the quality rather than the availability of relationships with others that counts. Furthermore, even positive and apparently supportive behaviours can have negative effects. The help and sympathy of others, no matter how well intended, can threaten autonomy, encourage dependency and confirm the patient's view of herself as ill or damaged (Ray 1985).

There is evidence from anthropological work that fear of abandonment during illness is not misplaced, nor is it always indicative of neurosis or paranoia. Cancer and AIDS sufferers are often worried that they will be abandoned. There are few occasions in life when the love and support of friends and family is more important than when ill, especially if the sufferer has chronic, progressive or terminal disease (Fallowfield 1990).

Mastectomy does not physically impose any limitations on a woman's social life, but the woman may become more withdrawn if she feels embarrassed by the fact of others knowing about her operation, even if it is accepted that the difference is not outwardly noticeable. She may feel that her image and identity has changed in their eyes, the image of her body and her identity as a woman, and that they are treating her differently. Others' behaviour may indeed change. People often respond with ambivalence to illness and disfigurement, avoiding the victim or treating her with pity or false cheerfulness and this can provide a very real incentive for social withdrawal (Dunkel-Schetter 1982).

Family and friends need to know that having cancer and being on chemotherapy can cause disturbances in relationships in the outside world. In a study by Ringler (1983), the patients reported that it was often useful to play down the seriousness of the disease or to keep it a

secret altogether in order to avoid certain problems with other people. The most important of these problems were:

- Being treated, as if having cancer were the only important thing about them.
- Upsetting other people or scaring them away.
- Becoming subjected to the idle curiosity of mere acquaintances.

It may help to be aware in advance that the responses of the outside world to one's having cancer are often not only not helpful, but also actually a cause of additional difficulty and emotional upset.

“We meet so many other cancer patients at the hospital. We make friends, drawn by our similar situations. We lose new friends too. Suddenly one day they are not there any more. Death becomes real. We share one another's ups and downs, elation and despair (Weitsz 1995).”

In general, good social support can provide a buffer against the adverse psychological impact of stressful events such as developing cancer (Barraclough 1994). The benefits of social support have generally been grouped into three categories:

- Tangible assistance.
- Information.
- Emotional support.

1.15.2 THE FAMILY

Stable support from family and friends, together with the ability to participate in social activities, are immensely important contributory factors to quality of life. Provision for family needs should form part of any good cancer treatment service. Problems may arise between couples – communication barriers, sexual dysfunction, role changes and mood disorders in the partner. The husband may feel helpless and terrified of losing his partner.

In a study by Ringler (1983) patients reported that their families helped them with the disease and treatment in many different ways. Many patients also reported that their families also treated them differently now than they had before the cancer and the chemotherapy. Most of these changes were improvements, but a number of patients said they were very bothered because their families had become overprotective, both physically and psychologically. Those patients who said their families were overprotective had higher emotional distress than other patients.

A woman's relationship with her husband is an important factor in determining how well she adjusts to her mastectomy. A supportive husband can help a woman to cope with life stress in general. In a study of depression among women it was found that in many of the cases identified, the person had faced a stressful life event in the previous nine months, for example a threat to a relationship, an illness, or a major material loss. However an important factor in determining whether or not such an event actually led to an affective disorder was the presence or absence of a confiding relationship with a husband or boyfriend. With such a relationship, it seemed that women were less vulnerable and were protected against the psychological effects of loss and disappointment. It is important to note that it was the confiding nature of the relationship that was important and not just the existence of a husband or boyfriend. Marital status alone did not correlate with adjustment to breast cancer (Brown 1978).

The husband's attitudes toward his wife's illness and mastectomy and the stability of the marital relationship are crucial in determining eventual adjustment. There is thus a case for involving husbands in any counselling that is offered (Ray 1985).

In metastatic patients there appears to be a convergence between the amount of social support wanted – which was determined by the number of side effects and the extent of disease disability – and the adequacy of that support. The prediction that better family support would be associated with less difficulty and distress was not confirmed. In metastatic patients, results were in the opposite direction from the prediction, perhaps because patients who get the best support were patients who had more advanced disease, which may result in distress and difficulty which are relatively intractable (Ringler 1983).

If patients are disabled because of the disease and treatment, this creates a situation, which requires care and tact on both sides. The family has to avoid insulting the patient by coddling and on the other hand, avoid leaving the patient with not enough support. The patient must be ready to protest if too much support is forthcoming, to accept that help is needed with good grace, and to ask for more without shame (Ringler 1983).

Both patients and families need to allow themselves to face and experience the upset that goes with the disease – anger, fear, grief, guilt, regret – and to share these with each other to the extent that it is comfortable. Patients, soon after their diagnosis discover that they need to work to minimise their difficulties and normalise their situation. Patients and families need to be careful that their relationships do not become invalidated by overprotectiveness or too much unreal niceness (Ringler 1983).

When unhappy relationships, social deprivation, and poor mental and physical health have been present for years, the diagnosis of cancer in a family member may precipitate complete chaos.

Communication problems can be most acute in happy families, where talking about cancer and the possibility of dying, is most likely to cause pain. When the communication needs of the two partners are different, such couples are adding to each other's distress.

Patients with stable personalities, a satisfying past life and strong support from their families and friends, generally adjust more readily to terminal illness, than those whose former existence was of a troubled kind. The prospect of death may, however, be especially difficult for those who have a great deal to lose by dying, such as young people who have not yet achieved their full potential, or those utterly unaccustomed to the "sick role" (Barraclough 1994).

The husband has to cope with his feelings of loss: the disbelief and denial of his wife's diagnosis, the rage and confusion during her treatment, the anxiety and fear of watching her suffer. A husband's pain can be especially difficult, because in listening to his wife's groans and ministering to her needs, now one acknowledges his feelings. It is always: "How is your

wife? How is she doing?" His own fears of being left behind are important and he too needs comfort and support during his wife's illness.

The husband's positive role must be emphasised and he must be involved in all stages of his partner's disease. The husband often feels guilt himself, but he needs to be reassured about it and urged to demonstrate his affection and to seek intimacy with his wife. In the majority of cases with adequate reassurance it is found that the stress of mastectomy may establish additional bonds of affection and mutual support that will further cement a marriage. Without a husband or significant partner, the mastectomy patient is particularly vulnerable and these women, together with those that have pre-existing psychological problems, need to be carefully watched for the detection of serious psychological morbidity that needs professional intervention (Baum 1988).

Happily married patients benefit from their husband's support in withstanding the stresses of their illness, but they also have more to lose if they do not survive.

In a study by Wilson & Morse (1991) the husbands became more attentive, compassionate and considerate. They no longer took their wives for granted. Although sexual relations decreased, husbands continued to experience intense emotions of affection, gratitude and love for their wives. The husbands maintained self-control at all times so that disruption to the household would be minimal despite their wives' mood swings, physical illness and mental apathy. It must be borne in mind that this is a select group who agreed to participate in this trial. There is obviously a wide spectrum of spousal behaviour from the caring types mentioned above, to the immature, selfish husband who further detracts from his ill wife's quality of life.

Wilson & Morse (1991) found that husbands feel obligated to be loyal, protective and supportive, to assume responsibility for commitment to the household and to assist their wives in fighting the disease. The commitment made at the onset of treatment tends to deny the option to leave the relationship during the current program of chemotherapy. Husbands who left the relationship usually did so after the disease was in remission.

In the study of Wilson & Morse (1991) the husband remained focused on his wife and on his own needs. They describe the process of buffering, which has two major components: First is

the "doer role" where the husband waits upon his wife by meeting her physical needs, following her instructions for completion of household chores, and taking care of children. The other component is the "protector and advocacy role" where the husband acts as an intermediary among his sick wife, their friends and relatives.

Anger is sometimes more marked in relatives than in patients themselves. Encourage the redirection of anger, when married couples seem to be taking out on each other their shared anger about the illness. Re-channeling energy elsewhere, towards for example exercise, music, creative activity or cancer-related charity, is sometimes an excellent strategy (Barraclough 1994).

Although they describe it as an important domain, Bernhard and co-workers (1997) did not include "partnership" in their Quality of Life Core Questionnaire (see Addendum 1, Chapter 2), because they considered it to be less relevant in comparisons of treatment related endpoints. Similarly, "sexual functioning" was not included due to feasibility problems in particular cultures and age groups.

Children often have a difficult time adjusting. It's hard for them to know how to cope, especially if their mother or grandmother returns home looking and acting sicker than when she left. They need reassurance that their loved one is back and ready to take care of them. But a survivor may feel too drained to take care of anyone other than herself. As a result, children may start acting out their fears and worries, finding it hard to concentrate at school or get along with other kids. They may be more reckless when they play, or they may worry obsessively about getting sick themselves. Their marks may drop or even improve as they throw themselves into their work as an escape. Any of these changes can occur when a child feels scared or worried and the best a mother can do is encourage her children to share their feelings, no matter how painful or hurtful they may be (see Addendum 6) (Runowicz 1995).

Depending on the patient's level of fatigue and other side effects, she might not be able to handle the concurrent roles of wife and mother, disciplinarian and homemaker, wage earner, mediator and friend. All the usual patterns may disappear and roles may be reversed. It may take extra care and attention to get family roles straightened out (Runowicz 1995).

1.15.3 SEXUAL RELATIONSHIPS

The breast should not be considered as a mere appendage of lactation, of no further use once the phase of childbearing is complete. The breast also has a role in sexual attraction, the maintenance of self-esteem, and body image, all of which may vary in importance with marital status, age and current fashion in dress (Baum 1988).

Marital and sexual problems are a general result of the stress of breast cancer and the treatment thereof. Especially younger mastectomy patients' sexual relationships are affected. It has also been shown that it is unlikely that a patient whose sexual relationship deteriorates in the first three months after mastectomy, will be unable to return to her previous level of functioning. Sexual problems were found despite the fact that most patients received emotional support and understanding from their spouses (Fourie 1996).

Most women are concerned at the time of mastectomy with what their husbands' reactions will be. They report that husbands can often be reassuring, persuading them of their continued love in spite of an altered appearance, or minimising the negative effects of the disfigurement by comparing it with the alternative of a progressive illness. Some women try to protect both their own and their husband's feelings by hiding the scar, and not allowing themselves to be seen naked, and there are some couples where the woman's changed appearance is not openly mentioned between them. The woman and her husband must evolve a way of dealing with the disfigurement, a way that takes into account the sensibilities and desires of each, although one partner may take more of the initiative or establish greater control in deciding this (Ray 1985).

In instances when the couple's sex life is adversely affected by the loss of the breast, this may be because of the wife's feelings, the husband's feelings, or both. Sometimes a woman experiences a loss of sex drive, or a "blocking" because of negative feelings about her own body (Ray 1985).

Several authors have pointed to the importance of the existing state of the marriage in determining sexual adjustment postoperatively. A warm and supportive relationship can withstand the strain of mastectomy and may even be further strengthened by the challenge it presents. On the other hand, when there is a lack of communication and support within a

marriage, mastectomy adds to the tension and may trigger a further deterioration in the sexual relationship where it was initially problematic (Ray 1985).

According to Derogatis (1980) the issue of sexuality is central rather than subordinate in women's appreciation of the impact of cancer and greatly affects their fear of the disease, the delay in time in seeking a diagnosis and the course of their response to treatment. It is important to recognise that in a very important sense gynaecological and breast cancers and the surgical interventions employed to treat them, are unique: they are different from other forms of the disease in that they possess the potential to devastate the patient by imposing a unique threat to her self concept and psychological integration. This occurs through the destructive impact of the disease on the patient's body image and sexual identity. The loss of a breast through cancer represents both a severe body image trauma and a serious blow to self-esteem.

Patients with a history of stable adjustment prior to disease, as well as those who are well-informed and have developed constructive attitude postures are likely to do better, just as women who are older and possess a balanced or androgynous gender role definition appear less psychologically devastated by the disease.

After cancer many women begin to doubt their sexuality and their appeal. Suddenly they find themselves wondering if they are still "whole" women. Physical deformities: the loss of a breast, scars post-surgery, radiation scarring – often cause enormous questions of sexual self-worth and the importance our culture places upon physical appearance and body image. A survivor wants to return to a healthy and active sex life and to accept her body postcancer, but she might suddenly begin wondering, "Does my partner still want me without my breast? Do I think I'm sexy?" (Runowicz 1995).

Instead of speaking openly about these fears and concerns, many couples hide behind a wall of silence. Often husbands are hesitant to initiate sex, afraid that contact may further hurt or damage his partner in some way. The wife, who may already be wondering how desirable she is, will take this hesitation as justification that she is somehow damaged or unappealing. By not discussing their feelings, a woman and her partner may find themselves embroiled in a

vicious cycle of misunderstanding, potentially placing their marriage or relationship in serious jeopardy (Runowicz 1995).

According to Wilson & Morse (1991) an additional stressor for the couple was the lack of sexual relations because husbands feared causing their wives psychological or physical pain.

Breast cancer patients are the most frequent cancer survivors in primary care practise. The multimodal treatment of breast cancer improves survival outcome, but it also causes prolonged periods of medical intervention with associated physical and emotional sequelae. There are multiple predisposing factors to sexual dysfunction in breast cancer patients, including pre-existing sexual problems and normal age-related changes in sexual functioning. Physiologic changes caused by chemotherapy and hormone therapy also play an important role. Induction of premature menopause can result in an estrogen-deficiency state that can cause hot flushes, poor vaginal lubrication and urinary symptoms, which may contribute to sexual dysfunction. Older patients also experience these problems as a result of the discontinuation of hormone-replacement therapy at the time of breast cancer diagnosis. Tamoxifen can exacerbate these symptoms. Psychologic reactions to cancer can also give rise to sexual dysfunction in certain patients (Ganz 1998).

Major sexual problems can occur as a result of both physical impairment and emotional traumas. Anxiety that any attempts at sexual activity will fail or be rejected by a partner can have a devastating impact on an individual's quality of life. Even if full intercourse is no longer possible, most people still enjoy the warmth and satisfaction of affectionate cuddling, kissing and intimate non-coital caressing. For most individuals, sick or well, touching is a basic human need, confirming that they are loved and wanted. Those people denied physical intimacy and tenderness, due to mutilating surgery and chronic or life-threatening disease, are extremely vulnerable to depression. The partner of the patient might also need support and help to explore new ways of expressing love and gaining sexual gratification (Fallowfield 1990).

Several factors contribute to sexual problems:

- Physical changes.
- Body image changes. Weight changes, hair loss, mastectomy etc. often inhibit sexual activity for psychological reasons. The patient feels unattractive even physically repellent and the partner often has similar feelings about the spouse.
- Relationship changes. The healthy partner refrains from making sexual overtures, out of concern for the sick person, who sees this as rejection and feels even more unattractive.
- Mistaken beliefs. For example that cancer can be transmitted to a sexual partner or that intercourse will harm the patient, may inhibit sexual activity.

Weitsz (1995) saw her partner becoming physically unattractive, but found that the spiritual aspect of their relationship deepened considerably. Her love deepened and matured: “Tenderness is indescribable. We are inextricably intertwined and interdependent. We talk deeply and philosophically about life, death and life after death. We talk about us. It gives us a sense of peace.”

Breast reconstruction has generally been found to contribute to an improvement in sexual functioning (Lerman 1984). It has been concluded that adaptation to breast cancer does not correlate with the type of surgery (mastectomy or lumpectomy), but rather to the subjective satisfaction with the breast, body image as a whole and the individual’s specific coping mechanisms. Patients undergoing chemotherapy have also reported a negative impact on their sexual relationships.

Health professionals need to be aware of the magnitude of sexual problems generated by cancer. Next, they should be appreciate how meaningful their efforts may be in enhancing the quality of life available to cancer patients and their significant others. Health care providers should evaluate and discuss sexual concerns with their patients as a matter of routine. Bullard et al. (1980) found that 63% of patients would have liked more information regarding the effects of cancer on their sexuality. Of particular interest is that for so-called “single” patients, 84% expressed interest in an educational program on intimacy and sexuality for persons with cancer.

Knowledge of the sexual consequences of cancer has some definite implications for the therapy of cancer. The disease is occurring in a whole person and we must attend to all the needs of that person, not just the lesion. Similarly, we need to broaden our concerns about the cancer patient to include the spouses, lovers, children, friends and relatives of cancer patients. It is clear that the disease affects a social network and the health professional can often do more to benefit the patient by attending also to the effects of the illness on the “significant others”. To fail to do so may mean that the psychological impact of the illness might be much more disabling than it need be. If we are genuinely concerned with improving the quality of life of cancer victims, we need to extend our efforts beyond the disease and beyond the patient (Golden 1980).

Morris and co-workers (1977) found that sexual difficulties were most often reported by women of peri-menopausal status.

Special problems are involved for the woman who is neither married nor in a stable relationship. She may feel that a sexual relationship is no longer a possibility for the future and that no man would now find her acceptable. The fact of having had a mastectomy may discourage her from even embarking on any new relationship, because of the embarrassment that would be involved in first telling her partner and the fear that he would then reject her (Ray 1985).

“Maybe it hurts to kiss, knowing that death will soon separate us. I have such a touch hunger – not for sex, but for tender intimacy. Maybe separation needs to be gradual – it’s a practise run for the real thing. I feel my role changing to that of mothering and caring. It is a massive adjustment as we have always treasured our sexuality and had a fun-filled marriage. Suddenly all this is a thing of the past and I feel cheated” (Weitsz 1995).

1.16 PHYSICAL APPEARANCE

According to Maguire (1985) at least one in every five mastectomy patients will develop body image problems. Of these one tenth will be serious in that they will feel less feminine and less attractive. It was found that body image and self-image would not be affected directly after mastectomy but that it will occur after a few months.

There have been conflicting reports about the advantages in terms of breast reconstruction in the literature. In general it has been shown that patients opting for breast reconstruction have a much better body image than patients who do not have a reconstruction. Some reports claim that the incidence of lowered body image post mastectomy is in fact very low.

Of importance however is that there is a very strong link between body image problems and the development of affective disorders and sexual problems. A negative body image after mastectomy is significantly correlated with weak sexual adjustment (Fourie 1996).

As chemotherapy progressed, a change in physical appearance became obvious and was a constant reminder of the impact of the illness. Husbands did not perceive hair loss due to chemotherapy to be as frightening as it was to their wives, even if hair loss occurred over the entire body. Some used humour to comfort and counteract their wives' humiliation and fear of feeling "neutered". As their wives became increasingly drawn and fatigued, social events were curtailed (Wilson & Morse, 1991).

1.17 FINANCIAL CONSIDERATIONS

The smooth transition back to the workplace is not always possible. Employment discrimination can rear its ugly head in a number of ways. One can be fired or demoted from an existing job, have her benefits reduced or eliminated, not get hired for a new position, or be shunned by co-workers. Closely tied to employment is access to insurance coverage (Leigh 1992).

The cost of the treatment of cancer can be prohibitive. Surgery and hospitalisation are expensive and many of the latest chemotherapy regimens are also highly priced. High-tech procedures like CAT-scans and MRI-scans are priced at over a thousand rand per test. Even something as ordinary as a blood test costs a few hundred rand per test and has to be repeated often during chemotherapy. Add to this the fact that long distances often have to be travelled to the major oncology centre and that patients often have to pay for accommodation during lengthy treatments. In addition, people often lose their job or have to give it up. Patients may lose their medical insurance and other insurance may also be curtailed or denied. Financial worries can add additional stress and detract from an already impaired quality of life.

Cancer confers a substantial physical and financial burden on those who are afflicted. These hardships are increasingly borne by a growing elderly population (Stafford 1997).

Wilson & Morse (1991) found that financial difficulties, with patients no longer working, drained energy.

1.18 ATTITUDE AND DISPOSITION

Cancer patients are often characterised as being negative in their attitudes toward themselves. They have been described as self-critical and self-sacrificing. It has been suggested that they are relatively low in neuroticism and emotional responsivity, but also that they show little anger and hostility. Such findings would in many circumstances be interpreted as an indication of good adjustment and emotional stability, but in this context they are more often regarded as resulting from poor emotional discharge, the assumption being that anxiety and anger are experienced but not expressed. Indeed, high levels of denial and repression have been documented in cancer patients. Perhaps the most frequently cited correlates of the disease are a clustering of negative mood states, all relating to depression. It is many centuries since Galen (second century AD) first made the claim of an association between melancholia and cancer, and current descriptions of the cancer patient still refer to despair and hopelessness (Ray 1985).

Psychosocial and spiritual factors influence a broad spectrum of medical and surgical disorders. The adverse effects of stress have been most clearly documented in cardiovascular disease. In cancer, unresolved questions include the following: Do emotional factors have a causal role in either initiating or promoting a malignant process, and can they possibly accelerate the dissemination of cancer? The literature, which consists of anecdotes, case-control methods, and randomised trials, is inconsistent and beset with major methodological problems. Psychosocial interventions can be life enhancing in sharp contrast to the guilt-ridden programs of some alternative practitioners. A social support system and an element of spirituality and religion seem to be the most consistent predictors of quality of life and possible survival among patients with advanced malignant disease (Creagan 1997).

One factor that might influence the impact of an event is a person's resources for coping. An event might have the same significance for two people in terms of the way it is evaluated and the readjustment needed, but one may be able to make the adjustment more easily than another. The person's capacity to master life changes will be an important variable when predicting the psychological and physical disturbance that will result. A "hardy" personality has feelings of commitment, control and challenge as factors determining resistance to stress and consequent illness vulnerability (Ray 1985).

With these last qualifications, the influence of personality is implicitly recognised as a causal factor in illness, mediating the impact of events. The person's own values and resources determine the way in which events are perceived and the ease with which adjustments are made, and vulnerability is thus determined by the interaction of external events and these internal factors. The theoretical construct that provides a unifying theme for this interaction is that of stress. Stress may be defined as a characteristic of a situation in which the demands placed on an organism is greater than the physical, psychological and social resources that are available to meet these. In any given situation stress can be primarily attributed to either the nature of these demands or to the resource capacity of the person, or to both in conjunction. Stress has emotional consequences but also physical ones. It has been suggested that the influence of physical agents is generally mediated by psychological factors. Neuroendocrine and other physiological changes associated with stress can provide the link between stress and the susceptibility to illness. Stress might not in itself produce illness, but could bring about conditions under which illnesses could be easily established, as the ability to adapt becomes generally exhausted. Stress could affect the immunological response via the central nervous system and endocrine systems, increasing the person's vulnerability and thus altering the balance between the person and any particular disease agents to which she is exposed (Ray 1985).

The General Adaptation Syndrome describes the sequence of distinct stages in the response to stress (Selye 1956):

- The first stage is that of alarm or emergency, during which there is a general increase in the activity of the pituitary-adrenocortical system.
- There follows a second stage of resistance, when the effects of the stress are successfully countered, but resistance to other stimuli may be decreased.

- Finally if the stress is maintained, there will be a breakdown in the process of adaptation as resources are exhausted and resistance fails.

In metastatic patients, the extent of using adjunctive methods of coping with the disease was correlated with other aspects of coping – how active patients were both in coping with side effects and in seeking information about test results. The use of more disease coping methods was also associated with lowered difficulty in metastatic patients (Ringler 1983).

There is in conclusion, a distinct possibility of a convergence between two areas of research hitherto unrelated: one being the influence of personality and stress on disease and the other being immunologic and endocrine studies. All disease is multifactorial – involving genetic, hormonal, neurochemical, immunological and emotional factors. The interactions between these are difficult to disentangle and the mediating mechanisms suggested are at present speculative and hypothetical. The study of these relationships is however, attracting increasing interest and offers the prospect of a novel perspective on an understanding of disease (Ray 1985).

1.19 THE INFLUENCE OF AGE

1.19.1 THE INFLUENCE OF AGE ON PROGNOSIS

Young women with early stage breast cancer do significantly worse when compared to older women in terms of relapse-free survival, cause-specific survival, distant metastasis and breast and regional node recurrence. However, the adverse effects of young age on outcome appears to be limited to node-negative patients. These findings suggest that node-negative early stage breast cancer in younger women is a more aggressive disease, with an increased risk for all patterns of failure and a decreased survival (Fowble 1994).

1.19.2 THE INFLUENCE OF AGE ON QUALITY OF LIFE

Age is another well-documented factor that has a strong influence in shaping a woman's response to potential traumas developing post mastectomy. Obviously the passage of time has no moderating effect; however, the events taking place in that time do. With childbearing and

rearing accomplished and a successful marital relationship to sustain her, a woman has already accomplished a number of very significant life milestones in our society. She is in general, less apt to be devastated by a cancer that may rob her of her capacity to reproduce and/or render her less desirable as a sexual or marital partner (Derogatis 1980). Younger women make a poorer adjustment to mastectomy and are more devastated by losing a breast.

Some researchers have suggested that the loss of the breast causes greater problems for premenopausal than postmenopausal women. Others have argued that this problem can only be resolved in the individual case, with the significance of both the illness and the loss of the breast being determined by their specific meaning within the context of that person's life style, attitudes and values (Ray 1985).

Intuitively and according to developmental theory, younger patients should be more angry and resentful about their illness because they are less likely to have come to terms with the certainty of death. Correspondingly, any psychological benefits of the illness, such as increased appreciation of life, should be more prominent at a younger age (Salmon 1996).

In a study where quality of life was assessed in the adjuvant situation, several symptoms were found to be age-related. The younger chemotherapy group tended to rate a higher frequency of treatment-related symptoms than the younger radiotherapy group. A possible explanation is that the chemotherapy resulted in a chemical castration in many of these patients. In the postmenopausal subgroup the chemotherapy patients perceived less symptoms than the radiotherapy patients. These patterns may be explained by a tendency to push chemotherapy harder for the younger than the older patients (Berglund 1991).

It was found that patients who believed they were more responsible for treatment decisions reported higher levels of quality of life. Patients who were more active in participating in treatment decisions were younger, more educated and perceived their physicians as making more of an effort to facilitate patient involvement (Street 1997).

Controversy about whether cancer has an independent impact on patient quality of life led the authors (Stafford 1997) to evaluate the effects of cancer on a range of quality of life and health care utilisation measures within an elderly population:

In the United States, for individuals age 65 years and older, 2% were diagnosed with cancer annually, compared with 0,2% of those younger than 65 years. Cancer was reported by 17% of the elderly. Individuals with cancer reported poorer health, more limitations of the activities of daily living (ADLs) and the instrumental activities of daily living (IADLs) and greater health care utilisation than individuals without cancer. For individuals with cancer, difficulty walking (38%) and getting out of a chair (21%) were the most commonly reported ADL limitations, whereas difficulty completing heavy housework (34%) and shopping (17%) were the most common IADL limitations (Stafford 1997).

Self-esteem is one of the key elements of the psychological dimension. Self-esteem is developed and maintained through social interaction. The social dimension involves satisfaction with family life and friendships. Social relations are an important resource for elderly women. Because social relationships can change, self-esteem is also liable to change. Since ageing is accompanied by negative social changes, the self-esteem of older people is vulnerable (Rijken 1995).

The view that elderly women are liable to receive less than appropriate therapy has been supported by a study from seven US hospitals. Local therapy, even when co-morbidity is taken into account, was less radical than would have been the case in younger patients (Forrest 1994).

1.20 ETHNICITY

In South Africa, the black population has traditionally been a disadvantaged one. It is an uneducated and mostly very poor population. Black people are often ignorant of the signs and symptoms of cancer and the implications thereof. The prevailing attitude in black cultures is not to have a mastectomy and rather to visit traditional healers than western medical doctors. The result is that black women tend to present very late and with disseminated disease at the major oncology centres, so that their prognosis is bleak.

Increasingly, the quality of life of women diagnosed with breast carcinoma is being studied. However, there is little information regarding long term survivors among ethnic minority women. The purpose of Ashing-Giwa and co-workers' (1999) study was to describe the

quality of life of long-term breast carcinoma survivors and to examine the role of ethnicity in influencing their well being. The survey instruments included standard measures of quality of life: the RAND SF-36 Health Perceptions Scale, the Cancer Rehabilitation and Evaluation Survey-Short Form (CARES-SF), the Ladder of Life and new items. It was found that differences in quality of life outcomes were attributable to socio-economic and life-burden factors and not to ethnicity.

1.21 SOCIOECONOMIC FACTORS

Epidemiological observations have fostered our understanding of the risks of developing breast cancer within a population. Female gender, increasing age, aspects of the menstrual history, family history and personal history of breast cancer are increasingly well-documented factors that contribute to the risk of developing this disease. Of the additional factors that possibly contribute to breast cancer risk, socio-economic status is one of the most influential. The exact manner in which this factor contributes to breast cancer risk is not fully understood. One possible explanation holds that women of higher socio-economic status delay having children until later in life than women of lower socio-economic status, thereby increasing their age at first pregnancy, a well known factor that increases breast cancer risk. Race and socio-economic status are directly related to breast cancer incidence in countries such as the United States, England and South-Africa where the population is diverse, racial discrimination is endemic and segments of the population are forced to live in conditions of poverty despite great national wealth (Henderson 1994).

Once diagnosed with breast cancer, consideration should be given in all patients as to socio-economic factors affecting survival. Nutritional status should be investigated and counselling offered with the goal of reducing relative body weight, improving overall nutritional status and eliminating or at least controlling comorbid factors such as alcohol and drug dependency (Pace 1994).

1.22 SURVIVORSHIP

Quality of survival is in the eye of the beholder. If the beholder is a physician, the factors defining quality survival are likely to be biomedical in nature, have scientific parameters

and be measurable. If the beholder is a social worker or psychologist, these factors encompass psychosocial components and are humanistic in nature. If the beholder is a nurse, there tends to be a greater capacity to blend biomedical and psychosocial factors. And if the beholder is a patient, the factors defining quality of survival include all of the above, along with personal, social and cultural values. While the science of survival attempts to understand the disease itself, the art of survival attempts to understand the human experience of that disease (Leigh 1992).

Survivorship is a new concept in relation to cancer and has yet to undergo rigorous conceptual development. It has been described as the act of living on: a dynamic concept with no artificial boundaries. Survivorship has also been viewed as a continual, ongoing process rather than as a stage or component of survival. It is the experience of living with, through or beyond cancer. Survivorship extends far beyond physical recovery. Survivorship is about the quality of our lives with or without cancer, about healing the visible and invisible wounds and about feeling satisfied that we have made the right choices and are doing the best we can (Leigh 1992).

As the idea of cure becomes a reality for millions of survivors, many pay a high price to overcome remaining problems. Successful treatment is such a cause for celebration that it usually overshadows concerns about chronic or delayed sequelae. The importance of continued medical follow-up couldn't be overemphasised, since survivors are at increased risk for recurrence, other malignancies and complications of therapy. Besides the anxiety about cancer recurrence, numerous other emotional, psychological and social obstacles may impede recovery. Examples of such obstacles include fear of death or abandonment, a sense of isolation, changes in relationships, feelings of vulnerability and emotional lability, depression, changes in body image, sexual dysfunction and post-traumatic stress disorder. As many of these are adjustment problems or situational disorders and not hard-core psychopathology, help is usually available if the survivor is willing to explore solutions (Leigh 1992).

Even if we cannot change our destiny, we can change the way we react to it. There is no meaning to cancer – it is simply cancer. Meaning comes from the individual interpretations of the disease and the treatments (Leigh 1992).

1.23 RECURRENCE

Perhaps the most difficult phase for a woman to cope with is the recognition of treatment failure by the appearance of local or distant metastases. If one then adds to the woman's psychological trauma, treatment such as removal of ovaries and cytotoxic chemotherapy, one might predict that the load would be too great and the majority of women would "crack up" completely (Baum 1988).

Although now feeling "better equipped" about what to expect, nevertheless, the feeling of devastation and loss of control, that husbands experienced, persisted. Metastases were feared because it meant, "game over" (Wilson & Morse, 1991).

The patient who experiences a recurrence of cancer needs to be closely monitored for signs of psychological morbidity. The palliative aims of therapy at this stage, where cure is definitely not an option should be at the forefront of treatment planning. It is very important to break bad news in an empathetic way and this is a time-point where extensive attention to the patient and her family's informational needs must be paid.

1.24 DEATH

There comes a time eventually when the clinician wishes to withhold further active therapy and recognises that the expectation of life is now limited to months rather than years. Terminal care is either organised in the patient's local community or instituted at the oncology centre. The help of the social worker, hospice, cancer association and family and friends is enlisted. Symptoms are addressed, in particular pain control, but any active procedures are avoided.

According to Wilson & Morse (1991) death was a topic which was never discussed between spouses.

"Grieving starts before death. It starts while you are awaiting the final onslaught. One is often told that grief encompasses different emotions, and this is certainly true. It should be stressed however, that not everyone experiences these emotions in the same way or even in the same

sequence. Certainly, elements of shock, denial, anger, grief, despair, gradual acceptance and an acquisition of a future perspective are part of the process. The nuances differ with each case. One of the problems with handling grief is the fact that it is often accompanied by anger” (Weitsz 1995).

Accounts of life-span emotional development maintain that the normal challenges of adulthood – and especially the approach of death in later life – stimulate a change in values. According to Erickson (1986), the final stage of adult psychosocial development revolves around a conflict between “integrity” (a sense of completeness and fulfilment) and “despair” (fear of death and regret at lost opportunity). Levinson (1990) identifies confrontation with one’s mortality as an important developmental task, from which greater fulfilment can emerge.

Hinton (1999) assessed the awareness and acceptance of dying in a sample of cancer patients. Depression was linked with greater awareness in relatives but not in patients. Patients were more anxious if death seemed probable rather than certain or no more than possible. Acceptance usually increased, with 51% of patients and 69% of relatives becoming nearly/fully accepting. Relatives accepted more if patients were over 70 years of age, weak, unable to concentrate or had a quality of life index (QLI) below five, but patients were more accepting if female and if the QLI was above five. Pain did not increase acceptance. Acceptance was described in terms of death’s inevitability, faith and spiritual values, life’s diminishing rewards, completing life, final benefits, humour, sharing etc. Individuals often used more than one concept.

Impressive gains in the survival of some patients with malignant diseases have primarily reflected the availability of multimodality programs among others, for subsets of patients with regional breast cancer. Most patients with advanced solid tumours, however, will die of their disease. Sophisticated psychosocial investigations of patients with advanced cancer have targeted several areas in which clinicians can positively influence quality of life. Families often “cascade through an avalanche “ of emotional upheavals as patients struggle with the sequelae of their illness. After a patient dies, clinicians should be familiar with some generally recognised patterns of behaviour that are indicative of a normal mourning process. This knowledge may help clinicians be aware of situations that might necessitate intervention of

other professionals, either medical or pastoral. Attention to psychosocial events is an integral part of a comprehensive oncologic program to facilitate patients and families to live in an atmosphere of peace and dignity (Creagan 1993).

1.25 INFORMATION

1.25.1 GENERAL

“The more I knew, the more secure I felt, even if the news was bad. Ignorance frightens me; knowledge soothes me. The worst part is not knowing...definitely the worst part is not knowing” (Wilbur 1991).

While highly stressed and vulnerable, patients are frequently bombarded with information. Much of the information is in medical language and is difficult, if not impossible to understand: informed consents, treatment protocols and potential side effects. The physician often acts as gatekeeper and controls the type and amount of information delivered most of which is medical. Information must be presented in such a way that it can be understood and effectively used and medical information must be integrated with the values and life goals of each patient (Leigh 1992).

The diagnosis of cancer can be seen as an “informational” crisis. The patient brings to bear on her own personal situation all that she knows or thinks she knows about the disease and its implications. She is recognizing her own mortality, revising assumptions and expectations that she has previously held about the course of her life, and confronting the uncertainty and ambivalences generally associated with the illness. For most, a key element of the informational crisis of cancer is that they do not know what the outcome will be. They do not know whether their previous assumptions and expectations for health and longevity are valid or invalid. Thus the patient has to come to terms not so much with death as with the unpredictability of the future and with the ambiguity of her current status (Ray 1985).

Previously, the diagnosis of cancer was concealed from patients. This was because cancer carries so many stigmas and implies such a grim prognosis. Nowadays in the Western

world almost all cancer patients are told what is wrong. Many patients continue to feel that they have been kept in the dark about the details of their illness and perceive various shortfalls in communication with their doctors. This may not be entirely the doctors' fault because, during emotionally charged interviews, patients often forget what questions they wanted to ask, or dare not ask them, or fail to take in what they are told. The flourishing of organizations to inform and support cancer patients, attest to the hunger for information felt by many patients (Barraclough 1994).

It is important to move away from the current reticence about discussing breast cancer towards more openness with appropriate support (Williamson, 1996). Luker (1996) found that lack of time and misconceptions about what patients most want to know hinder staff from being as helpful as they would wish. At least questions should be answered: being "fobbed off" or not answered increase patients' stress (Swindon 1995). Patients should be given all the pertinent information, so that the implications of treatment for the quality and practicalities of life during treatment are clear. This should be done in language that is clear and understood by the patients. They should not have to discover that choosing one treatment rather than another has trapped them into unexpected consequences (Alderson 1994). Pickering (1995) advocates nurse counselors for practical advice and emotional support, whereas Alderson (1994) found that some patients find complementary therapies useful.

Alderson (1994) found that patients thought that all options should be discussed with them, including the treatments' long term implications, benefits and risks. Most patients wanted detailed information about their cancer, most thought they should be told about uncertainties that exist, and most wanted to share decision making with their doctors.

Pickering (1995) found that treatment could sometimes be better organized. Diagnoses should be made and imparted as quickly as possible. Then the patient should have a few days to consider all the options. Access to good information is mandatory. He also found that continuity of care and follow up should be improved. The number of inexperienced and new personnel that a patient meets should be limited.

It is imperative that bad news be broken in a sensitive and compassionate way, as is elucidated by Weitsz (1995): “Don’t they teach them in medical school to break the news gently, or at least compassionately?” The nursing staff leaves us well alone. I guess they don’t like confronting patients and their families when the death sentence has just been passed.

According to Ault (1998) the key to educating patients is to be supportive and empathetic. It is important that women with breast cancer receive encouragement and support early on in their experience. The more factual and timely the information that women have, the better their ability is to make the right choice for themselves and their families. The realization that the information must be repeated frequently also allows women more time to contemplate the treatment options that have been offered. Finding out what the patient and family members already know or what they remember from the previous clinic visit is always a good place to start when helping them with treatment decisions. Allow the patient to make her own decisions and then respect her choices. Remind her that her decisions for treatment should be based on what is best for her and not on someone else’s experiences. With knowledge comes power and with power comes control – control over her life, her disease and her treatment.

When a woman is diagnosed with breast cancer, she often faces a complex series of decisions about her treatment (Monson 1998). Firstly, she may be presented with several choices about the treatment of her breast:

- Breast conservation with lumpectomy and radiation therapy, or mastectomy with the option of reconstructive surgery.
- An axillary node dissection may be discussed along with surgical options. This is an important consideration because most of the long-term side effects – lymphedema, numbness and pain – are due to the axillary node dissection.
- The new sentinel node technique may help prevent unnecessary axillary lymph node removal and its associated morbidity. If the sentinel node is negative, axillary node dissection can be avoided.

Decisions about systemic treatment (Monson 1998):

- It is generally accepted that women with positive lymph nodes will benefit from systemic treatment.
- There is however, a wide range of outcomes for women with negative lymph nodes.
- Systemic treatment may involve chemotherapy, hormonal therapy or both. Factors that are taken in to account when determining adjuvant therapy include estrogen receptor status, involvement of lymph nodes, patient age, menopausal status and general health.
- Systemic treatment for advanced disease is planned according to the extent and severity of the disease. For patients who do not have visceral involvement, as well as elderly patients, where co-morbid disease is often problematic, hormonal therapy is normally the first choice. The same factors that influence decision making for adjuvant therapy also apply. In addition the site of metastases, might influence the choice of treatment. For example tamoxifen works very well for bone metastases and the addition of a bisphosphonate has been proven to reduce complications that arise as a direct result of bony metastases. The treatment of choice for brain metastases is radiotherapy and corticosteroids.

What information is important to women making these decisions and what influences them to choose one option over another? The patient's physician will explain treatment options and their expected outcomes – both the benefits and the risks. After this consultation, however, the patient often feels unprepared to make important decisions about treatment, for a variety of reasons. The four basic principles of medical ethics – beneficence, non-maleficence, autonomy and equity – are important to consider when we offer patients choices about their breast cancer treatment.

Several studies show that there are psychological benefits to participating in the choice of surgical treatment. Women, who were offered a choice, tended to have less anxiety and depression post surgery, regardless of the surgery chosen. The woman's partner may also experience these benefits. Being given a choice may heighten anxiety for some patients. Other patients are not given a choice at all for a variety of reasons including race and educational status. In not giving patients a choice, the ethical principle of equity is violated.

Decision-making preferences regarding treatment (Monson, 1998):

Active

1. I prefer to make the final choice about which treatment I will receive.
2. I prefer to make the final choice after seriously considering my doctor's opinion.

Collaborative

3. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

Passive

4. I prefer that my doctor make the final decision about which treatment is used, but considers my opinion.
5. I prefer to leave all decisions up to my doctor.

Each person has a general preference. This tends to be influenced by age, gender and educational level. Preferences may also be culturally influenced. The more life-threatening the situation, the more passive a role is preferred. Cancer patients who play a more active role want more detailed information regarding their diagnosis and treatment. Given the variability of preferences, individual assessment of whether or not a woman prefers to participate in decisions about her treatment remains the best clinical approach.

When a woman is initially diagnosed with breast cancer, she typically feels overwhelmed due to the abundance of treatment options, new words and concepts, and sense of urgency often placed on the situation. It is important to provide each patient with the access to the information she needs to make her decisions. In some states in the USA, it is mandatory to provide patients with written information (Monson 1998). The ability to recall information conveyed during the stressful time of breast cancer diagnosis has been shown to be fair to poor (Hughes 1993).

The physician, nursing staff and trained breast cancer survivors should all be utilized to provide the patient with information. These different experts all contribute very different aspects of breast cancer management to the patient. The fact that women have been given information does not guarantee that they understand it. Patients should be asked to repeat information, to ascertain that they have fully understood it. Any misconceptions should be clarified.

For most women, the diagnosis of breast cancer comes as a shock – they didn't have any symptoms, were busy with their lives, then suddenly everything changed. The same stresses which make information recall difficult in this situation can also make it difficult for women to solve problems and overcome potential barriers to the treatment plan they prefer. The information that she receives may provide her with a list of pros and cons for different options, but still leave her confused about what those pros and cons mean to her. Value clarification, a technique used to explore the personal value placed on each issue involved in the decision, can be helpful. For example, she may face the choice of chemotherapy in a situation where less than 10% of those who receive the treatment will live longer because of it. Value clarification can help a woman explore the very personal decision about whether a small survival benefit at any cost is more consistent with her values, or whether a better quality of life with a slightly increased risk of death, is her preference (Monson 1998).

Numerous psychological factors influence the choice of breast cancer treatment. The most obvious factors are related to body image concerns and fears of deformity, mutilation and loss of femininity. Decision-making at the time of breast cancer diagnosis has a profound effect on quality of life and survival. Several psychosocial interventions may facilitate adjustment to breast cancer, promote adherence to medical treatment, and affect the overall course of the disease. Patients should be encouraged to build a supportive network and attend local breast cancer support groups. Spouses and other family members can also benefit from the positive affirmation offered in these programs (Monson 1998).

Patients seem to have a strong wish to know what's going on. This was shown by the accuracy of metastatic patients in judging their therapy's success and also by the fact that patients are always looking for information and using it to make inferences about what the disease is doing (Ringler 1983).

The diagnosis of breast cancer marks a significant transition from health to chronic illness. Informational needs and decision making styles of patients and their families, may change across the continuum of the illness, making ongoing assessment and tailored interventions necessary (Monson 1998).

Patients sometimes have difficulty in deciding whether the treatment would really be of benefit to them, but feel that advice and counseling are non-existent.

A few patients complain that they have been told too much. This often reflects tactlessness or poor timing in the way that information was given. It could also be that complete stark truthfulness is seen as essential and patients are not allowed to use denial as a mental defense (Barracough 1994). Patients should be given ample opportunity to question the situation but unwanted information should not be forced upon them.

Breaking bad news, can seem a daunting task. It may be helpful to remember that most patients find uncertainty (often accompanied by anxiety and morbid fantasies), harder to bear than knowing the facts (Barracough 1994).

Husbands noted that their ability to cope with their wives' condition was dependent upon the kind of information obtained. Receiving a poor diagnosis was preferable to "being (left) in the dark" and fearing the worst (Wilson 1991).

Wilson (1991) found that health care professionals rarely gave husbands information. The men hoped to hear something positive. Anger at the system, at the lack of compassion of health care providers and at having to wait for test results, strained their ability to cope. For example, being forced to wait up to five days for test results was common. It was demeaning when scans were not shown to the couple, particularly when wives who used visualisation to understand their disease, needed to see the scans. Requesting information or phoning the physician was often unsuccessful.

1.25.2 GENETIC COUNSELLING

Many crucial problems are associated with the diagnosis of inherited cancer susceptibility. One of the most important is related to the psychosocial consequences of the knowledge by the patients and their relatives of their own genetic status. In a study by Freyer and co-workers (1999), patients completed the Hospital Anxiety and Depression Scale (HADS) and the Subjective Quality of Life Profile (SQLP). A high level of frustration and latent dissatisfaction related either to the management of the genetic information given by the clinicians and its

psychosocial consequences or simply to the knowledge of the genetic risk factor, which was found. Further studies on the individual consequences of genetic testing, how information should be imparted and when psychotherapeutic interventions should be commenced, are needed to ensure the quality of pre-symptomatic genetic testing in this field of oncology.

1.25.3 PATIENT GROUP EDUCATION

Patient group education is an evidence-based and powerful intervention for supporting and guiding patients toward an understanding of the cancer experience. An education program for patients and families, entitled Learning to Live with Cancer, has been developed and evaluated in a Swedish research project and implemented clinically. The program is a core model with a structure that allows flexibility in addressing learning needs. It has grown into a pan-European program through “training the trainers” courses and is now available in many countries. This has taken the project into a new phase, since Europe is characterised not only by consisting of many different countries, but also by showing cultural diversity and variety in ethnical norms. The aim of this phase was to assess the presence of core-model divergences conditioned by cultural values and norms, and if present, to investigate adjustments proposed to increase the relevance of the program to best suit patients’ learning needs in different cultures. A questionnaire was distributed to former participants in “training the trainers” courses. The findings indicate that only minor divergences are present and that the core model thus has the potential to meet the learning needs of cancer patients in many cultures (Grahm 1999).

1.26 RESOURCES IN GAUTENG: THE CANCER ASSOCIATION OF SOUTH-AFRICA

1.26.1 VISION

To be a world-class community-driven organisation in cancer control.

1.26.2 MISSION

It is the aim of the cancer association of South African to fight cancer and its consequences in partnership with all South African communities and relevant stakeholders by providing direction for and supporting the following cancer control components:

- Health promotion through prevention and early detection.
- Patient service facilitation.
- Research to enhance the above.

1.26.3 SERVICES RENDERED BY CANSA

- Community based home care service where the family is trained as the primary unit of care and then is equipped to take care of the patient.
- An advisory information service.
- Support groups for cancer patients / families.
- 8 Interim homes in the larger cities for out of town patients who receive treatment in the larger centra. Accommodation, meals and where possible, transport is available.
- Medical equipment, wigs and prostheses.
- Health promotion for early diagnosis and to combat cancer through advocacy and lobbying for a healthy environment, as well as the distribution of educational material, educational talks and exhibitions.
- Financial support for cancer research.

1.26.4 REACH FOR RECOVERY

Reach for Recovery is a group of volunteers who try to convey a message of hope to patients who have recently undergone a mastectomy. The aim of this group is to utilise selected trained volunteers to visit pre- and post-mastectomy patients with the aim of giving support and practical advice. The volunteers are women who have personally undergone a mastectomy and are therefore guiding other patients on the ground of their personal experience.

1.27 MANAGEMENT OF SIDE EFFECTS

Presently, all methods of cancer treatment harm healthy tissue, while trying to exterminate the cancer cells (Knapp 1995). Unpleasant side effects are major contributors to the overall distress of cancer patients.

One aspect of clinic procedure, which could be improved, is the preparation of the patient for treatment side effects. Although preparation is generally quite good for the more common side effects, there were some side effects – pain in the joints or limbs, tearing of eyes, nose bleeds and mouth sores – for which preparation is inadequate (Ringler 1983).

Hemopoetic toxicity is often very serious and can be life threatening in cases where septic shock develops. Low white cell counts lead to increased risk of infection while thrombocytopenia can cause bleeding episodes and anemia leads to fatigue. Nausea and vomiting are probably the most general and also the most feared side effects of chemotherapy. With the new 5HT₃ antagonists, the management of nausea and vomiting has become much more effective. Alopecia, arthralgia, myalgia, fatigue, phlebitis, mucositis, altered taste, weight loss and diarrhea are often problematic. Neuropathy is not only extremely unpleasant and painful, but is sometimes a permanent side effect. Impairment of cardiac function can be permanent, debilitating or even life threatening. Anaphylaxis and allergies may occur as well as problems associated with a suppressed immune system.

In a study by Ringler (1983) it was found that adjuvant patients are most bothered by nausea, which is clearly a treatment side effect, while metastatic patients are most bothered by tiredness and weakness, which may be caused by either the disease or the treatment. This suggests that metastatic patients focus attention more on the disease and its effects, making them less attentive than adjuvant patients to the treatment and its side effects.

Measures to minimize nausea and vomiting (Barraclough 1994):

- Minimize waiting time before treatment.
- Minimize patients' bad expectations. Patients who have seen others being sick or who are told to expect terrible nausea and vomiting, are more likely to suffer badly during their own treatment.
- Give supportive counseling and ample opportunities to discuss anxieties.
- Distract attention from cues: sucking mints to mask hospital smells and tastes, listening to music or relaxation tapes, performing mental tasks.

Sohara and coworkers studied 59 patients with hepatocellular carcinoma to determine the incidence of nausea and vomiting and the antiemetic effect of ondansetron. They found that when arterial chemo-embolization was performed, antiemetic treatment for approximately three days was necessary to improve patients' quality of life to an acceptable level.

1.28 SUPPORTIVE CARE

The interest of the scientific community in the supportive care of cancer patients has constantly increased during the last few years. In fact, adequate supportive care has been demonstrated to improve the survival of cancer patients as well as their quality of life by preventing or reducing the severity of side effects induced by cancer chemotherapy and relieving the symptoms due to the neoplastic disease itself (Ballatori 1993).

By supportive care is meant any medication or intervention that can prevent or ameliorate side effects and disease symptoms, or any other aid to improve the quality of life of the patient. This includes the management of hematological and non-hematological toxicity. Examples of non-hematological toxicity include: mucositis, extravasation, mutagenicity, neuro-, nephro-, cardio-, pulmonary-, gastrointestinal- and endocrinologic-toxicity. The term supportive care also includes psychological support for cancer patients and their families. A self-help group is an additional form of supportive care that can be extremely beneficial (see 1.8 resources in Gauteng).

Counseling activity range across a broad spectrum, from the qualities and skills necessary for communicating effectively at one end through to specialist professional help at the other. The abilities of doctors to help their patients to understand and cope effectively with their problems and facilitating changes that may be necessary to bring these about, are intrinsic to good communication. Patients rated emotional support from senior doctors at least as highly as that from their family and more important than any other source. One effect of acquiring these skills is that doctors are then able to identify patients who may be in need of the specialist help provided by those with professional training and expertise. Studies show that between one quarter and one third of all cancer patients have significant psychological distress and that the majority accepts counseling if offered (Sweetenham 1997).

Many agents used as therapy for cancer cause unwanted effects on the bone marrow. The net results of these agents are immune defects and peripheral blood cytopenias. The marrow has considerable capacity for recovery, and this can be exploited to therapeutic gain by using chemotherapy (with or without myeloid growth factors) to mobilize early haemopoietic cells into the peripheral blood; these can be used as rescue following further high-dose therapy (Clark 1997).

The periods of bone marrow suppression following chemotherapy leave patients open to serious and often life-threatening infectious complications. Therefore broad-spectrum empirical antibiotic therapy should be initiated when a neutropenic patient presents with fever. This concept has dramatically improved survival and quality of life in patients undergoing chemotherapy. It is suggested that only those patients whose cancer chemotherapy regimens are anticipated to result in a greater than 40% incidence of febrile neutropenia should have adjunctive cytokine treatments. The importance of using these costly agents rationally and judiciously cannot be overly emphasized (Freifeld 1997).

Untreated anemia is common among cancer patients. Both the cancer and treatment with chemotherapy can suppress the normal endogenous erythropoietic response to anemia, necessitating transfusions. In placebo-controlled phase III studies, administration of recombinant human erythropoietin (epoetin alpha) increased hemoglobin levels and decreased transfusion requirements in patients undergoing cancer chemotherapy. In these

studies, an increase in self-perceived energy level, functional status and overall quality of life was noted in the subset of patients in whom hematocrit levels increased by $\geq 6\%$. Before and after the phase IV study, where all patients received epoetin alpha, each patient completed a linear analog self-assessment scale designed to measure energy level, daily activity, and overall quality of life. There was a progressive and significant increase in hemoglobin concentrations, decreasing the need for transfusions. The entire patient population demonstrated a statistically significant increase in mean scores for energy level, daily activity and overall quality of life, regardless of tumor response. The magnitude of the increase in these scores correlated with the magnitude of the increase in hemoglobin concentrations. These findings suggest that in cancer patients undergoing chemotherapy, the tradition of leaving anemia untreated may compromise the patients' ability to function and their quality of life (Glaspy 1997).

It is however still currently uncertain whether erythropoietin therapy really improves the quality of life of cancer patients, but some studies have shown decreased transfusion requirements in cancer patients.

The use of bisphosphonates (e.g. pamidronate) is an important supportive measure for patients with bone metastases. Pain, surgery, radiotherapy and hospitalizations can be reduced by bisphosphonate use.

Selective aspects of quality of life during supportive pamidronate treatment were assessed in breast cancer patients with osteolytic metastases. 144 patients were randomized to a pamidronate group ($n = 76$) or a control group ($n = 68$). A questionnaire specifically designed for this trial, measuring four domains, namely mobility impairment, bone pain, fatigue and gastrointestinal toxicity was administered at 3-monthly intervals. The analysis focused on changes in these quality of life domains over time. The median follow-up for both groups was 18 months. Mobility impairment and bone pain were significantly less in the pamidronate group as compared with the control group, due primarily to a rapid improvement shortly after pamidronate treatment. Thereafter, a gradual increase in these symptoms was noted in both groups. Gastrointestinal complaints and fatigue levels were similar over time in these two groups, suggesting that these symptoms are more dependent on disease-related events and cytotoxic treatment than on pamidronate treatment. The

results indicate that reduced skeletal morbidity in breast cancer patients during pamidronate treatment is associated with an improvement in selective aspects of quality of life (Holten-Verzantvoort 1991).

1.29 ADDITIONAL STRATEGIES

Other strategies that promote a sense of well being and increased control over one's life include stress management, good nutrition and exercise. Some researchers suggest that each of these strategies may decrease the risk of breast cancer or its recurrence:

- Managing stress: includes techniques such as visualization, meditation and progressive relaxation.
- Dietary recommendations: a healthy low-fat diet comprised of an abundance of fresh fruits, vegetables, grains and very little animal fat.
- Exercise promotes emotional well being.

Nonpharmacologic interventions to reduce emotional distress and control symptoms can also be undertaken, including psychotherapy, coping skills training, patient education programs, relaxation training and exercise programs.

1.29.1 PSYCHOSOCIAL INTERVENTION

The following quotation was found in an oncology textbook in the section on standard medical care for breast cancer patients: Once the diagnosis of breast cancer is established, the patient's psychosocial adaptation skills should be evaluated. A baseline profile may help guide therapy and skilled intervention and counseling should be available to help the patient with emotional problems that may arise throughout the course of therapy (Fisher 1994). However the question arises: In how many oncology centers is this really an integral part of the standard of care?

Psychotherapeutic interventions, such as crisis intervention, brief psychotherapy, family therapy and group therapy, have been shown to reduce emotional distress in patients. Patient education programs, many of which include coping skill training, can increase

knowledge about the disease, reduce anxiety, increase patient's feelings of purpose and meaning in life, reduce pain and depression, improve coping and increase confidence in the ability to manage pain (Taylor 1990).

There is a long and painful catalogue of psychological morbidity associated with breast disease. It is one of the privileges of dealing with these patients to recognize the incredible natural resources for coping that exist amongst the majority of women. But quality of care can be improved to reduce the stresses involved. The mere recognition of the psychological sequelae by husbands and by all professional groups caring for the women and a sensitive handling of the patient at each stage can go a long way to alleviating some of the stress (Baum 1988).

The Reach for Recovery Program consists of trained volunteers who have had a mastectomy themselves (see 1.8). In the USA specialist nurses known as Mastectomy Counselors, have been recruited into many breast clinics. These strategies should be scientifically evaluated as natural coping mechanisms do exist in the majority of women. Counselors are more reliable at detecting early evidence of psychological morbidity than clinic doctors so that patients can be referred on for medical or psychotherapeutic intervention.

Hammerlid and coworkers (1999) performed two studies of psychosocial intervention in head and neck cancer patients at different stages of their disease. The first study concerned long-term group psychological therapy for patients with newly diagnosed head and neck cancer. Quality of life was measured longitudinally for 1 year and compared with that of a control group. The second study comprised a short-term psycho-educational program 1 year after treatment for head and neck cancer. Quality of life assessments were made repeatedly from diagnosis until 1 month after the intervention. The quality of life of the therapy group improved more than that of a control group in most areas measured during the study year, in particular psychiatric morbidity, social functioning and global quality of life. The results indicate benefits from the therapy, although the therapy group scored worse than the control group at diagnosis. These pilot studies suggest that head and neck cancer patients can benefit from different psychosocial interventions.

Criteria to consider when deciding which patients need psychosocial intervention (Ray 1985):

- Not all patients want additional support. Those who refuse help may not be restricted to those who adjust well by themselves and adjust without intervention. Refusers tended to be avoiders or deniers with respect to their illness, and the former strategy at least is one that is associated with poor adjustment. No patient can be pressured into taking part in a program and self-selection is thus one criterion that must be taken into account.
- Traditionally, only patients whose distress is noticed and judged to be of unusual degree are given special help. This routine detection of need misses many patients whose problems then remain unresolved.
- With the specialist nurse model, all patients can be provided with some support and this alone might benefit patients if the nurse has the requisite counseling skills. Patients who fail to adjust are then referred for more intensive care, and it seems from evidence to date that it is the nurse's capacity to monitor all patients and more reliably detect problems that reduces psychological morbidity.
- An alternative would be to provide an active intervention for all patients, recognizing that all patients meet with some problems in adjusting and that the process of adjustment can be facilitated even in patients who would cope reasonably well alone. A further advantage of this approach is its preventive nature. If a person has to wait until significant problems develop before intervention, maladaptive methods of coping may by then have become engrained and be difficult to modify. The cost effectiveness of this approach must be taken into account as it has a high cost in terms of resources.
- Finally, questionnaires or interviews can be used as soon as possible after diagnosis to predict patients at high risk and support can be offered to these people only. This option is also preventive in nature but it does assume that the greatest overall benefit is achieved by focusing resources upon those who are the most disturbed.

1.29.2 THE ROLE OF PHYSIOTHERAPY

In the United States of America, breast cancer patients were among the first cancer patients referred to physical therapists in the early to mid-1970's. Physical therapists can provide

the cancer patient with improved function, increased comfort, and an acceptable cosmetic effect, resulting in restoration of the patient's self-esteem and body image (Adcock 1990).

Breast cancer patients can present with changes directly related to their cancer or resulting from their therapy. Some of these are ameliorable to physiotherapy. These deficits include upper extremity mobility, skin breakdown, neuropathic changes, postural changes and secondary edema. Since the majority of breast cancers do require some type of surgical intervention, the physical therapist plays a critical role in the area of preventive medicine. Therapists have the opportunity to provide treatment as well as to educate patients. If the patients understand that early intervention may prevent further problems and complications, they may be more compliant and actively participate in their care.

After surgery, the arm on the affected side must be slightly abducted and flexed at the shoulder and the distal aspect of the extremity elevated and supported. This position will inhibit post-surgical edema. The patient should be encouraged to actively move the hand, wrist, forearm and elbow. Patients should be educated about the increased danger of infection in the affected arm and that this will pose a threat throughout the rest of their life (see Table 2 and Addendum 8).

TABLE 2: PATIENT FORM LISTING SIGNS OF INFECTION (ADCOCK 1990)

Call your doctor or therapist if there are changes in your arms

COLOR – redness, streaking or blotching

TEXTURE – arm is softer, harder, skin is rough or indented

TEMPERATURE – arm feels warmer than the other extremity

SIZE - arm feels full or heavy

- clothing or jewelry do not fit as well

- increased circumferal measurements of 2/8 inch
for more than 3 consecutive days

Treatment of decreased mobility of the upper extremity, particularly at the shoulder girdle, is easily correctable by an exercise program. If the tissue is not supple, it can be corrected by a deep friction massage using a steroid in a petroleum base. This type of massage breaks down adhesions, increases circulation and conditions the skin.

Tissue massage, as described above will enhance the integrity of the skin. Those patients who have wounds caused by delayed healing due to radiation therapy, ulcerated chest walls due to advanced disease, erythemas or moist exfoliations will require instructions in skin care. Also, a large number of patients may develop herpes zoster on the affected side. General skin care instructions include cleansing the skin with tepid water and no soap, patting the area dry, wearing loose, non-binding clothing, discontinue use of skin creams or lotions and avoiding direct exposure to the sun. If the patients have moist desquamation, application of cornstarch and topical steroids is helpful. Those patients who have extensive skin breakdown or advanced disease may benefit from cleansing the area followed by moist to dry dressing using water and hydrogen peroxide or saline solution. Analgesics may decrease their discomfort. Patients with herpes primarily benefit from medication. Cool compresses and steroid cream may make them more comfortable and promote healing of lesions.

Physiotherapy is also important for patients with neuropathic and postural changes, where early intervention can prevent chronic problems developing. For patients with persistent long-term neuropathic changes with severe disability, protective measures such as the use of a sling must be employed.

The incidence of edema has been decreasing with the advent of less radical surgical intervention. It remains however, a troubling problem for 30 to 40 percent of patients. Massage, exercise, elevation and compression can be used independently or in conjunction with one another (Adcock 1990).

1.29.3 NUTRITIONAL SUPPORT OF THE CANCER PATIENT

Malnutrition is a common problem in cancer patients that results in a devastating quality of life, economic and survival issues. "Cancer cachexia" refers to a complex, multifactorial

syndrome characterized by anorexia or the spontaneous and unintended loss of appetite, generalized host tissue wasting, skeletal muscle atrophy, immune dysfunction and a variety of metabolic alterations. The malnourished cancer patient responds poorly to therapeutic interventions, such as chemotherapy, radiotherapy and surgery, with increased morbidity and mortality compared with well-nourished patients.

Many studies have reported the prevalence of malnutrition in cancer patients. In a multicenter cooperative study of more than 3000 cancer patients, it was reported that substantial weight loss was found in more than 50% of patients. Weight loss was identified in 40% of breast cancer patients. Cancer-induced malnutrition involves systemic and metabolic derangements (Rivadeneira 1998).

Evidence shows that losing weight and focusing on better nutrition and exercise may significantly decrease the chance of getting cancer. Scientists now suspect that as much as 80 percent of all cancers may be related to environment and to things we eat, drink and smoke (see Addenda 3, 4 and 5 for useful advice on eating correctly).

1.29.4 EXERCISE

Experimental studies in animals and epidemiological studies in human populations support an inverse association between exercise and the development of cancer. The proposed biological mechanism for the physical activity-cancer association includes exercise's effect on immune function, transit time of digestion, hormones and body fat. Additionally exercise may be beneficial in the treatment of cancer through mood elevation, decreased loss of lean tissue and increased quality of life (Oliveria 1997).

Dimeo and coworkers (1999) found that aerobic exercise could reduce fatigue and improve psychologic distress in cancer patients undergoing chemotherapy. A group of patients followed an exercise program during hospitalization for chemotherapy and a control group did not. Psychologic distress was assessed at hospital admission and discharge with the Profile of Mood States and Symptom Check List 90. By the time of hospital discharge, fatigue and somatic complaints had increased significantly in the control group but not in the exercising group. Furthermore, by the time of hospital discharge, the training group had

a significant improvement in several scores of psychological distress (obsessive-compulsive traits, fear, interpersonal sensitivity and phobic anxiety) and this outcome was not observed in the control group.

1.29.5 CYTOPROTECTIVE AGENTS

Dose-limiting toxicity secondary to anti-neoplastic chemotherapy is principally due to the inability of the drugs to differentiate between normal and malignant cells. This results in the damage of normal tissues, as well as the desired antitumor effect. Toxicity may be acute, as in cisplatin-induced nephrotoxicity or alkylating agent myelotoxicity and haemorrhagic cystitis, or cumulative, as in anthracyclin-related cardiac toxicity or cisplatin neurotoxicity. The consequences of this often include serious adverse effects and the inability to deliver adequate dose-intensive therapy against the cancer. Chemoprotective agents have been developed to provide site-specific protection against normal tissue toxicity, without compromising antitumor activity. Several chemoprotective agents have recently been developed, including dexrazoxane (ICRF-187), amifostine (ethiofos; WR-2721), mesna and ORG-2766. Initial results confirm their promise as selective protective agents. However, further randomized trials are required to identify their optimal role when used alone or in combination with other toxicity modifiers, including haematopoietic growth factors, with the ultimate aim being adequate dose escalation of chemotherapy to overcome tumor resistance (Lewis 1994).

Amifostine, a new cytoprotective agent has no significant effect on oncolytic efficacy, but side effect profiles improved for febrile neutropenia, neurotoxicity and nephrotoxicity in a study by Longo (1999). Amifostine's greatest disadvantage, is its' high cost.

1.29.6 ALTERNATIVE THERAPIES

Many patients with advanced cancers that are incurable with conventional treatment seek alternative methods of treatment. Practitioners of alternative medicine claim that the non-toxic natural therapies may result in cures and prolongation of life and undoubtedly give a better quality of life.

Interest in the use of complementary therapies as a means of helping patients cope with their illnesses and improve their quality of life is growing among the general public and health care professionals. Some cancer patients seek such therapies to help reduce anxiety and to enhance hope (Wilkinson 1996).

In a study of alternative medicine among women with newly diagnosed early-stage breast cancer, Burstein (1999) found that women who initiated the use of alternative medicine after surgery reported a worse quality of life than women who had never used alternative medicine. Mental health scores were similar at base line among women who decided to use alternative medicine and those who did not. But three months after surgery the use of alternative medicine was independently associated with depression, fear of recurrence of cancer, lower scores for mental health and sexual satisfaction, and more physical symptoms as well as symptoms of greater intensity. All women reported improving quality of life one year after surgery.

Research by Gotay (1999) investigated complementary and alternative medicine use by cancer patients in Hawaii. Thirty-six percent of patients use complementary and alternative medicine, most commonly religious/spiritual therapy and herbal treatments.

Complementary and alternative medicine use was linked with younger age, female gender, Catholic religion and more education.

Verhoef (1999) surveyed the extent of alternative therapy use in a cohort of brain tumor patients. Twenty-four percent of patients used alternative therapies and often more than one therapy at the same time. Motivation for use of these therapies was influenced by the desire for patient-focused treatment and a perceived need to take charge. Alternative therapy users were younger and more likely to be on sick or disability leave, to come in for repeat visits and to have conventional treatments. Users tended to have a lower quality of life with respect to physical well being, functional well being, disease specific and additional concerns. No major side effects or tumor responses were seen with alternative therapies. It was concluded that the use of alternative therapy in brain tumor patients is common and may reflect unmet patient needs with respect to their cancer care within the current model of health care delivery.

Massage is one complementary therapy that is now used in many cancer centers in the United Kingdom. It is time-consuming in terms of training and staff time, and there is little research to justify its use in terms of cost-effectiveness and benefits for patients. However, massage has been demonstrated to be physically and psychologically beneficial in a general hospital setting (Wilkinson 1996).

Cassileth (1991) compared survival and quality of life of patients with end-stage cancer treated at a prominent unorthodox cancer clinic and matched controls that received only conventional treatment. The study was not randomized, as patients who received the alternative therapy were self-selecting. This is clearly a limitation of the study. The study found no difference in survival between the two groups but the quality of life scores were consistently better among patients treated with conventional therapy, despite the fact that a greater proportion of these patients had received chemotherapy with the attendant side effects. The study suggests that the assumption that alternative therapies necessarily enhance the quality of life is not valid.

The value of alternative therapies can only be established meaningfully in the context of controlled clinical trials. Otherwise patients who do not have scientific training are at the mercy of people who are often only trying to make money out of unproved therapies.

Many factors contribute towards quality of life in patients with cancer, including quality of symptom control. Symptom control may be related to the effectiveness of therapy, social functioning, the degree of emotional support and the extent to which the patient feels hopeful and optimistic. Maximum symptom control is the first priority in trying to improve quality of life. It is nonsense to focus on emotional support when someone has uncontrollable pain or vomiting. One of the main argument in favour of patients with advanced incurable cancer seeing cancer specialists is the availability of expertise in symptom control which may be lacking in non-specialist centers (Slevin 1992).

1.29.7 RELAXATION TRAINING

Relaxation training is a widely used, promising nonpharmacological intervention with the chronically ill. Relaxation training decreases anxiety and nausea from chemotherapy and

decreases pain (Taylor 1990). Systematic desensitization and relaxation training can help reduce anticipatory nausea and vomiting and other adverse reactions to chemotherapy.

1.30 SPIRITUALITY

In nursing practice, emphasis has increasingly been placed on giving care to the whole person. This is usually said to involve looking at a person's physiological, psychological, social and spiritual needs. In palliative care, concern with spirituality is all the more pertinent since terminal illness raises many questions about the meaning and nature of existence. However, research suggests that nurses have difficulty in recognising and assessing spiritual needs (Turner 1996).

Part of the difficulty may lie in our definitions and understanding of the concept of spirituality and the failure to distinguish it from religion. For some, the notion of "spirit" relates to the inner part, the real person that is not limited by physical or external phenomena. For others, it is concerned with belief in a transcendent realm, or with a relationship with a higher being. Spirituality thus involves a search for meaning, whereas religion is most often concerned with systems of faith and worship (Turner 1996).

One way of looking at spirituality is in terms of the concepts of "being" and "doing". Doing may be viewed as those aspects of human life that are worldly and short-lived, whereas being may be seen as a more permanent state, which remains after doing has ended. A person's being is particularly active when doing is in decline or has ceased altogether, as in chronic and incurable illness. At such times it enables the human personality to continue to grow and to be enriched (Turner 1996).

Our difficulty in recognising the important contribution of spirituality to a person's well being may in part result from a Western world view that tends to value scientific and material thinking and doing, to the exclusion of being. A young man, dying from advanced cancer, was admitted for terminal care. The issue he faced was how to discover that his value lay not just in doing, but in being; that his wife and family loved him for who he was rather than for what he did for them. Failure to discover meaning in relationships and to transcend the realm of purely material things is, for many, a source of intense spiritual pain (Turner 1996).

How do we discover our meaning in being? Fundamentally we are physical, psychological and spiritual beings who have biological needs and an innate drive for love, security, identity and acceptance. Most of the time we find these needs met in our relationships and our jobs. But when somebody is dying all these things change. What was once significant seems less so and what previously seemed unimportant may take on an increased meaning. One of the strengths of the early hospice movement was that it successfully combined a scientific approach to symptom control with an emphasis on the spiritual dimension, often referred to as “being with” or “being there”. In its simplest sense this describes the notion of hospitality, that is providing someone with a safe place from which to begin to make sense of their predicament. At its highest it denotes the idea of using “the whole of ourselves to relate to our fellow human beings who are in trouble”. We need to value relationships and the intangible qualities of caring, as well as the more quantitative aspects of care (Turner 1996).

A rediscovery of spiritual care has never been more needed, even if it is only to make sense of the constant predicament faced by those health care professionals who struggle to adopt a whole-person approach with limited time and resources and little or no education in the whole area of spirituality. It is time for spiritual care to come fully on to the agenda (Turner 1996).

1.31 SOCIAL SUPPORT GROUPS

Social support groups represent another social support resource for the chronically ill. Potentially, such groups can satisfy needs for social support that have been unmet by family members and caregivers. Alternatively, such support groups may be viewed as an additional source of support provided by those going through the event. Chronically ill patients report a variety of positive as well as negative experiences from such contacts. On the positive side, fellow patients were reported to be especially helpful when they acted as good role models on whom patients could pattern their own coping efforts or when they functioned as role models by surviving over the long term (Taylor 1990).

Generally, beneficial effects have been found as a result of social support group interventions. Self-help groups may help victims cope with the stigma associated with certain disorders, such as cancer. Unfortunately support groups reach only a relatively small proportion of chronically ill patients. Moreover, support groups appear to appeal disproportionately to well-educated,

middle-class white females. The potential for self-help groups to be a general resource for the chronically ill has yet to be realised (Taylor 1990).

Family members and significant others who are going through stressful events with the patient could receive guidance in the most effective ways to provide social support and in the well-intended actions they should avoid because these actually make a stressful situation worse. In some cases even the simple provision of information may be supportive (Taylor 1990).

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ADDENDUM 1: TIPS FOR COPING DURING THE FIRST FEW MONTHS AFTER TREATMENT (RUNOWICZ 1995)

- *Be good to yourself.* Instead of trying to do everything for others, take some time off for yourself. Read a good book, have a manicure, take in a movie, or visit a new shop or art exhibit. Indulging yourself isn't selfish, it's good medicine for the mind.
- *Learn to say no.* You're in control of your life, and politely refusing to do something isn't rude, it's your right.
- *Pace yourself.* Not everything has to get done right away. If you're feeling overwhelmed, divide your list of tasks into manageable parts and prioritize them, being sure to delegate some of the work to others.
- *Take a walk.* It's the best kind of exercise to start with after treatment and will help clear your mind of tension and anxiety. Speak to your doctor about when you can resume normal activity.
- *Talk about your concerns.* Spoken out loud, worries have a way of seeming smaller and less overwhelming. If you don't have a friend or family member to chat with, call your doctor and ask her advice.
- *Pick your battles.* Not every skirmish is worth winning, not every argument worth fighting over.
- *Look at the positive side.* Nothing in life is ever perfect, not even before cancer entered your life. So think about all you've achieved, and be proud of it.
- *Get enough sleep.* Feeling tired is your body's warning signal that it needs to rest and replenish its energies.
- *Laugh at yourself.* If your hair has just started to grow back, think of how goofy you look. When you're feeling down, it's important to find something – no matter how self-deprecating – to giggle about and give yourself a lift.
- *Help someone else.* Whether its picking up a quart of milk for the neighbor or testing your daughter for a geography test, reaching out to others can help you feel stronger and more in control of your own life.
- *Try something new.* Taking on new hobbies and learning new skills can bolster your self-image and make you feel better about your life that lies ahead.

ADDENDUM 2: STAY ALERT (RUNOWICZ 1995)

At first it's hard not to react to every ache and pain as a sign of recurrent cancer. I tell my patients to make me a list and ask them to include even their slightest symptoms. More often than not, I end up reassuring them that it's nothing. But it helps when they write down their concerns, listing *all* the symptoms that they may be worried about. Often, when they come in, they're a bit befuddled and intimidated to be seeing the doctor. Sometimes they'll forget what it is that they wanted to discuss.

Between visits to your doctor, watch for any of the following problems:

- Changes in your breast or in your scar area such as lumps, thickening, redness, or swelling.
- Pain in your breast, shoulder, hips, lower back, abdomen or pelvis.
- Lumps in neck, under arms, in groin, or in breasts that could signal lymph node involvement.
- Persistent indigestion or gas.
- Nausea, vomiting, diarrhea or heartburn that lasts for several days.
- Bloating or a feeling of fullness after a light meal.
- Irregular vaginal bleeding.
- Backache.
- Nagging cough or hoarseness.
- Fever.
- Loss of appetite or sudden, unexplained weight loss or gain.
- Dizziness, blurred vision, severe or frequent headaches, or trouble walking.

ADDENDUM 3: TIPS TO CUT THE FAT (RUNOWICZ 1995)

Did you know that 60% of all cancers in women might be related to what they eat?

Numerous studies show that eating too much fat may increase a woman's chances of getting cancers of the colon, breast and endometrium. Every woman secretes a hormone from the adrenal gland called androstenedione. As part of the body's normal metabolic function, this hormone is converted to a weak form of estrogen in the fat cells. The more fat you eat and the more weight you carry, the more fat cells you have and the more estrogen builds up. Excess estrogen stimulates the development of uterine and breast tissue, which may cause some cancers to grow. Limiting the fat in your diet may reduce your cancer risk.

- Keep an honest food diary for two weeks. You will find out what (and how much) you eat. Identifying bad food habits is the first step toward changing them.
- Eat leaner cuts of meat, low-fat or no-fat dairy products, more seafood and fewer fried foods.
- Trim all visible fat from meats before and after cooking; remove skin from poultry before cooking.
- Use nonstick pans for sautéing. Instead of oil, use chicken broth or spray lightly with vegetable oil.
- Use fruit preserves or unsweetened applesauce in baking instead of butter or margarine.
- Boil, grill, bake, poach or steam foods instead of pan-frying or deep-frying. Use a rack to allow fat to drip into a pan. Baste with wine, lemon juice or orange juice. Do not use fatty drippings. Self-basting poultry can be high in saturated fat, so read the label first before you buy it.
- Instead of mayonnaise or sour cream, mix one-third low-fat yogurt with two-thirds low-fat cottage cheese.
- Substitute low-fat yogurt, skim milk or buttermilk for cream in gravies and dressings. Yogurt will not separate when heated if you add one teaspoon of cornstarch per cup of yogurt.
- Use low-fat recipes. Look for cookbooks that list calorie and percent of fat per serving in their recipes to help you eat the healthy way.
- Learn to use spice instead of fat to flavor your foods.

- Eat more fruits, vegetables and whole grains. The National Cancer Institute recommends that you eat at least five or more servings of fruits and vegetables a day to reduce risk of developing colon and other cancers.
- Limit red meats and cheese. Instead use more poultry, fish, beans and grains for sources of protein in your diet.
- Shop for low-fat or no-fat alternatives.
- Resist that second helping. Your brain needs twenty minutes to register that you are full.
- Don't try to be perfect. Your eating habits took a long time to develop and will take some time to change as well. If you try to cut out everything, you'll end up feeling deprived and risk one high-fat binge after another. When you eat a high-fat meal just try to balance it with low-fat foods the rest of the day. Keep low-fat, low-calorie nibbles on hand to cope with hunger pangs and cravings.

ADDENDUM 4: SWITCHING FROM HIGH-FAT FOODS TO LOW-FAT ALTERNATIVES (RUNOWICZ 1995)

Instead of This

Ice cream
Butter
Cream soups
Sour cream dip
Potato chips
Iced cake or doughnuts
Brownies
Croissants
Salami, Bologna
Oil-packed tuna
French-fries
Sour cream
Corn chips
Cheddar cheese
One whole egg
Ham and cheese omelet
Fruit-flavored yogurt
Olives
Whole milk

Try This

Nonfat frozen yogurt or sorbet
Unsweetened fruit preserves
Gazpacho, minestrone and consommé
Salsa
Pretzels
Angel food cake
Gingersnaps, fig bars
Plain bagel or whole-wheat roll
Turkey, roasted lean ham
Water-packed tuna
Roasted or baked potato
Yogurt or low-fat cottage cheese
Air-popped corn
Part-skim mozzarella
One or two egg whites
Vegetable and egg white omelet
Nonfat yogurt with sliced fresh fruit
Pickles
Skim milk

ADDENDUM 5: TAKING CARE OF YOUR HEALTH: DIET NUTRITION AND LIFESTYLE (RUNOWICZ 1995)

- Too much fat may promote cancer.
- The need for fiber – eat five half-cup servings of fruits and vegetables per day.
- Limit your amount of animal protein – rather eat complex carbohydrates and vegetable protein like beans, rice or soy products like tofu or tempeh.
- Drink alcohol rarely, if at all – maximum one to two glasses of wine or one shot of hard liquor per day.
- What about supplements? – there is still too much confounding data to recommend taking beta-carotene, vitamin E and vitamin C to prevent cancer. The advice is rather to eat lots of fresh fruits and vegetables.
- The need for calcium – the recommended daily allowance for premenopausal women is 800 milligrams daily and for postmenopausal women, 1500 milligrams daily.
- The need for exercise – to reap the full benefit of a low-fat, high-fiber diet, it's important to add regular physical activity. Regular exercise can stimulate the immune system, reduce your risk for chronic diseases and degenerative conditions like coronary heart disease, diabetes, osteoarthritis and osteoporosis. It also lessens depression. Twenty minutes of fast walking, biking or jazz dancing two or three times a week.
- Smoking – If you're a cancer survivor and still continue to smoke, you might as well put a gun to your head and fire: sooner or later it will kill you. Evidence shows that tobacco eventually kills close to 25% of those who use it.
- Unprotected sun exposure – these days getting a tan isn't healthy, it's downright dangerous. A history of sunburn and a family background are two main risk factors for malignant melanoma, a deadly form of skin cancer that strikes thousands of women each year. Use a sun-protection factor of at least 15 and limit time out of doors. Regular self-examinations are an important part of early detection. Most skin moles are harmless, but ask yourself these questions: Has it changed in size, thickness, shape or texture? Does it have an irregular border? Is it bigger than a pencil eraser? Is any new mole translucent, tan, brown, black or multicolored? Is it painful, itchy, bleeding or does not heal? Notify your oncologist.

- Food additives and meal preparation – some cooking methods, such as high-temperature grilling, smoking, salt-curing and pickling, can produce possible cancer-causing substances in foods.
- Alternative cancer regimens like shark cartilage, raw juice therapy, shiitake mushroom tea, kinesiology – at present none of these unorthodox methods have been proven.

ADDENDUM 6: REASSURING YOUR CHILD ABOUT CANCER (RUNOWICZ 1995)

- Having cancer doesn't necessarily mean a person will die from it.
- Nothing you did or didn't do caused mommy to get cancer.
- Nothing you thought or said caused the cancer to grow.
- Cancer isn't contagious – you can't catch it from someone else.
- Because your mom or grandmother has cancer doesn't always mean you or someone else in your family will get it too.
- The way you behave can't change the fact that your mom had cancer or that your family is upset.
- It's important to continue with school and outside activities.
- There are others to talk to besides your parents about your fears.

ADDENDUM 7: THE MONTHLY BREAST SELF-EXAMINATION (RUNOWICZ 1995)

When it comes to breast cancer, early detection can make all the difference. That's why it's essential you examine your breasts every month using these guidelines:

- *In the shower*, with fingers flat, gently slide your hands over every part of both breasts, checking for any lump, hard knot or thickening.
- *Lying down*, place a pillow under your right shoulder and put your right hand behind your head. Using your left hand, with fingers flat, press gently in a small circular motion, starting at the outermost top edge of your breast and spiraling toward the nipple. Repeat with the left breast. Then check your underarm area – which is also, breast tissue – using the same circular motion.
- *Before a mirror*, with arms at your sides, then with arms raised overhead, check for changes in the size, shape and contour of each breast. Look for swelling, dimpling or changes in skin texture. Gently squeeze both nipples and look for any discharge.
- *Report any changes* immediately to your doctor. Only about one in ten lumps that premenopausal women report to doctors turns out to be malignant. But your best defense against breast cancer is to know for sure.

Make it a habit to check your breasts thoroughly at least once a month. The examination should be done the week following your menstrual period or the first day of the month if you are no longer menstruating.

ADDENDUM 8: SPECIAL INSTRUCTIONS FOR HAND AND ARM CARE (ADCOCK 1990)

1. AVOID CUTS, SCRATCHES AND IRRITATION

- use cuticle cream instead of scissors
- wear heavy gloves and long sleeves when gardening and avoid thorns
- use rubber gloves for washing dishes and cleaning

2. DO NOT HAVE INJECTIONS OR VACCINATIONS IN THE AFFECTED ARM - ASK TO HAVE THEM ON THE OTHER SIDE

3. AVOID WASPS, BEES AND OTHER INSECTS

- call the doctor if you get a wasp or bee sting
- use insect repellent if you are going to be exposed to insects

4. AVOID BURNS

- if you smoke, hold your cigarette in the other hand
- always use a padded glove when reaching into the oven
- avoid sunburn – use protective sun lotion and tan gradually – if possible, cover your affected arm when in the sun (with long sleeves or a towel)

5. AVOID BINDING OR SQUEEZING YOUR ARM

- do not have blood pressure taken on the affected side
- wear loose jewelry (wrist watch, bracelets and rings)
- wear loose sleeves
- do not carry your handbag on the affected shoulder or in the affected hand: carry it on the other side

6. AVOID UNDERARM IRRITATION

- talk to your doctor and/or therapist before shaving your underarm
- ask your doctor and/or therapists advice about deodorant – do not use any product which causes rash or other irritation

7. AVOID STRAINING YOUR ARM

- let others carry heavy objects
- do not move furniture
- ask your therapist's advice about strenuous activities you want to do

8. TAKE EXTRA CARE OF YOUR HAND AND ARM

- use lanolin cream on your hand and arm several times a day

- in case of minor breaks in the skin (insect bites or scrapes), wash the affected area and cover it with a bandage
- burns or cuts should be seen immediately by a doctor and/or therapist, an antibiotic is usually needed
- call your doctor or therapist promptly if any sign of infection occurs